NHS London Clinical Networks

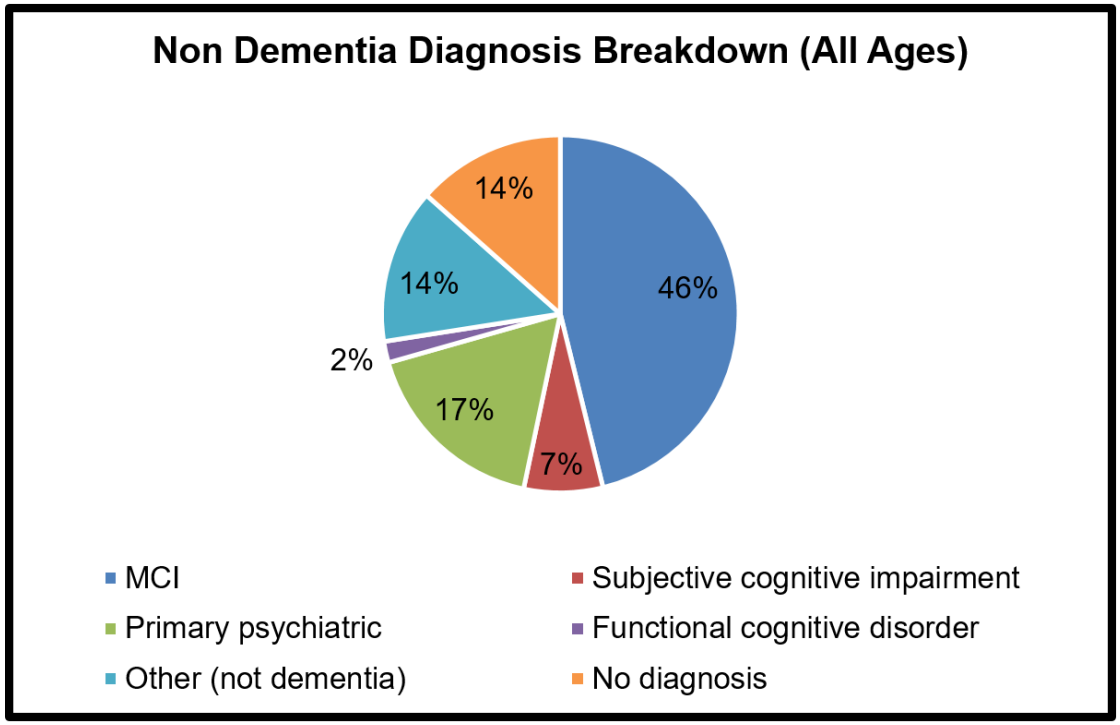
Non-Dementia Pathways

Guidance from the London Dementia Clinical Networks

The aim of this document is to provide commissioners and clinicians in memory services and primary care with guidance on the appropriate pathways for patients who present with memory complains due to a range of non-dementia causes

Introduction

The 2019 London memory service audit looked at 988 case notes across 20 services. In addition to finding considerable variation between services; the audit found that overall 40% of patients were not given a diagnosis of dementia and 85% of patients under the age of 65 were not given a diagnosis of dementia.



Introduction

The main purpose of memory assessment services (MAS) is to diagnose dementia and initiate treatment. If they are to do this effectively, they need to ensure that people with cognitive problems but without dementia get quick access to the interventions they need. This is especially relevant for people aged under 65 referred to memory services. But it is imperative that people who do have young onset dementia receive a timely and accurate diagnosis. The young dementia network has produced a useful referral decision making guide for primary care.

An expert working group reviewed pathways for non-dementia diagnosis and produced a guidance document aimed at commissioners and clinicians within memory services and primary care. The pathways which follow – mild to moderate depression and/or anxiety, alcohol misuse, mild cognitive impairment and functional cognitive disorder – are to be used as a guide alongside clinical judgement.

Mild to moderate depression and/or anxiety

The principles of this pathway may also be useful for other psychiatric disorders e.g. post-traumatic stress disorder (PTSD)

Click on the text in each box below to find out further information

Primary care (referral)

MAS triage

MAS assessment and diagnosis

Case study

IAPT and memory service relationship example

Cognitive concerns in the context of alcohol misuse

The general principle of this pathway may also be useful for cognitive concerns in the context of drug misuse.

