

Dementia diagnosis and management

A brief pragmatic resource for general practitioners



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Introduction

This resource pack has been brought together with the aim of supporting GPs to identify and appropriately manage dementia patients in the primary care environment.

Currently, patients who do not wish to attend a memory clinic or undergo investigations and frail patients, especially in care homes, frequently fail to receive a timely diagnosis of dementia. The records then do not clearly flag up their diagnosis which can have negative consequences for the patient and the true prevalence of dementia remains unknown.

Patients should not be denied a diagnosis because they are not suitable for the memory clinic pathway. In addition, there are patients whose memory loss is simply not identified. It is therefore in the interest of the patients and the health care community for GPs to play an active role in the diagnosis and management of dementia patients. This will have implications regarding training and resource allocation.

'Dementia revealed – what primary care needs to know' (the Dementia Primer) is an overview of dementia management. If that document is "What to do?" then this contribution is "How to do it?" The Dementia Primer has been summarised in this resource pack to provide a quick overview of the key points. It is anticipated that the summary of the Dementia Primer will raise questions and uncertainties for GPs, so we have added an "Ask the expert" section in which practical questions are posed to Professor Alistair Burns (National Clinical Director for Dementia, NHS England). These are then supported by descriptions of some clinical case scenarios.

The process of reading this resource pack, running a data quality toolkit to interrogate the practice IT system to find missing dementia patients, reviewing notes and cases and reflecting on the management of dementia is ideal material for GP appraisal and some further ideas about this are given later.

After reading and reflecting on this resource pack GPs should be able to:

- Describe the key features of dementia and explain which patients particularly merit referral to the specialist service;
- Describe the role of cognitive testing in the diagnosis and management of dementia and produce a plan for their own practice which incorporates appropriate tools;
- Explain how and when anti-dementia treatments in primary care are safe to be introduced
- Create a strategy for themselves and their practice to improve the detection and management of dementia

Dementia revealed. What primary care needs to know

The following is a summarised and slightly updated version of the original document, which provides further and more detailed information and is available at:

<http://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf>

Increasing role for the GP

GPs need to build up their capabilities to assess, detect (including diagnose) and treat dementia and its common causes. Patients who you know have dementia but cannot or will not go to specialist clinics should not be deprived of diagnosis, support and medication.

Diagnosis of dementia

Dementia is a syndrome (essentially brain failure) affecting higher functions of the brain. There are a number of different causes. There is no single 'dementia test'. Cognitive decline, specifically memory loss alone, is not sufficient to diagnose dementia. There needs to be an impact on daily functioning related to a decline in the ability to judge, think, plan and organise. There is an associated change in behaviour such as emotional lability, irritability, apathy or coarsening of social skills. There must be evidence of decline over time (months or years rather than days or weeks) to make a diagnosis of dementia – delirium and depression are the two most common conditions in the differential diagnosis.

'Timely' diagnosis is when the patient wants it OR when the carers need it. Sub-typing dementia is important in guiding prescribing decisions. Most sub-typing can be arrived at by taking a careful history. Differentiating vascular dementia and Alzheimer's becomes more challenging in older patients and in terms of post diagnostic support may not significantly influence management. Sub-types include:

- Alzheimer's Disease
- Vascular Dementia
- Mixed Alzheimer's/Vascular dementia
- Lewy Body Dementia (LBD)
- Dementia in Parkinson's disease
- Dementia unspecified

Advice on the coding of the various types of dementia can be found in the appendix.

It is helpful for someone in the practice to be familiar with a couple of cognition tools since it is unrealistic to do anything but a brief 'screen' in a normal primary care consultation. Being able to draw a perfect clock, to all intents and purposes, renders a diagnosis of dementia unlikely.

Brain scans (CT or MRI) are **not** essential for a clinical diagnosis of dementia. If a scan is justified, detailed clinical information is crucial for the radiologist.

Blood tests rarely contribute to the diagnosis but are needed to rule out underlying pathology and are necessary for QOF reporting.

Indications for referral

The following are some examples of patients who would normally benefit from referral:

- Suspected Parkinson's Disease Dementia (PDD) or Lewy Body Dementia (LBD);
- Younger people with suspected dementia, where the chances of there being a rarer neurological condition are greater;
- An atypical presentation or course which may indicate focal dementia or a brain tumour;
- High risk situations, such as challenging behaviour, psychosis or other risks;
- Safeguarding concerns;
- Potentially contentious legal issues;
- Associated significant psychiatric morbidity or history;
- Patients with Learning Disability (LD) (especially patients with Down's Syndrome, who have a particularly high risk of developing dementia). Assessing dementia in patients with LD requires specialist psychological input;
- Suspected alcohol related dementia.

