



Wellbeing for Life Getting a Timely Diagnosis



Learning Outcomes

- To understand what Timely Diagnosis is.
- To know how to prepare for the assessment process.
- To be familiar with the dementia diagnosis pathway and your role in supporting the person.
- To be informed and able to advocate for the person when the outcome of assessment(s) is known.
- To understand the importance of baseline screening and monitoring to facilitate Timely Diagnosis in the future.



What is 'Timely' Diagnosis?

NHS England 2015 defines a 'Timely' Diagnosis as:

“When the patient wants it OR when the carers need it”

<https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf>

The reason a diagnosis is described as '*timely*' rather than '*early*' is because early can sometimes be so early that it is extremely difficult, if not impossible, to accurately diagnose a person's dementia.

Diagnosing a person in a timely way should allow for symptoms to become clear enough that accurate records can be used to assist in the diagnosis process. There should be evidence of decline over time (months rather than weeks) to make a diagnosis of dementia. For more information, please see our Module on 'Signs and Symptoms' in Theme 5 The Dementia Pathway.

What is 'Timely' Diagnosis?



A person with a learning disability is less likely to receive a timely diagnosis of dementia.

This is because the person's diagnosis is often adversely delayed due to diagnostic overshadowing, where changes in the person are attributed to their learning disability and '*behaviours*', rather than being seen as a potential health condition like dementia.

A person with a learning disability will need additional support to understand the diagnostic process, any resulting diagnosis, and what their diagnosis means for them. For more information, please see our Module on 'Dementia and Learning Disability' in Theme 5 The Dementia Pathway.



Why get a Diagnosis?

First consider this:

- Some people choose not to have an assessment.
- Some people choose to have the assessments/tests to rule out treatable health conditions, but don't want to know if they have dementia. (This might be because pharmacological treatments are limited and there is no cure).
- People with a learning disability are often not asked if they want to participate in the assessment process; it is just assumed they will.
- People with a learning disability are often not told that they have been diagnosed with dementia, and may not have the meaning of the word explained to them.

So Why Get a Diagnosis? Some Reasons Include:

- To rule out other conditions that may have similar symptoms and may be treatable, including depression, chest and urinary tract infections, severe constipation, and vitamin and thyroid deficiencies.



Why get a Diagnosis?

- To rule out other possible causes of confusion (e.g. poor eyesight or hearing), emotional changes and upsets (e.g. moving house or bereavement), or the side effects of certain drugs or combination of drugs.
- To provide a person with dementia with an explanation of their symptoms, removing uncertainty and allowing them to begin to adjust.
- To allow a person with dementia to access treatment as well as information, advice and support (emotional, practical, legal and financial).
- To allow a person with dementia to plan and make arrangements for the future, before they lose capacity to tell us their own preferred end of life care preferences and wishes For more information, please see our Module on 'Person Centred Planning: An Advance Care Plan in Theme 6 End of Life Care.
- To allow a person to have control over their own life and future as much as possible.



What is the Assessment Process Like?

The assessment for possible dementia takes time. There is no single '*dementia test*'. It is very important to involve the person throughout the diagnostic process and enable them to make as many decisions as possible about the information they and others receive.

For the person and those close to them, the assessment process and waiting for the results after each test or assessment can be an uncertain, anxious and stressful time.

Being prepared for how everyone might be feeling is helpful in managing the emotional upheaval involved and minimising distress.

If you are supporting someone who you suspect may have dementia, keeping written records of their health needs and changing health needs is very important to receiving a diagnosis. For more information, please see our Module on 'Emotional Impact of Dementia' in Theme 5 The Dementia Pathway.



How to Prepare for the Assessment Process

Staff (and family if they are involved in the person's life) have a crucial role to play in the assessment process. Your role includes:

Preparing the person:

You play a vital role in supporting the person to understand why they are seeing the doctor.

To do this you should keep the person informed about appointments; try to make appointments that fit around the person's activities so that there is minimal disruption to the things the person enjoys in their life, and ensure that a member of staff who knows the person well and the person is happy with and trusts is able to accompany them to their appointment.

Ideally, if multiple appointments are involved in the person's assessment process, it is preferable that the same staff member accompanies the person, or if this isn't possible, keep the number of staff involved as small as possible to maintain continuity.

How to Prepare for the Assessment Process

Sharing information:

The majority of information shared will be from staff or family members. It is crucial that accurate and reliable information is recorded and shared. In order to facilitate this, you will need:

- Comprehensive person-centred health records for the person.
- A detailed medical history which should include any past history of thyroid disease, head injury, heart disease, epilepsy, diabetes.
- A chronological date order of concerns and examples of how symptoms have impacted upon the person's daily life. For example:



- When were changes first noticed?
- How long do symptoms last for?
- In what order where symptoms noticed?
- Have symptoms got worse?



