Hertfordshire

NHS
Herts Valleys
Clinical Commissioning Group

DEMENTIA DIAGNOSIS AND HEALTHCARE PATHWAY FOR PEOPLE WITH A LEARNING DISABILITY

NHS
East and North Hertfordshire
Clinical Commissioning Group

as one

Hertfordshire Partnership
University NHS Foundation Trust

NHS

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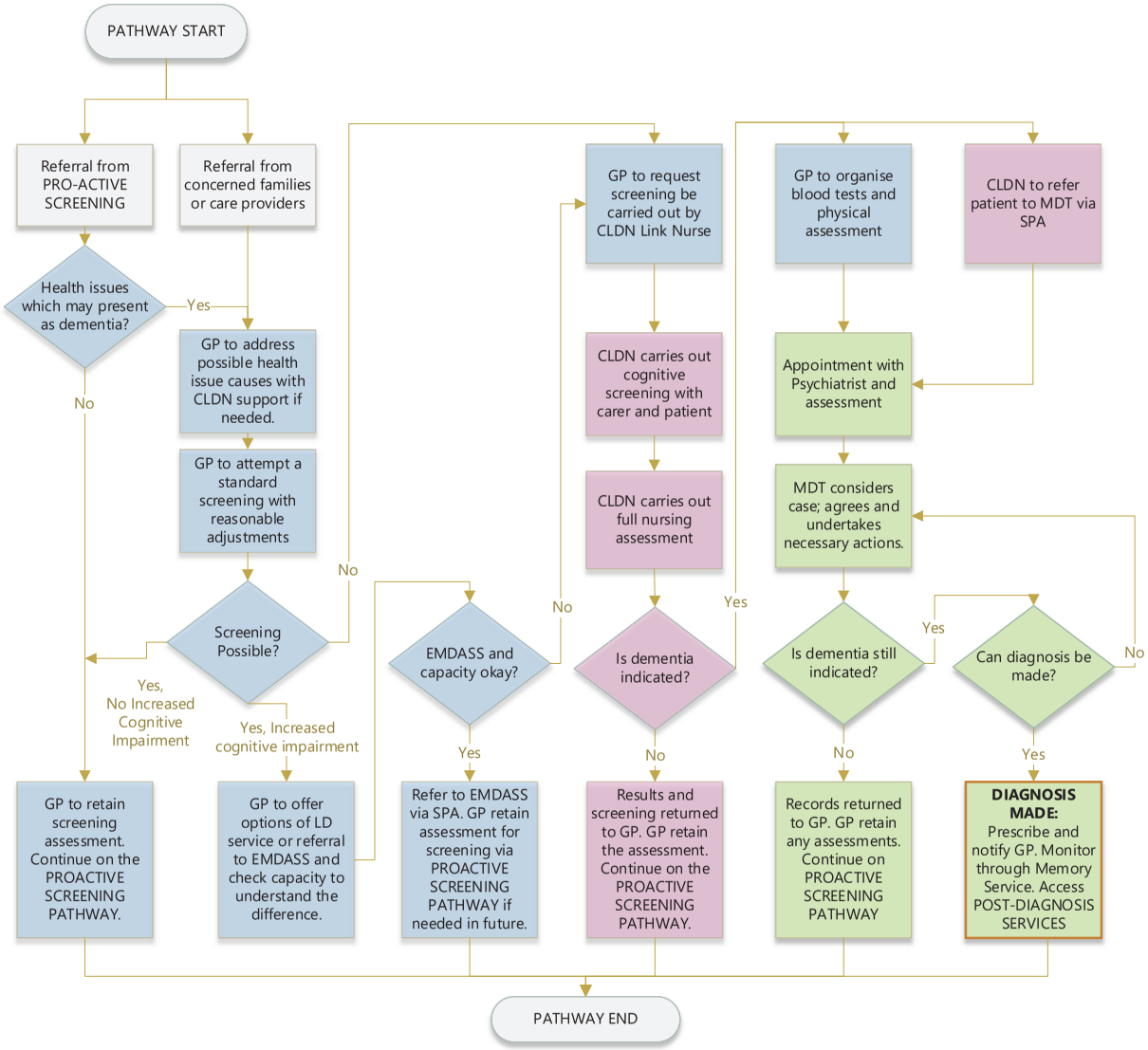
Contents

Dementia Diagnosis and Healthcare Pathway for People with Learning Disabilities



PROACTIVE SCREENING:
Does person have Down's Syndrome Diagnosis? If so then offer baseline screening at 30 years of age or older if a baseline assessment has not been completed.
Then invite the person back for re-screening at the age of 40 and then every two years until the age of 50 after which time screening should be annual.

NOTE: Invitations should initially be from the GP. The results of screening should be held on GP records, but the CLDN may also hold these on the agreed database and will link with the GP re future screenings.

Multi-Disciplinary Meeting [MDT]:
The case will be brought to the multi-disciplinary team. At these meetings the case is considered and actions agreed and monitored through the meeting.

Both screening tools are DLD (Dementia Questionnaire for People with Learning Disabilities) and the NTG – EDSD (Early Detection Screen for Dementia) to be used.
Post-diagnosis package of support to be covered in new pathway. Comparable to normal dementia pathway.

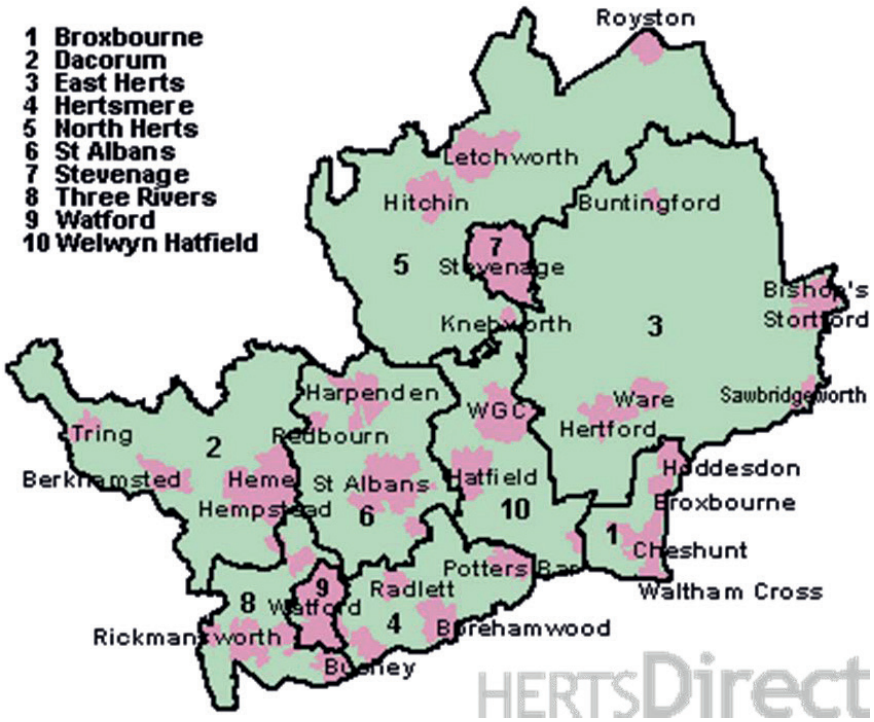
Mainstream services can link back into Memory Service should that be needed.

KEY:
Blue = GP lead;
Pink = CLDN lead;
Green = MDT lead

Introduction

This document describes the dementia diagnosis and healthcare pathway for people with a learning disability in Hertfordshire. The pathway aims to support a standard approach to referrals for people with a learning disability (LD) where symptoms indicate or there may be a concern that the individual may be suffering from dementia. The pathway guides the team around the individual through the sequence of events from referral to screening and diagnosis, and post-diagnosis. The aim is to ensure that a coordinated approach is taken by the multi-disciplinary team and the individual provided with the most suitable person-centred care in the diagnosis and healthcare process.

Hertfordshire



Key Facts and Figures

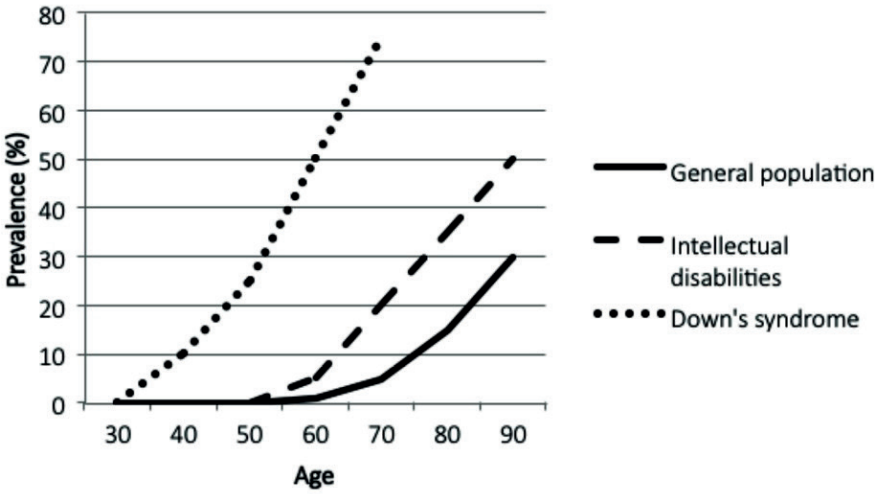
Hertfordshire comprises a single county council and ten district councils across two clinical commissioning groups (CCG): Herts Valley CCG with 70 General Practitioner (GP) practices, and East and North Hertfordshire CCG with 62 GP practices. The county's specialist Learning Disability (LD) services are delivered by Hertfordshire Partnership University Foundation Trust (HPFT) across seven localities. Mainstream dementia services including the Early Memory Diagnosis and Support Service (EMDASS) sit under a different strategic business unit to the LD services.