Click on the text in each box below to find out further information

Primary care (referral)

MAS assessment

MAS triage

Case study

Mild cognitive impairment (MCI)

There are several definitions of MCI. The term used in ICD-11 is “mild neurocognitive disorder”. According to ICD-11, this is characterized by the subjective experience of a decline from a previous level of cognitive functioning, accompanied by objective evidence of impairment in performance on one or more cognitive domains relative to that expected given the individual’s age and general level of intellectual functioning that is not sufficiently severe to significantly interfere with independence in the person’s performance of activities of daily living. The cognitive impairment is not entirely attributable to normal aging. (ICD-11)

Click on the text in each box below to find out further information

MAS assessment

Diagnosis

Post diagnostic pathway

What is MCI?

MCI register in primary care

Functional cognitive disorder (FCD)

Working definitions of FCD are still being developed. In ICD-11, it is referred to as “dissociative neurological symptom disorder, with cognitive symptoms”. According to ICD-11, this is characterised by impaired cognitive performance in memory, language or other cognitive domains that is internally inconsistent and not consistent with a recognised disease of the nervous system, a neurodevelopmental or neurocognitive disorder, other mental and behavioural disorder, or another health condition and does not occur exclusively during another dissociative disorder. (ICD-11)

Click on the text in each box below to find out further information

Primary care

Diagnostic and post diagnostic pathway

MAS triage

FCD flags

MAS assessment

Case study

Glossary

CBT – Cognitive behavioural therapy

Extended brief alcohol advice - Using brief motivational interviewing additionally to simple advice

GAD-7 – Generalised Anxiety Disorder Assessment; this self-administrated patient questionnaire is used as a screening tool and severity measure for generalised anxiety disorder.

IAPT - Improving Access to Psychological Therapies (IAPT) is an NHS initiative to provide more psychotherapy to the general population.

MOCA - The Montreal Cognitive Assessment (MoCA) is a brief cognitive screening tool for mild cognitive impairment http://www.mocatest.org/splash/ .

NHS Health Check - NHS Health Check is a health check-up for adults in England aged 40-74. It's designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes or dementia.

PHQ-9 – Depression module of the patient health questionnaire; a self-administered instrument for common mental health conditions

PTSD - Post-traumatic stress disorder

SCI – Subjective cognitive impairment; can be defined as the presence of cognitive complaints in the absence of pathological neuropsychological testing[6]

Short MAST Geriatric Version is a modified version of the evidence based Short Michigan Alcoholism Screening Test which asks specific questions relevant for the older population.

Structured brief alcohol advice – giving short structured advice (e.g. benefits of reducing alcohol intake); leaflet here

References

1) London Memory Service Clinical Audit 2019 https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2019/11/FINAL-London-memory-service-audit-2019.pdf
2) 27 Suspected neurological conditions: recognition and referral https://www.nice.org.uk/guidance/ng127
3) NICE (2018) NG97 Dementia: assessment, management and support for people living with dementia and their carers https://www.nice.org.uk/guidance/ng97
4) NICE (2009) CG91 Depression in adults with a chronic physical health problem: recognition and management https://www.nice.org.uk/guidance/cg91
5) Nasreddine et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. J Am Geriatr Soc.; 2005;53: 695–699.
6) Cooper et al. Modifiable Predictors of Dementia in Mild Cognitive Impairment: A Systematic Review and Meta-Analysis. Am J Psychiatry. 2015
7) Reisberg B, Prichep L, Mosconi L, John ER, Glodzik-Sobanska L, Boksay I, Monteiro I, Torossian C, Vedvyas A, Ashraf N, Jamil IA. de Leon MJ The pre-mild cognitive impairment, subjective cognitive impairment stage of Alzheimer's disease. Alzheimers Dement 2008;4:S98-S108. [PubMed]
8) World Health Organization. (2018). *International classification of diseases for mortality and morbidity statistics* (11th Revision). Retrieved from https://icd.who.int/browse11/l-m/en

