The NTG-Early Detection Screen for Dementia, adapted from the DSQIID®, can be used for the early detection screening of those adults with a learning disability who are suspected of, or may be showing early signs of, mild cognitive impairment or dementia. It can also be used to monitor progression and change in the early stage of dementia or identify simultaneous health conditions that may otherwise remain untreated. This complies with Scotland’s National Dementia Strategy 2013-2016 which states that everyone diagnosed with dementia from April 1, 2013 is entitled to a minimum of one year’s post-diagnostic support; longer than one year is suggested for people with learning disabilities. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative tool that can be used by staff and family carers to note functional decline and health problems and record baseline information useful for further assessment and review.

It is recommended that this tool be used with adults with Down’s syndrome at age 30, repeated every two years up to age 40, and annually thereafter (more often if required). With persons with learning disabilities other than Down’s syndrome this tool should be used when suspected of experiencing cognitive change with a baseline taken at age 50. The form can be completed by anyone who is familiar with the adult (recommended to have known him or her for over six months), such as a family member, support worker, community learning disability nurse, learning disability psychiatrist, post-diagnostic link worker or health specialist, using information derived by observation or from the adult’s support plan or health record. The estimated time necessary to complete this form is between 15 and 60 minutes.

If you would like more information about the background to the National Task Group Early Detection Screen for Dementia or an electronic version of this tool, please visit www.aadmd.org/ntg/screening (Scotland version).

Name of person: (1) First____________________ (2) Last: __________________________

(3) Known as: ____________________________ (4) Date of birth: __________________

(5) Age: ___________________ (6) Sex: ___________________ (7) Date: __________________

SWIFT number (if applicable): ___________________ CHI number (if applicable): ___________________

| Female | Male |

(8) Best description of level of learning disability

- No discernible learning disability
- Borderline (IQ 70-75)
- Mild (IQ 55-69)
- Moderate (IQ 40-54)
- Severe (IQ 25-39)
- Profound and complex/multiple (IQ 24 and below)
- Unknown

(9) Diagnosed condition (tick all that apply)

- Autism
- Cerebral palsy
- Down’s syndrome
- Fragile X syndrome
- Non-specific learning disability
- Prader-Willi syndrome
- Other

Instructions:
For each question block, tick the item that best applies to the individual or situation.

Current living arrangement of person:

- Lives alone with no paid support
- Lives with partner, spouse or friends
- Lives with parents or other family members
- Lives with paid carer
- Lives in shared learning disability group home
- Lives in single tenancy with support from staff
- Lives in care home for older people (non learning disability)
- Currently in respite or assessment unit
- Lives in other: ___________________
(10) General impression of current physical health:

| Excellent | Very good | Good | Fair | Poor |

(11) Compared to previous screening, current physical health is:

| Much better | Somewhat better | About the same | Somewhat worse | Much worse |

(12) Compared to previous screening, current mental health is:

| Much better | Somewhat better | About the same | Somewhat worse | Much worse |

(13) Conditions present (tick all that apply)

- Vision impairment
- Registered blind/partially sighted
- Vision corrected by glasses
- Hearing impairment
- Deaf (very limited or no hearing)
- Hearing corrected by hearing aids
- Mobility impairment
- Not mobile – uses wheelchair independently
- Not mobile – is moved about in wheelchair
- Assisted to mobilise with use of walking aid

(14) Significant recent [in past year] life event (check all that apply)

- Death of someone close
- Changes in living arrangement, work, or day supports
- Changes in staff close to the person
- New housemates
- Illness or impairment due to accident
- Adverse reaction to medication or over-medication
- Relationship difficulties
- Victimisation / abuse / bullying
- Menopause

(15) Seizures

| Recent onset seizures | Long term occurrence of seizures | Seizures in childhood, not occurring in adulthood | No history of seizures |

(16) Diagnostic History

Has dementia or mild cognitive impairment or previously been diagnosed?

[ ] No

[ ] Yes, mild cognitive impairment
  - Date of diagnosis:

[ ] Yes, dementia
  - Date of diagnosis:
  - Type of dementia:

Diagnosed by:

- Geriatrician
- Multi-disciplinary learning disability team
- Learning Disability Psychiatrist
- Psychologist
- GP
- Other: _____________________________

(17) Is this the first screening for a baseline?