Hertfordshire has 1.2M residents circa 5,000 of whom with a Learning Disability have been detailed on the Quality and Outcomes Framework (QOF) register. The prevalence of Down's Syndrome in this population is estimated at 15% to 20%, i.e. 750 to 1,000 people within Hertfordshire based upon the QOF.
However, Emerson & Hatton (2008) estimate that there should be 20,000 people in Hertfordshire with LD/learning difficulties.

Prevalence

People with intellectual disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age (as demonstrated by the chart below). Life expectancy of people with Down's syndrome has increased significantly and the number of older people with Down's syndrome has been increasing. The incidence and prevalence of Down's syndrome remains relatively stable.

Chart: Comparison of dementia prevalence by age (Dementia and People with Intellectual Disabilities, BPS, April 2015).



It is expected that the proportion of individuals with a learning disability over the age of 65 will have doubled by the year 2020. And of those people with a learning disability:

- 12% of people over 50 years will develop dementia (Moss and Patel 1995)
- 20% of people over 65 years will develop dementia (Cooper 1997)

For those with Down's syndrome the prevalence is even more pronounced:

- 54% of people over 60 years will develop dementia

Comparative Statistics

- 3 – 7% over the age of 65 of the general population have dementia
- 22% over the age of 65 with a learning disability have dementia
- 50 – 60% over the age of 65 with Down's syndrome have dementia

This is 3 to 4 times higher than the general population

Other associated conditions in older people with a learning disability:

- Higher rates of arthritis
- Impaired mobility
- Respiratory conditions

In people with Down's Syndrome:

- Thyroid problems
- Hearing problems often due to narrow ear canal

(Strydom 2014) (The British Psych Society 2015)

How the pathway was developed

A multidisciplinary working group was established to look at clarifying and further developing this clinical and healthcare Pathway. The group included a General Practitioner lead and representation from the fields of: Psychiatry, Psychology, Nursing, Occupational Therapy; Speech and Language therapy; and Commissioning. The aim was to develop a pathway to support all individuals with a learning disability who develop dementia or where there may be a query around the possibility of dementia.

Aims of the pathway

- To document and confirm a baseline screening programme
- Ensure early assessment and appropriate diagnosis
- Provide a coordinated approach to the assessment and intervention
- Provide a process for monitoring the person over time
- Support carers, clients and professionals via information and training
- Spread knowledge and information
- To address the need for training various disciplines in using assessment tools
- Raise awareness and education for family and carers about dementia
- The need for continuous monitoring and evaluation of the dementia services through auditing the service and screening for client/carer satisfaction.

Proactive screening pathway

Baseline screening assessment for dementia is important to establish a baseline level of functioning and cognitive ability when the person is healthy, it is very difficult to detect early signs of dementia later in life.

There is a national agreement for the need for baseline screening for people with Down's syndrome and learning disabilities. Currently, evidence suggests the need for prospective screening for only people with Down's syndrome. There is not enough evidence to indicate the need for prospective screening for people with a learning disability without Downs Syndrome. Screening for this group should be in response to concerns raised about changes in their memory, behaviour or skills.

For people with a learning disability the following tools will be used: where baseline screening has already been undertaken utilising the Dementia Questionnaire for People with Learning Disabilities (DLD), formerly known as the DMR (Evenhuis et al 2007). This will continue to be used. The DLD is a screening tool for early detection of dementia in adults with a learning disability. It is completed by carers and consists of 50 items. There are eight subscales, short-term memory and long-term memory, orientation, speech, practical skills, mood, activity and interests, and behavioural disturbance.

For those people with a learning disability who are new to screening then, in addition to the DLD, it is proposed to use the Early Detection Screening Tool (NTG-Early Detection Screen for Dementia) developed by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), Moran et al., 2013). The HPFT he senior doctors' meeting on have recently confirmed that both DLD and NTG should be completed as screening tools, as they are both complementary and provide useful information to determine whether more detailed cognitive assessments should be completed.

Baseline screening

Baseline screening will be offered to all people with Down's Syndrome at the age of 30 and all people with a learning disability at the age of 50. The screening will be carried out by Community LD Nurses (CLDN) at the request of the individual's General Practitioner (GP).

Issues regarding capacity to consent and best interests will always be taken into account before conducting such an assessment.

A copy of the baseline assessment for each individual will be kept in client GP records, Care Management records, client's personal files (at their place of residence) and in the CLDN's multi-disciplinary notes.

Prospective monitoring

Prospective monitoring entails regular assessment to check for early signs of dementia by repeating the baseline assessment. This requires that the same tool be used for monitoring as has been used for the baseline.

Individuals with Down's syndrome - Further to the baseline assessment at the age of 30, another assessment will be carried out at the age of 40 and every two years thereafter. Once the client reaches the age of 50 the assessment will be done annually. If at any stage a decline has been noticeable, either from repeated assessment or from concerns raised by client carers, the client will move to reactive monitoring.

Individuals without Down's syndrome - The evidence does not currently indicate a need for prospective monitoring for people with a learning disability without Down's syndrome. Screening for this group should be in response to concerns raised about changes in their memory, behaviour or mood.

Reactive monitoring

Reactive monitoring starts when concerns are raised about deterioration of the client's cognitive ability, level of functioning or a change in personality. The reliability and efficiency of reactive screening will be greatly enhanced if a baseline assessment is available. The start of reactive monitoring very much relies on carers noticing relevant signs of changes and alerting relevant people. The reality is that this does not always happen due to the high turnover of staff in care homes, therefore, regular checklists at annual reviews should be completed.

Reactive monitoring starts by completing the appropriate monitoring tools. Depending upon whether a baseline assessment has been carried out this should as a minimum be done utilising the same tool for comparison. However, new assessments should use both the Dementia Questionnaire for People with Learning Disabilities (DLD) and the Early Detection Screening Tool (NTG-Early Detection Screen for Dementia). These assessments provide analysis of a broad range of skills and behaviour, Including communication, daily living skills, socialisation, motor skills and maladaptive behaviour.

Dementia care pathway description

The pathway is entered via the proactive screening process or through referral from concerned families, care providers or the individual themselves. Once a proactive screening has been undertaken, the records are held with the GP and if there are any health issues which may present as dementia the GP will address these with the support of the CLDN as required.

Families and carers of the individual with a learning disability who have concerns about the individual will also enter the pathway at this point, perhaps during the annual health check or as a specific appointment. Again, the GP will look to address any health concerns with CLDN support if needed and attempt a standard screening using assessment tools for dementia in the general such as the Mini-Mental State Examination with reasonable adjustments.

If there is no decline in cognitive impairment and health issues have/are being addressed, then the individual will continue on the proactive screening pathway – this focuses on those with Down's Syndrome and the GP will retain any screening as a baseline.

If screening using the standard tool with reasonable adjustments was able to be carried out, then the GP will be able to offer options to the patient to utilise the mainstream Early Memory Diagnosis and Support Service (EMDASS) or to make use of the specialised LD services. The GP will need to ensure that the patient has the capacity to understand the options available and make their choice.

Should the patient make an informed choice and select the EMDASS option then the GP would retain the assessment in their records and make the referral to EMDASS via the Hertfordshire Single Point of Access (SPA).

If the patient chooses to utilise the LD Memory Services or it has not been possible to carry out the standard screening despite reasonable adjustments, then the GP will request that the a screening be carried out by the CLDN. The CLDN will then carry out a cognitive screening assessment using both assessment tools (NTG – EDSD and DLD). The CLDN will also carry out a full nursing assessment. If dementia is not indicated, then the results will be returned to the GP for retention and the patient will continue on the proactive screening pathway. If, however, dementia is still indicated then the CLDN will refer the inpatient to the memory service SPA and arrange for the GP to organise blood tests (the attachments to this pathway give details of the current requirements) and a physical assessment.

The physical screening should include physical examination, attention should be paid to: -

- Neurological examination including focal deficit, gait abnormality, speech abnormality
- Endocrine system e.g. signs of hypothyroidism
- Cardiovascular system
- Screening for visual and hearing impairment
- Blood investigations – including full blood count, urea and electrolytes, blood sugar, thyroid function, liver function, B12 and folate, lipid profile.
- At this stage the client will be seen by the psychiatrist for an assessment and will have all physical information to hand. A cognitive assessment will be undertaken utilising CAMCOG and also informant interviews. This may require more than one appointment.