Authors

Georgina Charlesworth, Strategic and Clinical Lead for Older People's Psychological Services, North East London NHS Foundation Trust

Helen Souris, Clinical Project Manager, Dementia Clinical Network, NHS England and Improvement (London Region)

Sergi Costafreda, Consultant Psychiatrist and Senior Lecturer in Old Age Psychiatry, Islington Memory Service, Division of Psychiatry, UCL

Laura Cook, Clinical Programme Lead, Dementia Clinical Network, NHS England and Improvement (London Region)

Jeremy Isaacs, Clinical Director, Dementia Clinical Network, NHS England and Improvement (London Region)

Mild to moderate depression and/or anxiety

For adults who have an anxiety disorder, be aware that memory problems and concentration difficulties might be part of this disorder. (NICE NG127)[2]

In the context of depression and anxiety it is important to consider what is going on in a patient's life and the correlation with onset of memory symptoms:

Social circumstances and life events, stress at work, carers stress and long-term conditions

Memory problems can be caused by stress; for patients under 50 with memory problems and no other neurological signs, do not routinely refer to neurology if brief testing shows memory function to be normal and symptoms are consistent with concentration difficulties. (NICE NG127)[2]

Patients under 65 should have a course of treatment for their mood/anxiety symptoms (e.g. IAPT or antidepressant therapy) before a memory service referral. If cognitive symptoms persist or worsen despite this, then a referral should be made.

There should be a low threshold for referring older adults with new symptoms of depression (with lack of a trigger) and cognitive impairment due to the higher risk of dementia.

NICE recommends referring the person to a specialist dementia diagnostic service if reversible causes of cognitive decline, including depression, have been investigated and dementia is still suspected. (NICE NG97)[3]

Mild to moderate depression and/or anxiety

Clinicians should discuss potentially 'inappropriate' referrals with the GP (e.g. people under the age of 60 in the context of depression and anxiety) and offer advice, as above.

Screening questions can be used if discussing the referral with the patient:

- During the last month, have you often been bothered by feeling down, depressed or hopeless?
- During the last month, have you often been bothered by having little interest or pleasure in doing things?

(NICE CG91)[4]

Mild to moderate depression and/or anxiety

Professionals completing a memory service assessment should have the competencies to diagnose anxiety disorders and depression.

Informant history is useful to distinguish between depression/anxiety and dementia.

Consider using IAPT tools – PHQ9 and GAD7 as part of the assessment

If appropriate, support patients to self refer to IAPT whilst attending the memory service (phone together in clinic).

Memory services should have a good working relationship with their IAPT colleagues.

Mild to moderate depression and/or anxiety

A 52 year old woman was worried that she might have dementia as her mother had developed dementia in her 80s. She presented with: minor forgetfulness, for example forgetting appointments and some conversations. She had become increasingly reliant on her phone calendar and continued to work, but not at her best.

She had no problems with procedural tasks or activities of daily living, but had reduced motivation. There was no history of mental illness, head injury or falls, no word/name finding difficulties, and no significant medical history.

On mental state examination, she was low in mood objectively, although subjectively she denied depression. She acknowledged reduced appetite, reduced energy levels and some insomnia. She had had no significant adverse life events and had a supportive family. Mild impairment was noted on memory testing.

She was given advice to address depressive symptoms in the first instance including self referral to IAPT.

Mild to moderate depression and/or anxiety

Waltham Forest Talking Therapies has a close working relationship with the Older Adults and Memory Services. Services users from the memory service who have cognitive impairment in the context of mild to moderate depression/anxiety are able to access the IAPT service directly or by referral. Clinicians from both services have good joint working relationship and are able to facilitate case discussion. A link therapist is allocated to the Older Adults and Memory Service.

