

Diagnosing Dementia

Guidance and Standards



**Guidance and standards for diagnosing
dementia in primary health care and
specialist memory services**

Introduction

This Guidance sets out the process and associated standards for making a diagnosis of dementia in primary health care services, and by specialist memory assessment services.

The Guidance sets out the role of primary care in the initial assessment, diagnosis and long term management of the person with dementia. It takes account of and reflects the need for ongoing advice, support and services for the person with dementia and their carers/families, irrespective of where or when that diagnosis is made.

It sets out the standards essential to making a diagnosis, by a specialist Memory Assessment Service or within primary care.

The Guidance has been produced by a Working Group established by the South West Dementia Partnership. (Appendix 1: Working Group Membership.) It supplements the South West Dementia Partnership's Guidance on commissioning memory assessment services, 2010.¹

It is intended as guidance and source of information to inform the commissioning, redesign and delivery of services for people with dementia in primary and secondary care.



1. South West Dementia Partnership (2010) [Guidance on the Commissioning of Memory Assessment Services](#). South West Dementia Partnership, Bridgwater.

Background

Following the publication of the National Dementia Strategy (Department of Health, 2009) ² work has been undertaken both nationally and regionally to identify the key features to be included in a specification of a Memory Assessment Service.

National guidance has been predicated on the assumption that a Memory Assessment Service would be a specialist service delivered by secondary care mental health services, and operate from a secondary care setting, and/or reach into the community in order to offer a service at home, or closer to home. This is reflected in the Royal College of Psychiatrist's accreditation programme for Memory Assessment Services,³ and by the Department of Health's Dementia Commissioning Pack, Service Specification for a Memory Service (2011).⁴

Dementia care in primary care

In recent years there has been a significant shift for people with long term conditions to be supported closer to home and within primary care. For some conditions this will include the whole patient journey from diagnosis, through to chronic disease management, to end of life care. Specialist services tend to only become involved in the assessment and management of people who have significant complications or complex presentations.

Dementia is a long term condition, and should be considered within the long term conditions model. Treatment, care and support in primary care will include:

- awareness of presenting symptoms or signs warranting further diagnostic assessment
- initial assessment
- diagnostic assessment
- post-diagnosis information, support and education for patient and carers/family members

2. Department of Health (2009) [Living well with dementia: National Dementia Strategy](#). Department of Health, London.

3. Royal College of Psychiatrists (2010) [Memory Services National Accreditation Programme. Standards for Memory Services Assessment and Diagnosis](#). CCQ1099. Royal College of Psychiatrists, London.

3. Department of Health (2010) [Service specification for dementia: memory service for early diagnosis and intervention](#). Department of Health, London.

- prescribing, and medicines management
- health and well being promotion
- active planning for future needs and wishes
- signposting to support agencies and community facilities
- monitoring of disease progression; regular review as the patient's presentation changes, including review of carer's needs, and
- advance planning and care towards the end of life.

As awareness about the prevalence of dementia is improving, so is the recognition that the ongoing management and support of people with dementia and their carers/families sits with primary health care teams. To be effective, primary health care teams need to work in partnership with people with dementia, carers/families, health and social care services, and local voluntary and community services.

Specialist advice – later stages

General Practitioners and primary health care teams may require other specialist advice at later stages of the patient's dementia journey, relating to

- people with complex psychological presentations or co-morbidities
- people who present with behaviours that challenge
- pain management
- prescribing; medications management
- carers' support and assessment
- domiciliary care and support
- planning and providing care towards the end of life.⁵

5. Ibid. 4.

Models of delivery – memory assessment

There has been an emerging debate about the role of General Practitioners in the diagnosis of dementia, and the recognition that they would need the associated specialist clinical skills in order to do so in line with NICE standards.⁶ Given that there is no simple, accurate diagnostic test for dementia, and that the GP with an average practice list will only see about two or three new cases per year, the determination of an accurate diagnosis of dementia at an early stage in primary care will be challenging.

This raises the question of whether management in primary care could, or should, also include 'diagnosis', and if so how the quality of and confidence in a diagnosis is preserved to the satisfaction of patient, carers/families, and the wider health and care system.

