Kirklees

Memory Monitoring Service Pathway & Dementia Info Pack 2018

In this pack you will find:

- Memory Monitoring Flow Chart
- Memory Monitoring Primary Care Guidance
- Confirming a diagnosis in the community DiADeM
- Diagnosing Early Onset Dementia
- The Well Pathway for Dementia
- Dementia Guidance for Primary Care in Kirklees
- Dementia Diagnosis in 2018 and Clinical System Codes
- Kirklees Dementia Info and Resources

A collaboration between NHS North Kirklees Clinical Commissioning Group, NHS Greater Huddersfield Clinical Commissioning Group and NHS South West Yorkshire Partnership Foundation Trust. In partnership with Kirklees Council and Kirklees Dementia Action Alliance
Memory Support Services
All patients with cognitive problems to be seen by Memory Support Services for assessment of their, and their carer's needs.

Information & advice 01484 503908

Post diagnosis, patients can also be referred to Kirklees Dementia Hub on 07387 019180 for a structured programme of support.

Kirklees Memory Monitoring Pathway

Referral from Primary Care

Memory Service Assessment

Not Dementia

MCI confirmed

Dementia, Anti-dementia medication not indicated
E.g., Vascular dementia

Discharge to GP, no follow up required

Practice to review if any change in symptoms

Dementia Diagnosis confirmed

Early Dementia

Anti-dementia medication indicated

Medication prescribed by psychiatrist and monitored by memory service until stable, typically 3 months

Discharge to GP with Care plan

Practice to review care plan annually, see separate guidance

Dementia with complex needs.
Management remains with Secondary Care until stable.

Practice to refer back to memory clinic if deterioration for speedy assessment/advice (01484 434630)
Primary Care Guidance for managing patients with memory problems

Rule out reversible causes of Cognitive Impairment
- Non organic mental health problem e.g. Depression
- Drugs – consider reviewing dose or stopping drugs that may impact on cognition; E.g., TCA’s, Opiates, Benzo’s, anti-convulsants
- Delirium e.g. Infection, CVA, Constipation, Endocrine Pain.

Scan Guidance: To be arranged at time of referral
- Please use this guidance prior to making a request for a scan for patients with memory problems
- If in doubt, please refer to the memory service where the scan request can be completed following assessment
- Choose CT Scan – Appropriate for the majority of patients
  - Insidious onset and gradual history >12 months;
  - >65 years;
  - No history of stroke;
  - No sudden change in personality.
- Choose MRI Scan –
  - Acute onset <6 months;
  - Young Patient;
  - History of stroke;
  - Sudden change in personality;
  - Atypical history.

Advanced dementia /patient declines referral
- If advanced/long standing/patient declines referral please refer to: “Confirming a diagnosis of established dementia in the community” Document.

Memory Support Services
Consider signposting Memory Support Service/ Kirklees Dementia Hub at any point in the patient journey.
Information & advice 01484 503908
Or to explore the services available locally as detailed on Kirklees council’s website www.kirklees.gov.uk/dementia

Reassure and offer follow-up as appropriate.
- Impaired cognitive performance, impact on ADL’s or continued patient/carer concern.
- Basic screening is normal and ADLs not significantly affected.

Patient/Family/Carer expresses concern regarding memory
- Assess impact on ADL’s and perform basic cognitive screening
- Rule out reversible causes of Cognitive Impairment
- Offer referral to memory service. Pre-arranging a scan will speed up the diagnostic process.
- Refer to memory clinic

Basic Investigations
- Blood tests - Blood glucose/HBA1C, FBC, U&E, Bone profile, B12, Folate, Tfts, Lfts, CRP, MSU if urinary infection suspected, rarely HIV/Syphilis
- Consider ECG
- Treat any potentially reversible causes

Information & advice 01484 503908
Or to explore the services available locally as detailed on Kirklees council’s website www.kirklees.gov.uk/dementia

Consider signposting Memory Support Service/ Kirklees Dementia Hub at any point in the patient journey.
DiADeM Tool
Diagnosing Advanced Dementia Mandate (for care home setting)

A diagnosis of dementia is usually made within memory services. Some care home residents with advanced dementia have never had a formal diagnosis. In these cases a referral to memory services is rarely desirable. It is likely to be distressing for the individual and is usually unnecessary.

