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

An information leaflet for carers

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

This leaflet has been written for carers who are supporting an individual with a learning disability, who is or may be experiencing 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 Ashton House

Address: 26 Village Road, Oxton, Wirral, CH43 5SR

Tel: 0151 488 8100

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: The Drummer, Winsford, Cheshire, CW7 1AH

Tel: 01606 288 850

Cheshire East (South Cheshire) Stalbridge Road Clinic

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

Tel: 01270 654 400

Cheshire East Rosemount

Address: Chester Road, Macclesfield, Cheshire, SK11 8QA

Tel: 01625 663 631

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 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.

Why is the person who has been referred not involved in the dementia baseline assessment?

- We will tell the person you look after that we are carrying out a dementia baseline assessment and why. There is a separate leaflet called 'I am being assessed for Dementia' that we will give to the person you look after, and we will ask them to give their consent for the assessment to take place.
- The dementia baseline assessment takes a long time and can be distressing for an individual with learning disabilities. Since you know them well, you can tell us enough at this stage without needing to involve the person you look after and cause them distress.
- The dementia baseline assessment can help us identify the most appropriate and relevant tests to use when we need to carry out an assessment with the person you look after.

Is there anything I can prepare in advance?

- You do not need to bring anything with you. However the assessment is based upon your observations of the person you look after and so it would help for you to observe them more closely before the assessment so that you have a good idea of their abilities.

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.
- They will be assigned a named contact person who 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. This is to see whether there is any physical cause for the symptoms.
- If there are no physical causes for the symptoms then a dementia baseline assessment is carried out.

What is the dementia baseline assessment?

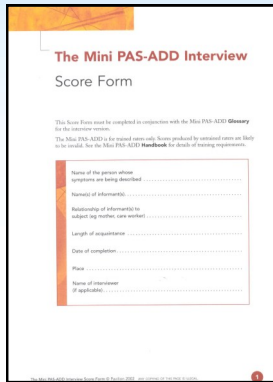
- The dementia baseline assessment is carried out by your contact person from the community team.
- It asks you questions about the person you look after and looks for changes in their behaviour and skills.
- It also tries to rule out things that are not dementia as a possible cause for the changes in behaviour, e.g. depression.
- It is undertaken by you as the carer. The person you look after will be asked to give consent for the assessment to take place. They do not have to be present at the assessment (see page 10).

What does the dementia baseline assessment involve?

The dementia baseline assessment uses four different questionnaires that will be described in more detail on the following pages. The questionnaires are called:

1. The Mini PAS-ADD
2. The ABAS
3. The CBSC
4. The DLD

The Mini PAS-ADD



The Mini PAS-ADD Interview Score Form is a document used for recording the results of the Mini PAS-ADD interview. It includes fields for the name of the person whose symptoms are being described, the name of the informant, the relationship of the informant to the person whose care is being described, the length of acquaintance, the date of completion, the place, and the name of the interviewer if applicable.

- 'PAS-ADD' stands for 'Psychiatric Assessment Schedule for Adults with Developmental Disability'.
- The purpose of the Mini PAS-ADD is to rule out other mental health problems such as depression or anxiety as a cause for the behavioural changes in the person you look after.
- The Mini PAS-ADD 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 Mini PAS-ADD 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.

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 behaviour 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 baseline 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 baseline assessment take place?

- You and your contact person will discuss the best place for the dementia baseline 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, although it does take several hours.
- It can be done in one session or several, depending upon your preferences. You can discuss this with your contact person.

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.
- If the person you look after has dementia more tests might be carried out in the future to monitor for changes.

How often will the dementia baseline assessment be carried out?

- The results might not tell us whether the person you look after has dementia, but will tell us their current level of ability and which questionnaire we need to repeat in a few months time so that we can compare the scores.
- Comparing the scores will show us changes in the person you look after, and what areas those changes are in.
- Some of the questionnaires might have been done before with the person you look after. We will still do them in the dementia baseline assessment so that we can compare their previous results with their current ones.