An audit of commissioning plans in the South West region, May 2011⁷ indicated that three models for dementia assessment services are being commissioned:

- **Primary care-led diagnosis:** patients are assessed and diagnosed in primary care. This includes patients who present with established dementias.
- **Memory Service - targeted:** following initial assessment in primary care, referral of people with early symptoms of dementia, and people with more complex presentations and/or co-morbidities is made to a specialist Memory Service for a comprehensive assessment, and/or for advice on treatment and care. In this model patients who present with established dementias tend to be diagnosed in primary care.
- **Memory Service – comprehensive:** referral of all people with cognitive impairment to specialist memory services following initial assessment in primary care.

6. National Institute for Health and Clinical Excellence (2010) [Dementia Quality Standards](#). NICE, London.

7. Clinical skills, skill mix, service costs, and cost pressures on services as rates of diagnosis increase were not considered in this audit.

Competent practice

NICE Clinical Guideline 42 ⁸ sets out the process and investigations to be undertaken to inform the diagnosis of dementia (Appendix 1).

Clinicians require a range and level of skills to be competent in making a diagnosis of dementia and its sub types; traditionally this workforce is located in a specialist memory assessment service, but not necessarily exclusively.

General Practitioners may decide that not all patients presenting with dementia will require referral to a specialist memory assessment service; GPs may conclude a diagnosis of dementia where the condition is already established, that is, where the patient is in the intermediate-to-advanced stages of the disease.

Where a patient presents with possible early onset dementia, possible early dementia, or complex presentations a specialist dementia assessment will be required.



8. National Institute for Health and Clinical Excellence, Social Care Institute for Excellence (2006) [Dementia – Supporting people with dementia and their carers in health and social care. CG42](#). NICE / SCIE, London.

Summary of Standards for diagnosis

1. Memory assessment is offered early in the course of the disease
2. The diagnosis of dementia is made in line with NICE guidelines and best clinical practice.
3. The assessment of dementia excludes reversible and physical causes.
4. The diagnosis is sufficiently detailed with probable type of dementia.
5. Carers / families are invited to contribute to the assessment, where appropriate and possible.
6. A diagnosis of mild cognitive assessment (MCI) is only made after appropriate assessment and in line with the National Institute for Clinical Excellence (NICE) definition.
7. People with diagnostic or management complexity are identified and referred to an appropriate service.
8. Anti dementia medication is initiated and reviewed in line with NICE guidelines and local protocols.
9. Diagnosis is given sensitively, in an appropriate environment.
10. People with dementia have an assessment and an ongoing personalised care plan that addresses their individual needs and identifies a named person to co-ordinate their care.



11. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, where indicated, agree a care plan and receive tailored interventions to address those needs.
12. People with dementia are offered a regular review by their primary health care team.
13. People are involved in planning for their future needs.
14. People diagnosed with dementia and /or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
15. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviours that challenge, are offered an assessment at an early opportunity in order to establish generating and aggravating factors. Interventions to address such behaviours or distress are included in their care plan.
16. People in later stages of dementia are assessed by primary care teams in order to identify and plan for their palliative care needs.
17. People with dementia receive care from staff appropriately trained in dementia care.
18. The diagnosis pathway is monitored to establish standards of access and delivery, and patient and carer reported outcomes.



1. Memory assessment is offered early in the course of the disease.

Access to early diagnosis of dementia should be promoted and facilitated.

Screening

Screening for dementia is not recommended routinely, with the exception of:

- people with Down's Syndrome
- people who present with mild cognitive impairment (memory problems).

Case finding

Primary health care teams should take steps to identify patients at higher risk of developing dementia. Consideration should be given to patients with:

- mild cognitive impairment
- Down's Syndrome
- chronic neurological diseases such as Huntington's Chorea, Parkinson's Disease and Multiple Sclerosis
- vascular disease and diabetes
- patients with recorded non-specific diagnosis of memory loss
- or older people:
 - with symptoms of depression
 - presenting with minor injuries, for example from falls or domestic accidents.

2. The diagnosis of dementia is made in line with NICE guidelines and best clinical practice.

A diagnosis of dementia will be informed by a person's history, physical examination and investigations. These will be undertaken and interpreted by a suitably qualified and trained professional with experience in the diagnosis and management of dementia.

History taking should be holistic and include the assessment of physical, psychological, cognitive, social and functional aspects of a person's life. This should include discussion with family members or carers to acquire collaborative evidence.

Cognitive assessment will include one of a number of cognition tests⁹. Whilst scores may be supportive of a diagnosis of dementia they are not absolute, and relevance requires professional interpretation. They are unlikely to be relevant in the consideration of type of dementia.