People with advanced dementia, their families and staff caring for them, still benefit from a formal diagnosis. It enables access to appropriate care to meet individual needs and prompts staff to consider MCA and DOLs issues where appropriate.

A diagnosis of dementia can be made with a high degree of certainty if all five criteria listed below are met.

### Functional Impairment
The person is no longer fully independent in relation to basic activities of daily living, washing, dressing, feeding and attending to own continence needs. The requirement of prompting or supervision of staff constitutes a loss of full independence.

### Cognitive Impairment – 6 CIT assessment

<table>
<thead>
<tr>
<th>Question</th>
<th>Scoring</th>
<th>Score achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What year is it?</td>
<td>Correct - 0 points, incorrect - 4 points</td>
<td></td>
</tr>
<tr>
<td>2. What month is it?</td>
<td>Correct - 0 points; incorrect - 3 points</td>
<td></td>
</tr>
<tr>
<td>3. Give an address to remember with 6 components e.g. John, Smith, 42, High St, Wakefield</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. About what time is it (within 1 hour)</td>
<td>Correct - 0 points; incorrect - 3 points</td>
<td></td>
</tr>
<tr>
<td>5. Count backwards from 20-1</td>
<td>No errors - 0 points; 1 error - 2 points; more than 1 error - 4 points</td>
<td></td>
</tr>
<tr>
<td>6. Say the months of the year in reverse</td>
<td>No errors - 0 points; 1 error - 2 points; more than 1 error - 4 points</td>
<td></td>
</tr>
<tr>
<td>7. Repeat address phase</td>
<td>No errors - 0 points; score 2 points for every component wrong e.g. 3 errors, 6 points</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL SCORE:**

6 CIT scores: 7 and below normal; 8 and above indicate impairment. Assessment tools other than CIT can be used. If used does score indicate impairment Y/N?

**NB.** Scores obtained in this patient group would be expected to be at the severe end of scale and for some patients their cognitive impairment will be of such severity that they cannot undertake the assessment.

### Corroborating History
History of gradual cognitive decline (typically for the last few years) is confirmed by care staff, relatives and medical records. Staff/relatives confirm that in their opinion the patient consistently demonstrates both functional and cognitive impairment.

### Investigations
Dementia screening **bloods are normal** (where clinically appropriate and patient consents to bloods). If patient lacks capacity to consent to bloods, a best interest decision must be made and documented accordingly. **NB.** If intracranial pathology (e.g. subdural haematoma, cerebral tumour) is suspected, referral for a brain scan may be appropriate. Otherwise where dementia is advanced, differential diagnosis is unlikely to affect patient management & a brain scan is unnecessary.

### Exclusion Criteria
There is **no acute underlying cause to explain** confusion i.e. delirium (acute confusional state) has been excluded. Mood disorder or psychosis is also excluded.

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1. "Guidance for Commissioners of Dementia Services", published by The Joint Commissioning Panel for Mental Health states patients who present with advanced symptoms of dementia can be diagnosed and managed by primary care with or without CMHT help. www.jspm.org.uk. Thanks to Dr Ursula Pinder, assertive dementia care nurse FT and Dr Susan Finlayson, South West Yorkshire Partnership NHS FT.

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Picking up the critical signs of these diagnoses is not always easy, and at times is based on your, or your patients’ gut feeling that something is amiss. Family and friends may play an invaluable role in helping you to understand the full range of symptoms your patient might be experiencing.

This pilot diagnostic aid is designed to support GPs in understanding young onset and rarer forms of dementia. It is also a tool to identify "red flags" which suggest referral to specialist diagnostic services may be required.

**Diagnosing dementia in younger people**

A decision-making tool for GPs

- Between 42,000 and 65,000 people are living with young onset dementia in the UK.
- In 2018 it took twice as long for younger people to be diagnosed as it did older people, delaying access to treatment and support.
- Many people are misdiagnosed with depression, anxiety, stress, marital issues, menopause or personality disorder.

