

# Westminster Memory Services Pathways Toolkit (updated October 2016)

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## **Aims**

The aims of this document are:

- To promote awareness of conditions that may cause memory loss
- To provide information about pathways for assessment and support services in Westminster for people with memory problems
- To provide guidance about assessment and diagnosis of dementia

## **Memory loss experienced by service users**

People who are homeless live with serious health conditions, which are often only treated once they have developed to a significant or serious stage. These are usually accompanied by a range of other health problems.

Among the issues frequently reported by homeless people are conditions associated with memory loss and dementia. These include alcohol-related problems such as Korsakoff's syndrome and neurological problems.

19% of service users of St Mungo's Westminster Homeless Health Co-ordination Project reported that they struggle remembering things every day.<sup>1</sup> However, only 1.5% of respondents reported a diagnosis of dementia. Meanwhile, just 3% of respondents reporting a mental health diagnosis indicated that a memory service was helpful in managing their condition.

A report by St Mungo's<sup>2</sup> found that Korsakoff's was a common condition amongst its client group. Therefore the high number of service users reporting they struggle to remember things every day could be attributed to the fact that 53% respondents also drink alcohol. Nonetheless, the low number of service users reporting either a diagnosis of dementia or that they were benefiting from contact with a memory service could illustrate that work is needed to improve the pathway for service users to access memory services.

## **Signs of memory loss**

The person may be finding it difficult to remember things on a day-to-day basis and may be experiencing some of the following things:

- forgetting dates and appointments
- getting in a muddle with personal finances
- losing things
- finding it harder to remember names
- difficulties following conversations

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<sup>1</sup> St Mungo's (2016) Westminster CHAT Report 2015/2016

<http://www.mungos.org/documents/7294/7294.pdf>

<sup>2</sup> St Mungo's (2013) Health and homelessness: Understanding the costs and role of primary care services for homeless people <http://www.mungos.org/documents/4153/4153.pdf>

## **Alcohol dependency and memory loss**

The following conditions are associated with alcohol dependency and symptoms include memory loss:

- Korsakoff's Syndrome – a neurological disorder caused by a lack of thiamine (vitamin B1) in the brain, resulting in an irreversible state of confusion and amnesia. Its onset is linked to chronic alcohol abuse and/or severe malnutrition. Korsakoff's been witnessed in homeless clients from as early as 38 years of age.
- Wernicke's encephalopathy – a neurological condition which usually develops suddenly, often after abrupt and untreated withdrawal from alcohol. It has a range of different symptoms, but they may not be obvious and it can be difficult to make a diagnosis.
- Dementia due to alcoholism – impaired thinking that resembles Alzheimer's disease, caused by consuming excessive amounts of alcohol for several years or more. Memory, orientation, and attention deteriorate, although verbal skills are not always severely affected. In this type of dementia, abstinence from alcohol may partly restore mental functioning.

## **Other conditions that can cause memory loss**

More than 50 conditions can cause memory loss. These include:

- Alzheimer's disease – a form of dementia, and by far the most common intractable condition which causes memory loss in the general population. This type generally occurs from 65 years of age and has a slow progression.
- Vascular dementia - this is the second most common of memory loss in general population. A common form of dementia caused by an impaired supply of blood to the brain, such as may be caused by a series of small strokes. The progression of vascular dementia can be improved by making better lifestyle choices (not drinking, exercising).
- Dementia with Lewy bodies – a type of dementia caused by deposits of an abnormal protein called Lewy bodies inside brain cells. These deposits build up in areas of the brain responsible for memory and muscle movement. Dementia with Lewy bodies can cause hallucinations.
- Other degenerative disorders resulting in irreversible memory loss, such as frontotemporal lobar degeneration (Pick's disease), Parkinson's disease and Huntington's disease. Pick's disease can be seen in those under the age of 65 and during the early stages changes are seen in the person's personality and behaviour (e.g. losing inhibitions, losing interest in people and things, repetitive behaviours)
- Thyroid disease - including hypothyroidism, which is caused by vitamin B12 deficiency or an underactive thyroid
- Malnutrition, including vitamin and mineral deficiencies – severe malnutrition may lead to Korsakoff's Syndrome
- Infections of the central nervous system (for example, Creutzfeldt-Jakob disease)