How to Prepare for the Assessment Process

Sharing information:

Pay particular attention to changes in the person's;

- **Thinking skills** e.g. memory, speech, expressive communication, understanding, recognition of faces, objects, places.
- **Emotional and behavioural wellbeing** e.g. personality changes, changes in behaviour, mood changes, motivation, hallucinations, delusions, eating habits, sleeping patterns, sexual behaviour, aggression, fluctuating emotions.
- **Ability to conduct activities of daily living** e.g. dressing, washing, eating, household chores.
- **Physical symptoms which are new** e.g. seizures, incontinence, weight loss, stiffness.
- **Any significant events**, e.g. hospital admissions, bereavement, a change in lifestyle or staff.



Getting the most from Appointments

- It may be helpful to book a double appointment with the GP for the initial assessment, as a single 10 minute appointment is unlikely to allow enough time for the necessary investigations.
- Write down any questions as it can be difficult to remember everything to say during a consultation.
- During the consultation, write down any important points the doctor makes.
- Ask the doctor (or any other professional) to explain any words or phrases you or the person you support do not understand. They should be able to explain all terms in a way that makes sense to the person - it is their job.
- Ask the doctor to send you a copy of any letter(s) they will write.



Diagnosis and People with a Learning Disability

Some facts to consider:

- The diagnosis pathway for dementia is exactly the same as for people without a learning disability. However, *how* the steps are undertaken will vary.
- Accurate diagnosis of dementia in people with a learning disability, particular in the early stages, remains difficult and there is a high risk of an inaccurate or missed diagnosis.
- Often repeated assessments over time are the only reliable way of assessing change.
- Some reasonable adjustments will need to be made to ensure the person is able to access the assessments needed, for example, having a blood test may require an approach unique to the person.
- For people with a learning disability, diagnosis often relies on reports and written records and information from family and staff.



Diagnosis and People with a Learning Disability

Some facts to consider:

- Too often a diagnosis of dementia is made without the proper investigations being undertaken. An essential part of a definitive diagnosis requires investigations to be undertaken to rule out conditions that have similar symptoms but can potentially be treated and cured.
- Brain Imaging e.g. MRI and CT scans, are less reliable for people with a learning disability.
- Availability of assessments and treatment across the UK is inequitable.

NICE Pathways - Dementia Diagnosis and Assessment, 2016 advise:

“Refer people with learning disabilities who have suspected dementia to a psychiatrist with expertise in assessing and treating mental health problems in people with learning disabilities”

<https://pathways.nice.org.uk/pathways/dementia#path=view%3A/pathways/dementia/dementia-diagnosis-and-assessment.xml>



The Dementia Diagnosis Pathway

Step 1: Assessment by a GP

The GP is the first point of contact for anyone concerned about dementia.

The GP may suggest a home visit if they suspect the person has dementia, as it is often easier to assess and observe their behaviour in their home.

The GP will assess the person by:

Taking a '*history*' – talking to the person and someone who knows them well about how and when symptoms started and how they are affecting the person's life. The GP will look at the person's written Health Records kept by staff, medical history and family health history. They should also review the medicines the person is taking.

Physical examinations – The GP may carry out a physical examination, particularly if a stroke or Parkinson's Disease is suspected.

Test of mental abilities – if appropriate, the GP may ask the person a series of questions or give them a short pen-and-paper test designed to test thinking, memory and orientation.



The Dementia Diagnosis Pathway

After the GP's Assessment(s):

The GP should explain their findings and discuss what action needs to be taken. Depending on their expertise and training, they may feel able to make a diagnosis at this stage, although this is uncommon.

More likely is that the GP will refer the person to a memory assessment service, memory clinic or other specialist service including a specialist consultant in learning disability to conduct further assessments. If you, the person, or their family feels that a referral would be helpful, but the GP doesn't suggest or offer this option, you should ask about it.

The GP may ask you to make an appointment with the practice nurse for the person to have blood tests and possibly provide a urine sample so that they can rule out other conditions that can cause similar symptoms to dementia.





The Dementia Diagnosis Pathway

Step 2: Referral to a Specialist

If the GP has referred the person to a specialist, you can expect to wait on average 4-6 weeks for that appointment.

A specialist, such as a consultant, will have more knowledge and experience of dementia than a GP. They have more specialised investigations, such as brain scans and in-depth mental testing, and will usually work within a multi-disciplinary team (a team of healthcare professionals who have different, but associated, specialities).

Which specialty the person is referred to may depend on the age of the person, their symptoms, and what is available in the area where they live.

The main types of specialists are:

- **Old age psychiatrists** are psychiatrists who specialise in the mental health of older people, including diagnosing and treating dementia. They may sometimes also offer support to younger people with dementia.

