

Massachusetts Department of Developmental Services Risk Management

Subject: Dementia

What is it?

Dementia defines a group of symptoms caused by disorders that affect the brain. It is not a specific disease. People with dementia may not be able to think well enough to do normal activities, such as getting dressed or eating. They may lose their ability to solve problems or control their emotions. Their personalities may change. They may become agitated or see things that are not there.

Memory loss is a common symptom of dementia. However, memory loss by itself does not mean you have dementia. People with dementia have serious problems with two or more brain functions, such as memory and language.

What risk does it present?

Many of the individuals supported by the Department of Developmental Services, especially those with Down Syndrome are at a higher risk of cognitive and functional decline and the early onset of dementia as they age.

How is it managed?

When an individual presents with increased needs, changes in language and memory that require increased staff support the following conditions should be considered before making an assumption of dementia associated with aging:

- Exclude via a detailed physical assessment any acute medical events or related processes.
- Review all medications for drug interactions and closely examine medications that may be newly introduced, or where dosages of medications may have been recently changed.
- Establish a historic pattern with regard to the development and the progression of the cognitive deficits and changes
- Evaluate possible environmental causes of increased confusion, such as change of residence day program or staffing
- When other factors are ruled out causal factors for the change in behavior a screening tool such as those outlined below should be considered to assess for the onset of dementia
- Always notify the person's Service Coordinator or Area Office Nurse if you are concerned about an individual's decline in abilities

Cognitive Assessment for Adults with Developmental disabilities: This sample assessment tool (see below) is to be used for individuals with intellectual or developmental disabilities. It records common behaviors of adults with ID/DD as they grow older. Ideally, it should be completed by a clinician along with someone who knows the individual well. While no specific score would indicate dementia, the higher the total score, the more likely it is that the individual is exhibiting signs of dementia and further assessment by their primary care practitioner or neurologist would be indicated.

Functional Assessment Tool: This assessment tool (see below) is designed to assist direct care staff in identifying early and ongoing changes in an individual's functional ability. This sample tool (see below) is designed to identify early changes that could signal the onset of dementia. Change may indicate a need for a further clinical assessment. Ideally this evaluation should occur every six months.

Where and to whom does this apply?

- It is the expectation of the Department of Developmental Services (DDS) that a person's dementia is managed in the individual's environment(s) with as little disruption as possible to their home, wherever possible
- Information regarding the individual's status relative to this issue is to be handled in the same manner as any medical information according to HIPAA regulations.

Where can I find additional help?

- Alzheimer's Association
- DPH – www.mass.gov/dph
- DDS – Health and Wellness Promotion: www.mass.gov/dds

Cognitive Assessment for Adults with Developmental Disabilities

This sample assessment tool for staff assisting individuals with intellectual or developmental disabilities. It records the kind of behaviors that may be faced by adults with ID/DD as they grow older. While no specific score would indicate dementia, the higher the total score, the more likely it is that the individual is exhibiting some signs of dementia and further assessment by their health care provider is warranted.

Individual's Name: _____

Date of Birth: _____ Sex: Male ☐ Female ☐ Down Syndrome: Yes ☐ No ☐

Name of Person Completing Form: _____ Date: _____

<u>Behavior</u> Rate the behavior according to the description under "How Often", "Management Difficulty" and "Effect of Quality of Life". If it is not a recent change in the person's ability or behavior, score as 0.	<u>How Often</u> 0=Has not occurred in the past 2 weeks 1= Once in the past 2 weeks 2= More than 2-3 times in the past 2 weeks 3= All the time	<u>Management Difficulty</u> 0= No difficulty 1= Very Little difficulty 2= Moderate difficulty 3= Severe difficulty	<u>Effect on Quality of Life</u> 0= No effect 1= Very little effect 2= Moderate effect 3= Severe effect
1. Was restless: Paced up and down, was unable to sit still, fidgeted	0 1 2 3	0 1 2 3	0 1 2 3
2. Wandered during the night: Wandered at night without a clear purpose .	0 1 2 3	0 1 2 3	0 1 2 3
3. Wandered during the day: Wandered around the house, workplace or outside without a clear purpose	0 1 2 3	0 1 2 3	0 1 2 3
4. Was vocally disruptive: was vocal for no apparent reasons (moaned, shouted, screamed, called out)	0 1 2 3	0 1 2 3	0 1 2 3
5. Took something belonging to someone else: Took money or objects, went through other people's possessions (bags, coats, bedrooms).	0 1 2 3	0 1 2 3	0 1 2 3
6. Cried or became tearful: Became tearful for no apparent reason	0 1 2 3	0 1 2 3	0 1 2 3
7. Was uncooperative: Unwilling to carry out a daily task (bathing, dressing) Or comply with care requests (to go to bed, to eat)	0 1 2 3	0 1 2 3	0 1 2 3
8. Was aggressive towards others verbally or through gestures: (shouted, name called, threatened, swore)	0 1 2 3	0 1 2 3	0 1 2 3
9. Was aggressive physically towards others. Attempted to or was actually aggressive physically towards another person.(kicked, hit, spat, scratched, bit, pushed, grabbed)	0 1 2 3	0 1 2 3	0 1 2 3
10. Displayed sexually inappropriate behavior: Made an inappropriate sexual advance or gesture, made sexual references, non-accidentally exposed self	0 1 2 3	0 1 2 3	0 1 2 3
11. Said or gestured the same thing repeatedly: Communicated the same thing again and again although and appropriate response had been given (repeated a statement, question, request or demand)	0 1 2 3	0 1 2 3	0 1 2 3
12. Was inactive: Was not engaged in any activity, was unoccupied	0 1 2 3	0 1 2 3	0 1 2 3
13. Was hard to remember words, signs or symbols: Couldn't remember names of familiar people, objects or places	0 1 2 3	0 1 2 3	0 1 2 3
14. Showed no interest in a usual activity: Was not interested in an activity that was previously enjoyed, was difficult to engage, did not want to do anything	0 1 2 3	0 1 2 3	0 1 2 3