Cognitive concerns in the context of alcohol misuse

Be aware that memory problems can be caused by alcohol (NICE NG127)[2]

If someone presents in primary care with cognitive problems linked to the signs of alcohol misuse, primary care clinicians should:

- Offer a session of structured brief advice on alcohol.
- Depending on the context, explain the effects that alcohol has on memory and that if the person is able to stop drinking, their memory may improve.
- Offer prophylactic thiamine and vitamin B complex to people with significant liver disease or at risk of malnutrition. Also offer vitamin B complex to people with physical frailty and co-morbidity. For further guidance see NICE (thiamine) and discussion paper (vitamin B).
- If dependent on alcohol, refer for specialist treatment. If someone is reluctant to accept a referral, offer an extended brief intervention.
- Consider support for carer / relative.

The NHS Health Check leaflet on dementia prevention has a section on alcohol.

A referral to the memory service should be made if there are concerns that the person has dementia. Note that regularly drinking above higher risk levels increases the likelihood of alcohol related dementia.

Cognitive concerns in the context of alcohol misuse

Triaging clinicians may want to discuss with the referrer and if appropriate, the patient and relative to ascertain if the referral is appropriate for the memory service. If cognitive decline is more than can be explained by significant alcohol use, then the memory service should assess the patient.

If the referral is inappropriate refer to another service such as alcohol services.

Cognitive concerns in the context of alcohol misuse

Clinical staff should discuss with their team leader whether a patient who is misusing alcohol should be seen in clinic rather than at home due to potential risks.

Consider using the Short MAST Geriatric Version to assess alcohol misuse (other screening tools are available here).

Formal cognitive testing may be invalid if the person is intoxicated.

If the person does not have dementia then advice should be given as per primary care box.

Cognitive concerns in the context of alcohol misuse

A man in his 50s presented with longstanding memory lapses and cognitive concerns in the context of a stressful job and a past history of generalised anxiety and a depressive episode. He reported daily intake of alcohol (30-40 units per week), with no periods of abstinence in the last five years.

There was evidence of mild cognitive impairment, but mood was stable and he reported independence in all activities of daily living. No functional impairment was evident; he continued to work.

He was offered structured brief advice about a reduction of alcohol use within the guidelines of 14 units per week. He did not feel that he required support from specialist alcohol services to achieve this.

There was also a period of extended brief intervention, with discussion about the risks of continuous alcohol consumption to future mental and physical health; with an emphasis on increasing his risk of anxiety and depression as well as more serious memory problems in the future including the risk of dementia. Thiamine was not considered as his nutritional intake appeared to be adequate.

Mild cognitive impairment (MCI)

Informant history is vital in order to confirm that the patient is still able to perform their usual activities of daily living, such as work duties, handling finances, shopping and cooking. An informant might observe, for example, that the patient needs more time to complete tasks, but is still able to do them independently.

Use a brief screening tool validated for detection of people with MCI, such as the Montreal Cognitive Assessment (MOCA)[5].

Neuro-imaging may be useful to identify underlying brain pathology, but is not currently considered mandatory.

Neuropsychological assessment might be helpful where screening test results are inconsistent with the clinical picture.

Amnestic MCI[4] is associated with Alzheimer's disease; early review may be helpful.

Mild cognitive impairment (MCI)

People with MCI are at higher risk of dementia.

At diagnosis people should be given advice on reducing dementia risk factors[5] using the approach *what's good for your heart is good for your brain*.

- Cardiovascular health: diabetes, blood pressure, smoking
- Nutrition: healthy diet and weight
- Physical activity and social contact

You can find the NHS Health Check dementia leaflet in several languages and a video here.

It useful to include the relevant coding in correspondence to primary care:
SNOMED concept ID code 386805003 READ code: Eu057

Note - Faculty of psychology of older people are due to publish further MCI guidance.
Diagnosis should be clear documented to the GP including READ Code Eu057

Mild cognitive impairment (MCI)

People with MCI should be reviewed at least annually until:

- a non dementia cause is established
  OR
- it has resolved, such treated sleep apnoea (screening tools: Epworth, STOP Bang)
  OR
- they have been diagnosed with dementia.

Follow up can occur in primary or secondary care according to local commissioning. See guidance for primary care MCI review here.

