



# Dementia in Primary Care:

Guidelines for Prevention, Early Identification & Management

**NHS**  
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**Clinical Commissioning Group**

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# GUIDELINES FOR THE PREVENTION, EARLY IDENTIFICATION & MANAGEMENT OF DEMENTIA FOR ALL NHS ORGANISATIONS IN NOTTINGHAM AND NOTTINGHAMSHIRE

Dementia is used to describe a syndrome which may be caused by a number of disorders in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as aggression, wandering, depression, and psychosis. Early diagnosis and intervention is valuable in excluding treatable causes, improving the quality of life for people with dementia and their families, and can also assist in planning for the future, thus delaying or preventing unnecessary admissions to care homes. In addition it may allow secondary prevention interventions.

## DEFINITIONS

### *Dementia*

Dementia is characterised by global cognitive impairment, which represents a decline from previous levels of functioning, and is associated with impairment in functional abilities and in many cases, behavioural and psychiatric disturbances.<sup>1</sup>

### *Mild cognitive impairment*

Mild cognitive impairment 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.<sup>1</sup>

### *Delirium (acute confusional state)*

Delirium is an organic psychiatric syndrome – a psychological or mental response to a 'physical' cause. It comprises of a transient, usually reversible state, with variable, fluctuating and wide ranging abnormalities in attention, alertness, cognition, perception, sleep-wake cycle, agitation or psychomotor retardation.<sup>1</sup>

## PREVALENCE

Dementia can occur at any age but is more common in older people. It affects 1 in 20 over the age 65 and 1 in 5 over the age of 85.<sup>1</sup> The estimated numbers of people (of all ages) with dementia is 2749 in NHS Nottingham City, 8411 in NHS Nottinghamshire County CCGs and 1372 in NHS Bassetlaw.<sup>2</sup> By 2021, the number of people with dementia is predicted to increase by 5.4% in Nottingham City CCG, 29% in Nottinghamshire County CCGs and 35% in Bassetlaw CCG.<sup>2</sup> People with learning disabilities are at increased risk of early onset dementia and the prevalence is higher amongst older adults with learning disabilities compared to the general population. The prevalence of dementia in people with Down's syndrome is estimated at 8.9% in those aged 45-49, 17.7% in those aged 50-54, 32.1% in those aged 55-59 and 25.6% in those aged 60 and over.<sup>3</sup> Some studies suggest the prevalence of dementia in those with Down's syndrome rises rapidly after 60 years to between 50 and 75%.<sup>3</sup> Prevalence information from the dementia disease registers (QOF) when compared to the expected numbers suggests that dementia is currently under-diagnosed in primary care.

## OBJECTIVES

These guidelines are designed to assist those working in primary care in the prevention, early identification/diagnosis and management of people with dementia (including those with learning disabilities) by advising on:

- Risk factors and prevention.
- Investigations that can exclude treatable causes of cognitive impairment (e.g. hypothyroidism and B12 deficiency) and which will exclude conditions with similar symptoms (e.g. depression, delirium and psychotic symptoms, and concurrent physical illnesses) to support correct diagnosis.
- Referral routes for specialist assessment and diagnosis for all patients with suspected dementia.
- The role of the primary care team to provide support to patients with dementia and their carers.

- How to deal with the emotional and behavioural changes as the illness progresses.

## DEVELOPMENT

The guidelines were originally developed in 2005 by health services across Nottingham City and South and North Nottinghamshire and have been reviewed following publication of both the NICE guidance (2006)<sup>1</sup> and the National Dementia Strategy (2009).<sup>4</sup> A countywide working group was set up in 2010 to review the guidelines, consisting of health and social care partners, including secondary and primary care clinicians. This version has been updated in light of changes to prescribing guidelines for dementia drugs and anti-psychotics. A list of the main people consulted is given in Appendix 2.

## TYPES OF DEMENTIA

Recent post-mortem studies have shown that most cases of dementia (>80%) have the pathological changes of both Alzheimer's disease and vascular dementia.<sup>5</sup> Examples of 'pure' Alzheimer's disease and vascular dementia are relatively rare. In 10 to 15% of patients the cause will be dementia with Lewy bodies. Other causes are rare including other degenerative diseases (e.g. Huntington's), prion diseases (Creutzfeldt-Jakob disease), HIV dementia and several toxic and metabolic disorders (e.g. alcohol related dementia) and account for no more than 5% of cases. In young onset dementia frontotemporal dementia (Pick's disease) is common.

## SYMPTOMS (WHO ICD-10 DCR 1993)

	Early	Middle	Late
<b>Memory</b>	<ul style="list-style-type: none"> <li>▪ Sufficient to interfere with everyday activities but not to preclude independent living.</li> <li>▪ Problems mostly learning new material.</li> <li>▪ Difficulty taking in, retaining and recalling matters of everyday life, such as where things have been put, social arrangements or information from family.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Memory loss a serious handicap to everyday living.</li> <li>▪ Only very familiar material retained.</li> <li>▪ New information retained only occasionally or briefly.</li> <li>▪ Unable to recall basic information on local geography, recent activities and names of familiar people.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Complete inability to learn new information.</li> <li>▪ Only fragments of previously learned information remain.</li> <li>▪ Unable to recognise even close relatives.</li> </ul>
<b>Other cognitive functions: Judgement and thinking Planning and reasoning Processing of information</b>	<ul style="list-style-type: none"> <li>▪ Impaired performance in activities of daily living (ADL), but not to a degree that makes the individual dependent on others.</li> <li>▪ Complicated tasks cannot be undertaken.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Unable to function in ADL without the assistance of another.</li> <li>▪ Only simple chores can be performed.</li> <li>▪ Activities are restricted and poorly sustained.</li> </ul>	<ul style="list-style-type: none"> <li>▪ There is an absence (or virtual absence) of intelligible ideas.</li> </ul>

**Non-cognitive psychological symptoms** are common. These may include:

Agitation and restlessness  
Irritability  
Loss of motivation  
Emotional lability  
Depression  
Inappropriate social and sexual behaviour  
Aggression  
Suspiciousness and paranoia  
Hallucinations

### **Physical symptoms** (mostly in the later stages)

Dysphagia, Malnutrition, weight loss and dehydration  
Incontinence  
Poor balance and falls  
Decreased mobility  
Self neglect  
Primitive reflexes  
Seizures

### **RISK FACTORS**

Established **non-modifiable risk factors** for dementia in general and Alzheimer's disease in particular include advancing age, genotype, female gender, and having a learning disability. Those with Down's syndrome are at high risk of developing Alzheimer's disease, with an age of onset between 30 and 40 years, younger than the general population. Dementia also develops in between 30-70% of people with Parkinson's disease depending on duration and age.

