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NHS Leeds Clinical Commissioning Groups
Leeds Integrated Dementia Board

Dementia - timely diagnosis, care planning, and support for well-being. The pathway in Leeds

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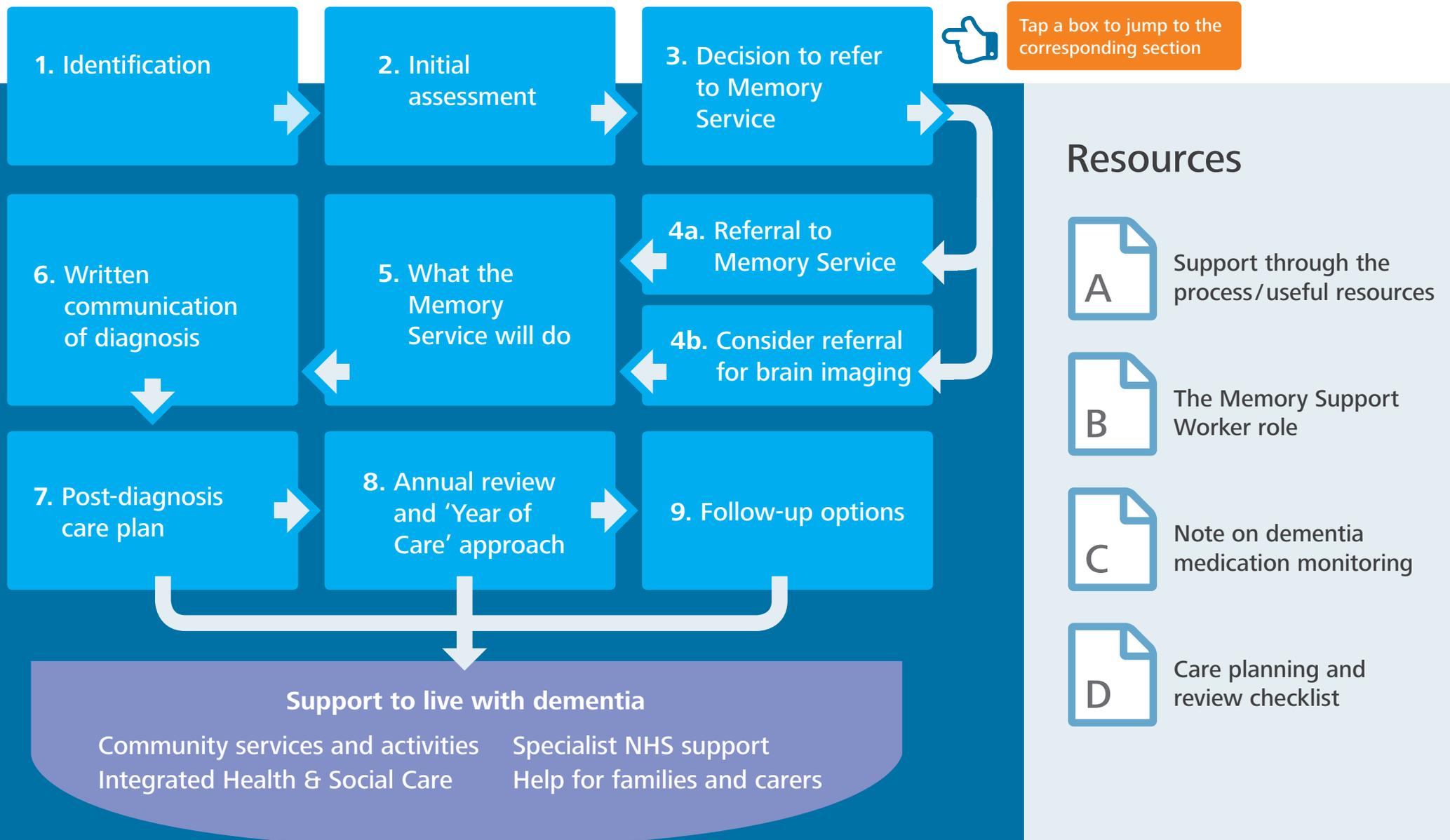
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Dementia - timely diagnosis, care planning, and support for well-being. The pathway in Leeds