### Is this your patient?

- Not feeling cognitively as "sharp" as in the past?
- Are family and friends expressing concerns but the patient doesn’t recognise these concerns?
- Are they aged 40–65?
- People under 40 can have dementia but this is less common. See website below for further guidance.
- As their GP, you feel that something isn’t right and further investigation is required?

### Have the patient, family, colleagues or friends identified a progressive decline in any of these areas?

**Language and communication**
- Word-finding difficulty, effortful, hesitant speech, vague or over-detailed speech, not getting to the point.

**Neuropsychiatric presentations**
- Later than usual onset of first episode psychosis (abnormal beliefs or organisations).

**Social and skills**
- Reduction in skills, struggling at work, more isolated.

**Movement disorder**
- Olfactory loss changes in gait, falls (particularly backwards), fine eye movements, involuntary movement, signs of Parkinson’s disease.

**Visual and spatial**
- Repeated visits to optician and finding nothing wrong, mis-reaching for objects in clear view, difficulty parcelling death and volume, words appear to float on the page, misperceive the obvious, problems judging distances when driving.

**Behavioural and personality changes**
- Changes in personality, reduced empathy, reduced emotional engagement, irrational and out of character decision-making, lack of insight, aggression, obsessive behaviour.

**Memory and disorientation**
- Forgetting conversations and future plans, repetitiveness, getting lost in familiar places, less sure of the day crate, forgetting names and faces.

### Take a detailed history

- Consider asking the family member what their overall experience of living with the patient is like. This type of open question will prompt discussions which could uncover relevant symptoms. The patient or family may want to consider keeping a diary to take to future appointments.

- Does your patient have a learning disability?
- See website below for further guidance.

- Is there a family history of young onset or atypical dementia?

- Consider using a brief cognitive instrument (refer to NICE Dementia Guidance) but bear in mind that passing these tests should not exclude the patient from being referred for memory assessment. The results should be used to supplement the detailed history only.

### Exclude reversible causes – carry out medication review, blood dementia screen, consider alcohol misuse or sleep disorder. For more information refer to NICE Dementia Guidance.

- Exclude or treat depression or anxiety – you may consider using PQ8.

### Refer to young onset dementia specialist in local diagnostic service

For more information, for you and your patient, please visit www.youngdementiainfo.org.uk/decision-making-tool
NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL
Risk of people developing dementia is minimised

“I was given information about reducing my personal risk of getting dementia”

STANDARDS:
Prevention (1)
Risk Reduction (6)
Health Information (4)
Supporting research (5)

DIAGNOSING WELL
Timely accurate diagnosis, care plan, and review within first year

“I was diagnosed in a timely way”
“I am able to make decisions and know what to do to help myself and who else can help”

STANDARDS:
Diagnosis (1)(5)
Memory Assessment (1)(2)
Concerns Discussed (3)
Investigation (4)
Provide Information (4)
Integrated & Advanced Care Planning (1)(2)(3)(6)

SUPPORTING WELL
Access to safe high quality health & social care for people with dementia and carers

“I am treated with dignity & respect”
“I get treatment and support, which are best for my dementia and my life”

STANDARDS:
Choice (2)(3)(4)(5)(6)
BPSD (6)(2)
Liaison (5)
Advocates (3)
Housing (3)
Hospital Treatments (4)
Technology (5)
Health & Social Services (5)
Hard to Reach Groups (3)(5)

LIVING WELL
People with dementia can live normally in safe and accepting communities

“I know that those around me and looking after me are supported”
“I feel included as part of society”

STANDARDS:
Integrated Services (1)(4)(6)
Supporting Carers (2)(4)(6)
Carers Respite (6)
Co-ordinated Care (1)(5)
Promote independence (1)(4)
Relationships (3)
Leisure (3)
Safe Communities (3)(5)

DYING WELL
People living with dementia die with dignity in the place of their choosing

“I am confident my end of life wishes will be respected”
“I can expect a good death”

STANDARDS:
Palliative care and pain (1)(2)
End of Life (4)
Preferred Place of Death (5)


RESEARCHING WELL
• Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
• Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL
• Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer’s Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL
• Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
• Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

TRAINING WELL
• Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
• Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

MONITORING WELL
• Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set ‘profiled’ ambitions for each.
• Use the Intensive Support Team to provide ‘deep-dive’ support and assistance for Commissioners to reduce variance and improve transformation.
Dementia Guidance for Primary Care in Kirklees

Two nationally produced resources provide a wealth of practical information in a readable, accessible format. You can follow the links below or find them under ‘Dementia Resources’ on the CCG intranet site.