Established **potentially modifiable risk factors** include hypertension, excessive alcohol consumption, diabetes, depression and head injury. Other potentially modifiable risk factors may include obesity, raised homocysteine levels and raised cholesterol levels. Vascular dementia risk factors are stroke, hypertension, diabetes and smoking.

### **PREVENTION**

Estimates suggest that delaying the onset of dementia by 5 years would half its prevalence.<sup>1</sup> The evidence for **protective factors/preventive strategies** for dementia remains inconsistent.<sup>6</sup> Prior long-term use of non-steroidal anti-inflammatory drugs, control of vascular risk factors, regular exercise and engagement in leisure and cognitively stimulating activities may be protective factors. Key prevention messages are<sup>7</sup>:

- Mind your brain – keep your brain active
- Mind your diet – eat healthily
- Mind your body – be physically active
- Mind your health checks – manage blood pressure, blood cholesterol, blood sugar and weight.
- Mind your social life – participate in social activities.
- Mind your habits – avoid tobacco smoke and only drink alcohol in moderation.
- Mind your head – protect your head from injury.

Statins, hormone replacement therapy, vitamin E and non-steroidal anti-inflammatory drugs are not recommended for the primary prevention of dementia.<sup>1</sup>

In people with dementia, risk factors (e.g. smoking, excessive alcohol consumption, obesity, diabetes, hypertension and raised cholesterol) should be reviewed and if appropriate, treated according to the relevant guidelines, for secondary prevention.

### **CASE FINDING**

General population screening for dementia is not recommended, however case finding is expected. Acute hospitals are expected to assess people aged over 75 admitted as an emergency, and then advise GPs of the outcome. GPs are expected to make those aged 65-74 aware of the signs and symptoms of dementia.

### **PRINCIPLES OF CARE<sup>1</sup>**

- **Person centred care**  
Care should demonstrate that the person with dementia is valued and respected, is individualised taking into account their retained abilities, biography, relationships, personality and preferences, problems should be seen from the point of view of the person with dementia, and relationships with family, professionals or others, should serve to provide comfort, identity, attachment, inclusion and occupation. People with dementia should have the opportunity to make informed decisions about their care and treatment in partnership with

their family, health and social care professionals. If a person does not have the capacity to make decisions the principles of the Mental Capacity Act need to be implemented.

- **Community based care**

People with dementia should be supported in the community as far as possible.

- **Diversity and equality**

People with dementia should not be excluded from services because of their diagnosis, age, communication difficulty or any learning disability. Services will comply with the Equality Act 2010.

- **Ethics and consent**

Valid consent should always be sought. This entails informing the person of options and checking that he or she understands, that there is no coercion and that he or she continues to consent over time. The Mental Capacity Act (2005) should be implemented if a person lacks capacity. While a person still has capacity discuss the use of:

- Advance statements.
- Advance decisions to refuse treatment.
- Lasting power of Attorney.
- A Preferred Place of Care Plan

Primary care staff should undertake Mental Capacity Act training to ensure that they are familiar with and confident to deal with the Act practically. More information about ethical issues and dementia are available at: [www.nuffieldbioethics.org/dementia](http://www.nuffieldbioethics.org/dementia)

The updated Dementia Clinical Guideline is available at:  
[NICE Dementia Quick Reference Guide revised March 2011](#)

## **RESPONSIBILITIES OF THE PRIMARY CARE TEAM**

- Raise awareness of dementia as part of NHS Health Checks for over 65s
- Review and treat risk factors for dementia in middle aged and older people.
- Watch for early symptoms of dementia in high risk groups - population screening is not recommended.
- Undertake appropriate investigations and assessments for those presenting with cognitive impairment.
- Prompt referral to suitable specialist assessment and diagnostic services when there are signs of cognitive impairment and impaired activities of daily living - **separate diagnostic services exist for people under the age of 65 and people with a learning disability** - see Note 2.
- Record all diagnoses of dementia on dementia register and provide an annual review for all these patients as per Quality Outcome Framework (QOF) guidance. Assess for any medical co-morbidities and key psychiatric features associated with dementia and identify and treat any risk factors for secondary prevention. For those with mild cognitive impairment offer follow up to monitor progression.
- Prescribe and review medication initiated by specialist, as set out in the Nottinghamshire Area Prescribing Guidelines. Review as appropriate to check for adverse drug reactions or possible interactions with any other drugs prescribed. Links are: [Memantine](#), [Donepezil Information Sheet](#), [Galantamine Information Sheet](#), [Rivastigamine Information Sheet](#)
- Monitor patients' overall health, welfare and compliance with treatment.
- Identify, manage or refer on episodes of delirium or other acute inter-current illness, and physical co-morbidities. Communicate the diagnosis of dementia to other service providers as needed and appropriate
- Refer those with early dementia to the Improving Access to Psychological therapy (IAPT) service for post diagnosis psychological adjustment if appropriate.
- Ensure that the carer has an assessment of needs and a care plan or refer for assessment to social care where appropriate. Refer carers with stress, anxiety and depression to the IAPT service (as above) as appropriate
- Ensure that information is available in an accessible form for those who require it.