Mild cognitive impairment (MCI)

MCI is a condition in which someone has minor problems with their mental abilities such as memory or thinking. In MCI these difficulties are worse than would normally be expected for a healthy person of their age. However, the symptoms are not severe enough to interfere significantly with daily life.

Many people with MCI remain stable or improve in cognition, but this condition does involve an increased risk of dementia.

In our service we assess people with mild cognitive impairment on a yearly basis, provided they consent to this.

Sergi Costafreda, Consultant Psychiatrist

Mild cognitive impairment (MCI)

In one CCG each GP practice keeps its own MCI register and should recall patients for an annual review. If there are concerns, a referral should be made to the memory service. The CCG is planning on adding this to their QIPP to ensure it is embedded in every practice.

Functional cognitive disorder (FCD)

For adults aged under 50 with memory problems and no other neurological signs, do not routinely refer if brief testing shows memory function to be normal and symptoms are consistent with concentration difficulties. Be aware that memory problems or concentration difficulties can be caused by alcohol, drugs (including medication), affective disorder and stress. (NICE NG127)[2]

Cognitive symptoms should be considered in the context of other medically unexplained symptoms, for example chronic fatigue syndrome (CFS), chronic pain, fibromyalgia (FM) or functional neurological disorder (FND). Memory problems and concentration difficulties can be part of FND. Do not routinely refer adults for neurological assessment if they have concentration difficulties associated with CFS or FM. (NICE NG127)[2]

Functional cognitive disorder (FCD)

Consider if enough has been done in primary care to rule out a non-organic cause and if appropriate support has been put in place (e.g. IAPT or referral to a CFS service).

Guidance on IAPT for medically unexplained symptoms

Functional cognitive disorder (FCD)

Most people with FCD are unaccompanied for MAS assessments; this can be diagnostically helpful. However, informant history is important in older people where the risk of dementia is higher.

Cognitive screening tools usually add little value to assessment in this cohort, particularly in patients aged under 60. Patients might score poorly due to poor attention or effort, leading to a false positive result. Instead observe speech for normal cognition such as the ability to reference earlier parts of the consultation and the absence of word finding pauses. However, in older people use of screening tools may be appropriate, due to the increased risk of dementia in this age group. Neuroimaging is not required if confident with the diagnosis.

Functional cognitive disorder (FCD)

The concept of functional cognitive symptoms should be discussed and feedback given on normal memory function. In mild cases normalisation of symptoms may be sufficient. Advice www.neurosymptoms.org to patients.

If there is any suggestion of depression discuss treatment options, consider other treatment options such as CBT if required. Patients who have significant impairment in function should be referred to neuropsychiatry services.

Functional cognitive disorder (FCD)

- Traumatic early life experiences,
- Perfectionistic expectations of memory ability
- Tendency to dissociate when stressed
- Past history of mood disorder or PTSD
- Sub-syndromal mood symptoms and personality traits
- Other somatic syndromes (e.g. CFS, FM, chronic pain)
- Other functional neurological disorders (e.g. non epileptic attacks)
- Hypervigilance to cognitive performance
- Catastrophic interpretation of cognitive lapses
- Internal inconsistency (e.g. memory lapses that are recalled in detail)

Dr Jeremy Isaacs, Consultant Neurologist

Functional cognitive disorder (FCD)

A man in his 40s presented alone with a history of cognitive symptoms including difficulty remembering numbers at work and word finding difficulties. He reported that he used to have a phenomenal memory and had some stresses at home. His father had dementia in later life. He had normal spontaneous speech, gave a fluent history and he spontaneously made a reference to an earlier part of the consultation (implying intact episodic memory).

The patient was given a diagnosis of functional cognitive disorder. He was informed that the term "functional" describes a situation where there isn't any disease or damage in the brain but it nevertheless isn't working completely normally. It's like a computer that has a software malfunction but normal hardware. He was informed about how stress can impair attention, which results in what feel like memory lapses. It was explained that some people have particular attributes or life experiences that make them vulnerable to functional symptoms called "predisposing, precipitating and perpetuating factors". Some of the patient's vulnerability factors were fed back to him. He was advised to look at www.neurosymptoms.org and to arrange CBT via IAPT.