- Depression – people sometimes manifest dementia-like symptoms—forgetfulness, disorientation, inattentiveness, and slowed responses—when they are depressed. This so-called pseudodementia can masquerade as the depression that often accompanies Alzheimer’s disease, but there are subtle differences.
- Anxiety, stress
- Post-Traumatic Stress Disorder
- Urinary tract infections
- Chest infections
- AIDS dementia
- Neurosyphilis
- Hydrocephalus
- Subdural hematomas
- Epilepsy and seizures
- Severe constipation

Other potential causes of memory loss are:

- a stroke
- a head injury
- a brain tumor

### **Memory loss as a reaction to prescription drugs**

Toxic reactions to medications can be a factor in mental decline. With aging, the liver becomes less efficient at metabolizing drugs, and the kidneys eliminate them from the body more slowly. As a result, drugs tend to accumulate in the body. Older people in poor health and those taking several different medications are especially vulnerable.

Many drugs can cause dementia-like symptoms. They include:

- antidepressants
- antihistamines
- anti-Parkinson drugs
- anti-anxiety medications
- cardiovascular drugs
- anticonvulsants
- corticosteroids
- narcotics
- sedatives

Abrupt withdrawal from benzodiazepines - a group of anti-anxiety drugs that includes diazepam (Valium), chlordiazepoxide (Librium), and alprazolam (Xanax) – can be another cause of memory loss.

Abuse of the drug flunitrazepam (Rohypnol) produces a sedative hypnotic effect, leading to short-term memory loss.

## **Assessment for memory loss and dementia**

It is essential that a thorough and timely assessment for possible dementia is carried out, in order to:

- rule out other conditions that may have similar symptoms and may be treatable, e.g. urine infections/ chest infections
- rule out other possible causes of symptoms – for example, side effects of certain drugs
- provide the service user with an explanation for their symptoms, reducing uncertainty and allowing them to begin to adjust
- allow a person with dementia to access treatment, information, advice and support (emotional, practical, legal and financial)
- allow a person with dementia to plan and make arrangement for the future.

Making a diagnosis of dementia is often difficult, particularly in the early stages. This is because there is no one simple test and early symptoms can be similar to those of lots of other common conditions, as mentioned above. A thorough assessment will often accurately diagnose the type of dementia, and people will usually be told the type, though this may only be confirmed after death if a post-mortem is done.

Knowing the dementia type will help to:

- understand symptoms
- predict how the dementia might progress
- suggest how best to manage it

Assessment for possible dementia is a process that takes time. Assessment proceeds through various stages and tests, and ends with the sharing of the diagnosis.<sup>3</sup> For the person and those close to them, this journey is often an uncertain, anxious and emotional one.

## **Pathways for assessment**

There is more than one way that a person in Westminster might end up being assessed for dementia:

### **1. Assessment by a GP**

In the case of suspected dementia, most people start by approaching their GP because of their symptoms.

GPs may also now ask certain patients who are at increased risk of dementia whether they have concerns about their memory. This includes people with Parkinson's disease or people who are over 60 and have diabetes or a heart condition, or have had a stroke. The GP may ask these patients about memory problems even if they are visiting them about something else.

The GP will assess the person by following these procedures:

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<sup>3</sup> For an outline of the current National Institute of Clinical Excellence (NICE) pathway for assessment and diagnosis of dementia, see the Appendix to this document.

- **Taking a 'history'** – The GP will spend some time talking to the person and someone who knows them well – this could be the person's support worker. They will ask about how and when the symptoms started and how they affect the person's life. The GP will look at the medical history of the person and their family members. They will review any medication the person is taking.
- **Physical examinations and tests** – The GP may carry out a physical examination. They will also take samples (blood and possibly urine) to send off for tests. This may help in diagnosing other conditions that are causing the symptoms.
- **Tests of mental abilities** – The GP will ask the person a series of questions or give them a short pen-and-paper exercise to do. These are designed to test thinking, memory and orientation.

At the end of the assessment, 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 often, the GP will decide that further assessment is needed to make sure. In such cases they will generally refer the person to a memory assessment service, memory clinic or other specialist service within a community mental health team.