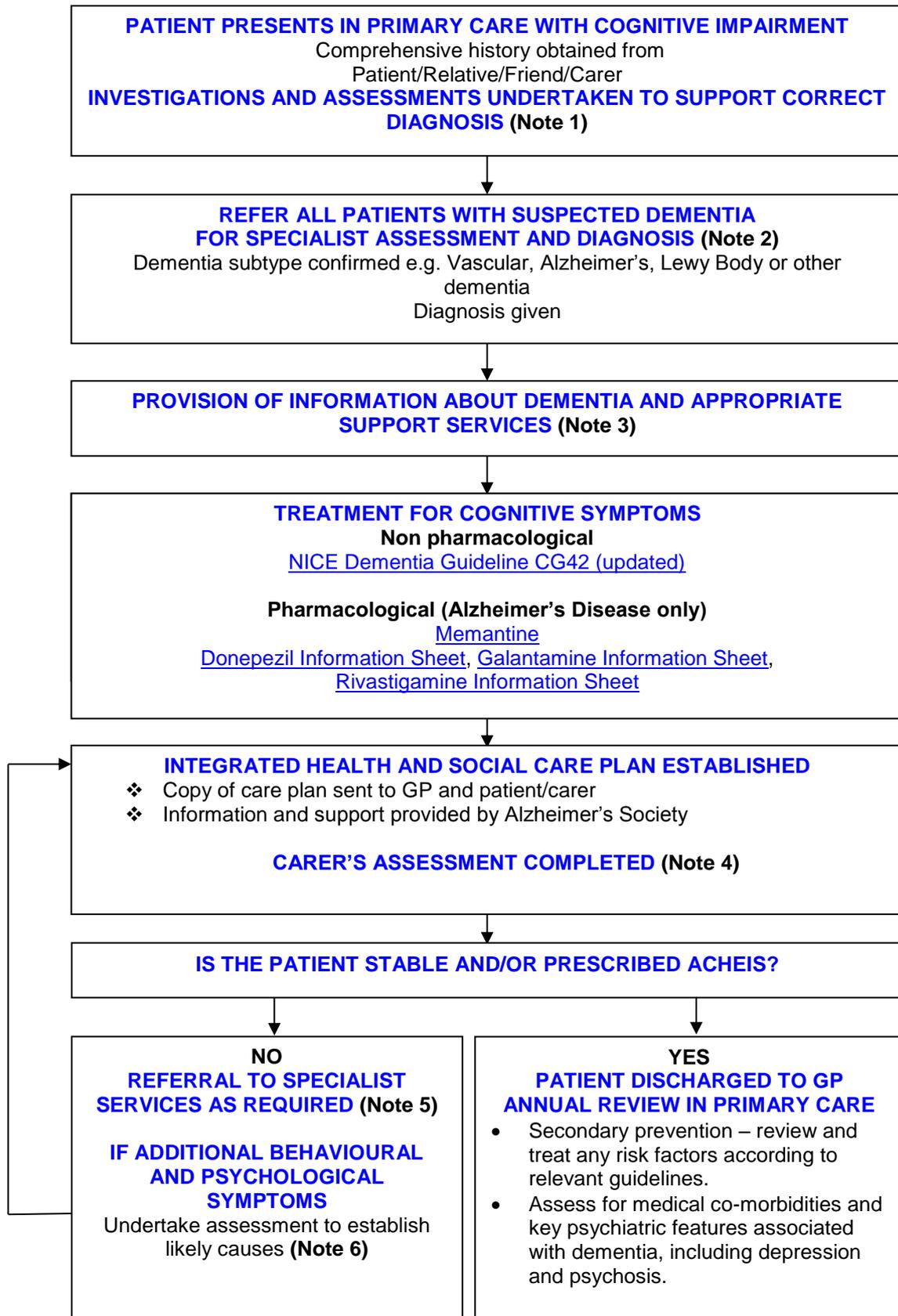
- Review patient annually in line with QOF to include cognitive, global, functional and behavioural assessment and medicines review
- Provide practical and emotional support and co-ordinate support services for patients and families/carers.
- Provide information to patients and families/carers about access to medical and social support and financial and legal (mental capacity) advice.
- Refer back to specialist older people's mental health services if changes or progress are cause for concern, or if advice is needed to discontinue acetylcholinesterase inhibitors
- Respond to requests for information from other agencies e.g. Social Services, but respecting patient confidentiality as appropriate.
- Promote and maintain the independence of people with dementia.
- Follow Guidelines for BPSD
- Provide advice on driving (in liaison with DVLA and the driving assessment centre).
- Assess the palliative care needs from diagnosis until death to enable an individual to die with dignity and in the place of their choosing. More information can be found in the [Nottinghamshire End of Life Care Pathway](#)

### **RESPONSIBILITIES OF SPECIALIST OLDER PEOPLE'S MENTAL HEALTH SERVICES**

- Provide a single point of referral for people with a possible dementia and 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.
- Prompt assessment and diagnosis, including type of dementia (within 12 weeks of referral) of all patients referred by GPs.
- Assess functional performance to assist in the formulation of diagnosis and provision of intervention to maintain skills, roles and quality of life.
- Refer for CT/MRI scan according to clinical judgement
- Counsel the patient/family/carer about the likely progress of the disease/treatment; provision of information in an accessible form for those who require it. Develop appropriate management plans alongside patient and carers, including communication management and changes to the environment.
- Identify those suitable for treatment with an acetylcholinesterase inhibitor. Recommend the initiation of treatment and dose titration to maintenance dose under the agreed shared care protocol. Monitor patients during this phase to check for side-effects, any dosage adjustment required and compliance. Advise on any other symptomatic treatment/therapy that may be necessary.
- Provide information to patients and their families/carers on appropriate support services.
- Carers should be given information and support on how to access a Carer's Assessment
- Refer carers with stress, anxiety and depression to the IAPT service as appropriate.
- Discharge stable patients back to GP with letter to patient/carer clearly stating that ongoing care will be from the GP
- Support the GP in the continued management of the patient.
- Liaise with GP, Social Services and other relevant services for long term care as appropriate.
- Provide advice on driving (in liaison with DVLA and the driving assessment centre).
- Provide information about advance care planning.
- Provide training and support to Primary Care.
- Receive referrals back for stopping dementia medicines where requested.

## OVERVIEW: INVESTIGATION, DIAGNOSIS AND MANAGEMENT

A diagnosis of dementia should be made only after a comprehensive assessment.



A palliative care approach from diagnosis until death should be taken to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing.

## **NOTE (1) Investigations and assessments undertaken to support correct diagnosis**

## **NOTE 1**

The following investigations and assessments need to be completed in primary care before referring a patient to specialist older people's mental health services for assessment and diagnosis.