Best practice (NICE guidance and BPS guidance), for which the memory service was recently audited (August 2016) indicate that the following should be undertaken:

- Structured History eliciting the difficulties with memory, e.g. using CAMDEX-DS (Cambridge mental disorders of the elderly examination- informant) or any other structured informant interview
- Objective assessment of cognitive and adaptive functioning using CAMCOG (Cambridge cognitive examination) or TSI (Test for Severe Impairment).
- Mental state examination
- Physical examination/assessment by GP.

- Sensory assessment, vision and hearing (documentation that it was done)
- Longer time and recent life events.
- Investigation: CT/MRI not essential. ECG only if indicated or starting acetyl cholinesterase inhibitors.
- MDT assessment – referral to occupational therapist (OT), speech and language therapist (SALT), community learning disability team (CLDT) (if appropriate).

The case will be brought to the multidisciplinary team. At these meetings the case is considered, and actions are agreed and are monitored through the meeting.

In the event of other health indicators being identified which have caused the decline in cognitive function, and a possible dementia diagnosis is no longer being considered; then records are returned to the GP who retains any assessments and the patient returns to the proactive screening pathway.

If dementia is still indicated, but a diagnosis cannot yet be made then the patient continues to be considered by the MDT until a diagnosis can be made or dementia is ruled out.

Once a diagnosis of dementia has been made then the psychiatrist will prescribe as appropriate and notify the patient's GP. The patient will then continue to be monitored through the memory service and post-diagnosis support addressed.

Client and carers will be given information about dementia as an illness and how to cope with it. There are dementia inserts for the Purple Folder if that is used and there is also a dementia handbook available. They will also be advised and helped to link with voluntary organisations such as Alzheimer's Society and Down's syndrome Association.

Roles and responsibilities

It is well recognised that effective care can only be provided when there is good partnership working within health services, between learning disability and generic dementia services and across statutory, private and voluntary agencies. Therefore, every effort will be made to liaise with other services involved and keep the client care coordinated well.

GENERAL PRACTITIONER

The GP is the main contact for the individual with a Learning Disability and their carers and family. The process of screening, diagnosis and support may take place over a significant time frame and the GP is likely to have most contact with the individual for annual health checks and on-going medical needs. The GP is therefore the holder of all the relevant screening records and information fed back from the MDT/memory service. The GP will liaise with the CLDN to ensure the necessary assessments and will also ensure the necessary tests are carried out to rule out other causes for dementia like symptoms.

COMMUNITY LEARNING DISABILITY NURSE (CLDN)

The nurse role is:

- To keep a database of assessments and carry out assessment updates according to timescales agreed.
- One nurse to attend the multi-disciplinary memory meetings on each patch. The function of the nurse attending is to:
    - Provide updates of assessments and re-assessments that have been carried out
    - Discuss cases that are open to the nurse
    - Establish if there are cases that require nurse support.
- Nurse will attend outpatient appointments relating to service users they have open to them and are actively working with but not with everyone who is on the database.
- Nurses will hold actively open cases with the following:
    - Someone newly diagnosed – will support care staff to action the purple folder dementia checklist.
    - When care providers are struggling with changes / lack of skills and awareness of how to support someone – nurse can provide some dementia awareness training and bespoke it to the individual needs of the person. Joint working with Speech and Language Therapy (SALT), psychiatry, etc. Then support the care staff to adapt their care plans.
    - When someone is prescribed dementia medication – nurse will monitor BP for initial period and then ensure care staff are enabled to continue this. The nurse will keep open if care support is not able to do this.
    - To support the completion of an end of life plan in line with the person's wishes.
- Once all equipment is in place, care staff are equipped in managing the person's changes and blood pressure (BP) has been monitored through the introduction of new medication, and care staff have a clear guide of how to continue this, then the nurse will close involvement. The person can be re-referred if changes indicate a further nursing need but, it would severely impact nurses capacity to have all people with dementia as open cases continuously.

PSYCHIATRIST

The Psychiatrist is responsible for making the decision with regards to diagnosis; they will be reliant on the information and assessments of other professionals to assist in this process. The Psychiatrist will then decide on the most appropriate pharmacological treatment.

OCCUPATIONAL THERAPIST (OT)

The primary goal of Occupational Therapy is to enable people to participate in the activities of everyday life. Occupational Therapists engage with clients using activities that are meaningful and purposeful to them to assess and treat the physical, psychological and social needs of the individual and their environment to enable them to reach or retain their optimum potential.

SPEECH AND LANGUAGE THERAPIST (SALT)

Speech and Language Therapists working with individuals with learning disabilities who have developed dementia cover the two main areas of communication and eating and drinking.

CLINICAL PSYCHOLOGIST

Clinical Psychologists often play an important role in diagnosing dementia, particularly when the person's difficulties are complex, and the diagnosis is unclear. To do this, they work with the individual with a learning disability, their family and any additional carers, to gather information and observe the individual in a variety of settings. They can do assessments of a person's capacity to make decisions, particularly in the early stages of illness; and can intervene where there are issues with challenging behaviour, depression and anxiety for example.

INTENSIVE SUPPORT NURSE (ISN)

The ISN will not play a role in working with behaviour changes relating to dementia as these relate to Person, Environment or Place. CLDN's will pick up referrals relating to these behaviour changes and work through the new Purple Folder Checklist with the person's carers / care providers.

References.

The British Psychological Society, the Division of Clinical Psychology and the Royal College of Psychiatrists “Dementia and People with Intellectual Disabilities – Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia”. April 2015

Department of Health (2009) Living Well with Dementia – A National Dementia Strategy. London TSO

Turk V. Dodd K & Christmas M (2001) Down’s syndrome and Dementia: briefing for commissioners (online). London: Mental Health Foundation/Foundation for People with Learning Disabilities. Available from: http://www.learningdisabilities.org.uk/html/content/dembrief.cfm

NICE (National Institute for Clinical Excellence) Dementia Assessment and Diagnosis Pathway, March 2017

HPFT Practice Audit & Clinical Effectiveness Team Report on Hertfordshire county wide audit of the assessment, diagnosis and intervention of people with Intellectual disability who develop dementia. November 2016.

Attachments

1. The NICE Dementia Assessment and Diagnosis Pathway. January 2018

2. Standards for the Hertfordshire county wide audit of the assessment, diagnosis and intervention of people with Intellectual Disability who develop dementia. February 2016.

3. Revised Protocol for the use of Anti-Cholinesterase Drugs in Alzheimer's Disease for People with Learning Disability March 2017 (HPFT)

4. National Task Group Early Detection Screen for Dementia NTG-EDSD Manual V1 May 2013 and Screening Tool

1. The NICE Dementia Assessment and Diagnosis Pathway. January 2018

The latest version of the NICE pathway for dementia is included as an attachment for convenience and reproduced as a printed and e-document under the NICE open content license.

The pathway includes people with Learning Disabilities and dementia and provides further links to other relevant quality standards, pathways and guidance documents.

For the most current version see the website. At the time of writing the links given were correct. The index and entry page to the dementia pathway which includes assessment and diagnosis and management is at the following link:

https://pathways.nice.org.uk/pathways/dementia

NICE National Institute for Health and Care Excellence

NICE Pathways

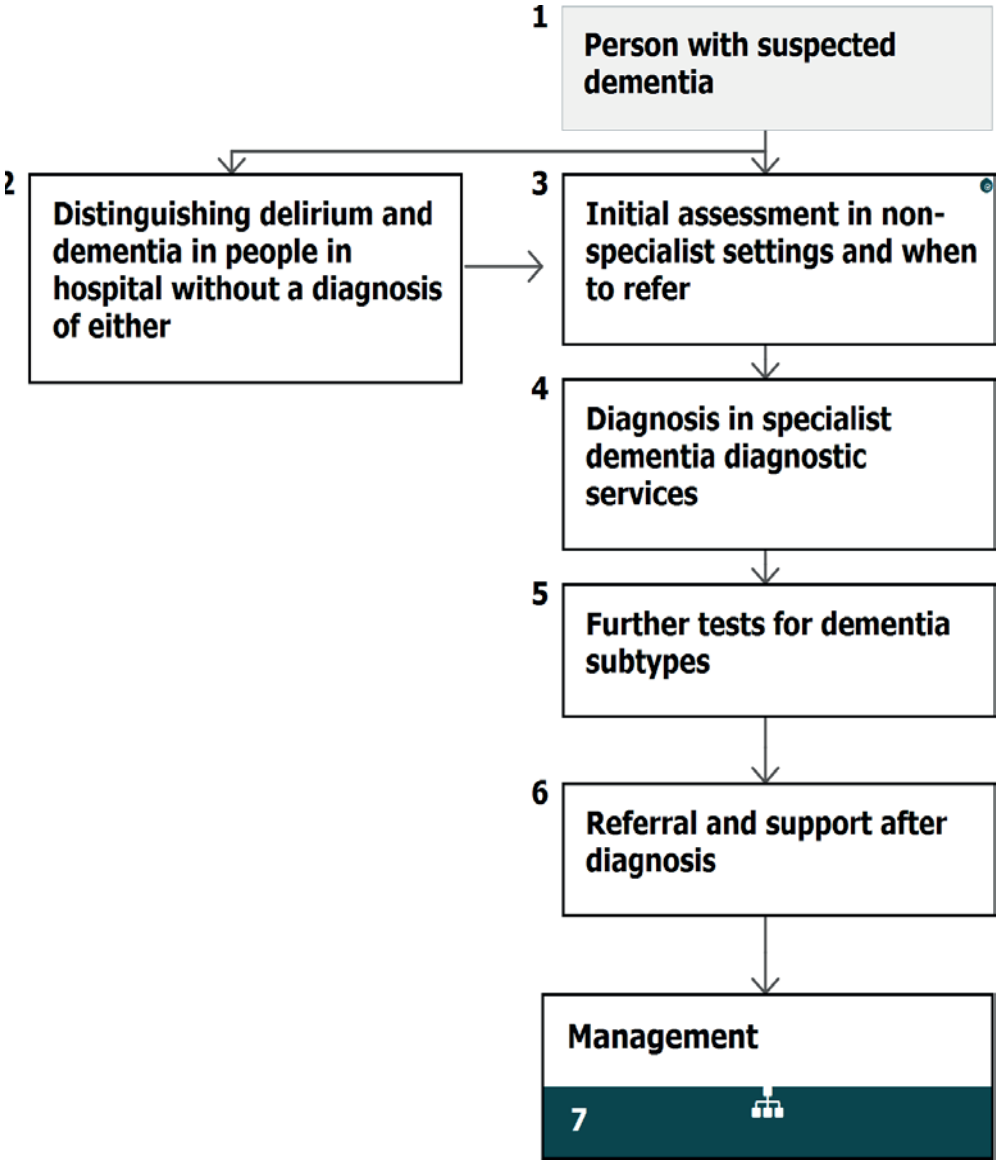
Dementia assessment and diagnosis

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/dementia
NICE Pathway last updated: 21 June 2018

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Person with suspected dementia

No additional information

2 Distinguishing delirium and dementia in people in hospital withouta diagnosis of either

For people who are in hospital and have cognitive impairment with an unknown cause, consider using one of the following to find out whether they have delirium or delirium superimposed on dementia, compared with dementia alone:

- the long confusion assessment method (CAM)
- the Observational Scale of Level of Arousal (OSLA).

Do not use standardised instruments (including cognitive instruments) alone to distinguish delirium from delirium superimposed on dementia.

If it is not possible to tell whether a person has delirium, dementia, or delirium superimposed on dementia, treat for delirium first. For guidance on treating delirium, see NICE's recommendations on delirium.

3 Initial assessment in non-specialist settings and when to refer

At the initial assessment take a history (including cognitive, behavioural and psychological symptoms, and the impact symptoms have on their daily life):

- from the person with suspected dementia **and**
- if possible, from someone who knows the person well (such as a family member).

If dementia is still suspected after initial assessment:

- conduct a physical examination **and**
- undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline **and**
- use cognitive testing.

When using cognitive testing, use a validated brief structured cognitive instrument such as:

- the 10-point cognitive screener (10-CS)

- the 6-item cognitive impairment test (6CIT)
- the 6-item screener
- the Memory Impairment Screen (MIS)
- the Mini-Cog
- Test Your Memory (TYM).

Do not rule out dementia solely because the person has a normal score on a cognitive instrument.

When taking a history from someone who knows the person with suspected dementia, consider supplementing this with a structured instrument such as the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) or the Functional Activities Questionnaire (FAQ).

Refer [See page 9] the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if:

- reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated **and**
- dementia is still suspected.

If the person has suspected rapidly-progressive dementia, refer them to a neurological service with access to tests (including cerebrospinal fluid examination) for Creutzfeldt–Jakob disease and similar conditions.

Medicines that may cause cognitive impairment

Consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives:

- when assessing whether to refer a person with suspected dementia for diagnosis
- during medication reviews with people living with dementia.

People with learning disabilities

For more guidance on assessing for dementia in people with learning disabilities, see NICE's recommendations on assessment of mental health problems in people with learning disabilities.

Case finding

Only conduct case finding [See page 9] for suspected dementia as part of a clinical trial that also provides an intervention to people diagnosed with dementia.

Hearing assessment

For guidance on hearing assessments for people with suspected or diagnosed dementia, see assessment and referral in NICE's guidance on hearing loss.

Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

Dementia: support in health and social care

2. Memory assessment services

Mental wellbeing of older people in care homes

3. Recognition of mental health conditions

4 Diagnosis in specialist dementia diagnostic services

Diagnose a dementia subtype (if possible) if initial specialist assessment (including an appropriate neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out.

If Alzheimer's disease is suspected, include a test of verbal episodic memory [See page 9] in the assessment.

Consider neuropsychological testing if it is unclear:

- whether the person has cognitive impairment **or**
- whether their cognitive impairment is caused by dementia **or**
- what the correct subtype diagnosis is.

Use validated criteria to guide clinical judgement when diagnosing dementia subtypes, such as:

- International consensus criteria for dementia with Lewy bodies

- International FTD criteria for frontotemporal dementia (progressive non-fluent aphasia and semantic dementia)
- International Frontotemporal Dementia Consortium criteria for behavioural variant frontotemporal dementia
- NINDS-AIREN criteria (National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherché et l'Enseignement en Neurosciences) for vascular dementia
- NIA criteria (National Institute on Aging) for Alzheimer's disease
- Movement disorders Society criteria for Parkinson's disease dementia
- International criteria for Creutzfeldt-Jakob disease.

Offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear.

For information on when to consider further tests see further tests for dementia subtypes [See page 6].

People with learning disabilities

Consider supplementing an assessment of dementia with an adult with learning disabilities with:

- measures of symptoms, such as the Dementia Questionnaire for People with Learning Disabilities (DLD), the Down Syndrome Dementia Scale (DSDS) or the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)
- measures of cognitive function to monitor changes over time, such as the Test for Severe Impairment (TSI)
- measures of adaptive function to monitor changes over time.

Complete a baseline assessment of adaptive behaviour with all adults with Down's syndrome.

5 Further tests for dementia subtypes

When to consider further tests

Only consider further tests if:

- it would help to diagnose a dementia subtype **and**
- knowing more about the dementia subtype would change management.

Alzheimer's disease

If the diagnosis is uncertain and Alzheimer's disease is suspected, consider either:

- FDG-PET, or perfusion SPECT if FDG-PET is unavailable

or

- examining cerebrospinal fluid for:
  - either total tau or total tau and phosphorylated-tau 181 **and**
  - either amyloid beta 1-42 or amyloid beta 1-42 and amyloid beta 1-40.

If a diagnosis cannot be made after one of these tests, consider using the other one.

Be aware that the older a person is, the more likely they are to get a false positive with cerebrospinal fluid examination.

Do not rule out Alzheimer's disease based solely on the results of CT or MRI scans.

Do not use Apolipoprotein E genotyping or electroencephalography to diagnose Alzheimer's disease.

Be aware that young-onset Alzheimer's disease has a genetic cause in some people.

Dementia with Lewy bodies

If the diagnosis is uncertain and dementia with Lewy bodies is suspected, use ^{123}I-FP-CIT SPECT.

If ^{123}I-FP-CIT SPECT is unavailable, consider ^{123}I-MIBG cardiac scintigraphy.

Do not rule out dementia with Lewy bodies based solely on normal results on ^{123}I-FP-CIT SPECT or ^{123}I-MIBG cardiac scintigraphy.

Frontotemporal dementia

If the diagnosis is uncertain and frontotemporal dementia is suspected, use either:

- FDG-PET **or**
- perfusion SPECT.

Do not rule out frontotemporal dementia based solely on the results of structural, perfusion or metabolic imaging tests.

Be aware that frontotemporal dementia has a genetic cause in some people.

Vascular dementia

If the dementia subtype is uncertain and vascular dementia is suspected, use MRI. If MRI is unavailable or contraindicated, use CT.

Do not diagnose vascular dementia based solely on vascular lesion burden.

Be aware that young-onset vascular dementia has a genetic cause in some people.

6 Referral and support after diagnosis

After a person is diagnosed with dementia, ensure they and their family members or carers (as appropriate) have access to a memory service or equivalent hospital- or primary-care-based multidisciplinary dementia service.

Memory services and equivalent hospital- and primary-care-based multidisciplinary dementia services should offer a choice of flexible access or prescheduled monitoring appointments.

When people living with dementia or their carers have a primary care appointment, assess for any emerging dementia related needs and ask them if they need any more support.

7 Management

See Dementia / Dementia management

A strategy of actively assessing people who are at risk for a particular disease, before they present with symptoms and before there is clinical suspicion of the condition. It does not refer to situations such as assessing people for dementia after an acute episode of delirium, where clinical suspicion of dementia is likely to already be raised.

Episodic memories include information about recent or past events and experiences (rather than factual knowledge, or habits and skills). They may be recent, or from the distant past (remote or long-term episodic memory). Tests to assess episodic memory may use either verbal or visual material. Examples of verbal episodic memory tests include reading the person a list of words or a short story and asking them to recall this information, both immediately and after a delay.