The Dementia Diagnosis Pathway

- **General adult psychiatrists** specialise in diagnosing and treating a wide range of mental health problems. A younger person (under 65) may be referred to such a psychiatrist to help with the diagnosis.
- **Geriatricians** specialise in physical illnesses and disabilities associated with old age, and in the care of older people. If the person being assessed is frail or in poor general health, they may be referred to one of these specialists to see whether their symptoms are due to a physical illness. They may have a physical illness as well as dementia.
- **Neurologists** specialise in diseases of the brain and nervous system. Some neurologists have particular experience in diagnosing dementia. They tend to see younger people and those with less common types of dementia.





The Dementia Diagnosis Pathway

Step 3: Assessment by a Specialist

Before continuing with any further assessments, the person should be offered the chance to talk things over with a healthcare professional. This is to help the person (and those close to them) understand why they have been referred, learn about the assessment process, give consent (or not) to go ahead, and prepare themselves for the possible outcomes.

It is also an opportunity for the person and those supporting them to share what they already know about dementia, express their feelings and raise any concerns.

The specialist will:

- **Take a history** – as with the GP, the specialist will talk to the person being assessed and those close to them. This could last up to 90 minutes.
- **Complete physical examinations and tests** – if they have not already been carried out by the GP. In many cases the blood tests will already have been done before the referral.



The Dementia Diagnosis Pathway

- **Complete tests of mental abilities** – a more detailed assessment of memory and other thinking processes. These test things like memory, orientation, language and visuospatial skills (e.g. copying shapes). The assessment can be used as a baseline to measure any changes over time, which can help with making a diagnosis. The test is given by a trained professional such as a mental health nurse, occupational therapist, clinical psychologist or neuropsychologist (professionals whose specialty includes the diagnosis of mental health problems).
- **Request Brain Scans** - to show any structural changes to the brain. There are several types of brain scan: – CT (Computerised Tomography), CAT (Computerised Axial Tomography) and MRI (Magnetic Resonance Imaging) scans are widely used. Less widely used are SPECT (Single Photon Emission Computerised Tomography) and PET (Positron Emission Tomography) scans to show changes in brain activity.

A scan showing no unexpected changes in the brain does not rule out dementia. This is because in the early stages of dementia the changes can be difficult to distinguish from those seen in normal ageing, and are particularly difficult to see in people with a learning disability. Specialist advice should be taken when interpreting scans in people with learning disabilities.



The Dementia Diagnosis Pathway

Some of the Common Mental Tests used with People who have a Learning Disability:

Dementia Questionnaire for persons with Intellectual Disabilities – this is a screening tool, it is a quick questionnaire completed by carers. It has 8 sections: short term memory; long term memory; spatial and temporal orientation (known as the Sum of Cognitive Scores); speech; practical skills; mood; activity and interests; behavioural disturbance (known as the Sum of Social Scores).

Dementia Scale for Down's Syndrome (DSDS) – this is a screening tool for dementia with people with Down's Syndrome, but NICE suggested it may be useful for all people with a learning disability, to assess cognitive deterioration in people with moderate to profound learning disability. It requires the psychologist to interview two people. There are 60 questions.

Test for severe impairment (TSI) – this is a brief neurological test and can be used across a range of learning disabilities as it minimises the use of language. It has six sections – motor; language; comprehension; delayed memory; general knowledge and conceptualisation.



The Dementia Diagnosis Pathway

Severe Impairment Battery – this is designed to assess cognitive abilities for those with a severe impairment. It is made up of 40 items which are presented with one step instructions and gestural cues.

Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) – this is an observation based screening tool with 43 questions.

CAMDEX-DS – this test includes a structured interview with a relative or carer who has known the person for at least six months.

Adaptive Behaviour Dementia Questionnaire – this was specifically developed to screen for Alzheimer's Disease. It requires the person to compare the level of functioning now to their previous level of functioning. It is an American tool so is unsuitable for some people who will not understand the American terminology.

Assessment of Motor and Process Skills (AMPS) – usually completed by an Occupational Therapist to assess skills which affect a person's ability to carry out day-to-day activities.



The Dementia Diagnosis Pathway

Step 3: The Outcome of Assessments

The specialist will bring together all of the information from the history, symptoms, physical exam, mental tests and any scans and make a diagnosis. It is important to bear in mind that sometimes a diagnosis of dementia is provisional and an accurate diagnosis may only emerge over a period of time.

If the diagnosis is dementia, the specialist should also be able to determine the type of dementia. Knowing the type of dementia (e.g. Alzheimer's Disease, vascular dementia, Dementia with Lewy Bodies) will help to understand symptoms, predict how the person's dementia might progress, and suggest how best to manage it. For example, certain drugs will be prescribed for Alzheimer's Disease (but not for vascular dementia) that will not cure the condition but may improve the person's quality of life. For more information, please see our Modules on: 'Dementia and Learning Disability' in Theme 5 The Dementia Pathway and 'Treatments' in Theme 5 The Dementia Pathway.