### **1. History taking & review of medication**

A detailed history from the person and, as the person may not be able to give a fully accurate history, a history from a relative or someone who knows the person well should be obtained. This should include the history of the presenting complaint, past medical and psychiatric history, medication use, drug or alcohol history, family medical and psychiatric history, a history of changes in personality or behaviour and assessment of changes in abilities to undertake everyday tasks.

Many conditions apart from dementia can present with cognitive impairment:

- delirium (acute confusional state)
- depression
- side effects of medication
- other psychiatric illnesses
- substance misuse
- medical conditions e.g. hypothyroidism, intracerebral infections or bleeds or tumour

The most important differential diagnoses are **depression** and **delirium**, both of which are treatable. Either or both may coexist with dementia.

#### **Depression**

Between 15 and 20% of people over 65 years have significant depressive illness, and depression commonly coexists with dementia. Primary care guidelines are being updated and will be reissued to include access to psychological therapies.

#### **Delirium**

The development of delirium (acute confusional state) characteristically takes place over hours or days, and is usually accompanied by signs of physical ill health such as infection or drug toxicity.

- The course generally fluctuates and is worse at night with lucid spells occurring during the day.
- The level of alertness fluctuates and the person is often disoriented for time and place, though not often for person.
- Short-term memory is always impaired, but this is a function of the confusion and lack of attention and usually resolves fully.
- The person is usually fearful, irritable and may be aggressive: paranoid ideas and visual and auditory hallucinations are common.

Look for signs of chest infection, urinary tract infection and hypoxia, and always check medication taken. Usually symptoms resolve with treatment of underlying cause.

## Clinical features of Dementia, Delirium and Depression

	<b>Dementia</b>	<b>Delirium</b>	<b>Depression</b>
<b>Onset</b>	Insidious	Acute	Gradual
<b>Duration</b>	Months/years	Hours/days/weeks	Weeks/months
<b>Course</b>	Progressive, maybe stepwise	Fluctuates: worse at night Lucid periods	Usually worse in mornings improves as day goes on
<b>Alertness</b>	Usually normal	Impaired, may fluctuate	Normal
<b>Orientation</b>	May be normal: usually impaired	Usually impaired	Usually normal
<b>Memory</b>	Impaired recent, and sometimes, remote memory	Recent memory impaired	May be problems in concentration, short term memory and attention Remote memory intact
<b>Thoughts</b>	Slowed reduced interests, perseveration (repetition) Delusional ideas, often paranoid in up to 60%	Often paranoid and grandiose Bizarre ideas and topics	Usually slowed Preoccupied by sad and hopeless thoughts
<b>Perception</b>	Hallucinations in 30-40% (often visual)	Visual and auditory hallucinations common	Mood congruent auditory hallucinations in 20%
<b>Emotions</b>	Depression, anxiety (40%) apathetic, labile, Often agitation in afternoons (sun downing)	Anxiety / depression common	Flat, unresponsive or sad and fearful May be irritable
<b>Sleep</b>	Often disturbed, nocturnal restlessness and confusion	Nocturnal confusion	Early morning waking
<b>Other features</b>		Physical disease may not be obvious	History of mood disorder Diurnal variation

### Medication review

Always undertake a medication review to identify if any could be causing memory impairment.

#### Common adverse effects of drugs

##### By drug

- *Antipsychotics* – drowsiness, extrapyramidal effects (even atypicals), falls, impotence, galactorrhoea.
- *Benzodiazepines* – drowsiness, falls, cognitive slowing or impairment, withdrawal effects.
- *Antimuscarinic* – delirium, dry mouth, urinary retention, blurred vision, dyspepsia, constipation
- *Tricyclic antidepressants* – antimuscarinic, drowsiness, falls.
- *Diuretics* – lower urinary tract symptoms, dehydration, hyponatraemia, hypokalaemia, hyperglycaemia, gout
- *Antihypertensives, antianginals, anti-arrhythmics* – hypotension (especially postural), heart failure.
- *Lithium* – polyuria, tremor.
- *Antiepileptic drugs* – drowsiness, cognitive slowing or impairment, ataxia.

##### By adverse effect

- *Delirium* – antimuscarinic (including tricyclic antidepressant, antiparkinsonian, surgical premedication, bladder instability drugs, disopyramide), opiates
- *Diarrhoea* – laxatives, antibiotics, metformin, proton pump inhibitors, NSAIDs.
- *Hypotension* – diuretics, all other cardiovascular drugs except digoxin, levodopa, antipsychotics

## Learning disabilities

As people with a learning disability are more at risk of developing dementia it is important to look for signs of dementia. This should be considered when patients with learning disability (and carers where appropriate) attend their annual health check under the Directed Enhanced Service. The following is a guide to the clinical stages of those with dementia (modified from the Frith Prescribing Guidelines, 2008).<sup>8</sup>

Stage	Main features
Early	Disorientation Memory impairment Deterioration of activities of daily living
Mild	Progressive loss of verbal and motor skills Significant deterioration in the level of functioning Changes in personality: loss of usual affectionate responses to others Tendency to be hyperkinetic or impulsive withdrawal automatic speech Emergence of psychiatric symptoms: hallucinations, delusions, mood changes, aggression
Late	Bladder/bowel incontinence Mutism Gait disturbance with frequent falls Myoclonus Seizures.

## 2. Cognitive and mental state examination

### *Clinical Cognitive Assessment*

In those with suspected dementia, clinical cognitive assessment should include examination of attention and concentration, orientation, short and long-term memory, praxis and language. It is recommended to use the 6 Item Cognitive Impairment Test (6CIT)

<http://www.patient.co.uk/doctor/six-item-cognitive-impairment-test-6cit> (Appendix 1) a validated tool. Free usage is allowed for healthcare professionals and the following Read codes are available for use in GP clinical systems:

EMIS, Synergy, Premiere, Vision 3AD3. - Six item Cognitive Impairment Test,  
TPP SystemOne – CTV3 code XaJLG – Six item Cognitive Impairment Test

Other standardised validated tests (as recommended by NICE) include:

- Mini Mental State Examination (MMSE) - this is copyrighted. Tests can be purchased from Psychological Assessment Resources.
- General Practitioner Assessment of Cognition (GPCOG)

These tests are unlikely to be useful for a person with learning disability and therefore it is recommended to refer for specialist assessment if the diagnosis of dementia is suspected.