[ ] Yes
[ ] No

(18) If changes have been experienced, but no diagnosis of dementia or mild cognitive impairment has been made, please give the month and year when changes were first noted:

Please explain your suspicions about dementia or mild cognitive impairment (if relevant):
**Activities of Daily Living**

<table>
<thead>
<tr>
<th></th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>Change in past year</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs help with washing and/or bathing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs help with dressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Undresses inappropriately (e.g., in public)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs help eating (cutting food, mouthful amounts, choking)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs help using the bathroom (finding, toileting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinent (including occasional accidents)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Language & Communication**

<table>
<thead>
<tr>
<th></th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>Change in past year</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does not initiate conversation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not find correct words</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not follow simple instructions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appears to get lost in middle of conversation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not read</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not write (including printing own name)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Sleep-Wake Change Patterns**

<table>
<thead>
<tr>
<th></th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>Change in past year</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excessive sleep (sleeping more)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate sleep (sleeping less)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wakes frequently at night</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confused at night</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleeps during the day more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walks or appears to wanders for no apparent reason at night</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wakes earlier than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleeps later than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does not want to sleep in a bed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Mobility**

<table>
<thead>
<tr>
<th></th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>Change in past year</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not confident walking over small cracks, lines on the ground, patterned flooring, uneven surfaces, up or down kerbs or stairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsteady walk, loses balance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Falls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requires aids to walk</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Memory
- Does not recognise familiar persons (staff/relatives/friends)
- Does not remember names of familiar people
- Does not remember recent events (in past week or less)
- Does not find way in familiar surroundings
- Loses track of time (time of day, day of the week, seasons)
- Loses or misplaces objects
- Puts familiar things in wrong places
- Problems with printing or signing own name
- Problems with learning new tasks or names of new people

### Behaviour
- Walks or wanders for no apparent reason
- Withdraws from social activities
- Withdraws from people
- Loss of interest in hobbies and activities
- Seems to go into own world
- Obsessive or repetitive behavior
- Hides or hoards objects
- Does not know what to do with familiar objects
- Increased impulsivity (touching others, arguing, taking things)
- Appears uncertain, lacks confidence
- Appears anxious, agitated, or nervous
- Appears depressed
- Shows verbal aggression
- Shows physical aggression
- Temper tantrums, uncontrollable crying, shouting
- Shows lethargy or listlessness
- Talks to self

### Adult’s Self-reported Difficulties
- Changes in ability to do things
- Hearing things
- Seeing things
- Changes in ‘thinking’ or talks about changes in ‘head’
- Changes in interests
- Changes in memory

### Notable Significant Changes Observed by Others
- In gait (e.g., stumbling, falling, unsteadiness)
- In personality (e.g., subdued when was outgoing)
- In friendliness (e.g., now socially unresponsive)
- In attentiveness (e.g., misses cues, distracted)
- In weight (e.g., weight loss or weight gain)
- In abnormal voluntary movements (head, neck, limbs, trunk)
Known Health Concerns and Conditions* | Recent condition (past year) | Condition diagnosed in last 5 years | Lifelong condition | Condition not present
--- | --- | --- | --- | ---
**Bone, Joint and Muscle**
1. Arthritis
2. Osteoporosis

**Heart and Circulation**
3. Heart condition
4. High cholesterol
5. High blood pressure
6. Low blood pressure
7. Stroke

**Hormonal**
8. Diabetes (type 1 or 2)
9. Thyroid disorder

**Lungs/breathing**
10. Asthma
11. Chronic bronchitis, emphysema
12. Sleep disorder

**Mental health**
13. Alcohol or substance abuse
14. Anxiety disorder
15. Attention deficit disorder
16. Bipolar disorder
17. Dementia/Alzheimer’s disease
18. Depression
19. Eating disorder (anorexia, bulimia)
20. Obsessive-compulsive disorder
21. Schizophrenia
22. Other:

**Pain / Discomfort**
23. Back pain
24. Constipation
25. Foot pain
26. Gastrointestinal pain or discomfort
27. Headaches
28. Hip/knee pain
29. Neck/shoulder pain

**Sensory**
30. Dizziness / vertigo
31. Impaired hearing
32. Impaired vision

**Other**
33. Cancer – type:
34. Chronic fatigue
35. Epilepsy / seizure disorder
36. Heartburn / acid reflux
37. Urinary incontinence
38. Sleep apnoea
39. Tics/movement disorder/spasticity
40. Dental pain

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)
Current medication for: □ Yes □ No

- Health conditions
- Mental health or behaviour that challenges others
- Pain

Note any medication changes since last review:

Attach list of current medications, dosage, and when prescribed (tick to confirm attached) □

Please use this space, or over page, for any other notable changes or concerns and to outline the proposed action plan:

Next Steps (tick the relevant boxes below)

If completed by Community Learning Disability Team:
□ If no changes noted, or this is a baseline assessment, update records and agree date for review.
□ If changes are noted, please update GP and discuss with multi-disciplinary team.

If completed by health, social care or allied health professional, Social Worker, or family carer:
□ If no changes noted, or this is a baseline assessment, update Community Learning Disability Team and agree date for review.
□ If changes are noted, please update GP and Community Learning Disability Team and agree next steps.

Date of next review:

Date form completed

Name of person completing form:

Relationship to individual

Date(s) form previously completed:

Acknowledgement: Derived from the DSQIID (*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

Adapted in Scotland by Dr Karen Watchman, Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland, Nicola Ewing, Edinburgh City Council and Susan Scotland, NHS Lothian. Contact: Karen.Watchman@uws.ac.uk

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National Task Group on Intellectual Disabilities and Dementia Practices
www.aadmd.org/ntg/screening