A referral to a diagnostic service does not have to involve a clinic appointment. People can be seen in community settings (such as their home or a care home), or advice can be provided to the referrer without a formal appointment being made. The key issue is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to post-diagnostic support and treatment. Specialists are those with the appropriate knowledge and skills and include secondary care medical specialists (for example psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in assessing and diagnosing dementia.

Glossary

AChE

acetylcholinesterase

cognitive stimulation

engaging in a range of activities and discussions (usually in a group) that are aimed at general improvement of cognitive and social functioning

cognitive training

guided practice on a set of standard tasks that are designed to reflect particular cognitive functions; there may be a range of difficulty levels, to fit the tasks to each person's level of ability

FDG-PET

fluorodeoxyglucose-positron emission tomography-CT

specialist clinician

(for the purpose of starting and monitoring treatment with cholinesterase inhibitors and memantine) those with appropriate knowledge and skills and include secondary care medical specialists (for example psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in diagnosing and treating Alzheimer's disease

SPECT

single photon emission CT

Sources

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97

Mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

2. Standards for the Hertfordshire county wide audit of the assessment, diagnosis and intervention of people with Intellectual Disability who develop dementia. February 2016.

The below are the standards used for the audit of dementia diagnosis records carried out by HPFT in Summer of 2016. They are based upon those in the guidance produced jointly by the British Psychological Society, the Division of Clinical Psychology and the Royal College of Psychiatrists in April 2015 “Dementia and People with Intellectual Disabilities – Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia”.

For the most April 2015 version of this guidance see the website at the link below. At the time of writing the links given were correct.

https://www1.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf

Standards for the Hertfordshire county wide audit of the assessment, diagnosis and intervention of people with Intellectual Disability who develop dementia

These were agreed 29th February 2016 and based on the British Psychological Society guidelines April 2015. The outcomes were published in HPFT Practice Audit & Clinical Effectiveness Team's "Report on Hertfordshire county wide audit of the assessment, diagnosis and intervention of people with Intellectual disability who develop dementia". November 2016.

The data collection took place between June 2016 and August 2016 and a total of 73 Service Users were seen in all 7 memory services in Hertfordshire. Service Users records were audited against the standards listed below.

Standards (British Psychological Society April 2015)

Screening for patients with Downs's syndrome on out case load/opened to us.

- To have a baseline at 30 years.
- 2 yearly monitoring >40 years
- Yearly monitoring >50 years

Monitoring and assessments for patients referred to dementia clinic

- Structured History eliciting the difficulties with memory.eg using CAMDEX-DS (Cambridge mental disorders of the elderly examination- informant) or any other structured informant interview
- Objective assessment of cognitive and adaptive functioning using CAMCOG (Cambridge cognitive examination) or TSI (Test for Severe Impairment).
- Mental state examination
- Physical examination/assessment by GP.
- Sensory assessment, vision and hearing (documentation that it was done)
- Longer time and recent life events.
- Investigation: CT/MRI not essential. ECG only if indicated or starting acetyl cholinesterase inhibitors.
- MDT assessment--- referral to occupational therapist (OT), speech and language therapist (SALT), community learning disability team (CLDT) (if appropriate).
- Information leaflets on dementia.

Monitoring for those starting anti-dementia medications

- Evidence/results of recent blood tests.
- Baseline pulse, BP and ECG.
- Involvement of CLDT nurse for monitoring of BP, PR and medication side effects.
- Information leaflets on anti-dementia medication to carers and service users.
- Follow up review.

3. Revised Protocol for the use of Anti-Cholinesterase Drugs in Alzheimer's Disease for People with Learning Disability March 2017 (HPFT)

Revised Protocol for the use of Anti-Cholinesterase Drugs in Alzheimers Disease for People with Learning Disability:

March 2017

Referral Guidelines:

1. Referrals can be self-referrals or can come via GP. CLDT, Nursing, SPA. GP should be made aware of all the referral as shared care with primary care

2. Dementia Blood screen: needs to be done by GP before the basic screening

Dementia Blood screen to include U& E, FBC, LFT, Glucose, Ca++, B12, Folate levels.

3. Access to recent annual physical health checks

4.CLDT Nurses to take lead on health check and Baseline DLD

First Clinic Assessment

1. Initial assessment can take up to 2hours and to include MDT member where possible
2. Semi-structured interview exploring changes in functional skills, memory, behaviour, orientation, mood and consider other factors for these changes. Also can us one of tools for e.g. CAMDEX DS,
3. Mental state examination,
4. Objectives assessment of cognitive and adaptive functioning.
5. Sensory assessment (documentation that it was done)
6. Discussion of Longer time and recent life events.
7. Investigation: CT/MRI not essential. ECG only if indicated or on starting medications.
    a. MDT assessment--- referral to OT, SALT, CLDT

8. Capacity to consent
9. Physical examination/assessment and baseline documentation of BP and pulse (>55).
10. Easy Read Leaflets on Dementia and medication to be given and discussed with Carers and Service user
11. Community Nurse to be allocated(where possible)

Initiation of Anti Cholinesterase Drugs in Alzheimer's Disease in PWLD

1.NICE Guideline recommends use of anticholinesterase Inhibitors for Mild to Moderate AD in LD

2. Memantine can be used for moderate Dementia or where ACHE have not been effective

3. Evidence to suggest starting at low dose for People with LD and Downs. Slower Titration of dose recommended and to be aware of other drug interaction

4. The drug should be monitored in the community by the community nurse within

4-6 weeks include BP, Pulse and monitoring of side effects

Follow up at Specialist Clinic at 3 months

a) Monitor drug effect

b) Review mental state

c) General improvement in mood and behaviour and functioning

d) Check Pulse and BP(DOCUMENT), Repeat ECG if indicated

At 6 Months:

1. Monitoring at Specialist Clinic

2. Repeat DLD

3. Drug review include tolerability

4. Discussion about Shared Care protocol including provision of the prescription

5. Consider Drug Continuation Criteria

6. Consider Drug Discontinuation Criteria

Continuation Criteria:

1. Improvement or no significant decline in baseline DLD scores (significant deterioration represented by an increase of cognitive score of 7 and an increase of social score of 5).

2. Patient (where possible), carer and clinician agree that continuing the drug is of benefit to the patient.

3. Pulse and ECG are satisfactory.

Discontinuation Criteria:

1. Poor tolerability

2. Poor Compliance

3. Withdrawal of Consent

4. Decline in Global functioning and behaviour based on DLD Scores (significant deterioration represented by an increase of cognitive score of 7 and an increase of social score of 5).

End of Life Care planning including Palliative discussion

1. Preparation for palliative and end of life care should be ongoing as dementia progresses from diagnosis onwards and embedded in personalised plans for care and support at every stage.

2. End of life strategy: PWID should have the same end of life care planning and access the same palliative care services as everyone else.

3. All care should be in accordance with provision of the Mental Capacity Act.

4. Partnership working and close collaboration between professionals in Intellectual disability and other health services ,particularly palliative services is important to ensure appropriate access and timing to specialist support and appropriate symptom management .

4. National Task Group Early Detection Screen for Dementia NTG-EDSD Manual V1 May 2013 and Screening Tool

The latest versions of the manual for the EDSD (Early Detection Screen for Dementia) screening tool and the tool itself are included as an attachment for convenience. NTG-EDSD is available for downloading and use by any interested families and organizations or agencies. .

For the most current version see the website. At the time of writing the links given were correct. The index and entry page to the dementia pathway which includes the manuals and forms, including a screening form which can be used for electronic data input is at the following link:

http://aadmd.org/ntg/screening

National Task Group on Intellectual Disabilities and Dementia Practices

National Task Group Early Detection Screen for Dementia

NTG-EDSD

Manual

Version 1 May 2013-e

Available at www.aadmd.org/ntg/screening

For suggestions, comments, or more information,
contact Dr. Lucille Esralew at drlucyesralew @gmail.com

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Version 1 May 2013-e

BACKGROUND

The National Task Group Early Detection Screen for Dementia (NTG-EDSD) is an informant-based rating tool for use with adults with intellectual and developmental disability who are suspected of having changes in thinking, behavior, and adaptive skills suggestive of mild cognitive impairment or dementia. It is considered an administrative, and not a clinical assessment, tool. The use of the NTG-EDSD provides an opportunity to review relevant information that can be used by the team and healthcare practitioner to aid in shared decision-making, and planning training, services, and supports. The NTG-EDSD was not designed to diagnose dementia, but to be a help in the early identification and screening process, as well as to provide information to begin the dialogue with health care professionals. Persons who complete this instrument are asked to indicate whether they have observed the occurrence of new problems or a worsening of problems that have previously been observed. The items are associated with changes in cognition, behavior, mood, and activities of daily living.

Why Early Detection?

Early detection is one of the aspects stressed by the *National Plan to Address Alzheimer's Disease*. With early detection, assessment and diagnosis can be carried out to determine whether cognitive changes are the result of a neuropathological process related to disease or trauma to the brain, or attributable to other causes, often treatable and reversible. However, early detection among persons with lifelong cognitive impairments can often be difficult and problematic (Prasher, 2005). Specialized measures are needed that help take in account lifelong impairment and assist in picking up on subtleties in dysfunction. The NTG-EDSD was developed to address these issues, capturing early changes in function and specializing in accounting for subtleties in these changes.