When interpreting the scores it is important to take into account other factors that may affect performance such as educational level, skills prior to level of functioning and attainment, language, sensory impairment, psychiatric illness and physical and neurological problems. Cognitive tests underestimate the abilities of older people in black and minority ethnic groups and so can give rise to a higher risk of mistaken diagnosis of dementia. Reasons include lack of familiarity with English, lack of literacy in own first language and culture specific factors related to individual test items. The MMSE has been developed in Hindi, Punjabi, Urdu, Bengali and Gujarati and in English for use in the African-Caribbean group. Practices will need to consider if an interpreter is required to undertake a cognitive assessment. 'Culture free' tests have been developed that are less dependent on language, literacy and other skills developed during formal education, however they require further evaluation to ascertain effectiveness.<sup>9</sup>

### 3. **Physical examination and other appropriate investigations**

A physical examination (including basic neurological and cardiovascular examinations) can detect evidence of physical disorders that can cause cognitive impairment, as well as other features that are important in making an accurate diagnosis.

Approximately 5-10% of people provisionally diagnosed as having dementia will have a potentially treatable cause, for example:

- Depressive pseudo dementia
- Delirium (acute confusional state)
- Hypothyroidism
- Normal pressure hydrocephalus
- Vitamin B12 deficiency
- Vitamin B6 (thiamine) deficiency
- Tumour

The following tests may be appropriate:

- Routine haematology - FBC, ESR
- Biochemistry tests (electrolytes, calcium, glucose, renal and liver function) according to local protocols.
- Thyroid function tests
- Serum vitamin B12 and folate levels
- Consider chest x-ray and MSU only if indicated
- For patients with existing or suspected cardiac disease or bradycardia (including those with cardiac arrhythmias or valve problems, and patients with hypertension who are being treated with antihypertensives that have a rate-limiting effect e.g. beta-blockers), an ECG should be carried out by the GP, as part of the baseline investigations prior to referral. Other patients should be referred with the GP confirming the absence of these conditions.

Do not routinely test for syphilis serology or HIV unless there are risk factors or the clinical picture dictates.

**NOTE (2) Referral for specialist dementia assessment and diagnosis**

All patients with suspected dementia should be referred for specialist assessment and diagnosis. The information required to process referrals for specialist services without delay is:

**Basic data**

- Full name of client
- Address and post code
- Telephone number including mobile
- Date of Birth/Gender
- Marital status
- Employment status /occupation
- Ethnic origin /religion
- Language spoken – is there a need for an interpreter.

**Nottingham City CCG** – GPs should refer people via the Single Point of Access (SPA), based at Highbury Hospital. Patients will then be allocated to the appropriate Mental Health Services for Older People (MHSOP) team within the city (City North West or City South). Referral is by letter, fax or Choose and Book (for Choose and Book phone with UBRN number first – Tel: 0300 300 0010).

**Nottinghamshire County CCGs** – GP's can refer by letter, fax or by Choose and Book to the Community Mental health team where they will be allocated to the appropriate Mental Health team/clinic.

**Bassetlaw CCG** – GP's can refer by letter or fax (Choose and Book not available) to the Community Mental health team where they will be allocated to the appropriate Mental Health team/clinic.

The **Working Age Dementia service (WAD)** is a whole county wide service for people below the age of 65 with suspected or confirmed diagnosis of dementia. GP's can refer by letter, fax or Choose and Book.

The **Learning Disability Specialist Health Service**. A care pathway for people with learning disability and dementia has been developed specifically for learning disability specialists. Referrals are accepted either directly from GPs to the consultant (who then discusses the case at the Community Learning Disability Team referral meeting) or via the Choose and Book system.

**The tables in Note 5 provide countywide information about:**

- **Specialist dementia assessment and diagnosis services**
- **Learning disability services for assessment and diagnosis of dementia**

### (Note 3) Provision of information about dementia and appropriate support services

#### 1. Dementia Support Service (DASS)

Following diagnosis, the Memory Assessment Service will direct patients and their carers to the Dementia Support Service provided by the Alzheimer's Society. A support worker will be available at memory clinics and will provide appropriate information after diagnosis about:

- Signs and symptoms of dementia
- Course and prognosis of the condition
- Treatments
- Local care and support services
- Support groups including local Dementia Cafes
- Sources of financial and legal advice, and advocacy
- Medico-legal issues, including driving
- Local information sources, including libraries and voluntary organisations

Where individuals do not want immediate help from the Alzheimer's Society, the service will follow up with a phone call in 3-6 months' time.

#### 2. Other national & local support services

To support primary care the following national and local services and information sources provide information about dementia for patients and their families.

##### National support services

- Age UK Information & Advice Helpline Tel: 0800 169 6565
- Alzheimer's Society – national helpline that can provide information, support, guidance and referrals to other appropriate organisations. Open 9.00am to 5.00pm Monday to Friday, 10.00am to 4.00pm Saturday & Sunday – Tel: 0300 222 1122.
- Down's Syndrome Association Tel: 0333 121 2300

##### Local support services

###### Nottingham City/Conurbation

- Alzheimer's Society - Castle Heights, 72, Maid Marion Way, Nottingham, NG1 6BJ, Tel: 0115 934 3800
- Age UK Nottingham & Nottinghamshire, 12 Shakespeare Street, Nottingham, NG1 4FQ, Tel: 0115 8440011
- The Carers Federation Tel: 0115 9858485
- Mabon House, Meadows Way, The Meadows, Nottingham. NG2 3DZ Tel: 0115 9867120. A working age dementia (WAD) day care service for 6 people per day. Open Wednesdays and Thursdays.