Drug treatment

(For full prescribing information please refer to the British National Formulary)

There is little to choose between acetylcholinesterase inhibitors (AChEIs). Price and tolerability are the key deciders. The main side-effects of AChEIs are syncope and GI upset and they are contraindicated in heart block, significant cardiac conduction problems or if the pulse rate is <60.

Memantine is an alternative, if cardiac problems preclude an AChEI, and also has a licence for use in severe dementia but it is more expensive. Renal function needs to be checked before prescribing. Consideration of Memantine should generally involve a specialist.

Most people with mild to moderate Alzheimer's disease will respond to and derive valuable benefits from one of the AChEIs or, as an alternative in moderate to severe disease, memantine. Their use is recommended by NICE (www.nice.org.uk).

Systematic follow-up is needed, but not necessarily in a specialist hospital clinic. AChEIs should be continued, even when dementia enters the more severe stages, providing they are well tolerated.

Behavioural and psychological symptoms of dementia

Behavioural and Psychological Symptoms of Dementia (BPSD) are manifestations of need and may be markers of distress. The first approach is to understand the need and try to address it. Underlying pain and infection must be sought and treated and carers should be trained and supported.

There is a relatively small range of drugs that can be used and drugs should not be the first option. Anti-depressants and anti-Alzheimer drugs may help BPSD. If anti-psychotics are considered to be justified for the management of BPSD, they should be initiated by (or in consultation with) a specialist and used only for short periods. Low dose, regularly reviewed risperidone is an option, ideally for a maximum of six weeks. Anti-psychotics are potentially fatal in Lewy Body Dementia and Parkinson's Disease Dementia and should not be used without specialist psychiatric advice.

Delirium

Patients with dementia are at increased risk of delirium which is common and may take far longer -sometimes months to recover from than people realise. Delirium can damage cognition. Anticholinergic drugs contribute to delirium risk and should be avoided.

Alcohol

Alcohol related problems are much more frequent in older people than is commonly realised. Alcohol misuse may be a cause, an effect, or a complication of dementia.

Dementia and driving

A diagnosis of dementia must be reported to the DVLA but many patients may continue to hold a licence and drive – their licence is taken away only when they are considered to be unfit to drive. Mild cognitive impairment is not automatically reportable to the DVLA. An independent driving assessment may be useful; although everyone may have an opinion, the only person qualified to say whether a person is safe to drive or not is a registered driving test examiner.

Further information about driving can be found on the Alzheimer's Society website.

Carers

Carers are the most valuable resource in dementia care and we should have a high level of awareness of their needs. Carers may be referred for a carer's assessment and benefit check. Carers' groups provide support and information.

Carers often neglect their own health because of their caring responsibilities. The Alzheimer's Society can help with counselling, social support, benefit forms and grant applications.

Social care and legal aspects

Social care is based on eligibility criteria and is means tested. It is helpful for the practice to know if patients have refused services that they have been assessed as needing.

The threshold for full NHS Continuing Care funding in dementia is high, and may be withdrawn if needs reduce. Funded Nursing Care may be awarded to pay for a nursing care component if needed.

Adult safeguarding has an increasingly high profile. There needs to be an adult safeguarding lead in the practice who is appropriately trained. Mental capacity is issue specific and must be based on a current assessment. Separate Lasting Power of Attorney (LPOA) forms are needed for financial affairs and for decisions about care. LPOA does not apply until the patient loses capacity and they can be rescinded at any time before that. It is good advice to recommend thinking about LPOA sooner rather than later.

End of life

End of life care planning is important in dementia. Patients with dementia should be encouraged to express their wishes and have them incorporated into advance care plans and Advance statements.

Relatives of residents in care homes often feel guilty and distressed. Bereavement reactions, following a death from dementia, can be complex and referral to bereavement support may be indicated.

Ask the expert – questions posed to Alistair Burns

Which cognition tool would you recommend for use in primary care to support the diagnosis of dementia?

There are a number of options and the most important advice is to become familiar and comfortable with a small selection. The choice may also be guided by the amount of time which is available:

One minute

If memory problems (or other symptoms suggestive of dementia) are raised as the person is just leaving or in passing during an already demanding consultation, then simply enquiring about memory can be a helpful general prompt, for example, **‘Has the person been more forgetful in the last 12 months to the extent that it has significantly affected their daily life?’** (For instance, difficulty using the phone, managing shopping lists, using money, managing their medication, driving, etc.). It is helpful to involve family or a close friend if possible.

