

Dementia in people with SPI(M)D



Diagnostic aid

Diagnostic aid for dementia in people with SPI(M)D

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Introduction

This diagnostic aid has been developed to identify dementia-related changes in people with severe/profound intellectual (and multiple) disabilities (abbreviated as SPI(M)D) and it can be used in the diagnostic process. The results of the diagnostic aid only are not sufficient to make a diagnosis. Changes can also be caused by other conditions with dementia-like symptoms. These potential differential diagnoses must be ruled out.

General data

The diagnostic aid consists of two parts. The first part asks general information about the interviewer, informant(s), and the person with SPI(M)D.

Dementia-related changes

The second part contains 42 items on dementia-related changes, categorized into seven symptom domains. For each item, it is asked whether a change has been observed in the last six months compared to the typical/characteristic functioning or behaviour. This refers to the functioning or behaviour that is typical of the person and that they have exhibited during adult life before deterioration occurred.

1. Changes in cognition
2. Changes in language and speech
3. Behavioural changes
4. Changes in eating and drinking
5. Changes in personal care
6. Changes in motor skills
7. Additional health problems

The collection protocol is described in detail in the accompanying manual. The manual must be followed carefully.

N.B.!

- A change that has been visible for more than six months is scored as a change if it is not typical.
- Progress in functioning is scored as 'No change'.
- If behaviour is not present at the time of collection or if behaviour is present but has not changed, then 'No change' is scored.

General details

Date of interview:

Interviewer

First and last name:

Profession:

Psychologist

Other

Care organisation:

Informant(s)

INFORMANT 1

First and last name:

Relationship to client:

Professional caregiver (residential facility)

Professional caregiver (daycare centre)

Parent

Brother/sister/brother-in-law/sister-in-law

Other

How long have you known the client (in years)?

Approximately how much time do you spend with the client per week (in hours)?

INFORMANT 2

First and last name:

Relationship to client:

Professional caregiver (residential facility)

Professional caregiver (daycare centre)

Parent

Brother/sister/brother-in-law/sister-in-law

Other

How long have you known the client (in years)?

Approximately how much time do you spend with the client per week (in hours)?

Person with SPI(M)D

Date of birth:

Age (in years):
[interview date - date of birth]

Sex:

- Male
- Female

Residential situation:

- At home
- Partly at a residential facility and partly at home (e.g., weekends)
- At a residential facility
- Other

Goes to daycare centre:

- Yes
- No

Level of intellectual disability:

[original level before deterioration occurred]

- Severe
- Profound

Cause of intellectual disability:

- Down syndrome
- Other syndrome
- No syndrome, but:
- Unknown

Intellectual functioning (IQ):

[original level before deterioration occurred]

- Unknown
- Known, IQ:

Adaptive functioning:

- Unknown
- Known

Social-emotional functioning:

[original level before deterioration occurred]

- Unknown
- 0 - 6 months (first adaptation phase)
- 6 - 18 months (first socialization phase)
- 18 - 36 months (first individuation phase)
- 3 - 7 years (first identification phase)
- 7 - 12 years (reality awareness)

Dementia

Questionable dementia: deterioration, but does not yet meet diagnostic dementia criteria.

Diagnosed dementia: based on clinical evaluation and multidisciplinary dementia diagnosis.

Has a dementia diagnostic procedure been performed before?

- Yes, with the conclusion:
 - No evidence of dementia
 - Questionable dementia
 - Clinically diagnosed dementia
- No

Verbal skills

Is the client typically able to express him/herself verbally (in words)?

- Yes
- No

Walking skills

Is the client typically able to walk?

- Yes
- No

Recent life events

Examples: moving house, death of a loved one

Has the client had to deal with significant changes/events in the last six months that have impacted functioning (clinical judgement)?