Support through the process

You can refer to Memory Support Worker for help before diagnosis

- people with memory problems who need practical or emotional support to access diagnosis
- the person is not ready or willing to seek diagnosis, but family/friends/carers may need help
- the person is seeking diagnosis, and support is needed whilst waiting

Useful resources

Awareness and understanding of dementia - for everyone

- [‘Dementia Friends’ awareness campaign](#)
- [NHS Choices: dementia diagnosis](#)
- [Alzheimers Society ‘Worried About Your Memory?’](#)
- [Alzheimers Society - ‘Dementia Guide’](#)

Local support and services - for everyone

- [Living with dementia in Leeds - information page](#)
(see ‘Documents’ tab for useful leaflets)

Resources mainly for professionals

- [e-learning package: Social Care Institute for Excellence - open dementia programme](#)
- [‘Worried About Your Memory’ poster and leaflet](#) - eg. for clinics and surgeries
- [Dementia Revealed: What primary care needs to know](#) (NHS England, 2014)
- [Helping you to assess cognition: A practical toolkit for clinicians](#) (Alzheimers Society / NHS England / Royal Colleges - 2015)
- [Leeds guideline for behavioural and psychological needs in dementia](#) (2013)

1 Identification

People with memory problems and possible dementia are identified throughout the NHS and by awareness-raising initiatives:

- Patient and/or family may initiate concerns;
- [Alzheimers Society](#) “*Worried About Your Memory?*” campaign
- Awareness-raising in NHS Healthcheck (age 65-74)
- Screening in primary care long-term condition reviews (follow dementia DES)*
- Screening and assessment in acute hospital and community services*

*These screening processes include initial assessment & consideration of referral to memory service.

A Timely Diagnosis

“We should respect the decision of patients and families to present themselves at the time that is right for them. We can, gently and sensitively, nudge people towards thinking about their memory, but there is no justification for ambushing them.”

What Is Normal ?

“It is normal to have occasional memory lapses and to lose things. It is normal to forget why we have gone upstairs, or to come back from a shopping trip without the very thing we went for. It is normal to have to search our brain for a name, sometimes.

“Our normal memory may suffer, from time to time, from impaired function through inattention, information overload or mild depression but, unless there is something wrong, we retain a huge store of general (semantic) knowledge, an ability to plan and manage our affairs and, under normal circumstances anyway, we retain our orientation in time and place.”

*from [Dementia Revealed: What primary care needs to know](#)
(NHS England, 2014)*



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2 Initial assessment

- **History-taking from patient and family (or other 'informants') is the most important information**, supported by:
- Simple cognitive test (e.g. GP-COG / 6-CIT / AMTS - these are included on templates)
- Blood tests: FBC, calcium, glucose, renal and liver function, thyroid function, serum vitamin B12 and folate levels (for GP practices, these are identified in QOF DEM005).

Blood tests are to investigate potential reversible causes of cognitive problems. The decision to refer to Memory Service is usually made prior to results coming back. This is to avoid undue delay; Memory Service can see results on Leeds Care Record/ICE.

Consider:

- Depression screening and / or assessment of anxiety, if indicated. Depression and anxiety can be linked to dementia, or present with some similar symptoms. Seek specialist advice if required.

Tips

- on 'ICE' system, the blood tests can be ordered as a single group: from *Pathology Requesting* screen, click on *QOF Test Panels* and then select *Dementia*.
- if considering referral to Memory Service (steps **3 & 4**), and it seems that the patient might forget or miss appointments, ask if the person consents to arrangements being made directly on their behalf with family member / carer, and communicate this consent to the Memory Service.
- **For people with a learning disability (intellectual disability):** symptoms of dementia can be very different, often presenting with changes in functional ability with or without behaviour change, and may require specialist assessment. If dementia is suspected, please seek advice from, or refer to, the specialists within the Community Learning Disabilities Team.