Clinicians and practitioners involved in diagnosis may include:

- General Practitioner
- General Practitioner with Special Interest in dementia care
- experienced mental health nurse or clinical psychologist
- secondary care consultant in psychiatry, elderly care medicine or neurology
- secondary care mental health clinicians and practitioners.



9. See Dementia care in primary care toolkit <http://www.southwestdementiapartnership.org.uk/primarycaretoolkit/>

A diagnosis of dementia may be made by a General Practitioner where a dementia is established.

The earlier in the course of the illness or the more complex the presenting symptoms, the greater will be the need for specialist, skilled assessment to provide a reliable diagnosis.

Commissioners should,

- establish the competence required of staff undertaking diagnosis of dementia, in any setting, by specifying competency requirements in the contract and assuring this via monitoring;
- ensure that local referral protocols are in place to clarify target groups, referral routes, and processes for the diagnosis of dementia.

3. The assessment of dementia will exclude reversible and physical causes

Clinical assessment, including history, examination and investigations, should identify those patients for whom more detailed investigations are required to exclude reversible or physical causes of presenting symptoms. This assessment should include assessment for depression, anxiety and other mental health problems.

All patients should be offered blood screening for full blood count, calcium, glucose, renal and liver function tests, serum vitamin B12 and folate levels. This should be recorded in primary care notes. (Appendix 3: Quality and Outcomes Framework guidance for GMS contract 2011/12.)

Structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the subtype diagnosis. Magnetic resonance imaging (MRI) is the preferred modality to assist with early diagnosis and detect subcortical changes, although computerised tomography (CT) scanning could be used ¹⁰.

The findings should be reported by a clinician competent in the diagnostic assessment for dementia.

Specialist advice should be taken when interpreting scans in people with learning disabilities ¹¹.

10. Ibid. 8.

11. Ibid. 8.

4. The diagnosis will be sufficiently detailed with probable type of dementia.

A diagnosis should be sufficiently detailed to indicate probable type of dementia (e.g. Alzheimer's Disease, vascular dementia, Lewy Body Dementia).

A diagnosis of subtype of dementia should be made by healthcare professionals competent in differential diagnosis using international standardised criteria ¹².

5. Carers / families are invited to contribute to the assessment, where appropriate and possible.

The assessment should normally be informed by contributions from the patient, and the carer/ family ¹³.

Wherever possible the patient's consent should be sought and established, in seeking this information.



12. Ibid. 8. (Section 1.4.3.1)

13. Ibid. 8. (Page 6)

6. A diagnosis of mild cognitive impairment will only be made after appropriate assessment and in line with the NICE definition.

Definition

Mild Cognitive Impairment (MCI) is a syndrome defined as cognitive decline greater than expected for an individual's age and education level, which does not interfere notably with activities of daily living. It is not a diagnosis of dementia of any type, although it may lead to dementia in some cases (NICE, 2006) ¹⁴.

Treatment and care

People diagnosed with MCI (including those without memory impairment, which may be absent in the earlier stages of non-Alzheimer's dementia) should be offered follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage ¹⁵.

People with MCI should be offered assessment and management of cardiovascular risk factors. Primary care assessment of cardiovascular risk factors is appropriate.

People with MCI should be offered annual review including cognitive assessment.



14. Ibid. 8. (Section 1.3.3.1)

15. Ibid. 8. (Section 1.3.3.3)

7. People with diagnostic or management complexity are identified and referred to an appropriate service.

Those patients with specific or complex needs should be identified and referred to an appropriate service. This may include people with:

- Downs Syndrome
- complex neurological diseases (e.g. Huntington's Chorea, Parkinson's Disease, Multiple Sclerosis)
- early onset of symptoms
- complex behavioural or psychological problems.

8. Anti-dementia medication is initiated in line with NICE guidelines and local protocols

The clinician or memory assessment service providing a diagnosis should identify those patients for whom anti-dementia drugs are appropriate.

Assessment and initiation of therapy should be in accordance with NICE Technology Appraisal guidance 217

- only specialists in the care of patients with dementia (that is, psychiatrists including those specialising in learning disability, neurologists, and physicians specialising in the care of older people) should initiate treatment
- patients who continue to receive treatment should be reviewed using cognitive, global, functional and behavioral assessment
- treatment should be reviewed by an appropriate specialist team OR should be in accordance with a locally agreed protocol for shared care (NICE, 2011) ¹⁶.

