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Supporting people with learning disabilities who are referred for a memory assessment

An information leaflet for family, friends and carers

For more information see www.cwp.nhs.uk.

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The information in this leaflet was valid at the date of production **August 2021** and is due for review in **August 2023**

Leaflet code: E-BRDA-09-299

Introduction

This leaflet has been written for carers who are supporting an individual with a learning disability, who is or may be experiencing symptoms of dementia and has been referred to the local community team for adults with a learning disability for assessment.

This leaflet provides information on:

- What dementia is
- The assessment process
- The role of the carer in the assessment process
- Questions you might have about the dementia assessment

Dementia

More detailed information about dementia is contained in the leaflet, 'Dementia and people with learning disabilities: An information leaflet for carers'.

What is dementia?

- Dementia is a term used to describe a collection of symptoms caused by structural and chemical changes in the brain as a result of physical diseases.
- It can affect anyone as they age but people with learning disabilities are four times more likely to develop dementia than the general population.
- People with a learning disability are likely to develop dementia at a younger age than the general population.

What are the main symptoms of dementia?

- The symptoms of dementia include a decline in memory, reasoning and communication skills and a gradual loss of the skills needed to carry out daily activities.
- Although symptoms might be present already it does not mean that a person has dementia. Change and deterioration indicate possible dementia.

Contact Details

The contact details for our community team bases are listed below.

Wirral Stein Centre

Address: Stein Centre, St Catherine's Hospital, Derby Road, Wirral CH42 0LQ

Tel: 0151 488 8050

Cheshire West Eastway

Address: Countess of Chester Health Park, Liverpool Road, Chester CH2 1BQ

Tel: 01244 397 222

Cheshire West (Vale Royal) Wyvern House

Address: Wyvern House, The Drummer, Winsford, CW7 1AH

Tel: 01606 288 850

Cheshire East (South Cheshire) Stalbridge Road Clinic

Address: 54 Stalbridge Road, Crewe, Cheshire CW2 7LP

Tel: 01270 636 335

Cheshire East Rosemount Lodge

Address: Lea Bank Close, Macclesfield, Cheshire, SK11 8HE

Tel: 01625 509 013

If you have a query please contact the team at the base nearest to you.

Further information on dementia is available. Please speak to your contact person from the community team or have a look on our website www.cwp.nhs.uk.

Is this the entire assessment?

- If the dementia baseline assessment is not enough to establish whether or not the person you look after has dementia, then more assessments will be carried out if the community team feels it is necessary .
- The assessments may be repeated in 6-9 months if we identify any changes.
- If the person you look after has dementia more tests might be carried out in the future to monitor changes.

Is the assessment different for people with learning disabilities?

- Yes. Dementia is more difficult to identify in people with learning disabilities, because of their lifelong difficulties.
- The assessments used are different to account for this.

Is there anything I can prepare in advance?

- It would help us with the assessments if you bring a summary from the care team and family outlining their views and comments e.g. memory difficulties observed, how you have noticed the changes and other important information.
- The person who knows the individual well should attend the appointment. It is important that you have worked with the individual longer than 6 months.
- Please bring a copy of the person's health file, or health action plan.

The Assessment Process

What will happen if dementia is suspected?

- If dementia is suspected in the person you are looking after then they will be referred to the community learning disabilities team.
- A registered health professional from the clinic will keep in contact throughout the assessment process.
- We will write to the GP of the person you are looking after, asking the GP to do a health check, a blood test and urine analysis. This is to see whether there is any physical cause for the symptoms.
- We will ask the GP for a copy of the results and medical summary.
- If there are no physical causes for the symptoms then a dementia baseline assessment is carried out.

What is the dementia baseline assessment?

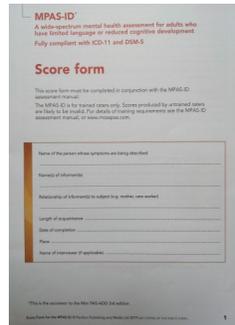
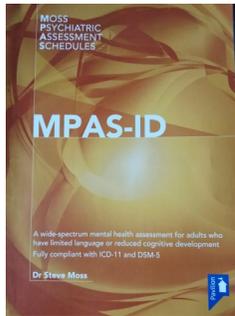
- The dementia baseline assessment is carried out by a registered health professional from the community team.
- It asks you questions about the person you look after and looks for changes in their behaviour, memory and skills.
- It also tries to rule out things that are not dementia as a possible cause for the changes in behaviour, e.g. depression.
- Some part of the assessment are undertaken by you as the carer. Some parts of the assessment will be completed with the person you look after. The person you look after will be asked to give consent for the assessment to take place.
- The registered health professional will ask the person for their consent to complete the memory assessments.

What does a dementia assessment involve?

The dementia baseline assessment uses a range of different assessments that will be described in more detail on the following pages. The registered professional will select the assessments that will be used. The assessments are called:

1. The Mini PAS-ADD
2. The Clinical Interview
3. The CBSC or the NAID (dependant on the level of learning disability the person you look after is diagnosed with)
4. The DLD

The MPAS-ID



The MPAS-ID stands for Moss Psychiatric Assessment Schedules for adults with Intellectual Disability.