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3 Decision to refer to Memory Service

Frail older people where presentation of dementia is clear and no other reason to refer - specialist referral may not be necessary. *"...patients who present with more advanced symptoms of dementia... may be diagnosed and managed in primary care..."*
(Extract from [RCGP & RCPsych guidance](#))

- GP can diagnose and record on practice system. The [Diagnosing Advanced Dementia Mandate](#) supports this, particularly for people in care homes.
- Refer to memory service if required eg. to consider prescribing; OR if management depends on diagnosis of sub-type.
- Consider for avoiding unplanned admissions, and/or referral to Memory Support Worker
- Consider Care Homes Liaison Service CMHT if needs and risks are complex.

Delirium may be slow to resolve eg. after acute infection/hospital admission, and make it hard to assess underlying cognitive impairment.

- Refer to Memory Service if cognitive decline preceded acute event;
- Monitor & review if cognition was normal prior to acute illness.
- Seek advice if required or history unclear - Memory Service or Community Geriatrician.

If history OR testing indicates cognitive impairment

- memory loss; difficulties with thinking, problem-solving or language;
- OR changes in behaviour, mood, personality, hallucinations not otherwise explained.
- OR if indicated by cognitive test score.

Offer referral to Memory Service

NB. if there are clear indications from history-taking, **do refer** - a 'normal' cognitive test score does not rule out dementia.

If there are support needs for the patient or family/carer whilst waiting to be seen by Memory Service, or if help is needed to eg. remember or attend appointments: involve Memory Support Worker and / or refer to other community services.



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4^a Referral to Memory Service

Include:

- Individual and family/social circumstances, history of concerns;
- Cognitive test scores;
- Medical history and current medication;
- Confirm that blood tests have been requested (p5), but do not await results if they are not yet available. Memory Service clinicians can view blood test and scan results on Leeds Care Record/ICE.
- **Consider referral for brain imaging (usually CT head scan) when referring to Memory Service (see step 4b).** This avoids serial waiting times which occur if memory service make the referral for a scan.
- If given, communicate consent for Memory Service to make arrangements directly with appropriate family member/carer.

Resources and notes:

- LYPFT referrals via Single Point of Access; other providers using local arrangements.
- [Information for patients and families/carers: NHS Choices: dementia diagnosis](#)
- Leeds now has Memory Clinics hosted at local GP practices - at least one for each old-age psychiatry consultant (LYPFT and TEWV). These offer more local options as an alternative to specialist hospital/outpatient locations.
- If support is needed whilst waiting; or people need practical or emotional support to access diagnosis: involve Memory Support Worker.



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4^b Consider referral for brain imaging

Refer for CT head scan at the same time as referring to Memory Service, to avoid serial waiting times. This is to inform the diagnosis, including type of dementia, and to exclude eg. injuries/tumours:

Unless

- current scan already available (e.g. carried out in hospital) OR;
- contra-indicated (e.g. frailty, declined by patient)

CT scans are quick to perform (1-2 minutes) and the large majority of patients tolerate it well.

Consider referral for MRI scan/consult with old-age psychiatrist for patients:

- with unusual or atypical presentations/acute or rapidly progressive dementia
- in the younger age group (generally < 65 years)

NB. MRI can be poorly tolerated by some patients. It takes 25 minutes to perform and the patient has to lie perfectly still in a tunnel with their head restricted within a helmet (the MRI coil). The scan produces an extremely loud noise which can be frightening and disorientating for the patient.

It is hoped to simplify CT scan requests for dementia diagnosis on the ICE system; in the meantime the following guidance is recommended:

“Scan reports are very dependent on the information provided by the requesting clinician. Key details about the patient should include: age, duration of memory problems, symptom progression, presence or absence of vascular disease... seek specific clarification on the presence of medial temporal lobe (hippocampal) atrophy, significant vascular ischaemic change and the presence of other intracranial pathology such as tumours.