###### Nottingham City Council, Adult Support and Health

- Referrals for social care services for Nottingham City residents should be made through the Adult Contact Centre on Tel: 0115 8838460, Fax: 0115 883855. (Open Mon – Thurs 8.30-5.00, Fridays 8.30-4.30). The Adult Contact Centre gives information and access guidance about social care and occupational therapy services, assessments and care management, specialist council-run dementia residential care, homecare and reablement, Jackdawe specialist dementia homecare, mental health intermediate care, carer respite, self-directed care, Telecare, home adaptations, meals at home, extracare and housing support options. [www.nottinghamcity.gov.uk](http://www.nottinghamcity.gov.uk)

## Nottinghamshire County

- Information Prescriptions contain a series of links or signposts to guide people to sources of information. It lets people know where to get advice, where to get support and where to network with others with a similar condition. Information prescriptions can be received by either accessing the information prescription website [www.nottsinfoscript.co.uk](http://www.nottsinfoscript.co.uk) or by having the information emailed or posted out to the patient or a carer.
- Alzheimer's Society - 1st Floor, Friary Chambers, 26-34 Friar Lane, Nottingham, NG1 6DQ, Tel: 0115 934 3800
- Carer Co-ordinator Team, Birch House, Southwell Road West, Mansfield, NG21 0HJ Tel: 0800 028 3693
- MIND Day Care Services: Central Nottinghamshire MIND, Concord House, 14 St John Street, Mansfield NG18 1QJ. Tel: 01623 658044. Fax: 01623 658044
- Carers Federation: Christopher Cargill House, 21-23 Pelham Road, Nottingham, NG5 1AP. Telephone: 01159 629 310, Fax: 01159 629 338
- Age UK: Bradbury House, 12 Shakespeare Street, Nottingham, NG1 4FQ. Telephone: 0115 844 0011 & 07872 839575

## Bassetlaw

- Information Prescriptions contain a series of links or signposts to guide people to sources of information. It lets people know where to get advice, where to get support and where to network with others with a similar condition. Information prescriptions can be received by either accessing the information prescription website [www.nottsinfoscript.co.uk](http://www.nottsinfoscript.co.uk) or by having the information emailed or posted out to the patient or a carer.
- Alzheimer's Society, Bassetlaw Community and Voluntary Service, The Centre, Northumberland Ave., Costhorpe, Worksop, S81 9JP, 01909 730886
- Dementia Café held 10.30 -12.30 every second Wednesday, monthly at Hallcroft Community Centre, Randall Way, Retford.
- Dementia Support Worker – Tel: 01909 730886

## Nottinghamshire County Council, Adult Social Care and Health Department (ASCH)

- Referrals for social care services for people living in Nottinghamshire County (including Bassetlaw) should be made through the Customer Service Centre (CSC) on Tel: 0300 500 8080. The CSC is open 8am-8pm Monday – Friday, 8am – 12pm Saturday. The CSC can provide information, advice and guidance on the range of services available through ASCH including: assessment and care management, occupational therapy services, welfare rights, carers services, home care, intermediate care, respite care, day care, direct payments, aids and adaptations, assistive technology, Telecare, extra care housing, residential and nursing care, self directed support services and individual budgets. [www.nottinghamshire.gov.uk](http://www.nottinghamshire.gov.uk)

## Useful Websites:

- [www.ageuk.org.uk](http://www.ageuk.org.uk) - Age UK (national website)
- [www.ageuk.org.uk/notts/](http://www.ageuk.org.uk/notts/) - Nottingham and Nottinghamshire website
- [www.alzheimers.org.uk](http://www.alzheimers.org.uk) – The Alzheimer's Society
- [www.carersfederation.co.uk](http://www.carersfederation.co.uk) - The Carers Federation
- <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy> Department of Health, National Dementia Strategy.
- [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk) – The Down's syndrome Association
- [www.easyhealth.org.uk](http://www.easyhealth.org.uk) - The Easy Health website provides accessible easy to understand information, particularly useful for people with learning disabilities.
- [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk) Royal College of Psychiatrists website which produces fact sheets.
- [www.scie.org.uk/publications/dementia](http://www.scie.org.uk/publications/dementia) - Dementia pathway: A website hosting a range of dementia resources to support those with dementia, their carers and those working in dementia services. It features practical tips and tools, including two free e-learning resources and includes coverage of key topics such as symptoms, types of dementia, myths about dementia, activity and nutrition.

**(Note 4) Carer assessments**

Carer assessments are a local authority duty and set out in the Carer's and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004. They should seek to identify any psychological distress and the psychosocial impact on the carer. Consideration should also be given to the needs of children under the age of 18 who are acting as carers with referral to appropriate services to meet their needs.

**Interventions**

Care plans for carers should include tailored interventions, such as:

- Access to Psychological Therapies (IAPT)
- Peer-support groups tailored to the needs of the individual.
- Telephone and internet information and support.
- Training courses about dementia, services and benefits, and dementia care problem solving.
- Management of communication difficulties.

Support (such as transport and short break services) may need to be provided to enable carer participation in interventions.

**Practical support**

Health and social care need to ensure that carers of people with dementia have access to a range of respite or short break services. These should meet the needs of both the carer (in terms of location, flexibility and timeliness) and the person with dementia and should include, for example, day care, day and night sitting, adult placement and short-term and/or overnight residential care, emergency and flexible respite, direct payments.

For more information contact:

**Nottinghamshire County Council** - Customer Service Centre (CSC) on 0300 500 8080

**Nottingham City Council** – Adult Contact Centre 0115 8838460

Contact details and website addresses on page 15 may also be useful.

**(NOTE 5) - Specialist Older People's Mental Health teams that support patients with dementia and their carers' in the community**

**Memory Assessment Services** The key components of the memory assessment service will include access to a high-quality service for the assessment, diagnosis and management of dementia. The service will establish collaboration between primary and specialist services in providing long term management of people with dementia. Memory assessment services will be delivered by specialist older people's mental health clinicians, ensuring high standards of care, quality and outcomes for patients. Ongoing support for dementia patients and carers will, wherever possible, be provided by the patient's GP through effective partnerships and utilisation of the revised shared care agreement for anti-dementia drugs.

**Community Mental Health Teams (CMHT) for Older People** provide community based assessment and treatment for people with mental health problems and for people with dementia who have additional behavioural and psychological symptoms or more complex needs. Each team has a multi-disciplinary mix of staff including psychiatric nurses, occupational therapists, consultant psychiatrists, social workers, physiotherapists, cognitive behavioural psychotherapists and psychologists. The teams are able to offer a comprehensive service to people in their own homes and act as gate keepers to other services which assist people to maximise their quality of life in the community.