## 2. Assessment in hospital

Anyone over 75 who is admitted urgently to hospital should now be assessed for confusion and memory problems.

## 3. Referral to a specialist

The GP is the usual person to make a referral to a specialist. If the person or their support worker feels that a referral to a specialist would be helpful and the GP does not suggest it, they should ask about it. A specialist such as a consultant will have more knowledge and experience of dementia than a GP. They will have more time allocated for the appointment and access to more specialised investigations, such as brain scans and in-depth mental testing. After referral, the person should have to wait no longer than 4–6 weeks to see a specialist.

The GP will make the referral to a consultant working in a particular specialism. Which specialism they refer them to may depend on the age of the person, their symptoms, and what is available to patients in Westminster. The main types of consultant are:

- **Old age psychiatrists** are psychiatrists who specialise in the mental health of older people, including dementia. They may sometimes also offer support to younger people with dementia.
- **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 consultant usually works with other professionals, including mental health nurses, psychologists, occupational therapists, social workers and dementia advisers (professionals who provide information, advice and guidance to people with dementia and their carers).

Assessment may take place in the home, in an outpatient's department at a hospital, in a day hospital over several weeks or, very occasionally, while the person stays in hospital as an inpatient. The specialist will carry out their assessment by following these procedures:

- **Taking a history** – As with the GP, the specialist will talk to the person being assessed and those close to them for up to 90 minutes.
- **Physical examinations and tests** – A physical examination and/or tests will be undertaken, if they have not already been carried out by the GP. In many cases the blood tests will already have been done before referral.
- **Tests of mental abilities** – The person will have a more detailed assessment of memory and other thinking processes. This assessment consists of a range of pen-and-paper tests and questions. These will test things like memory, orientation, language and visuospatial skills (eg copying shapes). These tests can be very good at helping to determine the type of problem a person may have, particularly in the early stages.
- **Scans** – The person might be sent for a brain scan. This may involve a wait of several weeks.

If a diagnosis of dementia is made, there is a lot to adjust to and a great deal of information to take in. The final diagnosis meeting will usually cover how the dementia is likely to progress and any treatments (drug or non-drug) as part of a care plan.

In some cases the consultant may diagnose mild cognitive impairment rather than dementia. Mild cognitive impairment is when the person has problems with memory or thinking but these are not severe enough to be diagnosed as dementia. The specialist may then discharge the person back to their GP and ask the GP to re-refer them if they are significantly worse after a further 6–12 months.

### **Getting the most from a consultation**

If possible, someone who knows the person being assessed well should go with them to the consultation. This could include their support worker. It may be helpful to do the following:

- Write down any questions or worrying symptoms beforehand to bring up with the GP or specialist. Try to include details of when symptoms first started. It can be difficult for the person to remember everything they want 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 that the service user or the person who is accompanying them does not understand.
- Ask the doctor to write down any medical terms, especially if English is not the service user's first language.
- If a professional refers to 'memory problems' when giving a diagnosis, and you're unclear what they mean, the person (or the support worker accompanying them) might want to ask, 'Do you mean (I

have) dementia?' or 'Is that the same as Alzheimer's?', for example. Make sure you are clear what type of dementia has been diagnosed.

- A specialist should offer to send the person a copy of the letter they will write to the GP. This letter will include details of the diagnosis. You can ask them to provide a more personalised letter, containing clear information about the diagnosis and care needs.

### **Pre-diagnostic counselling**

An assessment for possible dementia can be confusing and daunting, and a diagnosis of dementia is life-changing. Many memory services offer people who are about to go through assessment and diagnosis the chance to talk things over with a professional beforehand.

This pre-diagnostic counselling will help the person (and those supporting them) to:

- understand why they have been referred
- learn about the assessment process
- give their consent (or not) to go ahead
- prepare them for the possible outcomes
- share what they already know about dementia
- express their feelings and raise any concerns

### **Receiving the diagnosis**

At the end of a consultation the doctor will explain whether they can make any tentative diagnosis based on the information they have so far. When all the test results are known, a separate appointment will usually be made for the consultant, and often other professionals in the team, to give the final diagnosis. Very occasionally, the consultant will send a report to the person's GP, who will then give the diagnosis.