The Dementia Diagnosis Pathway



If the specialist diagnoses dementia but doesn't specify which type, ask if they are able to give you this information. If they can't, they should be able to explain why they are unable to ascertain the type of dementia the person has.

If the diagnosis isn't dementia, it may be that the person is given a diagnosis of Mild Cognitive Impairment (MCI). The specialist may want to regularly review a person with MCI for any changes in their symptoms or for any new signs that could indicate dementia is developing.



Discussing a Diagnosis of Dementia: Saying the “D” Word

Health professionals can be reluctant to speak openly and honestly to people with a learning disability and their families about dementia, with some refraining from using the “Dementia” word altogether.

Although initially discussing the diagnosis may be distressing, evidence suggests most people prefer to know if they have dementia in order to access appropriate support and treatment and to plan for the future.

Remember: when a person receives a diagnosis of dementia the impact this has will be unique to them. However, with the right support and planning, people can live well with dementia. For more information, please see our Module on ‘Living Well with Dementia’ in Theme 5 The Dementia Pathway.

If health professionals are reluctant to speak directly to the person, try to find out why. They may be reluctant to communicate with the person because they are unsure which communication method(s) would be best, or are unsure of how much information to give.



Discussing a Diagnosis of Dementia: Saying the “D” Word

As a staff member who knows the person well, you may be able to help the health professional to enable them to communicate directly with the person in a way that makes sense to the person and that the person can benefit from and the health professional is comfortable with.

Information that you will need:

Following a diagnosis of dementia health professionals should, unless the person with dementia clearly indicates to the contrary, provide them and their family with written information about:

- The signs and symptoms of their type of dementia
- The course and prognosis of the condition
- Treatments
- Support groups
- Sources of financial and legal advice, and advocacy
- Local care, support and information sources, including libraries and voluntary organisations.

Discussing a Diagnosis of Dementia: Saying the “D” Word

Copies of any letters received detailing the person’s diagnosis, treatment plan or post-diagnostic support should be kept in the person’s health records and not archived.

Ongoing Assessment:

At regular intervals ongoing assessment should be made for medical comorbidities (i.e. the effect of any or all other medical issues the person might have in addition to dementia) and key psychiatric features associated with dementia, including depression and psychosis, to ensure optimal management of co-existing conditions.





Enabling more Timely Diagnosis in the Future

Ongoing Assessment:

Over the years several recommendations have been made about baseline screening and monitoring for people with Down's Syndrome. Reasons for these recommendations include:

- The importance of establishing an accurate baseline of skills and abilities for people with a learning disability.
- Having a baseline of skills and abilities while the person is healthy provides evidence of change(s) in function.
- Self-reporting by people with a learning disability is limited compared to people who do not have a learning disability. Information is often provided by staff and/or family, therefore a clear and accurate written record is required to show changes.



Enabling more Timely Diagnosis in the Future

- Change is always measured from either a past baseline of evidence or, if this is not available, then the presenting skills and abilities become the baseline to measure change and deterioration. This may mean a significant delay in diagnosis and therefore any treatment.

A baseline of skills and abilities between the ages of 21 to 30 years is preferable and allows for post maturity changes.

Consent:

Whether you are proposing to conduct an initial baseline assessment, or the proposed assessment is part of ongoing baseline monitoring, the person must be fully involved and an explanation given that makes sense to them about what the assessment is and why it's important.

At every assessment, The Mental Capacity Act must be followed to assess whether the person has capacity to consent. If the person does not have capacity then a best interest decision is made.



Carrying out Baseline Screening

Healthcare Professionals:

Your local learning disability service may carry out baseline screening for people with Down's Syndrome.

Be aware that often baseline screening takes place as part of a "Well person" appointment and the person is not given any information or choice in taking part. You have a role to advocate for the person to be fully involved in all aspects of their healthcare.

Social Care Professionals:

We have already discussed the critical role that you have to ensure accurate information is shared at medical appointments. Having this information prevents delay and facilitates more timely assessment and diagnosis. It also means that if there is treatment available, it can be started sooner.

Keeping health records should begin once the person has begun using your service, is settled and confident with their surroundings and support has been offered. Health Records should then be reviewed regularly, at a time convenient to the person; this could be included as part of their person centred review.



After a Baseline is Established

Once a baseline has been established the information can be updated at regular intervals. These are suggested as:

- Every two years for those with Down's Syndrome in their 40s or those with another cause of learning disability 50 years and older.
- Annually for those with Down's Syndrome aged 50 years and over or those with another cause of learning disability 60 years and older.
- Six monthly if concerns are raised to ensure accurate information is contributed to the diagnostic process.

Remember: any apparent changes in skills and abilities do not necessarily indicate dementia, but allows the opportunity for further investigations.



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