**Working Age Dementia (WAD) Service** is a diagnostic service that aims to maintain individuals in the community with community based services as its focal point. Service users will be referred to the Mental Health Services for Older People (MHSOP) community team working in the area they live, where they will be able to access specialist community nurses and occupational therapists for ongoing assessment, treatment and support and access the support services. The service also signposts people to other services that are available to them.

**Dementia Outreach Teams** provide mental healthcare support to people with dementia in dementia registered residential/nursing homes. The service works in partnership with care home staff to develop their knowledge, skills and confidence in dementia care. The specialist workers in the County team will be based alongside the other members of the CMHT for older people and referrals should be directed to the relevant CMHT

**Mental Health Intermediate Care Services (County and Bassetlaw CCGs)** provide specific support for older people with mental health problems and people of any age with dementia. The City service offers assessment and rehabilitation either residentially or through the 'At Home' service. These services work to avoid unnecessary admissions to and support timely discharges from hospital and avoid inappropriate or premature admissions to long term care.

**Learning Disability Services** provide specialist health services for people with learning disabilities that are focussed on those for whom mainstream provision cannot meet their needs. Services are delivered by a range of approaches, including uni-professional, multi-professional and multi-agency approaches, depending on the needs of individual service users and the service offered. A care pathway for people with learning disability and dementia has been developed specifically for learning disability specialists.

The tables on page 18 provide information about specialist older people's mental health services available across the whole county that primary care can use to refer patients for additional support.

**Memory Assessment Services in Nottingham City, Nottinghamshire County and Bassetlaw**

	<b>BASSETLAW</b>	<b>NOTTINGHAM WEST (BROXTOWE)</b>	<b>CITY NORTH and SOUTH</b>	<b>CITY WORKING AGE DEMENTIA</b>	<b>NOTTINGHAM NORTH &amp; EAST (GEDLING)</b>	<b>MANSFIELD &amp; ASHFIELD</b>	<b>NEWARK and SHERWOOD</b>	<b>RUSHCLIFFE</b>	<b>COUNTY WORKING AGE DEMENTIA</b>
<b>Address</b>	Bassetlaw District General Hospital Blyth Road Kilton Worksop Notts S81 0BD	Sheila Gibson Unit Stapleford Care Centre, Church Street Stapleford Notts NG9 8DB	St Francis Unit City Hospital Hucknall Rd Nottingham NG5 1PB	St Francis Unit City Hospital Hucknall Rd Nottingham NG5 1PB	St Francis Unit City Hospital Hucknall Rd Nottingham NG5 1PB	Heather House 72 Portland Street Kirkby-in-Ashfield Notts NG17 7AG	Byron House Newark District General Hospital Newark Notts NG24 4DE	Lings Bar Hospital Beckside Gamston Nottingham NG2 6PR	Barchester Unit, Outreach Office, Forest Hospital Southwell Road Notts NG18 4HH
<b>Telephone Number</b>	01909 502408	0115 9560813	SPA - 0300 300 0010	SPA - 0300 300 0010	0115 969 1169 ext 56551	01623 403278	01636 685 954	0115 8837417	01623 415707
<b>Fax Number</b>	01909 502006	0115 9391172	N/A	N/A	0115 8402644	01623 752923	01636 685919	0115 8837478	01623 415713
<b>Method of Referral</b>	Fax Letter	Fax Letter Choose & Book	SPA/Choose & Book	SPA/Choose & Book	Fax Letter Choose & Book	Fax Letter Choose & Book	Fax Letter Choose & Book	Fax Letter Choose & Book	Fax Letter Choose & Book

**Learning Disability Services for Assessment and Diagnosis of Dementia in Nottingham City, Nottinghamshire County and Bassetlaw**

	<b>ASHFIELD</b>	<b>BASSETLAW</b>	<b>CITY NORTH (Bilborough and Bulwell) BROXTOWE</b>	<b>CITY NORTH (except Bulwell and Bilborough) RUSHCLIFFE</b>	<b>CITY SOUTH (Radford and Park, Arboretum, St Anns)</b>	<b>CITY SOUTH (all remaining) GEDLING</b>	<b>MANSFIELD</b>	<b>NEWARK and SHERWOOD</b>
<b>Address</b>	Dr Singh Portland Street Kirkby in Ashfield Notts NG17 7AG	Dr Habib Zaki Bassetlaw Community Learning Disability Team Worksop Library Memorial Avenue Worksop Nottinghamshire S80 2BP	Dr Deval Bagalkote Highbury Hospital Highbury Vale Bulwell Nottingham	Dr Peter Cutajar Highbury Hospital Highbury Vale Bulwell Nottingham NG6 9DR	Dr Habib Zaki Highbury Hospital Highbury Vale Bulwell Nottingham NG6 9DR	Dr Richard Welfare Highbury Hospital Highbury Vale Bulwell Nottingham NG6 9DR	Dr Barbara Houghton Chadburn House Weighbridge Road Mansfield Notts NG18 1AH	Dr N Singh Byron House Newark Hospital Boundary Road Newark Notts NG24 4DE
<b>Telephone Number</b>	01623 785484	Mon, Tue, Thur 01909 535363 Direct Line 01909 535388 07774 880253	0115 8542281	0115 8542282	Wed and Fri (AM) 0115 8542281	0115 8542280	01623 436627	Mon, Wed & ½ day Fri  01636 685968

## NOTE (6) – Non-cognitive (psychological) symptoms and behaviour that challenges

Non-cognitive symptoms of dementia include hallucinations, delusions, depression, anxiety, marked agitation and associated aggressive behaviour. Behaviour that challenges may include aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting. People with dementia, including those with learning disabilities, who develop non-cognitive symptoms that cause significant distress or who develop behaviour that challenges should be offered an assessment at an early opportunity to establish likely causes and factors that may generate, aggravate or improve such behaviour. The assessment should be comprehensive and include:

- Physical health
- Depression
- Possible undetected pain or discomfort
- Side effects of medication
- Individual biography, including religious beliefs and spiritual and cultural identity
- Psychosocial factors
- Physical environmental factors
- Behavioural and functional analysis in conjunction with carers and care workers.