Local protocols should be in place to ensure timely and appropriate access to anti-dementia medication, initiation arrangements and review protocols. These protocols need to be reviewed regularly to ensure compatibility with national guidance in the future.

16. National Institute for Health and Clinical Excellence (2011) [Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease. Technology Appraisal 217](#). Section 1.3 NICE, London.

9. Diagnosis is given sensitively, in an appropriate environment.

Diagnosis should be given in an appropriate environment, with adequate time for sensitive discussion. This should include details of the diagnosis, likely prognosis and treatment plan.

When appropriate and possible, the diagnosis should be given in the presence of a close relative or carer, and with the person's consent.

Where necessary, special arrangements (interpreter, BSL signer, advocate) should be made to ensure that the individual and relatives/carers can understand the diagnosis and other information. For example, this may include,

- people not fluent in English
- people with hearing impairment, and
- people with learning disabilities.

The diagnosis should be communicated to the patient's General Practitioner, ensuring that processes are in place for inclusion of the person's name on the practice Dementia Register (QOF DEM1) with appropriate Read coding. (Appendix 3: Quality and Outcomes Framework guidance for GMS contract 2011/12.)



10. People with dementia have an assessment and an ongoing personalised care plan that addresses their individual needs and identifies a named person to co-ordinate their care.

A care plan should be discussed and agreed with the patient and with the carer/family where appropriate.

This should include details of,

- prevention, e.g. management of cardiovascular risk
- plans to maintain the person's health and wellbeing
- physical and psychological needs, and treatment and support to address these needs
- medication plan
- risk and safe guarding
- legal considerations including driving, and Lasting Power of Attorney
- carer/family needs, education and support
- contingency or 'rainy day' plan, for example, if a carer becomes unwell
- sources of information; contacts including out of hours contacts
- local resources; directory of services
- next steps, including a date for review.

11. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, where indicated, agree a care plan and receive tailored interventions to address those needs.

Family / carers should be supported during a memory assessment, and included in the meetings with the person with dementia when the outcomes of the assessment are being considered and next steps planned.

The carer's own strengths, needs and rights should be acknowledged and addressed.

Carers should be respected as partners in planning care and support.

Carers should be offered:

- an assessment of needs, including their own care plan;
- a programme of education which takes account of their own physical and emotional health and wellbeing;
- signposting to information, advice, support and guidance, including contacts out of hours;
- a regular health check and review.



12. People with a diagnosis of dementia are offered a regular review by their primary health care team.

People diagnosed with dementia should be offered regular review at least every 15 months. (Appendix 3: Quality and Outcomes Framework guidance for GMS contract 2011/12.)

The review should consider:

- the physical and mental health needs of the person
- the need for information by the patient and carers, commensurate with the stage of the illness
- the impact of caring on the care-giver (if appropriate), and the option of signposting the carer to a carer's assessment
- any information or support required from a specialist dementia service
- the plan of care, agreed with the patient, and with the carer as appropriate
- contingency or rainy day plan for possible patient or carer illness, and
- patient and carer access to advice and help, as their needs change.

Quality and Outcomes Framework guidance to General Medical Services contract 2011/12:

- QOF guidance for GMS contract 2011/12 DEM indicator 1- the practice can produce a register of patients diagnosed with dementia. (Appendix 3: Quality and Outcomes Framework guidance for GMS contract 2011/12.)
- DEM indicator 2 Review of patients diagnosed with dementia - the percentage of patients diagnosed with dementia whose care have been reviewed in the preceding 15 months. (Appendix 3: Quality and Outcomes Framework guidance for GMS contract 2011/12.)

13. People are involved in planning for their future needs

People with dementia will experience gradual reduction in their memory and reasoning during the course of the illness. This change may have significant impact on their capacity to weigh up choices and make decisions.

People with dementia often experience a high rate of distressing and sometimes inappropriate interventions towards the end of life. There is a higher possibility of hospital admissions which have a potentially negative impact on a patient's experience, symptoms of dementia, and presenting physical illness¹⁷.