In general, dementia is not a condition that can be solely determined on the basis of one laboratory or medical test. The diagnosis of dementia is based on a combination of data, including the confirmed observations of changes in cognition, mood, behavior, and adaptive functioning with a rule-out of other known conditions and factors that might mimic dementia, but which are not related to dementia (such as sensory loss, delirium, depression, or environmental stressors). Recent evidence indicates that signal biological markers may be present some twenty years prior to the observation of behavioral changes. However, by the time these observable changes occur, significant neurological changes have already begun to occur. . Therefore, the earlier that change in cognition, behavior and functioning is recognized in adults with intellectual disabilities, the greater the opportunity for families and staff to allocate necessary resources, access available treatment, and plan for future programming, services and supports.

Early detection is necessary in cases where functional changes are suspected or observed so as to pick up areas of concern that may require immediate or prolonged attention. The early

detection of functional change can signal the need for a more comprehensive evaluation and help in identifying the cause of the functional decline. Early detection can result in treatments or interventions that reverse functional change or introduce a period of greater surveillance to check for other areas of decline or change. For instance, early recognition of change in cognition might lead to recognition of unaddressed sensory impairments, untreated depression or difficulties adjusting to a new life situation (such as a new roommate or new living arrangement).

Early detection can be an outcome of individual screening (Borson et al., 2013). There is an important distinction between *screening*, involving the use of the NTG-EDSD and *evaluation or assessment* which is conducted using formal instruments designed to diagnose dementia. The function of screening is the identification of current atypical functioning indicative of decline or cognitive impairment. A screening tool does not help establish the origins of change; but, it is useful in substantiating change. On the basis of this observation, the person with suspected dementia can be referred for an assessment using a standard dementia assessment instrument and other medical measures. Screening tools generally are quick, easy to administer, can be completed by a family member or staff caregiver, and can be used at intervals to ascertain changes. Such screening results in a determination that the adult meets a clinical, behavioral, or functional threshold to be referred for assessment and / or to initiate dementia-related services and supports.

Conversely, the function of an assessment is to comprehensively evaluate the health and functioning of the person when changes are suspected. The assessment is conducted by a qualified individual with the appropriate credentials; the focus is on those areas of functioning that are most relevant in confirming a diagnosis of dementia. In the case of individuals with intellectual disabilities, instruments must be selected that are appropriate to the level of the individual's known cognitive abilities. Assessment instruments that have been developed for the non-IDD population will not be informative. Usually assessments result in a preliminary diagnosis of possible or probable dementia or determination of underlying causes of atypical functioning or progressive cognitive impairment. Assessment may also be used to determine that the individual does not meet criteria for dementia and observed functional changes may be attributed to other, potentially reversible, causes (e.g., medication interaction, depression, nutrition or hydration problems, etc.)

The NTG recommends conducting a screening either on a prophylactic basis or when caregiver suspicions are raised. The early identification of signs and symptoms of cognitive impairment and dementia is an important first step in managing the course of the disease and providing quality care.

Why the need for an administrative tool?

The NTG-EDSD is considered an administrative tool. Such a tool is meant as a first pass screening to identify individuals who might need more comprehensive assessment. Each service

setting may develop its own protocol regarding how information from this assessment can best be utilized on behalf of the consumer. However, it is conceivable that care paths might include sharing the information with the consumer's physician, deciding if there needs to be a change in programmatic or personal care supports, a reallocation of resources, or provide an implication for the residential setting. The team may want to adopt a "watchful waiting" approach in which certain areas of identified change are further monitored through additional data collection. As many agencies indicated that they did not have access to professionals who could provide a cognitive screening, the NTG wanted to make a tool available that was accessible to caregivers who were not necessarily trained to do assessment, but had valuable information regarding day-to-day changes in functioning. The tool needed to be easy to administer, cannot be time consuming, and should be sufficiently robust to yield information that could be used as an aid in shared decision making.

The items that make up the NTG-EDSD are associated with the changes typically observed in dementia. Via the use of this screening tool caregivers or staff can substantiate if a person with and intellectual disability manifests these changes and can then share the information with health care providers.

The NTG-EDSD can also be helpful in training caregivers or staff in being good observers and reporters of information which will be valuable in making decisions to advance the care, supports, and services of persons with intellectual disability. This can provide an opportunity for family and provider data to support initial suspicions, to provide preliminary data for an initial assessment interview, and to provide longitudinal information. The tool can be used by caregivers to record observed behavior and can be used by providers to have a running record of health and function that can complement any in-depth personal and clinical records. An administrative tool can also serve as addition to the permanent record and augment any other periodic assessment information kept on the individual.

DEVELOPMENT OF THE NTG-EDSD

Historical basis

The NTG-EDSD has its roots in a meeting held in the mid-1990s, which was the first time a collection of researchers interested in dementia and intellectual disabilities came together. In 1994, a conference support grant from the National Institute for Health helped support a meeting held in Minneapolis, Minnesota, held in association with an international Alzheimer's conference, which was one of the early iterations of the international Alzheimer's conference now known as the ICAD [International Conference on Alzheimer's disease]. The outcomes and products of this meeting included a number of reports and publications as well as the formation of an informal network of the researchers in the field of intellectual disabilities and dementia. One of the papers that resulted from the meeting was co-authored by a team lead by Drs.

Elizabeth Alyward and Diana Burt (see Alyward et al., 1996) and published in the *Journal of Intellectual Disability Research*. The paper addressed the rationale for and reviewed assessment and diagnostic tools relevant to conducting research on individuals with intellectual disabilities affected by dementia. These tools were for direct assessment of adults with intellectual disabilities suspected as having cognitive changes associated with dementia and were in use for various purposes (some purely clinical and some research based). The interested reader is directed to the work of Alyward and Burt (Alyward et al., 1996; Burt et al., 2000). See also Jokinen et al. (2013) for a listing of prevalent assessment instruments currently in use and their applications.

The work accomplished by these reviewers put in play an analysis of the utility of the various instruments for both research and clinical purposes, but also spoke to their limitations with respect to how to best assess cognitive change associated with dementia in persons with diverse intellectual capacities. While the work of this group was useful to researchers, it left open what might be applicable for use by lay workers and family caregivers. Over the years, there evolved a growing interest in the early recognition of cognitive, behavior, and adaptive changes that could be substantiated by family and staff caregivers. Provider agency staff indicated that they needed an instrument for early detection and initial screening that could be used by direct support workers and families. The original instruments cited in Alyward et al. (1996) were direct assessments requiring professional level administration and were tied to full diagnostic workups. Many agency staff and families did not have access to psychologists and other practitioners who had the expertise to conduct such assessments; however, there was a need for something that could serve as an early detection measure. Furthermore, there was increasing demand for a rating instrument that could help capture information about changes that could then be shared with health care practitioners to advance service planning, supports and decision-making.

Given the increasing number of adults with intellectual disabilities who were growing older and the uptick in the prevalence of adults affected by age-related cognitive and functional decline, there was a general call for some type of screening or instrumentation that could help families and agencies better prepare and become aware when changes were occurring. For this and for other reasons, there was a need for some type of national conversation on ways to identify early and address suspected dementia among adults with such lifelong disabilities.

When the National Task Group on Intellectual Disabilities and Dementia Practices was organized in late 2010, among its first tasks was to identify a screening tool that could be widely used as a first pass screen for early detection of changes that would identify individuals who needed additional, more comprehensive assessment. Group S (for ‘screening’), one of the NTG’s three original working groups, was tasked to look at extant instruments and see which, based upon the literature and professional judgment, would be best suited to be adapted for more general usage as a screen. During this process Group S had input and involvement from some of

the original members of the 1994 workgroup on diagnosis and assessment. Group S members elicited feedback from the other NTG members regarding tools that were in current use and which have proved helpful in identification of individuals who might have dementia.

Development process

In preparation for the inaugural June 2011 NTG meeting in St. Paul, Minnesota, Group S had been charged with determining whether individuals could be identified for possible or probable signs of dementia. Members of Group S submitted 11 screens for review. Most of the respondents favored an informant based instrument. The instruments reviewed represented a delimited sample of instruments in use in the US and elsewhere. Criteria were that a first instance instrument should be tied to behavioral indicators of dementia or warning signs and still capture newly presented and successive changes in function. It should also be constructed in a manner so it could be completed by direct support staff or family caregivers with minimal training or orientation. Further, the screen could be used to confirm suspicions or changes in function to support decisions to refer individuals for further assessment. One of the instruments that was favorably rated by Group S was an adaptation of the Dementia Screening Questionnaire and Interview for Intellectual Disabilities (DSQIID), originally developed in the United Kingdom by Professor Shoumitro Deb of the University of Birmingham in the United Kingdom, and adapted for use by the Philadelphia PMHCC [Philadelphia Mental Health Care Corporation] for use with the Pennhurst class. The resulting adaptation was an easily administered screen that could help family and direct care providers open up a dialogue around declining function.