A diagnosis of dementia should be communicated sensitively, honestly and in a way that is tailored to the needs of the individual.

The person being assessed has the right to:

- be told their diagnosis
- be asked if they wish to know the outcome
- choose not to know the outcome
- be asked if they are happy for the person attending with them to be told

Occasionally the doctor will decide not to tell the person with dementia their diagnosis. This may be because the doctor thinks that the person would not understand the diagnosis, or may feel that the person would find this knowledge too distressing.

Some doctors will refer to 'memory problems' instead of using the word 'dementia'. What is important is that the doctor uses language that the person understands and takes things at a pace that works for them.



## **Ongoing assessment**

Once a diagnosis of dementia is confirmed, any medication has been started, and any post-diagnostic sessions have been completed, the person will generally be discharged from the memory service back to their GP. (An exception may be that there is a need for ongoing specialist support for specific symptoms or behaviours.) As the dementia progresses, the GP may refer the person with dementia back to a specialist for help in assessing changes, and for advice on ways to deal with certain difficulties such as changes in behaviour. The GP remains responsible for the general health of the person with dementia.

Prescription of drugs for Alzheimer's disease will be started by the specialist and then routine prescribing will usually transfer to the GP. A review of these drugs is generally carried out every six months by the specialist or GP.

## **Supporting a person with memory problems**

A person with dementia or memory problems should also be allowed to plan and make arrangements for the future. They should be able to access the following:

- **Treatment**
- **Information and advice** (via Westminster Dementia Advice Services, or <http://www.alzheimersresearchuk.org/supporter-orders/>)
- **Emotional support** (see [http://www.westminsterhhcp.org/mental\\_health\\_services.htm](http://www.westminsterhhcp.org/mental_health_services.htm))
- **Practical support.**
  - Telecare may be suitable to support a client with memory problems; e.g. to remind them to take their medication or to track them when they lose their way outside. Further information can be found at: <http://www.peoplefirstinfo.org.uk/at-home/staying-in-your-own-home/gadgets-to-help-you-stay-safe.aspx>
  - An identifier card that the individual carries around in case they become lost [https://www.alzheimers.org.uk/site/xfp/scripts/xforms\\_form.php?formID=345&language=en](https://www.alzheimers.org.uk/site/xfp/scripts/xforms_form.php?formID=345&language=en)
- **Legal support** – further information at: [https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?&documentID=160](https://www.alzheimers.org.uk/site/scripts/documents_info.php?&documentID=160)
- **Financial support.** It may be appropriate to set up Power of Attorney to support clients with finances if a diagnosis is provided. Find further information at: <http://www.ageuk.org.uk/money-matters/legal-issues/powers-of-attorney/power-of-attorney/>

## **Support for people with memory problems in Westminster**

### **Admiral Nursing Direct**

Admiral nurses provide information, practical advice and emotional support for people caring for someone with dementia. They can help with obtaining professional assessment, support services, welfare benefit and relief care.

Contact: **0800 888 6678** or email [direct@dementiauk.org](mailto:direct@dementiauk.org)

### **Westminster City Council**

If the person is having difficulty in managing day to day tasks because they have dementia, then Westminster City Council may be able to provide support. Contact the appropriate social care team to request an assessment of what sort of help the person needs and whether they qualify for support services provided through the council.

For contact details and guidance on making a referral to Westminster City Council's social care teams, refer to the **Social Services Referral Guidance** document for the Westminster Homeless Health Co-ordination Project.

### **Westminster Dementia Adviser Service - (can self-refer to this service)**

The Dementia Adviser Service for Westminster supports those with memory problems and those who have received a diagnosis of dementia. The Adviser can visit service users and provide telephone and email support, acting as a continuous point of contact for as long as is needed. The Dementia Adviser Service offers information, advice and support at all stages of dementia to help people feel informed and able to access appropriate help when needed.

