

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. 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 on an annual, or as required basis with adults with Down's syndrome beginning with age 30, and with other persons with learning disabilities when suspected of experiencing cognitive change. 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, Alzheimer Scotland 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 (NTG) please visit <https://www.the-ntg.org/ntg-edsd>

Name of person: <sup>(1)</sup> First \_\_\_\_\_ <sup>(2)</sup> Last: \_\_\_\_\_

<sup>(3)</sup> Known as: \_\_\_\_\_ <sup>(4)</sup> Date of birth: \_\_\_\_\_

<sup>(5)</sup> Age: \_\_\_\_\_ <sup>(6)</sup> Sex: \_\_\_\_\_ <sup>(7)</sup> Date: \_\_\_\_\_

<input type="checkbox"/>	Female
<input type="checkbox"/>	Male

<sup>(8)</sup> Best description of level of learning disability

<input type="checkbox"/>	No discernible learning disability
<input type="checkbox"/>	Mild
<input type="checkbox"/>	Moderate
<input type="checkbox"/>	Severe
<input type="checkbox"/>	Profound and complex/multiple
<input type="checkbox"/>	Unknown

<sup>(9)</sup> Diagnosed condition (*tick all that apply*)

<input type="checkbox"/>	Autism
<input type="checkbox"/>	Cerebral palsy
<input type="checkbox"/>	Down's syndrome
<input type="checkbox"/>	Fragile X syndrome
<input type="checkbox"/>	Non-specific learning disability
<input type="checkbox"/>	Prader-Willi syndrome
<input type="checkbox"/>	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 characterisation of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(15) Seizures

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

(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
	Blind (very limited or no vision)
	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 service
	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
	Other:

(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):

[Tick column option as appropriate]

	Always been the case	Always but worse	Change in past year	Does not apply
<b><sup>(19)</sup> Activities of Daily Living</b>				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
<b><sup>(20)</sup> Language &amp; Communication</b>				
Does not initiate conversation				
Does not find correct words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
<b><sup>(21)</sup> Sleep-Wake Change Patterns</b>				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Walks or appears to wanders for no apparent reason at night				
Wakes earlier than usual				
Sleeps later than usual				
Does not want to sleep in a bed				
<b><sup>(22)</sup> Mobility</b>				
Not confident walking over small cracks, lines on the ground, patterned flooring, uneven surfaces, up or down kerbs or stairs				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	Change in past year	Does not apply
<b><sup>(23)</sup>Memory</b>				
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				
<b><sup>(24)</sup>Behaviour</b>				
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				
<b><sup>(25)</sup>Adult's Self-reported Difficulties</b>				
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				
<b><sup>(26)</sup>Notable Significant Changes Observed by Others</b>				
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)				

[Tick column option as appropriate]

	<sup>(27)</sup> Chronic (Long-term) Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	<b>Bone, Joint and Muscle</b>				
1	Arthritis				
2	Osteoporosis				
	<b>Heart and Circulation</b>				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	<b>Hormonal</b>				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	<b>Lungs/breathing</b>				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	<b>Mental health</b>				
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:				
	<b>Pain / Discomfort</b>				
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	<b>Sensory</b>				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	<b>Other</b>				
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)

<p><sup>(28)</sup> <b>Current medication for:</b></p> <p>Chronic conditions <span style="float: right;"><input type="checkbox"/> Yes <input type="checkbox"/> No</span></p> <p>Mental health or behaviour that challenges others <span style="float: right;"><input type="checkbox"/> Yes <input type="checkbox"/> No</span></p> <p>Pain <span style="float: right;"><input type="checkbox"/> Yes <input type="checkbox"/> No</span></p> <p>Note any medication changes since last review:</p> <p>Attach list of current medications, dosage, and when prescribed (tick to confirm attached) <input type="checkbox"/></p>	
<p><sup>(29)</sup> <b>Please use this space for any other notable changes or concerns:</b></p>  <p><sup>(30)</sup> <b>Next Steps (tick the relevant box):</b></p> <p><b>If completed by paid or family carer:</b></p> <p><input type="checkbox"/> If no changes noted, or this is a baseline assessment, inform Community Learning Disability Team of completion and review again on agreed date. Next date:</p> <p><input type="checkbox"/> If changes are noted, please update GP and Community Learning Disability Team, and agree next steps. Next date:</p> <p><b>If completed by Community Learning Disability Team or health professional:</b></p> <p><input type="checkbox"/> If no changes noted, or this is a baseline assessment, update records and review again on agreed date. Next date:</p> <p><input type="checkbox"/> If changes are noted, please update GP and Community Learning Disability Team, and agree next steps. Next date:</p> <p><b>If completed by Alzheimer Scotland link worker:</b></p> <p><input type="checkbox"/> No changes noted, or this is a baseline assessment, advise Community Learning disability team and review again at an agreed date. Next date:</p> <p><input type="checkbox"/> If changes are noted, please update GP and Community Learning Disability Team, and agree next steps. Next date:</p>	
<p><sup>(31)</sup> Date form completed</p>	<p><sup>(32)</sup> Organisation (if appropriate)</p>
<p>Name of person completing form</p>	
<p>Relationship to individual (staff, relative, health professional, support staff, Alzheimer Scotland link worker etc.)</p>	
<p>Date(s) form previously completed</p>	

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.

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