An example request:

80 year old with 3-year history of short term memory difficulties. Vascular risk factors include history of hypertension. Need to clarify the presence of significant vascular ischaemic changes, medial temporal lobe atrophy (hippocampal atrophy) or space occupying lesion.”

[Guidance on Neuro-imaging in Dementia - Yorks & the Humber Strategic Clinical Network](#)



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5 What Memory Services will do

Memory assessment and diagnosis

- Further information-gathering from patient and family/carer
- Specialist cognitive testing (usually Addenbrooke's Cognitive Examination - ACE III)
- Review neuroimaging report (visible via Leeds Care Record for LYPFT)
- Consider further brain imaging
- Diagnosis (by old-age psychiatrist).

Immediate post-diagnosis

- Formulation of medical, psychological and social needs
- Initiate, review and titrate medication where appropriate
- As appropriate, offer of group or 1:1 nursing/OT/psychology interventions e.g. Memory Group, Cognitive Stimulation Therapy
- Offer "*Dementia Guide*" and "*Living With Dementia In Leeds*" leaflet, and other information according to individual needs and wishes
- Offer referral to Memory Support Worker.



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6 Written communication after diagnosis

The Memory Service will

- write back to the referring GP on a standard letter format, including:
 - Diagnosis code in ICD, SystemOne and EMIS formats
 - Summary of prescribing, treatment, interventions
 - Recommendations for follow-up
- Copy to patient and carer, subject to informed consent.

This standard is agreed with LYPFT; GPs referring to other providers may receive similar information in a different format.

GP practice - on receipt of diagnosis letter

- Record diagnosis accurately, to ensure that the coding of dementia diagnosis will show on GP register (QOF - DEM001)
GP practice admin staff should seek advice if correct coding is not clear.
- Continue with any recommended prescribing, as initiated and titrated in Memory Service
- Consider for avoiding unplanned admissions
- If 'Mild Cognitive Impairment' (MCI) is diagnosed, ensure this is flagged for review annually, or as recommended (unless Memory Service are reviewing). 10-15% of people diagnosed with MCI go on to develop dementia.

For any problems with coding dementia diagnoses on GP systems, please refer to [NHS North Guidance on Dementia & Delirium Coding](#)



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The Memory Support Worker

This role was introduced in October 2015.

Memory Support Workers will:

- support people with memory problems to overcome practical and emotional barriers to seeking diagnosis, and / or families when the person is reluctant to seek diagnosis
- help people and carers connect to support if required during the diagnosis process
- offer a visit shortly after diagnosis; support to adapt to and live with dementia; inform about and connect to local services and networks
- screen for frailty and falls risk, and consider other physical health issues including those linked to avoidable hospital admissions
- be a named contact for the patient and family
- work closely with GP practices, including sharing care plans and follow-up from annual review.

Memory Support Workers, with the agreement of each GP practice, access GP practice systems (SystemOne, EMIS).

This makes it easy to take referrals as direct requests from practice teams; and to share information and care plans following interventions.

7 Post-diagnosis Care Plan

The Memory Support Worker will:

- complete a simple care plan document
- share it with patient and family/carer, and GP (subject to consent and capacity)
- check that care plan completion is recorded on GP dementia DES template
- check ethnicity coding is recorded and correct on GP system.

The Care Plan will include and share information about:

- physical, mental health and social needs and include referral/signposting to local support services
- where possible and through encouragement, include a recording of the patient's wishes for the future
- record discussion of permissions for the practice to speak directly with family/carers
- offer health check to carer(s)/inform carers' GP practice.

(This meets 'advanced care plan' requirement of the Dementia DES)

- prevention of unplanned hospital admissions. Leading causes for people with dementia are falls/fractures; respiratory, urinary and kidney infections
- names of family/friends trusted by the person to help and advocate; consider need for advocacy services
- communication needs and how to meet them eg. reminders about appointments; best approaches for conversations. (cf. [NHS Accessible Information Standard](#)).