A few minutes within the consultation

If the issue of dementia arises during the interview and there is no time to go into it in detail, the Mini- Cog (a brief cognitive screening test) may be suitable.

The Mini-Cog is administered as follows:

1. Instruct the patient to listen carefully to and remember three unrelated words (e.g. ball, car, man) and then repeat the words.
2. Ask the patient to draw the face of a clock, either on a blank sheet of paper or on a sheet with the clock circle already drawn on the page. After the patient puts the numbers on the clock face, ask him or her to draw the hands of the clock to read a specific time (ten to two or ten past ten is popular as it resembles a smiley face).
3. Ask the patient to repeat the three previously stated words.

If the three words are correctly recalled, then this suggests there is no significant cognitive impairment.

If none are recalled, this suggests there is significant impairment.

If 1 or 2 are recalled, use the clock drawing test as an arbiter – if it is normal, then there is unlikely to be significant impairment, if it is abnormal, then further enquiry is needed.

Ten minute consultation

For the ten minute consultation, we would recommend GPCOG (the General Practitioner assessment of Cognition) which is available at <http://www.gpcog.com.au/index.php>

It is quick and easy to administer and has the advantage of incorporating the view of a carer or relative.

An alternative tool would be the 6-CIT which is available at <http://www.patient.co.uk/doctor/six-item-cognitive-impairment-test-6cit>

Cognition tools should not be used in isolation, but abnormal results alongside a careful history, examination and normal screening blood tests should enable a diagnosis to be made by GPs in those with a typical presentation.

Fifteen minute planned review

In the primary care setting, the Montreal Cognitive Assessment (MOCA), <http://www.mocatest.org/>, is the instrument of choice. It can take up to 15 minutes and would clearly need a special session to make a diagnosis.

General considerations in diagnosis

There should be a long history reflecting the progressive and insidious course of dementia. It may not be possible to diagnose dementia in a single consultation but rather after a period of current and historic review of the patient. The diagnosis should usually include input from a carer or relative which corroborates the history and demonstrates the negative effect of the memory loss on the functional abilities or personality of the patient over a prolonged period.

What are the main differential diagnoses/potential contributing factors?

The three Ds

- **Depression** which may be contributing to the presentation in a patient with dementia
- **Drugs** with strong anticholinergic activity such as tricyclic antidepressants (e.g. amitriptyline), older drugs for bladder problems (e.g. oxybutynin) and first generation antihistamines (promethazine, chlorpheniramine) should be stopped if possible or substituted for a drug with less anticholinergic activity. All opiates affect cognitive function- consider regular paracetamol or topical analgesia or use the lowest possible dose of opiate.
- **Delirium** - the diagnosis should be clear from the time scale (starts suddenly and stops suddenly) and the general condition of the patient (i.e. they look unwell). Asymptomatic bacteriuria is unlikely to be a significant cause of delirium.

Currently, which patients are most suitable for GP management?

The frail and elderly, where continuity of care and on-going management of co-morbidities can be most appropriately provided by the GP with support from other agencies. Patients who are reluctant to engage with the specialist service.

Do you see an evolving role for the GP in dementia management? Will uncomplicated cases be diagnosed and treated in primary care and if so how do we ensure that they receive the appropriate support that might have been offered by a memory team?

As local care pathways evolve and the relationship with the specialist memory service matures, it is anticipated that GPs will gradually take an increasing role in managing those patients with standard presentations. This must be complemented by direct access to appropriate community dementia resources.

Is it necessary to follow up patients on anti-dementia drugs with repeat scores to assess the effectiveness of the treatment?

No. It is more important to make an assessment of the global functioning of the patient and the GP and relatives/carers may be in a good position to make this assessment. Small changes in scores may not be significant. For GP management it is anticipated that, providing the patient is tolerating the treatment and there are no contraindications the treatment will be maintained until such a time as it becomes inappropriate such as in extreme frailty.

Can you explain how you distinguish between mild cognitive impairment and early dementia and when to offer treatment in this situation? Would you have flexibility on the score if there is significant concern from the patient and family regarding the effect on functioning?

This reflects a significant complexity which should be managed by engagement of the specialist service. It is addressed in the dementia narrative which was included in the national Enhanced Service for dementia identification specification (Appendix 1).