Steps should be taken actively to plan for future needs and wishes. This will include,

- early consideration and regular review of the person's capacity
- informing the person with dementia and carers about the opportunities of Lasting Power of Attorney for finance and for health and well being decisions
- consideration of possible developments in physical illness and options for treatment, care and place of care
- advanced care planning as end of life approaches
- consideration of the recording and communication of wishes and advance care plans
- encouragement for use of person held records
- good hand over arrangements between services in out of hours periods, and
- close working with carers and family members as partners in care.

17. Alzheimer's Society (2009) [Counting the cost: caring for people with dementia on hospital wards](#). London, Alzheimer's Society.

14. People diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment, and the support options in their local area.

People with dementia have complex health, social and personal needs that will change at different stages of their illness. Consideration is required for:

- changes in physical or mental health
- support to remain independent e.g. walking partners
- support with personal care
- housing and assistive technology
- peer contact and support
- information
- education
- support to retain skills and express preferences whilst recognizing their current abilities
- support to retain social networks.

Signposting to support services should be offered to all people with dementia and their carers.

This will involve,

- the commissioning of a range of support services from health and social care providers
 - clarification of who signposts, and of the pathways for referral
 - understanding by primary care teams of services available and how they can be accessed.
- Informing patients and carers about services available as part of their review (see Standard 12).

15. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviours that challenge, are offered an assessment at an early opportunity in order to establish generating and aggravating factors. Interventions to address such behaviours or distress are included in their care plan.

People presenting with distress of behaviours that challenge should be assessed and managed effectively in line with current recommendations to ensure:

- person-centred care
- effective assessment of pain and treatment to provide pain relief
- assessment within primary health and social care services, where indicated
- use of preventative measures
- watchful waiting and use of simple non - drug treatments/interventions ¹⁸
- consideration of referral for consultation with specialist services
- cautious use of medication according to approved guidelines, and
- planned follow up and review.

18. Alzheimer's Society (2011) [Optimising treatment and care for people with behavioural and psychological symptoms of dementia: A best practice guide for health and social care professionals](#). Alzheimer's Society, London.

16. People in the later stages of dementia are assessed by primary care teams in order to identify and plan for their palliative care needs.

Health and social care staff should ensure that people who are in the later stages of dementia have their palliative care needs met in accordance with the Department of Health's End of Life Care Strategy (2008) ¹⁹. This includes use of appropriate tools and pathways, such as:

- End of Life Care programme, preferred priorities for care
www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare
- Gold Standards Framework www.goldstandardsframework.org.uk
- Liverpool Care Pathway www.mcpcil.org.uk/liverpool-care-pathway/

Steps will include:

- early and realistic advanced care planning
- joining up of end of life and dementia policies and services within each health and social care organisation
- close partnership working with carers and family members, taking account of their specific needs over time and anticipated bereavement support
- effective partnership working with all health, social care and third sector services in caring for the individual person. This may include faith organisations
- person-focused care utilising tools developed for improving care and assessment of symptom management, for example the Liverpool Care Pathway, pain assessment tools.

19. Department of Health (2008) [End of Life Care Strategy](#). Department of Health, London.

17. People with dementia receive care from staff appropriately trained in dementia care.

All staff involved in assessment and the process of making a diagnosis should have appropriate education, experience, continuing professional development and professional support to ensure a good quality diagnosis is made.

Commissioners should require evidence of the competence of clinicians undertaking diagnostic procedures, and of health and social care staff contributing to the diagnosis of dementia ²⁰.

18. The diagnosis pathway is monitored to establish standards of access and delivery, and patient and carer reported outcomes.

Clinical governance procedures should be fully implemented.

Audit processes should be in place to ensure compliance with service models, pathway standards and the delivery of a high quality service.

The service should capture outcome measures and indicators specified in the Dementia Commissioning Pack service specification: memory service for early diagnosis and intervention (Department of Health, 2011)²¹.

There will be a year-on-year increase in the diagnosis of people with dementia having a formal diagnosis compared with the local predicted prevalence.

There will be a year-on-year increase in the proportion of people with dementia receiving a diagnosis in the mild stages of the illness.

There will be a year-on-year increase in the number of patients and carers who have a positive service experience.

20. South West Dementia Partnership (2011) [Dementia Competency Framework](#). South West Dementia Partnership, Bridgwater.

21. Ibid. 4.

Appendix 1 Membership of working party

- Martin Freeman, GP Regional Lead for Dementia, NHS South of England (West)
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Appendix 2: Extracts from the NICE-SCIE Quick Reference Guide on Dementia ²²

Diagnosis and assessment

Except where indicated, recommendations in this section are mainly relevant to healthcare professionals.