15. Withdrew from communicating: Did not speak, or respond to a familiar person, did not reply to a question, used the least amount of words or gestures	0 1 2 3	0 1 2 3	0 1 2 3
16. Was confused about the time of day: Mixed up night with day (put night clothes on during the day, their breakfast at night)	0 1 2 3	0 1 2 3	0 1 2 3
17. Was confused about the day, season or year: Believed it to be summer in winter or had wrong year	0 1 2 3	0 1 2 3	0 1 2 3
18. Was confused about themselves and others: Did not recognize themselves in a mirror or picture or other familiar people.	0 1 2 3	0 1 2 3	0 1 2 3
19. Was confused about where they were: Forgot where they were or thought they were somewhere else.	0 1 2 3	0 1 2 3	0 1 2 3
20. Lost their sense of direction: Got lost in familiar surroundings (got lost on their way to their workshop, could not find their bedroom)	0 1 2 3	0 1 2 3	0 1 2 3
21. Behaved as though they were living in the past: Asked for someone who had died many years ago (parent or friend), tried to perform a past routine (leaving the house to go somewhere they no longer go)	0 1 2 3	0 1 2 3	0 1 2 3
22. Had a toileting accident: Defecated, or urinated inappropriately (did not use the toilet or went in an inappropriate place, or did not use incontinence aids correctly).	0 1 2 3	0 1 2 3	0 1 2 3
23. Experienced difficulty eating or drinking: Appeared to have difficulty coordinating eating and drinking actions (putting food or drink to mouth, using cutlery). Found it hard to swallow , choked. Appeared to forget how to chew or swallow.	0 1 2 3	0 1 2 3	0 1 2 3
24. Got muddled/ mixed up when carrying out an everyday task or activity: Such as: dressing, washing, cooking, cleaning (put clothes on backwards, forgot how to set the table, put things away in the place)	0 1 2 3	0 1 2 3	0 1 2 3
25. Experienced difficulty concentrating: Became easily distracted, found it hard to stay with a task	0 1 2 3	0 1 2 3	0 1 2 3
26. Was not alert: Slept a lot during the day, appeared drowsy, dozed at inappropriate times (while eating or on the toilet)	0 1 2 3	0 1 2 3	0 1 2 3
27. Appeared to be slow physically: Takes longer for them to complete familiar tasks (dressing, washing, eating)	0 1 2 3	0 1 2 3	0 1 2 3
28. Had a fall: Fell down or tripped (tripped on a curb or fell on the stairs)	0 1 2 3	0 1 2 3	0 1 2 3
TOTALS:			

Functional Assessment Tool

This assessment is designed to identify early changes that could signal the onset of dementia. It is suggested that this checklist could be completed twice a year by direct support staff. This is especially important for persons with Down Syndrome. Any aspect that changes from the previous assessment should be marked in red so a clear pattern can be outlined. Decline in functional assessment indicates a referral to a primary care provider, provider nurse or other health care professional.

CODE

1- always 2- usually 3- rarely 4- never Yes or No to * items	Name of Individual: _____ Date of Birth: _____ Name(s) of Interviewer _____
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Date

MENTAL STATUS					
1. Alert					
2. Naps during the day					
3. Awake at night					
4. Initiates activities and/or social contact					
5. Becomes easily discouraged					
6. Forgetful					
7. Combative					
8. Cries					
9. Fearful					
10. Oriented to time					
11. Oriented to place					
12. Recognizes familiar people					
13. Organizes leisure time					
DAY/WORK CHANGES					
1. Attends day/work program as scheduled					
2. Able to complete work/day routines					
3. Work/day outcomes are consistent					
4. Maintains energy for complete day					
5. Stays focused on tasks					

SEIZURES					
*1. History of seizures					
*2. Takes seizure medications					
*3. Seizure activity noted (not seen before)					
COMMUNICATION					
1. Speaks in full sentences					
2. Speaks in phrases					
3. Difficulty in word finding					
4. Uses sign language					
5. Indicates needs and wants					
6. Follows simple directions					
7. Uses coherent speech					
MOBILITY					
1. Travels independently					
2. Walks up and down stairs alone					
3. Walks with assistance					
4. Gets up from chair independently					
5. Uses walker					
6. Uses wheelchair					
7. Gets disoriented or lost when traveling					
EATING					
1. Eats independently					
2. Uses utensils correctly					
3. Holds cup correctly					
4. Chews properly					
5. Swallows without problems					
TOILETING					
1. Independent					
2. Incontinence of urine					
3. Incontinence of feces					