GPs may be concerned about recognising and subsequently accurately coding the subgroups of dementia. The narrative in the dementia enhanced service specification says that GPs can confidently diagnose dementia, but then goes on to say that specialist advice is often needed to determine the subgroup and recommend treatment choices, including differentiating between vascular dementia and Alzheimer's. If this is the case then this would limit the value of any GP diagnosis. Do you have any practical advice about this?

The diagnosis of dementia is based on the recognition of the typical syndrome of 'chronic brain failure'. Atypical presentations should be referred for specialist advice regarding the more unusual sub-types. Vascular dementia in isolation is rare; the

majority of presentations are Alzheimer's or mixed dementia i.e. Alzheimer's and a vascular element. It is important to note that ageing changes may be identified on the CT scan in older patients particularly in the white matter. It is not usually appropriate to attribute dementia solely to vascular disease and therefore withhold medication unless there is a clear relationship to a significant stroke. (See Case 5).

Can you give some practical advice about the initiation and follow up of medication for Alzheimer's disease?

Initiation of the most commonly used anti-Alzheimer drugs (the acetylcholinesterase inhibitors) is usually by a specialist. Shared care protocols should be in place to facilitate their prescription by GPs in appropriate circumstances where this is locally agreed. More and more memory clinics are relying on primary care colleagues to follow up patients who have been established on medication and so GPs will gradually become more familiar with the drugs.

The acetylcholinesterase inhibitors are licensed for the treatment of mild to moderate Alzheimer's disease. Donepezil is the most commonly used. The class of agents can cause bradycardia and can exacerbate symptoms of gastric and duodenal ulcers, precipitate bronchospasm and may cause convulsions. Dizziness, headache and nausea are the most common side effects with abdominal disturbance and nightmares also commonly reported. NICE state that initiation of cholinesterase inhibitors should only be by specialists although we know of protocols being developed jointly by GPs, pharmacists and memory clinic specialists. Where there is interest in developing things further, local conversations should take place.

They should be used with great caution if the pulse rate is <60. If the pulse rate is > 70 beats per minute and regular there is no necessity to undertake an ECG. If the pulse is < 70, or irregular, an ECG is required and if there is a conduction abnormality, or an abnormal rhythm, specialist advice should be sought. It is usually safe to prescribe when atrial fibrillation is well controlled, providing the pulse is above 60. Similarly, if the patient is on beta-blockers it may be worthwhile considering a reduction in dose to keep the pulse rate >60.

First line treatment is donepezil 5mg once daily. Patients should be reviewed at one month to check for side effects and at three months to review its benefit, at which point the dose can be increased to 10mg if it is well tolerated with no slowing of the pulse. A dose increment would justify a further 3 month review and subsequently follow up should be annual in line with QOF. The review should include input from the carers and any community dementia resources that have interacted with the patient either at their home or at an appropriate site in the community.

Memantine usually requires some specialist assessment before prescribing.

Is there any evidence that managing vascular risk reduces the progression of dementia? In practical terms are we likely to be diagnosing patients with vascular dementia who are already known to have vascular disease and therefore already had consideration of anti-platelet treatment and statin?

There is no consensus that managing vascular risk factors for a patient with vascular or mixed dementia slows the progression. Empirically, there should be good control of these factors independent of a vascular dementia diagnosis. Agree that most patients with an element of vascular dementia will already have been considered for secondary prevention.

Can you give advice on how to recognise Lewy Body Dementia?

There is an association with symptoms of Parkinsonism. Patients often exhibit daytime fluctuations in alertness and confusion, experience visual hallucinations and typically have disturbed sleep with increased nocturnal motor activity. There may be a history of sensitivity to neuroleptics.

Should patients be coded with dementia when this diagnosis is obvious but they have made it clear that they do not accept the diagnosis and would be upset to have this label on the records?

It would be appropriate to include the diagnosis in the record in this situation since this is important to support the care, safety and well-being of the patient, especially in situations such as hospital admissions and social care assessments. It would be important to include a comment explaining the patient's views on the matter.

This is a difficult clinical presentation and the GP should strive to engage with the patient to help them to come to terms with the diagnosis and enable them to receive appropriate management. Even when they are reticent to accept the diagnosis patients should receive appropriate support and this can sometimes be achieved through gradual involvement of the specialist service and support workers. It is also essential to regularly revisit their views and understanding to support their management. Such cases, whilst relatively rare, are complex and advice from the specialist service may be appropriate, particularly if there are concerns about vulnerability and safety. The involvement of family members and carers may also be influential in progressing the understanding of the patient and their management.