Risk factors and prevention

Risk factors

- Do not conduct general population screening.
- In middle-aged and older people, review and treat vascular and other risk factors for dementia, such as smoking, excessive alcohol use, obesity, diabetes, hypertension and raised cholesterol levels.

Genetic counselling

- Offer referral to genetic counselling to those thought to have a genetic cause of dementia¹ and to their unaffected relatives.
 - Genetic counselling should be provided by regional genetic services.
 - Do not use clinical genotyping if a genetic cause for dementia is not suspected, including late-onset dementia.

Prevention

- Do not use the following as specific treatments for the primary prevention of dementia:
 - statins
 - vitamin E
 - hormone replacement therapy
 - non-steroidal anti-inflammatory drugs.
- For the secondary prevention of dementia, review and treat vascular and other risk factors in people with the condition.

Early identification

- In primary care, consider referring people with signs of mild cognitive impairment (MCI)² for assessment at memory assessment services.
- If undertaking health checks, including those conducted as part of health facilitation, be aware of:
 - the increased risk of dementia in people with learning disabilities and
 - the possibility of dementia in other high-risk groups (for example people who have had a stroke or have a neurological condition such as Parkinson's disease).

Memory assessment services that identify people with MCI (including those without memory impairment, which may be absent in the earlier stages of non-Alzheimer's dementias) should offer follow-up to monitor signs of possible dementia.

¹ Examples include familial autosomal dominant Alzheimer's disease or frontotemporal dementia, cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL) and Huntington's disease.

² MCI is a syndrome defined as cognitive decline greater than expected for an individual's age and education level that does not interfere notably with activities of daily living. It is not a diagnosis of dementia of any type, although it may lead to dementia in some cases.

²² National Institute for Health and Clinical Excellence, Social Care Institute for Excellence (2006) [Dementia: quick reference guide](#). NICE / SCIE, London.(Pages 9-12)

Diagnosis and assessment

- Make a diagnosis of dementia only after a comprehensive assessment, including:
 - history taking
 - cognitive and mental state examination
 - physical examination
 - review of medication to identify any drugs that may impair cognitive functioning.
- Ask people who are assessed for possible dementia whether they wish to know the diagnosis and with whom it should be shared.
- If dementia is mild or questionable, conduct formal neuropsychological testing.
- At the time of diagnosis, and regularly afterwards, assess medical and psychiatric comorbidities, including depression and psychosis.

Clinical cognitive assessment

- Examine:
 - attention and concentration
 - orientation
 - short- and long-term memory
 - praxis
 - language
 - executive function.
- Conduct formal cognitive testing using a standardised instrument, such as:
 - Mini Mental State Examination (MMSE)
 - 6-Item Cognitive Impairment Test (6-CIT)
 - General Practitioner Assessment of Cognition (GPCOG)
 - 7-Minute Screen.

Take into account other factors that may affect performance, including educational level, skills, prior level of functioning and attainment, language, sensory impairment, psychiatric illness and physical or neurological problems.

Investigation of suspected dementia

- Conduct a basic dementia screen at the time of presentation, usually in primary care. Include:
 - routine haematology
 - biochemistry tests (electrolytes, calcium, glucose, and renal and liver function)
 - thyroid function tests
 - serum vitamin B₁₂ and folate levels.
- Perform a midstream urine test if delirium is a possibility.
- Conduct investigations such as chest X-ray or electrocardiogram (ECG) as determined by clinical presentation.
- Do not routinely:
 - test for syphilis serology or HIV unless there are risk factors or the clinical picture dictates
 - examine cerebrospinal fluid.

Diagnosis of subtype

- Diagnosis of subtype of dementia should be made by healthcare professionals with expertise in differential diagnosis using international standardised criteria.

Type	Recommended diagnostic criteria*
Alzheimer's disease	Prefer NINCDS/ADRDA criteria. Alternatives include ICD-10 and DSM-IV.
Vascular dementia	Prefer NINDS-AIREN criteria. Alternatives include ICD-10 and DSM-IV.
Dementia with Lewy bodies (DLB)	International Consensus criteria for DLB.
Frontotemporal dementia (FTD)	Lund-Manchester criteria, NINDS criteria for FTD.

*See NICE-SCIE guideline for further details (available from www.nice.org.uk/CG042).

