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

An information leaflet for 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 2018** and is due for review in **August 2020**
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 dementia and has been referred to Trafford Community Learning Disability Team 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 Trafford Community Learning Disability Team Base is: are listed below.



Community Learning Disability Team
1st Floor
Waterside House
Sale Waterside
Sale
M33 7ZF

Tel: 0161 912 2810

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 & the length of time to complete the assessments also accounts for this.

Why does the person who has been referred not have to be involved in all of the dementia assessment?

- We will tell the person you look after that we are carrying out a dementia assessment and why. There is a separate leaflet called 'I may have dementia' that we will give to the person. We will ask them to give their consent for the assessment to take place.
- The dementia assessment takes a long time and therefore maybe too long for the person to sit and contribute.
- Some questions and answers may be difficult or distressing for the person to hear. Since you know them well, you can tell us whether or not it will be suitable for them to be participate in the whole assessment.
- Remember one of the four assessments is carried out directly with the person. The other 3 questionnaires are usually completed with the carer but the person can contribute.

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.
- For paid carers, please ensure that the carer who knows the person well is interviewed. When the assessment is repeated, the same carer will need to be interviewed.

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 & learning disability assessment is carried out.

What is the dementia assessment?

- The dementia assessment is carried out by your contact person from Trafford Community Learning Disability Team (CLDT).
- 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.
- Part of 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 for all of the assessment.

What does the dementia assessment involve?

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

The questionnaires are called:

1. Clinical Interview (Baseline & / or Suspected Dementia Interview)
2. The Mini PAS-ADD
3. The Dementia Questionnaire for People with LD (DLD)
4. The NAID

Other assessments such as AMPS & The Cognitive Behavioural Skills Checklist (for those with a severe learning disability) may be used.

The Clinical Interview

- The purpose of the clinical interview is gather information about the person you look after in all areas of their life.
- Where possible, the interview is completed with family, home staff and day service staff so all areas of the person's life are discussed.
- The interview covers topics such as:
 - Accommodation
 - Activities
 - Routines
 - Personal care
 - Support
 - Communication
 - Behaviour
 - Mental health
 - Physical health
- The initial interview gathers information about the person's 'normal' routine and support.
- If further deterioration is noted an additional, more in depth, interview is completed allowing family and staff to explain the changes in the person's presentation across all areas of daily living.

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 Trafford CLDT 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?

- The dementia assessment process is lengthy as we need to complete the initial dementia assessment and repeat it 6-9 months later
- For people with Down's syndrome who have already had a dementia baseline assessment, this assessment process is quicker.
- Sometimes there is not enough evidence to establish whether or not the person you look after has dementia. Therefore the CLDT will discuss the option with you.
- If the person you look after has dementia more tests might be carried out in the future to monitor changes.

What will happen after the dementia assessment?

- Trafford CLDT will write a report and then meet to discuss the results of the assessment.
- If there have been a changes in scores which indicates that the person may possibly have dementia, we will refer them to Trafford Memory Assessment Service. A copy of the Dementia & LD Assessment report will be forwarded with the referral as well as a copy be sent to the GP.
- Prior to Trafford Memory Assessment Service proceeding with the referral, they will require the results from a recent blood test (within the past 3 months). Therefore an appointment with the GP will need to be made.
- Trafford Memory Assessment Service will send a clinic appointment to meet with their Psychiatrist. Someone from Trafford CLDT will be more than happy to support the person you look after and you at this appointment—so just ask.
- If it looks like the person you look after has dementia, a diagnosis of 'likely dementia' is made. Treatment options will be discussed by the Trafford Memory Assessment Service Psychiatrist.
- Trafford Memory Assessment Service remain involved until the treatments options are implemented and the person you support is stable. Once stable, they discharge back to the GP.
- Trafford CLDT remain involved and offer post diagnostic practical support . They will ensure the person has an up to date care plan & risk assessment. There will be periods throughout the person's dementia journey where Trafford CLDT will be not be actively involved but can be contacted at any time for advice and support.
- 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.

The Mini PAS-ADD

- '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, bereavement etc.

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.

The NAID

- NAID stands for 'Neuropsychological Assessment of Dementia in Individuals with Intellectual Disabilities'.
- The purpose of the assessment is to assess the current level of cognitive functioning of the person you look after.
- This assessment is completed with the person. You do not need to be present during this assessment unless to provide reassurance to them.
- Tasks include: picture 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 person.

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 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 to discuss the results and what they mean.

How often will the dementia assessment be carried out?

- The results from the initial assessment might not tell us whether the person you look after has dementia, but it will tell us their current level of ability.
- As we need to evidence changes, the dementia assessment process needs to be repeated. This is usually carried out between 6-9 months after the initial assessment, dependent on the concerns.
- The scores from both assessments are compared and will show us changes in the person you look after as well as what areas those changes are in.
- For individuals with Down's syndrome, a dementia baseline assessment may have already been completed. Therefore we will be able to compare their previous results with their current ones. This often speeds up the diagnosis process dependent on the outcome of the assessments.
- If the dementia assessment is unable to determine whether or not the person you look after may possibly have dementia, then we will discuss with you the direction for further assessment.