The members of Group S then reviewed the instruments on a variety of indicators. On the basis of this review, the members endorsed the use of the DSQIID (Deb, 2007). This recommendation was reviewed when the full NTG convened at its June 2011 meeting in St. Paul in conjunction with the AAIDD's annual conference. At this meeting, Group S was further tasked to come up with an early detection screen that included an augmentation and adaptation of the DSQIID and which could be used by family and staff caregivers. It was decided also to include ancillary information so as to broaden its content and usefulness for clinicians. Thus, items gathering information on individual demographics, co-incident medical conditions and impairments, and significant life factors were added.

Coincident, with the working group's efforts, the Philadelphia PMHCC also undertook a secondary adaptation of the DSQIID with the assistance of Dr. Karl Tyler of the Cleveland Clinic (Philadelphia Coordinated Health Care Group, 2011). This version was further adapted by the working group to include items felt to be pertinent to early detection. The draft composite instrument went through several revisions and then was field tested over the summer of 2012 in eight sites, including agencies in the continental U.S., Canada, and Austria. The Austrian field test used a German language translation.

Field Testing of the NTG-EDSD

The field test was designed to elicit feedback on items and the process of completing the instrument. Each participating site was asked to rate at least five adults suspected of having dementia using the instrument and to provide feedback in the utility of the tool. The feedback provided included comments on wording of items, formatting, content, and utility. The eight field test sites all indicated that the NTG-EDSD was helpful in relevant data collection and was user friendly. Comments were also received from agency reviewers who, while not 'officially' applying the draft instrument, scrutinized it and offered suggestions. Specific comments and suggestions on wording and structure were assessed and final changes were made to the instrument at a working group meeting in December 2012.

Unlike the DSQIID, the tool upon which the NTG-EDSD was based, the instrument was not intended to provide a definitive diagnosis of dementia. The instrument was designed as a way of collecting seminal information, and recording indicators and signal behavioral markers of significant change. The purpose was to give family and professional caregivers a tool that would enable them to capture objective data on changes in function when suspicions arose and prior to making a referral for a comprehensive assessment. As such, the NTG-EDSD is regarded as an administrative rating tool and not an assessment instrument. The NTG-EDSD can also present helpful data which can be shared during the annual wellness visit under the Affordable Care Act as many agencies are looking forward to that process to help them with identifying any significant potentially neuropathologic functional and cognitive changes among the individuals whom they support. See Cordell et al. (2013) for a discussion of instruments in use with the general population for this function.

THE NTG-EDSD

Description of the NTG-EDSD

The NTG-EDSD is composed of four primary sections containing some 40 questions or question groupings about relevant demographics, ratings of health, mental health and life stressors, a review of multiple domains associated with adult functioning, and a review of chronic medical conditions. It also provides for a notation on the number and nature of medications being taken, and permits comments on observations to be entered. Specifically, the NTG-EDSD contains ten basic demographic items (such as identification data, personal characteristics, diagnostic, and residential setting information, eight health and function items, and the adaptation of the DSQIID (including queries as to Activities of Daily Living, Language and Communication, Sleep-Wake Change Patterns, Ambulation, Memory, Behavior and Affect, the Adult's Self-Reported Problems, and Notable Significant Changes Observed by Others. The NTG-EDSD also contains an adapted form of the University of Illinois at Chicago's Longitudinal Health and Intellectual Disability Survey (Rimmer & Hsieh, 2010) which is used to

note co-incident conditions (these include the following categories: Bone, Joint and Muscle; Heart and Circulation; Hormonal; Mental Health; Pain-Discomfort; Sensory; and Other). The last section of the NTG-EDSD contains an item on current medications, a place to note comments related to other notable changes or concerns, and next steps and recommendations, as well information on the form completion.

Uses of the instrument

The NTG-EDSD can be completed at any point in time on an adult with an intellectual disability. Minimally it can be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change.

The NTG-EDSD can also be used in preparation for the annual wellness visit under the Affordable Care Act. Having concise information available for the examining physician can help instigate queries and any follow-up assessments. For recommendations on it use as part of any physician visit, see Moran et al. (2013).

The initial review using the NTG-EDSD can be accompanied by notes indicating onset of conditions. Following the initial review which would serve as a baseline, the caregiver completing the form can indicate whether there has been a change within the last year since the last review. At the point that the individual is determined to need more comprehensive assessment, a referral should be made for more comprehensive work-up that would include medical and psychological testing.

The interdisciplinary team can share ratings of "new symptoms" or "always but worse" with the health practitioner and discuss among members of the team implications for programming, personal assistance, residential placement, services and supports. With the advent of the Diagnostic Statistical Manual-5th edition (DSM-V), the health care practitioner can link documentation of change with updated criteria for the diagnosis of dementia. .

Who can complete the NTG-EDSD?

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record.

Useful information to have available to aid completion

Sources such as the individual's medical record, information on living arrangement and personal functioning, as well as consensus information on functioning from other staff or family members would be highly beneficial to have on hand. A list of laboratory tests that can be useful in determining if there are medical conditions that may contribute to cognitive or adaptive changes are found in Appendix B.

How to complete the form

See Appendix A for a 'pull-out sheet' on how to respond to the items on the NTG-EDSD.

How to use the information obtained from this review

The information may be used in various ways: (1) if no signal items pop up as warranting further attention, then the form should be retained for comparison against any future administrations; (2) if select signal items begin to show, then the form can be used to begin a conversation with available clinicians to determine their relevance and immediacy for concern; (3) the information on the form can be shared with the examining physician during any health visit (and in particular during the annual wellness visit as provided for under the Affordable Care Act); and (4) the form may be shared with the agency's consulting psychologist as part of any follow-up procedures put in place specific observations for noted change areas

What are some signal items?

Signal items are those items throughout the ***NTG-EDSD*** that are linked to the general warning signs of MCI or early dementia, and include:

- Unexpected memory problems
- Getting lost or misdirected
- Problems with gait or walking
- New seizures
- Confusion in familiar situations
- Changes in personality

Limitations

It is important to understand that the ***NTG-EDSD*** is NOT a diagnostic instrument and should not be solely used to determine the presence or for the diagnosis of dementia.

Areas for further development

There is no scoring system currently associated with the use of the NTG-EDSD. This instrument provides the opportunity for a qualitative, not a quantitative review of changes that

may be associated with the types of changes in cognition and adaptive functioning observed in dementia. As the instrument gains more widespread use there would be value in collecting data linking confirmed diagnoses with results of screening. This may result in a scoring system or allow for identification of signal items most likely indicative of dementia.

Versions of the NTG-EDSD

The NTG-EDSD is currently available in English, German, Greek, and Italian language versions. Versions in Dutch, French, and Spanish are in development. See www.aadmd.org/ntg/screening for copies of available language versions.

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For suggestions, comments, or more information, contact Dr. Lucille Esralew at drlucyesralew@gmail.com

APPENDIX A: Instructions for the completion of the NTG-EDSD.

Item #	Item Title	Comment
1	File#	For agency use
2	Date	Date form completed
3/4	Name of person	Fill in first and last name of person being screened
5	Date of birth	Provide day, month, year
6	Age	Age when form was completed
7	Sex	Indicate male or female
8	Best description of level of intellectual disability	Draw from any previously completed assessments or estimate if none ever done
9	Diagnosed condition	Draw from any previously completed assessments or estimate if none ever done
-	Current living arrangement of person	Pick most appropriate item
10	General characterization of current physical health	Pick most appropriate item
11	Compared to one year ago, current physical health is:	Pick most appropriate item
12	Compared to one year ago, current mental health is:	Pick most appropriate item
13	Conditions present	Indicate those diagnosed as well as observed
14	Significant recent [in past year[life event	Indicate those that occurred
15	Seizures	Pick most appropriate item
16	Diagnostic history	Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic report
17	Reported date of onset of MCI/dementia	Indicate month/year when first symptoms were noticed
18	Comments/explanation about dementia suspicions	Indicate any behaviors that triggered suspicions or referral for assessment
19	Activities of daily living	Pick most appropriate column item for each **'Always been the case'** means the need, problem or behavior has been present for a very long time ***'Always but worse'*** means the existing need, problem or behavior has further declined requiring more personal assistance ***'New symptom in past year'*** means this need, problem or behavior was not present until recently *'**Does not apply**'* means these needs, problems or behaviors are not present
20	Language & communication	Pick most appropriate column item for each

21	Sleep-wake change patterns	Pick most appropriate column item for each
22	Ambulation	Pick most appropriate column item for each
23	Memory	Pick most appropriate column item for each
24	Behavior and affect	Pick most appropriate column item for each
25	Adult's self-reported problems	Pick most appropriate column item for each 'Self-reported' means the adult has expressed one or more of these things
26	Notable significant changes observed by others	Pick most appropriate column item for each Assume that these are new behaviors
27	Chronic health conditions	Pick most appropriate column item for each Draw from any previously completed medical evaluations or current health notes in record
28	Current medications	This item is to help the physician or other clinician assess whether current medications may be the cause of behavioral or functional changes. Best to include a listing of current medication, with dosages, when sending or bringing form to assessment.
29	Comments related to other notable changes or concerns	Use this item to make comments of use related to behavior, function, or any events that may influence behavior
30	Next steps/recommendations	Check most relevant item
31	Date completed	Date form completed
32	Organization/agency	Name of organization providing services to the adult
-	Name of person completing form	Indicate your name
-	Relationship to individual	Indicate whether you are staff, a relative or someone else
-	Date(s) form previously completed	If the ***NTG-EDSD*** has been completed before, indicate when