The purpose of the MPAS-ID is to rule out mental health problems such as depression or anxiety as a cause for the behavioural changes in the person you look after.

The MPAS-ID provides statements, such as “appears depressed, sad or down”.

You are asked to indicate how much you agree or disagree with each statement for the person you look after.

The statements cover a wide range of areas, such as:

- Memory
- Concentration
- Mood
- Sleep patterns
- Eating habits
- Social interactions

The MPAS-ID also asks how the person you look after might react in certain situations (including physical reactions) and asks about any recent life events that might have happened to them, such as moving house.

- If it looks like the person you look after does not have dementia, then we will discuss the options for monitoring for future changes, and we will discuss the possible causes for the problems that caused the original referral.

What is my role in the process?

- Since you know the person you look after best, you will be very important in monitoring whether their clinical presentation has changed, thus helping in their diagnosis.
- You can also take the person you look after to their GP for a health check, and can offer them your support through the assessment process.
- Once the assessment has been completed we will meet with you and the person you look after to discuss the results and what they mean.

Questions you might have

Where will the dementia assessment take place?

- You and your contact person will discuss the best place for the dementia assessment visit to take place.
- It can be at the community team base or somewhere that suits you.

How long will it take?

- The length of time varies greatly between different people. The assessments may take 1-7 hours to complete. You can discuss the length of time with the registered health professional to agree a plan.
- It can be done in one session or several, depending upon your preferences. You can discuss this with your contact person.

How often will the assessments be carried out?

- The baseline assessment results might not tell us whether the person you look after has dementia, but will tell us their current level of ability.
- If you are concerned that the person you look after has dementia the assessments can be repeated after 6-9 months.
- Comparing the scores will show us changes in the person you look after, and what areas those changes are in.
- If you are not immediately concerned that the person you are looking after has dementia the assessment results can be stored for reference in the future if concerns arise.
- If the person you are looking after has Down's Syndrome we will invite them for repeat assessments at different intervals depending on their age:
 - Aged 30 – 44 years old – 5 yearly
 - Aged 45 - 51 years old – 2 yearly
 - Aged 52+ - yearly

What will happen after the assessment?

- After the assessment, the team will meet to discuss the results of the assessment. We may then invite you and the person you look after to come in to discuss the results with your contact person and our psychiatrist.
- If you attend one of the clinics we may be able to provide you and the person with the results from the assessment the same day. We may also refer the person for further assessments such as a CT scan.
- If it looks like the person you look after has dementia, a diagnosis of dementia may be made, and we will discuss the options for treatment and possible types of dementia.
- The person may not of had previous assessments, but their clinical presentation is indicative of a clinical decline this will be discussed at their appointment.

The Clinical Interview

- The purpose of the clinical interview is gather information about the service user in all areas of their life.
- The interview is completed with family, home staff and day service staff so all areas of the service users life are discussed.
- The interview covers topics such as:
 - Mental health
 - Physical health
 - Accommodation
 - Activities
 - Routines
 - Personal care
 - Support
 - Communication
 - Behaviour
 - A good day and what a bad day looks like.
- The clinical interview completed during the baseline assessment gathers information about the service users previous and current level of functioning.
- It would be helpful to gather as much information as possible. We may ask you to complete the clinical interview with the persons care team and family.
- If further deterioration is noted an additional, more in depth, interview is completed allowing family and staff to explain the changes in the service users presentation across all areas of daily living.

The NAID

- NAID stands for ‘Neuropsychological Assessment of Dementia in Individuals with Intellectual Disabilities’.
- The purpose of the assessment is to assess the service user’s current level of cognitive functioning.
- Tasks include: naming, picture identification, orientation questions, card sorting, object memory, picture memory, performing actions on request and memory for sentences.
- This assessment takes approximately 1 hour however can be broken down into individual tasks if this better suits the service user.
- If further deterioration is noted the assessment will be repeated and the initial scores will be used to compare against to assess for changes in cognitive functioning. If noted, these changes will be discussed with you following the whole assessment.

If the individual is unable to complete the NAID assessment the registered health professional will complete the CBSC assessment:

The CBSC

- CBSC stands for ‘Cognitive Behavioural Skills Checklist’.
- The purpose of the CBSC is to provide a clear picture of the current daily skills of the person you look after and how they have changed so far. This is used for service users with a severe/profound learning disability.
- You will be asked to tell us what support the person you look after needs such as with eating and dressing, and how this has changed compared to how they used to be.
- This can tell us straight away whether you think there have been changes and where they are.

The DLD



- DLD is the short name for the ‘Dementia questionnaire for persons with learning disabilities’.
- The purpose of the DLD is to monitor dementia-related changes in the person you look after.
- The DLD provides statements such as “knows which month it is”.
- For each statement you are asked to respond with ‘yes’, ‘sometimes’ or ‘no’.
- The DLD covers a wide range of behaviours and cognitive abilities such as memory, orientation and mood.
- If further deterioration is noted the assessment will be repeated and the initial scored will be used to compare against to assess for changes in cognitive functioning and social functioning. If there is a significant change of score this may indicate a dementia related change. If noted, these changes will be discussed with you following the assessment.