Case scenarios

Examples of cases which would justify referral

1. A 53-year-old man with Down's syndrome who is usually well and only normally attends for routine check-ups. He is well supported by the local learning disability team. Five years ago, he had an episode of depression which was treated for six months with antidepressants. The history now goes back about a year, characterised by some agitation and his memory appears worse according to his elderly parents. He always used to be punctilious about his arrangements in going to the Day Centre but now he often lies in bed and doesn't seem to remember he has to go there on Tuesdays and Thursdays. He has put on some weight and people have noticed he has a predilection for sweet fruits. On two occasions in the last six months, he seems to have had some visual hallucinations describing seeing small people in his room at night which made him frightened. In your consultation, he appears disorientated and withdrawn and certainly not his usual self. You have concerns about his memory.

Comment: *We know that about half of people with Down's syndrome develop pathological changes of Alzheimer's disease. The presentation of the accompanying dementia can be complex and physical and psychiatric comorbid conditions such as hypothyroidism and depression or psychosis are important to exclude or treat. A specialist assessment including input from the learning disability service is needed here.*

2. A 62-year-old, successful, recently retired businessman attends complaining of memory loss. He says his wife and family have noticed a problem over the last few months. In his last year at work he had missed several appointments. He has become depressed in mood over the last few months as he sees little future now he has retired. His speech has changed in that it has become 'sticky' and his childhood stammer has returned. His wife has said that, curiously, he has started to make sudden muscular movements at night while he is asleep.

Comment: *This is a rather unusual presentation in a relatively young person. The symptoms could well be due to Alzheimer's disease. The myoclonic jerks are unusual in the early stages and the speech disturbance may be connected with a primary progressive aphasia. The fact that he is coming complaining of the symptoms suggests a degree of insight. He is describing symptoms of depression so a trial of antidepressants (e.g. sertraline 50mg a day, increasing after two weeks all being well to 100 mg) might be appropriate while referring him to a memory clinic, or possibly a neurology clinic.*

3. A 78 year old man presents with a nine month history of episodes of confusion with visual hallucinations and some paranoid ideas (that his wife is stealing his money). He had a transient ischaemic attack four years ago and made a full recovery. His only medication is aspirin. His family have remarked that sometimes he seems back to normal but at other times he can be very disorientated. He has become agitated when he does not recognise family members. His wife has noticed that his gait is shuffling sometimes. A few months ago, he became very agitated one night and was seen by a doctor who prescribed some risperidone – he became very stiff after two doses and his family did not give him any more. On examination, he has a blank expression, he is fully orientated to time and place and there is no evidence of depression. He is guarded when talking about his wife.

Comment: *The symptoms are suggestive of Lewy Body Dementia. His symptoms could easily be incorrectly attributed to cerebrovascular disease given the history of TIA since this may also cause Parkinsonism (in which the absence of tremor is common). The giveaway is the fluctuation of his mental state, the Parkinsonian features and the psychiatric symptomatology along with previous sensitivity to neuroleptics. This may be someone who you might refer to a physician with an interest in Parkinson's disease since they would know about Lewy Body Dementia, or a memory clinic to be seen by a consultant psychiatrist. This may vary depending on local arrangements.*

Cases which could be safely diagnosed by a GP

4. An 85 year old woman attends with her husband who reports that she has been increasingly forgetful since a hip replacement last year. Her speech is more repetitive so that she sometimes asks the same question four or five times within an hour. She is also more anxious and tends to get in a muddle with paperwork. She has addressed birthday cards to the wrong people and last week she burnt her ready-meal in the oven. She is relatively independent in her activities of daily living but requires some prompting. She denies there is a problem and puts her memory problems down to “just getting old”. She has a past medical history of a TIA two years ago, has treated hypertension and is on atorvastatin and aspirin. She has some osteoarthritis and mild hearing impairment but is otherwise well.

Comment: *Likely Alzheimer's Disease though may have a vascular component. Does not need a scan but does need cognitive assessment, an examination, full dementia blood screen, a more detailed history and brief risk assessment (driving, fire, falls etc.). Potential candidate for ACEI if there are no contraindications. Will need signposting to any available community support.*

The son attends to speak to the GP and wants to know why his mother has not been referred to a memory clinic which he has read about in the paper. Why has she not had a scan? Would her care be better if she saw a specialist? He is worried that his father may have difficulty coping.