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www.aadmd.org/ntg/screening

APPENDIX B: Some of the laboratory and medical tests that might be used to rule out other sources of cognitive change among persons with intellectual or developmental disabilities

1. Recent Primary Care Physician appointment/review
    - Review of existing lab results and follow up on out of range values
    - DD Diagnosis
      Recent Blood work (within 3 months) that includes
        - Liver panel (especially if on psychotropic medications
        - Kidney function (GFR)
        - Complete Blood Count (CBC)- to account for some causes of potential delirium) Complete Blood Count
        - Comprehensive Metabolic Panel
        - Hepatic testing
        - Renal Function Test
        - Thyroid Studies(including TSH)
        - Vitamin B 12
        - Folic Acid
        - Hormone levels in women over 30

    - Sleep Apnea ruled out
        - If sleep apnea then investigate possibility of vascular dementia
    - Specifically for people with Down Syndrome, celiac screening (total serum IgA if not done previously, and tTg)
2. Hearing/Audiology Testing
3. Electroencephalogram
4. Urinalysis
5. Chest X-Ray
6. Computerized Tomographic Scan
7. Magnetic Resonance Imaging
8. Vision Testing

Explore conditions which are likely to involve pain/discomfort (including dental pain) and put in place a pain management protocol

Explore medication side effects or interactions (pharmacist and or PCP are most likely resources)

Special thanks to Isabelle Grenon, Ph.D. and Melissa DiSipio, MSA for their assistance in compiling this list.

NTG-EDSD

v.1/2013.2

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

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(1) File #: _____ (2) Date: _____

Name of person: (3) First_____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

(7) Sex:

	Female
	Male

Instructions:
For each question block, <u>check the item that best applies</u> to the individual or situation.

(8) Best description of level of intellectual disability

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

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:

- □ Lives alone
- □ Lives with spouse or friends
- □ Lives with parents or other family members
- □ Lives with paid caregiver
- □ Lives in community group home, apartment, supervised housing, etc.
- □ Lives in senior housing
- □ Lives in congregate residential setting
- □ Lives in long term care facility
- □ Lives in other: _____

(10) General characterization of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(11) Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(12) Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(13) Conditions present (*check 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
	Not mobile – is moved about in wheelchair

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

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

(15) Seizures

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

If MCI or dementia is documented complete 16, 17, &18

(16) **Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:

[ ] No

[ ] Yes, MCI

Date of Dx:

[ ] Yes, dementia

Date of Dx:

Type of dementia:

Diagnosed by:
□ Geriatrician
□ Neurologist
□ Physician
□ Psychiatrist
□ Psychologist
□ Other:

(17) Reported date of onset of MCI/dementia
[When suspicion of dementia first arose]
Note approximate year and month:

(18) Comments / explanations about dementia suspicions:

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
[19]**Activities of Daily Living**				
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)				
[20]**Language & Communication**				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
[21]**Sleep-Wake Change Patterns**				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
[22]**Ambulation**				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	New symptom in past year	Does not apply
[23]**Memory**				
Does not recognize 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				
[24]**Behavior and Affect**				
Wanders				
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				
[25] **Adult's Self-reported Problems**				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
[26]**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)				

[Check column option as appropriate]

	[27]Chronic Health 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 apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

(28) **Current Medications**

Yes	No	Indicate type
□	□	Treatment of chronic conditions
□	□	Treatment of mental health disorders or behavior problems
□	□	Treatment of pain

For reviews, attach list of current medications, dosage, and when prescribed

□ List is attached for reviews

(29) **Comments related to other notable changes or concerns:**

(30) **Next Steps / Recommendations**

□ Refer to treating physician for assessment

□ Review internally by clinical personnel

□ Include in annual review / annual wellness visit

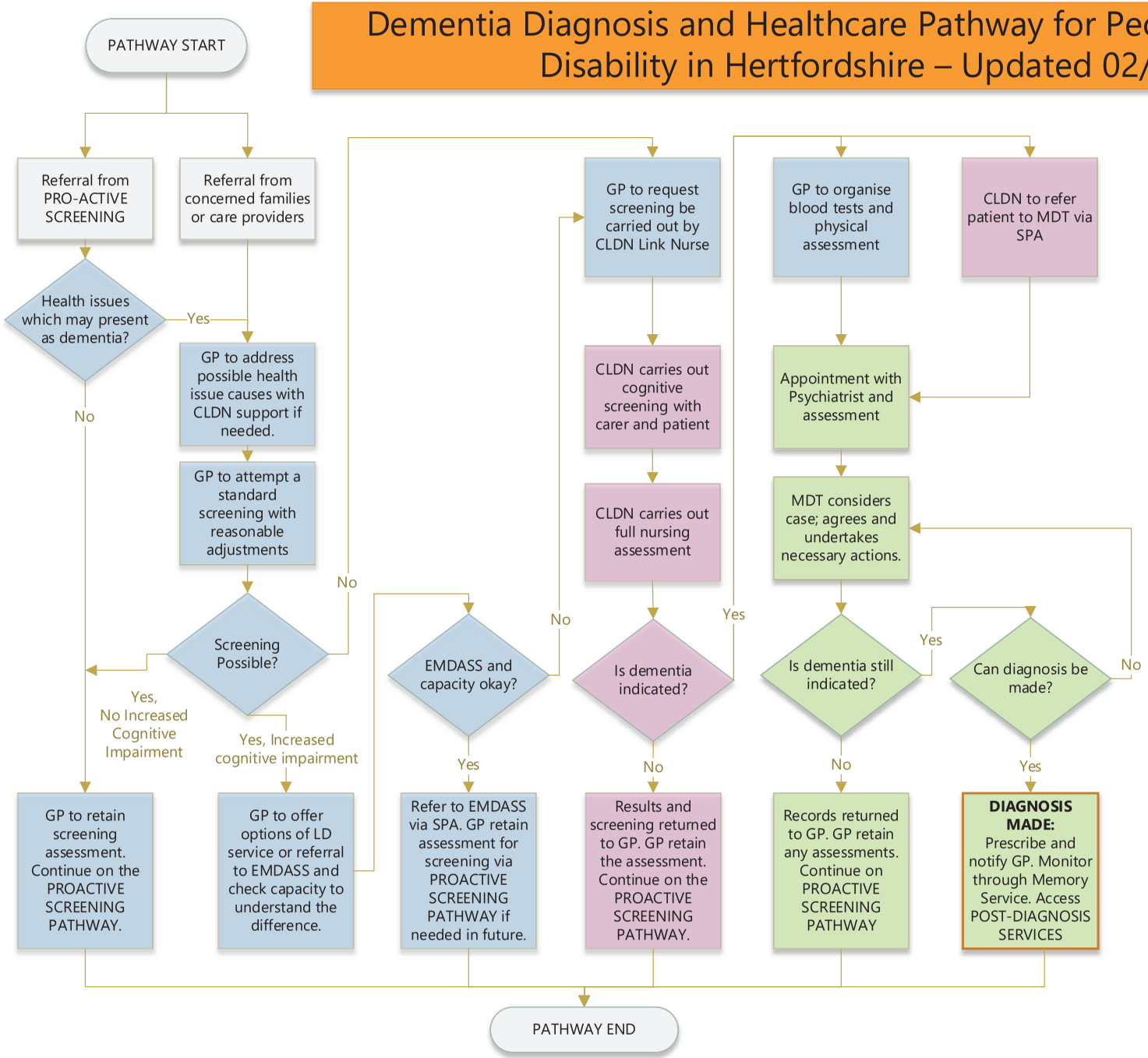
□ Repeat in _____ months

Form completion information

(31) Date completed	(32) Organization / Agency
Name of person completing form	
Relationship to individual (staff, relative, assessor, etc.)	
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.

Dementia Diagnosis and Healthcare Pathway for People with a Learning Disability in Hertfordshire – Updated 02/08/2018



PROACTIVE SCREENING:
Does person have Down's Syndrome Diagnosis? If so then offer baseline screening at 30 years of age or older if a baseline assessment has not been completed.
Then invite the person back for re-screening at the age of 40 and then every two years until the age of 50 after which time screening should be annual.

NOTE: Invitations should initially be from the GP. The results of screening should be held on GP records, but the CLDN may also hold these on the agreed database and will link with the GP re future screenings.

Multi-Disciplinary Meeting [MDT]:
The case will be brought to the multi-disciplinary team. At these meetings the case is considered and actions agreed and monitored through the meeting.

Both screening tools are DLD (Dementia Questionnaire for People with Learning Disabilities) and the NTG – EDSD (Early Detection Screen for Dementia) to be used.
Post-diagnosis package of support to be covered in new pathway. Comparable to normal dementia pathway.

Mainstream services can link back into Memory Service should that be needed.

KEY:
Blue = GP lead;
Pink = CLDN lead;
Green = MDT lead