- Yes, **still** an obvious effect on functioning
- Yes, with **no** obvious effect (anymore) on functioning
- No

Comorbidities

Examples: epilepsy, hypothyroidism (underactive thyroid), vitamin B12 deficiency, hearing problems, vision problems, sleep apnea

Does the client have comorbidities that affect functioning (clinical judgement)?

- Yes
- No

Psychotropic drugs (behaviour-regulating medication)

Has there been a change in psychotropic drug use in the last six months that has had or has an impact on functioning (clinical judgement)?

- Yes
- No

Prolonged hospitalization

Has the client been admitted to hospital for a long period of time in the last six months?

- Yes
- No

Terminal phase of life

Explanation: the terminal phase of life is the last phase of a person's life, where life expectancy is a maximum of three months.

Is the client in the terminal phase of life?

- Yes
- No

Other matters worth mentioning:

Dementia-related behavioural changes

1. Changes in cognition

1.1 Recognizing daily activities

Examples: no longer recognizing that you are going to eat/drink, dress/undress, take a shower, that you have to urinate in the toilet

Has there been a change in the recognition of daily activities in the last six months?

- Yes, **less** recognition of daily activities
- No change
- Not applicable, skill never developed

Notes

1.2 Making simple choices

Examples: choices concerning food/drink, activities

Has there been a change in making simple choices in the last six months?

- Yes, **less** able to make simple choices
- No change
- Not applicable, skill never developed

Notes

1.3 Recognizing people

Examples: caregivers, family members, other clients

Has there been a change in recognizing people in the last six months?

- Yes, **less** recognition of people
- No change
- Not applicable, skill never developed

Notes

1.4 Recognizing objects

Examples: spoon, cup, chair, piece of clothing, cuddly toy, puzzle

Has there been a change in recognizing objects in the last six months?

- Yes, **less** recognition of objects
- No change
- Not applicable, skill never developed

Notes

1.5 Preference for objects

Examples: no longer wanting to touch an object that the client always used to hold, liking objects that the client previously disliked

Has there been a change in preference for certain objects in the last six months?

- Yes, **less** preference for certain objects
- Yes, **more** preference for certain objects
- No change
- Not applicable, skill never developed

Notes

1.6 Losing objects

Examples: no longer remembering where the toys were put down, where the walker is

There has been a change in the loss of objects in the last six months

- Yes, losing objects **more often**
- No change
- Not applicable, skill never developed

Notes

1.7 Perceiving distances

Explanation: being able to perceive distances to people/objects (table, chair, curb).

Examples: more often walking into something/bumping into things with the wheelchair, more difficulty with steps/transitions (for example, between floors)

Has there been a change in the perception of distances in the last six months?

- Yes, **less** perception of distances
- No change
- Not applicable, skill never developed

Notes

1.8 Finding the way

Explanation: finding the way to familiar spaces (living room, bedroom, toilet) or places (daycare, home)

Has there been a change in the ability to find the way in the last six months?

- Yes, **less** able to find the way
- No change
- Not applicable, skill never developed

Notes

1.9 Recognizing daily routines

Examples: no longer recognizing that you are going to have breakfast after getting dressed, skipping steps in the daily programme more often, starting an activity at the wrong time, letting go of the daily structure

Has there been a change in recognizing the daily routines in the last six months?

- Yes, **less** recognition of the daily routines
- No change
- Not applicable, skill never developed

Notes

1.10 Recognizing day and night

Example: waking up at night and acting like it is morning

Has there been a change in the recognition of the difference between day and night in the last six months?

- Yes, **less** recognition of day and night
- No change
- Not applicable, skill never developed

Notes

2. Changes in language and speech

N.B.! Only answer questions 2.1 and 2.2 if the client can typically express themselves verbally (in words).

▶ 2.1 Number of words used

Explanation: the number of different words the client uses to express themselves verbally

Has there been a change in word usage in the last six months?

- Yes, using **fewer** words
- No change

Notes

2.2 Speaking intelligibly

Has there been a change in intelligible speech in the last six months?