The GP knows the lady well and there are no signs to suggest this is anything like a stroke or brain tumour which could be revealed on a brain scan. A scan has a small dose of radiation and can be distressing. If the son is worried about his father coping,

that is something which can be managed straight away with a referral to a dementia advisor plus support from local agencies. Of course, his mother can have a second opinion and a brain scan if she and the family wish it.

5. A 90 year old man is seen for review. He has been in a nursing home for six months following a stroke which caused a dense left hemiparesis and mild motor dysphasia. On admission to the care home he was noted to be drowsy and had frequent visual hallucinations. Following treatment of a UTI these symptoms improved, but he remains disorientated in time and place, with repetitive muddled speech and often does not remember the names of staff. He is on regular co-codamol, oxybutynin, and anti-hypertensive medication as well as low dose aspirin and a statin.

Comment:- *This is either vascular dementia (post-stroke) or mixed Alzheimer's Disease / vascular dementia. The distinction is a little academic, but a description of his functioning before the CVA and the progression or otherwise of his symptoms post-stroke may help to decide. Multiple medications (opiate and anticholinergic) may be contributing to his impairment. Delirium would be unlikely as there is a long history and no obvious acute medical problems. He does not need a scan and definitely has dementia – GP can make this diagnosis. A blood screen, physical examination and urine dipstick may be helpful if feasible and not distressing to the patient. Oxybutinin and codeine should be stopped if possible. A cognitive assessment is needed. Ensure care home manager and relatives know the diagnosis.*

The patient's son and daughter ask for an appointment. They want to know why their father has not been offered medication for his memory loss. He was not perfect before the stroke, so how do we know that he would not respond to treatment?

A fair question. Be clear what the likely improvements would be – they are generally in terms of memory and general functioning and will not make a difference to his symptoms of stroke which are disabling to him. There can be side effects to medication and can be upsetting if he has swallowing difficulties. If there is a significant element of Alzheimer's disease before the stroke (i.e. memory difficulties and functional disabilities which significantly affected the person's life, more than just "not perfect") then a trial of an acetylcholinesterase may be appropriate - probably one for a specialist opinion at some point but a diagnosis of dementia can be recorded and acted upon.

What next?

The link between dementia care enhanced services

The additional dementia enhanced service encourages GPs to diagnose dementia and also encourages practices to use a dementia data quality toolkit to find potential cases and improve dementia coding. GPs are going to be looking at ways of improving their knowledge of dementia, reviewing cases and discussing with colleagues. They may wish to involve their CCG with regard to developing resources to support dementia care in the community. As professionals, doctors will want to view the enhanced service as an opportunity to add quality to the lives of their patients who are suffering with dementia

Continuing professional development (CPD) and appraisal

If you have read this document and considered its implications for your practice then it counts towards your CPD. If you hold a clinical meeting to discuss the management of dementia this would be further CPD. Time can be allocated for preparation for the doctor who leads the meeting. It is easy in the time-pressured environment of the surgery to forget that this is what GP appraisal is all about. We often do the work but do not give ourselves the credit for it in our appraisal documentation.

Quality improvement activity (QIA)

Dementia data quality toolkits provide practices with a list of potential dementia patients. If you write up your response to running a toolkit you will have satisfied the requirement to provide a quality improvement activity for appraisal and revalidation. The potential responses will vary depending on the findings.

If there are patients who have attended the memory service and been diagnosed with dementia, but do not have a GP code, how has this happened? This could be written up as a significant event. Do you need to look at your system for coding out-patient letters for example? Have you found a number of patients who have been labelled with a code which highlights memory loss but have not been followed up? Lack of time or lack of confidence in making the diagnosis may be possible explanations for failing to diagnose dementia. Do you need to develop a system to highlight memory issues with a due diary or recall system? Are you familiar with suitable cognitive assessment tools? How do you currently manage patients in care homes who have dementia but have never had a formal diagnosis?

Evidence of quality improvement of this type which has resulted from engaging with an enhanced service and undertaking self-directed learning justifies further credits which should be commensurate with the time taken to undertake the activities.

Request for feedback

This format is a new venture and we are keen to receive your feedback. We would like to know if you have found the style useful. Have we covered the topic in a way which has addressed your learning needs? Have we covered the learning outcomes successfully? Do you have any suggestions for improvement?