The Dementia Adviser Service can help with:

- understanding and managing the symptoms of dementia
- providing tips on maintaining memory and quality of life
- information on how to stay independent at home
- information about local clubs and activities
- information about travel options in Westminster
- information about financial support and legal issues linked with dementia (Attendance Allowance & Power of Attorney etc.)
- information about care, respite, long term housing and accessing Social Services
- dates and information on the Memory Café sessions that held across the month in the North and South of Westminster

### **Westminster Dementia Adviser Service**

42 Westbourne Park Road  
London  
W2 5PH

Mobile: 07540 502379

Email: [terezie.holmerova@housingandcare21.co.uk](mailto:terezie.holmerova@housingandcare21.co.uk)

## **People First**

More resources and information about support that may be available for people in Westminster with memory problems can be found at: <http://www.peoplefirstinfo.org.uk/health-and-well-being/dementia-and-memory-loss.aspx>

## **Westminster Memory Service**

The Memory Service is a specialist service for people in Westminster experiencing memory difficulties. The Memory Service offers a comprehensive assessment of the person's memory, providing useful strategies and treatments to help the person to minimise their memory difficulties and to help them live independently and safely.

The Memory Service will work closely with the person, and those supporting them, to prioritise what the person needs and what they would like to achieve.

The Memory Service can offer:

- strategies to help the person manage their memory on a day-to-day basis.
- talking therapy to explore their worries, concerns and feelings.
- groups where they can meet other people in a similar situation and can share tips and ideas.
- some people may benefit from medication which the Memory Service can prescribe.
- information, advice and guidance that can help the person now or in the future
- support, advice, information and education on memory problems and dementia, for those close to the person

To be referred to the Memory Service, the service user can contact their GP and ask for the referral to be made. The GP may want to take a blood test at this point to rule out any other health concerns.

The service user can also contact the Memory Service directly to refer themselves (alternatively, after having consulted with the service user, a support worker may make the referral on the service user's behalf). The Memory Service may still ask the service user to see their GP to rule out any other health concerns.

The Memory Service will phone the service user and/or their support worker to make an appointment at a convenient time. The Memory Service may visit the service user to complete their assessment. The service user may also arrange to visit the Memory Service if they prefer.

The Memory Service always asks that the person has a relative, friend or support worker with them during the visit so that they can support and help the person during the visit.

## **Kensington and Chelsea and Westminster Memory Service**

42 Westbourne Park Road

London

W2 5PH

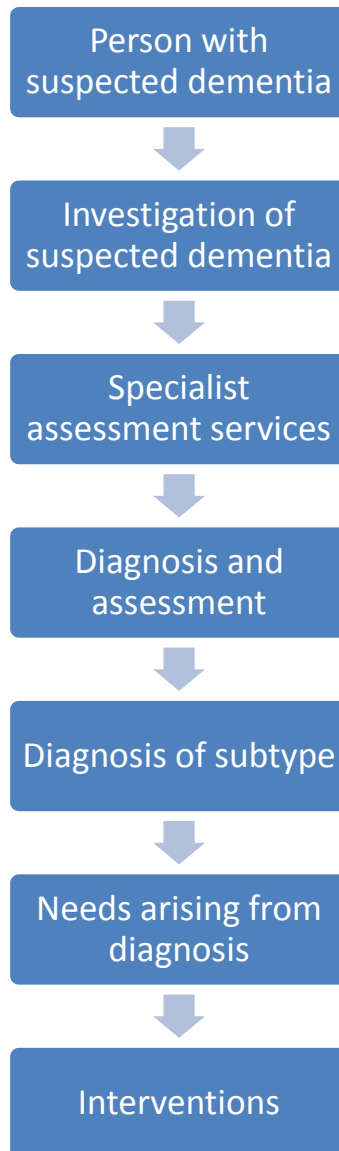
Tel: 020 3219 0910

Web: [www.cnwl.nhs.uk](http://www.cnwl.nhs.uk)

**Appendix – NICE Dementia diagnosis and assessment:**

**NICE (National Institute for Health and Care Excellence)**

Dementia diagnosis and assessment pathway:



NICE Pathways are interactive and designed to be used online. They are updated regularly as new NICE guidance is published.

This pathway version is correct as at 7 October 2016.

To view the latest version of this pathway see: <http://pathways.nice.org.uk/pathways/dementia>