What will happen after the dementia baseline assessment?

- After the dementia baseline assessment, the team will meet to discuss the results of the assessment. We will then invite you and the person you look after to come in to discuss the results with your contact person and our psychiatrist.
- If it looks like the person you look after has dementia, a diagnosis of 'likely dementia' is made, and we will discuss the options for treatment and possible types of dementia.
- 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.
- If the dementia baseline assessment is unable to determine whether or not the person you look after has dementia, then we will discuss with you the direction for further assessment.

The ABAS

The image shows a screenshot of the ABAS (Adaptive Behaviour Assessment System) Adult Form, Part 1, Nonverbal, Ages 16-89. The form is divided into two main sections: 'ADULT INFORMATION' and 'RATER INFORMATION'.
ADULT INFORMATION:
- Name of Adult Being Evaluated: _____ Age: _____
- Sex: Male Female
- Education in Years: _____
- Occupation: _____
- Does the adult being evaluated have any disabling conditions? Yes No
- If you, please describe:
 - Race/Ethnicity: African American Asian Hispanic American Other
 - Job Status: No job Part-time job Full-time job
RATER INFORMATION:
- Rater's Name: _____ Age: _____ Occupation: _____
- Your relationship to the individual you are rating:
 - Self Parent Relative Partner
 - Working Friend Other (please describe) _____
 - Neighbour Friend Teacher Supervisor
 - Professional Caregiver Other (describe) _____
The form is from PsychCorp, Copyright © 2002, 2005 by Pearson Assessment, Inc. and includes a barcode and the text 'PsychCorp'.

- 'ABAS' stands for 'Adaptive Behaviour Assessment System'.
- The purpose of the ABAS is to measure the functional and social skills in the person you look after.
- The ABAS asks how often the person you look after is able to perform a particular task, such as "operating a microwave oven".
- For each statement you will be asked to say whether the person you look after 'is not able', 'never does it when needed', 'sometimes does it when needed' or 'always does it when needed'.
- It covers a wide range of skills, which are divided into several areas, including:
 - Communication
 - Health and safety
 - Self-care

The CBSC

Client name: _____ D.O.B.: _____ NHS No: _____

Cognitive Behavioural Skills Checklist
for use with Comprehensive Assessment (CASC) Developed by the National Cognitive Behavioural Skills Checklist

Please tick appropriate box and comment

1. PRACTICAL SKILLS	Current baseline	3 months	Today's date	Review date	Review date	Review date
Eating and Drinking						
Uses knife and fork correctly and neatly						
Feeds self with spoon						
Feeds self with fingers						
Must be fed						
Drink/meal eaten at a reasonable pace (not too slow/fast)						
Eating pattern changed (increased)						

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- 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.
- 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

DEMENTIA QUESTIONNAIRE FOR PEOPLE WITH LEARNING DISABILITIES **DLD**

Screening Instrument for Diagnosis of Dementia
in People with Learning Disabilities

H.M. Smeets, M.M.E. Kempen, H.A.L. Eurlings

Name: _____ Gender: M/F

Date: _____

Completed by: _____

Date of completion: _____

Address: _____

Other information: _____

Instructions: The questionnaire has to be completed by a caregiver who is familiar with the observed person. Answer each question by tick (yes) or cross (no) in the column provided. Tick (yes) if you think the person has the skill or ability mentioned in the statement or if you are not sure. Cross (no) if you think the person does not have the skill or ability mentioned in the statement.

Notes: If the observed person is not able to read independently, have about 10 minutes to read the questionnaire. If the observed person is not able to engage in longer tasks, it is recommended to read the questionnaire out loud to the person. If the observed person is not able to read independently, have about 10 minutes to read the questionnaire. If the observed person is not able to engage in longer tasks, it is recommended to read the questionnaire out loud to the person. If the observed person is not able to read independently, have about 10 minutes to read the questionnaire. If the observed person is not able to engage in longer tasks, it is recommended to read the questionnaire out loud to the person.

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- 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.