We are keen to facilitate a dialogue between general practice, clinical leads and dementia specialists with a view to developing closer links and improved joint working. We would be happy to receive any further questions which you might like to ask our expert resources. These will be collated to look for themes and incorporated into our planned revision of this document which should be available in around three months. Similarly you might like to send case scenarios for comment.

Please send your feedback, questions or comments to paul.twomey@nhs.net

Appendix 1

Dementia narrative

Diagnosing dementia: any appropriately skilled clinician can and brain scanning not always needed

Dementia is a clinical syndrome and implies brain failure (analogous to heart failure or liver failure). The diagnosis is a two stage process.

Step 1 is to make a diagnosis of dementia, differentiating it from: depression; delirium; the effect of drugs and; the changes in memory expected as part of normal ageing. A key feature is that for a diagnosis of dementia, it should affect daily living activities and should be progressive.

Step 2 is to determine the cause of condition – the commoner causes are Alzheimer’s disease, Vascular Dementia and Lewy Body Dementia.

Both stages are based on a comprehensive assessment including a history, including one from an informant, a physical and mental state examination, including a specific assessment of cognitive function and selected ancillary investigations (Dementia: NICE Clinical Guideline 42, www.NICE.org).

Any clinician who has the appropriate skills can recognise and make a diagnosis of dementia.

Specialist advice may be needed in particular clinical situations where the presentation or course is atypical and in groups such as people with learning disabilities. Also, specialist advice is more often needed to diagnose the exact cause of the dementia. This may have clinical implications for the prescription of medication such as drugs for Alzheimer’s disease, treatment of vascular risk factors in Vascular Dementia or avoidance of neuroleptics in Lewy Body Dementia.

In terms of brain scanning, the NICE Dementia Guideline states “**Imaging may not always be needed in those presenting with moderate to severe dementia, if the diagnosis is already clear.**”

Post diagnostic support which should be person centred goes hand in hand with the diagnosis (which does not necessarily have to result in the prescription of medication) and is largely independent of the cause of the dementia.

Alistair Burns
National Clinical Director for dementia
NHS England October 2014

Appendix 2

Dementia Coding across the North Region

This guidance document is prepared for use across the North region to provide a consistent way of coding dementia in GP practices. It was agreed by members of the north regional mental health, dementia and neurological conditions oversight group on Monday 28th July 2014 to use central guidance as the regional standard. Further changes were included following circulation to dementia clinical leads of north strategic clinical networks and the development of a CSU data quality tool to assist in data cleansing. The guidance continues to be refined as comments are received from users of this guidance.

Elements of this model are adopted from NHS London Guidance on Dementia Coding produced by Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia, and Leeds North CCG to identify codes which correlate directly to the dementia register.

This guidance will be utilised in the coding clean-up exercise carried out across the North region as part of the Intervention & Support team proposal in 2014/15.

This guidance is provided to encourage memory services to code correspondence to primary care and to help practices decide how to code those patients who aren't currently on the GP practice register but should be – whether derived from the need to correct coding identified by the practice or diagnosing a patient for the first time. It is important that any code used, adds patients to the GP practice dementia register. There is no requirement for practices to change codes already in use or cease using preferred codes, as long as those codes include patients on the GP practice dementia register.

We are aware of issues with local coding on EMIS systems such as 'EMISNQDV1', which are used as default codes by the system supplier, and are looking into how this can be corrected.

Guidance on Dementia Coding

What is the big issue for North GPs in coding dementia?

There is a dementia diagnosis gap of 40.7% in the North, which means that only 59.3% of those who we would expect to have dementia, based on population prevalence rates, are recorded on GP practice dementia registers¹. We believe one of the reasons behind this apparently low diagnosis rate is a lack of accurate coding due to there being confusion with the available codes. This note for GPs contains guidance to help address this.

Why is it so important to diagnose and accurately code dementia?

1. It means the patient's care can be planned, managed and monitored, so that they can be signposted to supportive services and prescribed appropriate medication.

¹ QOF data Sept 2014

2. Diagnosis gives power to the patient and their families, as it brings clarity in terms of what is happening to them, and provides them with the ability to make choices themselves (National Dementia Strategy, 2009).
3. The coding of dementia and putting the patient on the dementia register means we can develop an accurate picture of North dementia rates to inform commissioning of high quality, cost effective services in response.
4. It means that GPs can see their own practice performance rise.

Making dementia coding simple

The North region has adopted elements of this GP dementia coding guideline from colleagues previously at NHS London (created by a team of GPs working to improve dementia care in London with support from specialist experts)² and work carried out by Leeds North CCG to identify codes which correlate directly to the dementia register.