- Yes, **less** able to speak intelligibly
- No change

Notes

3. Behavioural changes

3.1 Anxiety

Examples: shouting/screaming, freezing up, fear of being alone (e.g. following caregivers/family members around, not daring to let go)

Has there been a change in anxiety in the last six months?

- Yes, **more** anxious
- Yes, **less** anxious
- No change

Notes

3.2 Sadness

Examples: being sad/teary more often, suddenly starting to cry for no apparent reason

Has there been a change in feeling sad in the last six months?

- Yes, **more** sadness
- Yes, **less** sadness
- No change

Notes

3.3 Interest in the direct living environment

Examples: other clients, caregivers, activities, music, objects

Has there been a change in interest in the immediate living environment in the last six months?

- Yes, **less** interest in the direct living environment
- Yes, **more** interest in the direct living environment
- No change

Notes

3.4 Withdrawing

Examples: not making eye contact, sitting quietly in a chair or wheelchair, distancing him/herself from the group

Has there been a change in withdrawal in the last six months?

- Yes, withdrawing **more**
- Yes, withdrawing **less**
- No change

Notes

3.5 Waking up during the night

Has there been a change in waking up during the night in the last six months?

- Yes, waking up during the night **more** frequently
- Yes, waking up during the night **less** frequently
- No change
- Unknown, no insight into sleeping behaviour

Notes

3.6 Daytime sleeping

Has there been a change in daytime sleeping in the last six months?

- Yes, sleeping **more** during the day
- Yes, sleeping **less** during the day
- No change

Notes

3.7 Irritable behaviour

Examples: irritated, frustrated, angry, grumbling, groaning

Has there been a change in irritable behaviour in the last six months?

- Yes, **more** irritable behaviour
- Yes, **less** irritable behaviour
- No change

Notes

3.8 Resisting help that is needed

Examples: opposing actions, turning head away, not accepting aids

Has there been a change in resistance to needed help in the last six months?

- Yes, **more** resistance to needed help
- Yes, **less** resistance to needed help
- No change

Notes

3.9 Physical aggression

Examples: hitting, kicking, biting, scratching, pinching, self-mutilation

Has there been a change in physical aggression in the last six months?

Yes, **more** physical aggression

Yes, **less** physical aggression

Notes

3.10 Restless behaviour

Examples: being unable to sit still, walking back and forth (aimlessly).

Has there been a change in restless behaviour in the last six months?

Yes, **more** restless behaviour

Yes, **less** restless behaviour

Notes

3.11 Stereotypical behaviour

Examples: repetitive, 'pointless' habits or actions such as tapping, picking at clothes, rocking back and forth

Has there been a change in stereotypical behaviour in the last six months?

Yes, **more** stereotypical behaviour

Yes, **less** stereotypical behaviour

Notes

3.12 Compulsive behaviour

Examples: feeling compelled to tap/straighten objects, perform rituals

Has there been a change in compulsive behaviour in the last six months?

Yes, **more** compulsive behaviour

Yes, **less** compulsive behaviour

Notes

3.13 Disinhibited behaviour

Examples: undressing in front of others, flinging him/herself around people's necks, constantly touching or grabbing someone

Has there been a change in disinhibited behaviour in the last six months?

- Yes, **more** disinhibited behaviour
- Yes, **less** disinhibited behaviour

Notes

3.14 Mood swings

Explanation: Rapidly changing moods, such as happy one moment, angry shortly afterwards

Have there been any changes in mood swings in the last six months?

- Yes, **more** mood swings
- Yes, **fewer** mood swings

Notes

3.15 Hallucinations/delusions

Examples: looking at something/noticing things/naming things that are not perceived by others.

▶ *N.B.! This does not include fantasy images/figures*

Has there been a change in hallucinations/delusions in the last six months?