Individually tailored care plans that address the challenging behaviour should be developed and reviewed regularly.

### *Non-pharmacological interventions*

Wherever possible, simple measures based on the principles of person-centred care should be attempted before prescribing psychotropic medication. Sometimes it is possible for members of the primary care team to identify what is causing the problem behaviour and suggest ways of lessening its impact; often it will be necessary to re-refer to the specialist older people's mental health team for assessment and management.

### *Pharmacological treatment*

Prescribing of antipsychotic medication to manage psychotic and behavioural symptoms associated with dementia is the subject of a Department of Health initiative to reduce its use since it is associated with serious adverse effects. Please refer to updated Clinical Guidelines 'Managing Behaviour and Psychological Problems in Patients with Diagnosed or Suspected Dementia'. [Managing Behavioural Problems in People with Dementia](#)

For those people with dementia already receiving antipsychotic medication, GPs should discuss with the specialist older people's mental health team how to address dose minimisation and cessation.<sup>10</sup>

## **Interventions for co-morbid emotional disorders**

### *Non-pharmacological interventions for depression and /or anxiety*

Cognitive behavioural therapy, which may involve the active participation of carers, should be considered for people with dementia who have depression and/or anxiety. In addition a range of tailored interventions such as reminiscence therapy, multi-sensory stimulation, animal assisted therapy, and exercise may be beneficial.

### *Pharmacological interventions*

Medication may be offered as below:

- Specialist staff should start treatment after risk-benefit analysis.
- Treatment should follow NICE guidance on depression.
- Drugs with anti-cholinergic effects should be avoided because they may adversely affect cognition e.g. procyclidine, tricyclic antidepressants
- The need for adherence, time to onset of action and risk of withdrawal effects should be explained to the patient and carers.

**Try to perform the test in a quiet place with no obvious clock or calendar visible to the patient**

**THE 6 ITEM COGNITIVE IMPAIRMENT TEST**

What year is it?	0	Correct	4	Incorrect		
What month is it?	0	Correct	3	Incorrect		
Remember the following address: John/Brown/42/West Street/Bedford						
What time is it? (Within 60 minutes)	0	Correct	3	Incorrect		
Count backwards from 20 to 1	0	Correct	2	1 error	4	>1 error
Months of the year backwards	0	Correct	2	1 error	4	>1 error
Repeat memory phrase	0	Correct	2	1 error	4	2 errors
	6	3 errors	8	4 errors	10	All incorrect

**Interpreting results**

0-7 not significant

8-9 probably significant – referral advised

10-28 significant = refer

6CIT at a cut off of 7/8: Sensitivity 78.57%, Specificity 100%

This is the Kingshill Version 2000© of the 6CIT

## Nottingham City, Nottinghamshire County and Bassetlaw Dementia Guideline Consultation 2013

Name	Title	Organisation
Coral Osborn	Senior Prescribing and Governance Adviser	NHS Nottinghamshire County CCGs
Sangeeta Bassi	Lead Pharmacist – Mental Health & Learning Disabilities	Sherwood Forest Hospitals NHS Trust
Jane Cashmore	Commissioning Manager Older People	Adult Social Care, Health Department & Public Protection, Nottinghamshire County Council
Mary Corcoran	Consultant in Public Health	Nottinghamshire County Council
Ola Junaid	Consultant/Clinical Director, Mental Health Service Older People	Nottinghamshire Healthcare NHS Trust
Hilary Lovelock	Mental Health Lead GP, Mansfield & Ashfield (Dementia lead)	Mansfield & Ashfield CCG
Barbara Houghton	Consultant Psychiatrist, Mansfield Community Learning Disability Team (CLDT)	Nottinghamshire Healthcare NHS Trust
John Lawton	Clinical Pharmacy Services Manager (Nottingham)	Nottinghamshire Healthcare NHS Trust
Peter Morley	Commissioning Officer: Older People	Adult Support & Health Department, Nottingham City Council
Marcus Bicknell	GP, Beechdale Medical Practice and GP Executive member	NHS Nottingham City CCG
Gill Oliver	Senior Public Health Manager	Nottinghamshire County Council
Anandamandiram Ramakrishnan	Consultant Old Age Psychiatrist	Nottinghamshire Healthcare NHS Trust
Kazia Foster	Service Development Manager - Partnerships	NHS Bassetlaw CCG
Therese Jordan	GP, NHS Bassetlaw	NHS Bassetlaw CCG
Kehinde Junaid	Consultant Old Age Psychiatrist	Nottinghamshire Healthcare NHS Trust
Aimee Baugh	Joint Commissioning Manager Adult Services	NHS Nottingham City CCG
Professor Rowan Harwood	Consultant Geriatrician	Nottingham University Hospitals NHS Trust

## References

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- <sup>2</sup> Dementia QOF register accessed by PH Info November 2012
- <sup>3</sup> Janicki M & Dalton A (2000) Prevalence of dementia and impact of intellectual disability services. *Ment Retard* 38: 276 – 88.
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- <sup>5</sup> Neuropathology Group Medical Research Council Cognitive Function and Aging Study (2001) Pathological correlates of late-onset dementia in a multicentre, community-based population in England and Wales. *Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). Lancet*, Jan 2001, vol./is. 357/9251(169-75), 0140-6736;0140-6736 (2001 Jan 20)
- <sup>6</sup> Coley N et al (2008) Dementia Prevention: methodological Explanations for Inconsistent Results. *Epidemiologic Reviews* 30 (1) 35-66  
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- <sup>8</sup> The Frith Prescribing Guidelines for adults with Intellectual Disability. (2008) Edited by Bhaumick S & Brandford D
- <sup>9</sup> Parker C & Philp I (2004) Screening for cognitive impairment among older people in black and ethnic minority groups. *Age and Aging* 33: 447-452.
- <sup>10</sup> Department of Health (2009) The use of antipsychotic medication for people with dementia: Time for Action. A report for the Minister of State for Care Services by Professor Sube Banerjee