Guideline

1. We propose the use of **eight codes** in primary care, which are listed below. Using these codes will ensure that the patient is added to the GP practice dementia register.
2. If the specific type of dementia is unknown, for whatever reason, please use the Read Code **Eu02z “Unspecified dementia”** or **CTv3 code XE1Z6**, as appropriate for your GP practice system. This can always be changed later when more information is available. Please DO NOT use 1461.00 “h/o dementia”, 28E..00 “cognitive decline” or similar codes for this purpose – these codes will not add the patient to your practice dementia register.
3. If the patient is diagnosed with Mild Cognitive Impairment (not dementia), please use Read Code Eu057 or CTv3 code X00RS, as appropriate for your GP practice system.
4. Please use this guidance in conjunction with your local CSU developed data quality tool when conducting data cleansing.

² Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia, Feb 2012

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The main codes which General Practitioners should use to code for dementia in primary care are:

| ICD code & description | | Read Code (e.g. EMIS practices) & description | | CTv3 Code (e.g. SystmOne practices) & description | |
|------------------------|--|---|---|---|---|
| F00 or [X]Eu00 | Dementia in Alzheimer's disease | Eu00. | Dementia in Alzheimer's disease | Eu00. | Alzheimer's disease |
| F01 | Vascular dementia | Eu01. | Vascular dementia | XE1XS | Vascular dementia |
| F00.2 or [X]Eu002 | Dementia in Alzheimer's disease, atypical or mixed type (Mixed Dementia) | Eu002 | Dementia in Alzheimer's dis, atypical or mixed type | Eu002 | Dementia in Alzheimer's dis, atypical or mixed type |
| F02.3 or [X]Eu023 | Dementia in Parkinson's disease | Eu023 | Dementia in Parkinson's disease | Eu023 | Dementia in Parkinson's disease |
| F03 | Unspecified dementia | Eu02z | Unspecified dementia | XE1Z6 | Unspecified dementia |
| G31.0 | Circumscribed brain atrophy including: fronto-temporal dementia, Pick's disease, progressive isolated aphasia | Eu020 | Pick's Disease | X0034 | Frontotemporal dementia– includes Pick's Disease and progressive isolated aphasia |
| | | Eu02y | Dementia in other diseases specified elsewhere | | |
| G31.8 | Other specified degenerative disease of the nervous system including: grey matter degeneration, lewy body disease, lewy body dementia, subacute necrotizing encephalopathy | Eu025 | Lewy body dementia | X003A | Lewy body dementia |
| F10.7 | Residual and late onset psychotic disorder due to alcohol Including: Alcoholic dementia Other alcoholic dementia Chronic alcoholic brain syndrome | E012. | Residual and late onset psychotic disorder due to alcohol | Xa25J | Alcoholic dementia |

‡ Lower level codes can also be used i.e. e.g. Eu000-z Early, late, mixed and unspecified

‡‡ Lower level codes can also be used i.e. Eu010-z

All the Read Codes and CTv3 codes included in the above table will add patients to the QOF dementia register.

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With thanks to NHS London and Dr Paul Russell, GP, London Dementia Clinical Team & Professor Sube Banerjee, London Clinical Director for Dementia and Leeds North CCG for sharing their documentation and learning to inform this guidance. Thanks also to those who have commented and supported the further development of this guidance.

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In collaboration with the Northern England, Yorkshire & Humber, Cheshire & Merseyside and Greater Manchester, Lancashire & South Cumbria Strategic Clinical Networks.

Useful further reading and sources of information

- For assessment of cognition: a handy guide to the major scales
www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1045
- For management of agitation and behavioural and psychological symptoms in dementia (BPSD), using a stepped care approach
www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=609
- Specific alternatives to medication for agitation
www.bps.org.uk and search “alternatives to antipsychotics”
- Dementia partnerships: a very useful source of information on all aspects of dementia www.dementiapartnerships.com
- The dementia prevalence calculator – a guide to your local dementia prevalence rate. You need to register.
www.dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/
- Bishara D. and Harwood D. (2014). Safe prescribing of physical health medication in patients with dementia. *International Journal Geriatric Psychiatry*, 29, 1230–1241.
- Corbett A, Burns A and Ballard C. Don't use antipsychotics routinely to treat agitation and aggression in people with dementia BMJ 2014; 349 doi: <http://dx.doi.org/10.1136/bmj.g6420> (Published 03 November 2014).