8 Annual review and 'Year of Care' approach

Monitoring in primary care - the annual review (QOF DEM004)

- **Recommended: the Leeds 'Year of Care' approach** enables a 'whole-person' approach to how the person and family / carer are living with dementia alongside other long-term conditions
- This approach encourages and support people to decide goals and actions to achieve them
- The Year of Care review template is designed so that QOF annual review requirements can be checked off for each long-term condition
- Alternatively, a 'standalone' dementia review can be completed.

Many patients coming for review will not have a post-diagnosis care plan in place. Consider offering a referral to Memory Support Worker if a more in-depth conversation about living with dementia would be helpful.

Note on Memory Service involvement

- will continue active involvement with those patients with dementia, or with mild cognitive impairment, who require specialist biopsychosocial interventions (including those with associated behavioural and psychological symptoms of dementia and significant risk history)
- will no longer see patients solely for the purposes of routine medication monitoring
- will respond to requests for advice and re-referral when changes in need and risk are identified in primary care and elsewhere.



Note on dementia medication monitoring

The dementia drugs (Donepezil, Galatamine, Rivastigmine and Memantine) are now classified in Leeds as “Amber Level 2” – initiated by specialists, with little or no drug monitoring required.

- The main reported side effects for donepezil, rivastigmine and galantamine (the ‘Cholinesterase Inhibitors’) are loss of appetite, nausea, vomiting and diarrhoea. Other side effects may include muscle cramps, headaches, dizziness, fatigue and insomnia.
- The side effects of Memantine are less common and less severe. They include dizziness, headaches, tiredness, raised blood pressure and constipation.

Side effects of dementia medication usually occur early in treatment and are picked up by Memory Services during the initial stabilisation and review period. For concerns about possible side effects, seek advice from Memory Service.



Care Planning and Annual review - checklist

This checklist is to support clinical judgement; cover an item if it is relevant for the patient and carer.

- The review is essentially a helpful conversation with the person and family / carer, about how they are living with dementia, to agree goals and actions to achieve them.

Physical - consider:

- any problems with balance, falls risk, frailty; independent living / managing activities of daily living.
- whether medication being taken appropriately.
- prevention of unplanned hospital admissions. Leading causes of unplanned admissions for people with dementia are falls / fractures; respiratory infections; urinary and kidney infections

Consider for "2%" admission avoidance planning; community services as appropriate - eg. falls services, eating and drinking team, social worker, community matron, community geriatrician.

Psychological

- how is the person coping emotionally with the condition?

- changes to memory, mood, behaviour; concerns about boredom and frustration.

Consider seeking specialist advice / referring to Memory Service regarding risky or aggressive behaviours.

Social

- social life, activity and occupation.
- family and wider support networks.
- changes to communication needs.

Consider involving Memory Support Worker or social prescribing service

Carer / significant others

- How well is the carer coping? Are they getting a break from the caring role?

Consider carer support services (eg. Carers Leeds) - offer carer health check.

9 Annual review - options for follow-up

Any or all of the following may be appropriate, following annual review or at other times when changes or concerns come to light:

Concerns about

Social isolation, lack of networks, family/carer strain, need to discuss options and navigate the system, boredom.



Behavioural and psychological risks, consideration of dementia medication changes, concerns about side effects.



Other concerns about the progress of dementia, physical health, effects on independence/daily living/self-care.



Consider

- Memory Support Worker
- Carers Leeds
- Social Prescribing

These services can use their local knowledge of community support to identify the right help.

Refer to secondary mental health services:

- Advice from, or referral back to, Memory Service
- Other specialist teams, eg. Care Homes Liaison, CMHT.

Options include:

- Integrated Neighbourhood Team, including social care needs assessment
- Community geriatrician
- Falls services
- Eating and drinking team
- End of life care.