- Yes, **more** hallucinations/delusions
- Yes, **fewer** hallucinations/delusions

Notes

4. Changes in eating and drinking

4.1 Eating/drinking skills

Examples: using cutlery, eating from a spoon, bringing cup to mouth

Has there been a change in eating/drinking skills in the last six months?

- Yes, **less** eating/drinking skills
- No change
- Not applicable, skills never developed

Notes

4.2 Eating/drinking appetite

Has there been a change in the eating/drinking appetite in the last six months?

- Yes, **less** eating/drinking appetite
- Yes, **more** eating/drinking appetite
- No change

Notes

4.3 Choking

Has there been a change in swallowing in the last six months?

- Yes, choking **more often**
- No change

Notes

4.4 Chewing

Explanation: chewing is a process in the mouth in which food is ground by teeth and molars or jaws (when someone has no teeth).

Examples: no longer chewing bread crusts properly, more difficulty chewing meat

Has there been a change in chewing in the last six months?

- Yes, **less** able to chew
- No change
- Not applicable, skill never developed

Notes

4.5 Body weight

Has there been a change in body weight in the last six months?

- Yes, **increase** in body weight
- Yes, **decrease** in body weight
- No change

Notes

5.Changes in personal care

5.1 Personal care

Explanation: dressing/undressing, bathing/showering, using the toilet, grooming

Examples: no longer being able to put on socks/trousers/jacket, dry off, use toilet paper, brush teeth

Has there been a change in personal care in the last six months?

- Yes, **less** able to perform personal care
- No change
- Not applicable, skills never developed

Notes

6. Changes in motor skills

6.1 Mobility/transfers

Examples: changing lying/sitting position, getting up from a sitting position, getting in/out of bed, moving from bed to chair, getting into a car/bus

Has there been a change in mobility/transfers in the last six months?

- Yes, **decline** in mobility/transfers
- No change

Notes

6.2 Balance

Explanation: even distribution of body weight that allows a person to remain upright and stable

Example: slanting

Has there been a change in balance in the last six months?

- Yes, **less** balance
- No change

Notes

6.3 Fall frequency

Has there been a change in fall frequency in the last six months?

- Yes, falling **more often**
- No change

Notes

6.4 Wheelchair use

Has there been a change in wheelchair use in the last six months?

- Yes, using a wheelchair **more often**
- No change

Notes

6.5 Stiffness

Explanation: stiffness can manifest itself in being less able to sit back into the wheelchair, more difficulty getting an arm into a sleeve, less ability to cooperate physically while being dressed.

Has there been a change in stiffness in muscles/joints in the last six months?

- Yes, **more** stiffness in muscles/joints
- No change

Notes

6.6 Muscle strength

Explanation: reduced muscle strength can manifest itself in less ability to get up, sitting slanted in the chair, or the head falling forward.

Has there been a change in muscle strength in the last six months?

- Yes, **less** muscle strength
- No change

Notes

► *N.B.!* Questions 6.7 and 6.8 are only answered when the client is typically able to walk.

6.7 Gait

Examples: smaller steps, no longer lifting feet, shuffling/sliding, feet wider apart

Has there been a change in gait in the last six months?

- Yes, **decline** in gait
- No change

Notes

6.8 Walking distance

Has there been a change in walking distance in the last six months?

- Yes, **cannot** walk as far anymore
- No change

Notes

7. Additional health problems

7.1 Incontinence

Has there been a change in incontinence in the last six months?

- Yes, **more** incontinence (including the development of incontinence)
- No change
- Not applicable, always been incontinent

Notes

The development of the diagnostic aid for dementia in individuals with SPI(M)D was part of the project *Practical questions about Dementia in Individuals with Profound Intellectual (and Multiple) Disabilities*, a collaboration between the University of Groningen (UG), University Medical Center Groningen (UMCG), Hanze University of Applied Sciences Groningen, Alliade, 's Heeren Loo, Ipse de Bruggen, and Visio, subsidized by the ZonMw Memorabel research programme (project number 733050863).

More information: www.vb-dementie.nl