Dementia Revealed What Primary Care Needs to Know: A Primer for General Practice

Dementia diagnosis and management: A brief pragmatic resource for general practitioners

Diagnosing Dementia

A timely diagnosis of dementia is important. It gives patients the opportunity to plan for their future, and to access support and treatment earlier.

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Even though the national Enhanced Service incentivizing proactive case finding was withdrawn in April 2016, continuing to improve diagnostic rates locally remains a priority, and is something on which we are benchmarked.

It remains good practice to opportunistically ask at-risk patients about concerns regarding their memory, and to offer them further assessment.

Tools and reports to help practices identify patients with potential memory problems can be found within the clinical system.

Details can be found here, starting on page 61:

Providing Quality Care and Follow Up: Dementia QOF Element

High-quality care, including regular monitoring and appropriate symptomatic treatment, is essential to maintain quality of life for individuals with dementia.

The dementia domain constitutes a significant proportion of QOF and in 2015/16 is worth 50 points, with the majority of these being earned by providing a face-to-face review of the patient’s care plan.

What are the requirements for practices?

1. Practice to establish and maintain a register of patients diagnosed with dementia.
3. Newly diagnosed patients to have a record of ‘dementia bloods’ in the 12 months before or 6 months after entering the register.

Details can be found here, starting on page 79:

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**The Advanced Care Plan**

For the purposes of the Enhanced Service, newly diagnosed patients should have been offered an advanced care planning discussion ideally within 6 months. This remains good practice and should include:

1. Establishment of their physical, mental health and social needs.
2. Identification of the patient’s carer, and seeking permission to speak directly to the carer if appropriate.
3. A record of the patient’s wishes for the future.
4. Referral/ signposting to appropriate support services.
5. The offer of a health check to the carer if registered with the practice.

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**The Annual Face-to-Face Review**

This should focus on the support needs of the patient and their carer, reviewing the above plan or putting one in place. It should cover the following key issues:

1. Assessment of:
   - **Physical health**, including mobility, falls risk, nutrition, swallowing, continence, and co-morbidities.
   - **Mental health**, including cognition, behavioural issues and mood.
   - **Medication**, including response to cognitive enhancers and neuroleptics, side-effects and interactions.
   - **Social needs**, including capacity, safeguarding and need to consider Power of Attorney
3. Co-ordination and communication arrangements with secondary care and social services
4. Review of the carer’s needs

Standardised templates for SystmOne and EMIS have been developed regionally and are now available.
Management of patients with Mild Cognitive Impairment

In Mild Cognitive Impairment (MCI) there is minimal memory loss above what can be attributed to normal aging, but it is not severe enough to significantly impact on daily functioning.

MCI is a known risk factor for the development of Alzheimer’s disease, but not all patients with MCI get worse, and some may improve. Evidence would suggest that patients with MCI go on to develop dementia at a rate of about 10 – 15% per year.

It would be advisable to review these patients as appropriate, at least annually.

There is currently no licensed drug treatment and management is supportive:
- Healthy lifestyle advice
- Regular exercise
- Management of vascular risk factors
- Enabling mental wellbeing – through mental and socially stimulating activities

Refer to memory service if cognitive decline/ADL’s affected.

Managing Behavioural and Psychological Symptoms of Dementia (BPSD)

More than 90 per cent of patients with dementia will experience BPSD difficulties during the course of their illness. These include sleeplessness, wandering, agitation, pacing, aggression (including spitting), and disinhibition (including sexual disinhibition).

Challenging behaviour needs to be seen as a manifestation of unmet need, which the patient may not be able to express. It can also be a manifestation of underlying pain and physical illness.

They can often be managed by providing training and support to relatives and carers, but the expectation is often put on GPs that they should provide a quick drug fix for patients with troublesome symptoms. This can lead to inappropriate prescribing.

