

Down Syndrome Dementia Questionnaire

Name of Individual with DS: _____ Age: ____ Date: _____

Relationship of individual completing this questionnaire to the subject (parent, sibling, caregiver, etc): _____

INSTRUCTIONS:

- The questionnaire should be completed by a family member or caregiver who is familiar with the individual with Down syndrome and should reflect the individual's behavior over the last approximately 2 months.
 - The individual completing the questionnaire is asked to rate how often the individual with Down syndrome knows a fact, exhibits a behavior, etc.
 - Score the behavior carefully by checking box 0, 1, or 2. Each item should be scored to the best of the completer's knowledge, even if they are not sure. **No question should be left blank.**
 - If the third choice (score = 2) is selected for a particular question, however the individual with Down syndrome has never known the fact or has always exhibited the behavior at baseline, an additional fourth box may be checked to reflect that this has been long-standing.
- The purpose of this questionnaire is to help determine the individual with Down syndrome's level of cognitive ability and to help document any behavioral disturbances.
 - This questionnaire may be used as a baseline assessment of level of functioning, perhaps first at age 25 or after a change in a living situation to determine a new baseline.
 - This questionnaire may also be administered at periodic intervals, perhaps every few years, to see if there has been a change in the level of functioning from baseline.
- Once the questionnaire has been completed, the points from each page should be totaled on the last page of the questionnaire. The number of question qualifiers should also be totaled and recorded.
- There is no specific total score that should raise concern for the individual's cognitive ability. Significant changes from baseline in terms of behavior or forgetfulness should prompt a medical evaluation.
- Give a copy of the completed questionnaire to the individual's primary care provider and also store a copy of the completed questionnaire in a safe place.
- This questionnaire should not replace the advice of a physician.

1. Understands what you want to make clear to him/her (by means of speaking, writing, or gesticulation):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

2. Remembers where he/she put away something just a minute ago (no longer than half an hour ago):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

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3. Remembers an impressive event that took place during the last weeks (tells about it or recognition is apparent when it is spoken about):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

4. Knows which month it is (e.g. March in the first week of April is permitted):

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

5. Remembers family members or friends whom he/she has not seen for a long time or who are deceased:

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

6. Knows whether it is spring, summer, autumn or winter (not necessary to the very day):

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

7. Knows what year it is (a mistake of a year is permitted):

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

8. Is interested in outdoor activities (e.g. clubs, festivities, family parties, trips):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never did this at baseline

9. Hits or kicks other people or shows aggression in any other way:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she did this at baseline

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10. Remembers events from his/her youth:

- 0 = Remembers a lot
- 1 = Remembers a little
- 2 = Remembers nothing
- If remembers nothing, he/she never remembered this at baseline

11. Is able to undress (perhaps with some help or stimulus):

- 0 = Always
- 1 = Sometimes
- 2 = Never
- If never, he/she never did this at baseline

12. Is during the day:

- 0 = Continent
- 1 = Only continent with help of others
- 2 = Incontinent (always or several times a day)
- If incontinent, he/she was continent during the day at baseline

13. Speaks (to an unknown person) intelligibly and comprehensibly (for individuals who only speak some stereotype words, score "no"):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never did this at baseline

14. Remembers an instruction, given just a moment ago (no longer than five minutes ago):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

15. Can find his/her way to places that are familiar to him/her in the surroundings of the home:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

16. Keeps his/her clothes and things tidy:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never did this at baseline

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17. Is able to wash him/herself under the shower or at the wash-stand (perhaps with some help):

- 0 = Always
- 1 = Sometimes
- 2 = Never
- If never, he/she was never able to do this at baseline

18. Can tell something to those who stayed at home, after returning from holiday or trip (by words or gestures):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

19. Is able to dress (perhaps with some help or stimulus):

- 0 = Always
- 1 = Sometimes
- 2 = Never
- If never, he/she was never able to do this at baseline

20. Is interested in what is going on in the home:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never interested in this at baseline

21. Is interested in papers and/or T.V.:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never interested in this at baseline

22. Speaks:

- 0 = Yes
- 1 = Only some stereotyped words
- 2 = No
- If no, he/she never did this at baseline

23. Recognizes persons, whom he/she came to know during the last weeks (calls them by name or recognition is apparent from behavior):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

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24. Is on familiar terms with one or more persons, living in the home:

- 0 = Often
- 1 = Sometimes
- 2 = Never
- If never, he/she never did this at baseline

25. Understands simple instructions:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

26. Recognizes staff members or acquaintances whom he/she has known for more than a year (calls them by name or recognition is apparent from behavior):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never did this at baseline

27. Gets angry easily:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she did this at baseline

28. Knows that today is a weekend or a weekday:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never knew this at baseline

29. Can tell something about what he/she has been doing today:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

30. Keeps him/herself busy at home on his/her own initiative (e.g. with hobbies, playing games, reading, talking with others):

- 0 = Always
- 1 = Sometimes
- 2 = Never
- If never, he/she never did this at baseline

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31. Threatens others by words or gestures (without a clear motive):

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she often did this at baseline

32. Accuses other people of harming him/her in any way (e.g. hitting or stealing), whereas that is not true:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she often did this at baseline

33. Remembers something that has been told (or communicated in any other way) recently (no longer than an hour ago):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never did this at baseline

34. Weeps over the slightest provocation:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she often did this at baseline

35. Maintains consistent routines/patterns/habits:

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she never knew this at baseline

36. Is able to get into and out of his/her bed:

- 0 = Always
- 1 = Sometimes
- 2 = Never
- If never, he/she was never able to do this at baseline

37. Is spontaneously helpful (e.g. washing the dishes or setting the table):

- 0 = Often
- 1 = Sometimes
- 2 = Never
- If never, he/she never did this at baseline

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38. Is restless or awake during the night:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she was often restless or awake during the night at baseline

39. Is gloomy or sad:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she was often gloomy or sad at baseline

40. Knows which was the profession of his/her father or mother:

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

41. Is incontinent during the night:

- 0 = Never
- 1 = Sometimes
- 2 = Always
- If always, he/she was always incontinent during the night at baseline

42. Knows his/her age (a mistake of up to five years is permitted):

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

43. Knows name and or address of the home he/she lives in:

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

44. Is readily upset:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she was often readily upset at baseline

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45. Remembers where he/she has been born or living:

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

46. Can find his/her way about the home (e.g. to bedroom, toilet, his/her place at the table):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

47. Knows the name of the president (the preceding president is permitted):

- 0 = Yes
- 1 = Sometimes
- 2 = No
- If no, he/she never knew this at baseline

48. Utters physical complaints (excessive attention to physical complaints is meant here):

- 0 = Never
- 1 = Sometimes
- 2 = Often
- If often, he/she often did this at baseline

49. Uses familiar objects in the correct manner (e.g. comb, scissors, toothbrush):

- 0 = Normally yes
- 1 = Sometimes
- 2 = Normally no
- If normally no, he/she was never able to do this at baseline

50. Performs acts that are necessary in the toilet, reasonably well (perhaps with some help):

- 0 = Always
- 1 = Sometimes
- 2 = Never
- If never, he/she never did this at baseline

A. Total points for entire questionnaire: _____

B. Total number of fourth boxes checked: _____

C. Adjusted score = Line A – (Line B x 2): _____