- Use cerebrospinal fluid examination if Creutzfeldt–Jakob disease (CJD) or other forms of rapidly progressive dementia are suspected.
- Do not routinely use electroencephalography (EEG). Consider in:
 - suspected delirium, frontotemporal dementia or CJD
 - associated seizure disorder in those with dementia.
- Consider brain biopsy only if a potentially reversible cause is suspected that cannot be diagnosed in any other way.

Imaging

- Use structural imaging to exclude other cerebral pathologies and help establish the subtype.
 - Prefer MRI to assist with early diagnosis and detect subcortical vascular changes. However, CT scanning could be used.
 - Take specialist advice when interpreting scans in people with learning disabilities.
- Use perfusion hexamethylpropyleneamine oxime (HMPAO) single-photon emission computed tomography (SPECT) to help differentiate Alzheimer's disease, vascular dementia and frontotemporal dementia.
 - The test is not useful in people with Down's syndrome, who may have SPECT abnormalities resembling Alzheimer's disease throughout life.
 - If HMPAO SPECT is unavailable, consider 2-[¹⁸F]fluoro-2-deoxy-D-glucose positron emission tomography (FDG PET) as an alternative.
- Use dopaminergic iodine-123-radiolabelled 2β-carbomethoxy-3β-(4-iodophenyl)-N-(3-fluoropropyl) nortropane (FP-CIT) SPECT to confirm suspected DLB.

- Usually manage dementia with mixed pathology according to the likely dominant condition.

Specialist assessment services

Memory assessment services (provided by a memory assessment clinic or community mental health teams) should be the single point of referral for people with possible dementia. They should provide:

- a responsive service with a full range of assessment, diagnostic, therapeutic and rehabilitation services to accommodate different types and all severities of dementia and the needs of families and carers
- integrated care in partnership with local health, social care, and voluntary organisations.

Needs arising from diagnosis

Following a diagnosis of dementia:

- make time available to discuss the diagnosis with the person with dementia and, if the person consents, with their family. Both may need ongoing support.
- offer the person with dementia and their family written information about:³
 - signs and symptoms
 - course and prognosis
 - treatments
 - local care and support services
 - support groups
 - sources of financial and legal advice and advocacy
 - medico-legal issues, including driving
 - local information sources, including libraries and voluntary organisations.

Record any advice and information given in the notes.

Consider mentoring or supervising less experienced colleagues if you regularly diagnose dementia and discuss this with people with the condition and carers.

Appendix 3: Quality and Outcomes Framework guidance for GMS contract 2011/12

Dementia	Points	Payment stages
DEM 1. The practice can produce a register of patients diagnosed with dementia	5	
DEM 2. The percentage of patients diagnosed with dementia whose care has been reviewed in the preceding 15months	15	25 – 60%
DEM 3. The percentage of patients with a new diagnosis of dementia (from 1 4 2011) with a record of FBC, calcium , glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded 6months before or after entering on to the register	6	40 – 80%
Carers		
Management 9. The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment	3	
Quality and productivity		
QP 8. The practice engages with the development of and follows 3 agreed care pathways for improving the management of patients in the primary care setting (unless in individual cases they justify clinical reasons for not doing this) to avoid inappropriate outpatient referrals and produces a report of the action taken to the PCO no later than 31/3/2012.	11	
QP11. The practice engages with the development of and follows 3 agreed care pathways(unless in individual cases they justify clinical reasons for not doing this) in the management and treatment of patients in aiming to avoid emergency admissions and produces a report of the action taken to the PCO no later than 31 March 2012	27.5	

Appendix 4: Dementia Read Codes

It is recommended that general practices and memory services standardise Read coding for diagnoses of dementia.

Recommended QOF read codes

- **F110** Alzheimer's Disease
- **F111** Pick's Disease (front temporal dementia)
- **Eu01** Vascular dementia
- **Eu025** Lewy Body Dementia
- **Eu023** Dementia in Parkinson's disease
- **E00** Senile and pre senile organic psychotic conditions, and for advanced dementia (not being referred for memory assessment)
- **Eu01** 'Mixed Dementia'

Associated QOF read codes

Consider checking any patients with the following codes:

- **1B1A** Memory loss symptom
- **1B1A0** Temporary loss of memory
- **Eu057** Mild cognitive disorder

Appendix 5: References

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