If drugs have to be used, you should use the safest drugs you can, at the lowest doses that work, and set a review date for reducing or stopping them. Most BPSD symptoms settle within a few weeks. Please see the excellent section on the most appropriate drug treatments in aforementioned ‘Dementia Revealed What Primary Care Needs to Know: A Primer for General Practice’, see link above.
When and how to stop treatment

When they no longer appear to be working:
In the early years of use, AChEIs were stopped when the MMSE reached 10/30 but evidence has emerged that supports their continued usage in severe dementia. The effectiveness of an AChEI becomes more difficult to assess the longer a patient is on it because the baseline will have changed and sometimes the only way to know if it is still helping is to stop the drug and be prepared to re-start it if there is a sudden significant deterioration. It is therefore reasonable to continue these drugs indefinitely.

When they are not tolerated:
AChEIs should be stopped if they are thought to be causing problems – such as nausea, weight loss or bradycardia. Anxiety or agitation might prompt a trial without AChEIs as they are stimulant drugs. The result might be more apathy but less agitation.

On deciding to stop medication:
Donepezil, Galantamine and Memantine: reduce the dose gradually every two months to the minimum dose, then discontinue for a trial period of 4 weeks
Rivastigmine: reduce the dose by 1.5mg every 4 weeks, then discontinue for a trial period of 4 weeks
If using a patch, reduce to the lower dose patch for 2 months then discontinue.
A discussion needs to be had about the potential emergence of discontinuation syndrome (agitation, sleeplessness, delusions etc.). The clinician needs to be particularly careful in patients with Lewy Body Dementia.
### Diagnostic description

<table>
<thead>
<tr>
<th>Diagnostic description</th>
<th>Read Code (eg EMIS)</th>
<th>CTv3 code (eg SystmOne)</th>
<th>ICD10 Codes</th>
<th>Comments</th>
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</thead>
<tbody>
<tr>
<td>Alzheimer's Disease</td>
<td>Eu00z</td>
<td>F110.</td>
<td>F00</td>
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<td>Alzheimer's Disease with early onset</td>
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<td>X002x</td>
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<td>F1101</td>
<td>X0030</td>
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<td>Vascular Dementia</td>
<td>Eu01z</td>
<td>XE1XS</td>
<td>F01</td>
<td>including all subtypes - F010, 11, 12, 13, 18 &amp; 19</td>
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<td>Dementia in Parkinson's disease</td>
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<td>F023</td>
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<td>X0034</td>
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<td>XE1Z6</td>
<td>F03X</td>
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<td>Mild Cognitive Impairment</td>
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</tbody>
</table>
Support and Resources
www.kirklees.gov.uk/dementia

Information, advice and support for people with dementia or memory loss and their carers in Kirklees.

Living with dementia in Kirklees guide
- About dementia
  - Dementia support in Batley
- Getting a diagnosis
  - Dementia support in Cleckheaton and Spenborough
- Activities and local support groups
  - Dementia support in Dewsbury and Mirfield
  - Kirklees-wide dementia services and support
  - Dementia support in Rural Huddersfield
- Money matters
  - Find local Day opportunities for adults with dementia in Kirklees
  - Find local activities through Kirklees Making Space
- Caring for someone with dementia
- Living arrangements - staying in your own home
- Living arrangements - housing options and support service
- Getting out and about
- Dementia friendly communities

Across Kirklees all GP practices are working towards becoming Dementia Friendly Organisations.

Anyone can become a Dementia Friend by attending a friendly 1hr information session. Find one near you at www.dementiapractices.org.uk/WEBSession

NHS Choices - dementia guide

NHS information and advice for people with dementia and their friends and families, including dementia symptoms, diagnosis, treatment, and how to live well with the condition.

Dementia guide
- About dementia
- Symptoms and diagnosis
- Living with dementia
- Care and support
- How you can help

Find dementia services

NHS England has developed a guide Dementia: Good Care Planning, with input from people living with dementia, their carers and health and social care professionals. The guide highlights key characteristics of a person-centred dementia care plan and is intended for primary care, commissioners and anyone tasked with writing and providing care plans and reviews.

https://www.england.nhs.uk/mental-health/resources/dementia/