



Department  
of Health



# **Dementia Revealed**

## **What Primary Care Needs to Know**

### **A Primer for General Practice**

Prepared in partnership by NHS England and Hardwick CCG with the support of the Department of Health and the Royal College of General Practitioners



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General Practitioners

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What Primary Care Needs to Know  
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## CONTENTS

Introduction to the first edition .....	5
Introduction to the second edition .....	6
What can people with dementia and their carers expect? .....	8
Prevention of dementia .....	8
What is 'normal'? .....	8
The syndrome of dementia.....	9
Identification and diagnosis of dementia .....	9
Types of dementia.....	11
Assessing cognition.....	13
Activities of daily living (ADLS) .....	15
ECGs and brain scans .....	16
Who to refer .....	17
What happens in a memory clinic? .....	17
Drugs used for Alzheimer's disease.....	18
Other treatments for dementia .....	19
Treatment – when to start, what to expect, how to monitor, when to stop?.....	20
Behavioural and psychological symptoms of dementia.....	21
Delirium, dementia and anticholinergics.....	25
Dementia and alcohol.....	26
Cognition and driving.....	27
Falls.....	28
Carers .....	28
Benefits advice and carers' assessments .....	28
Social services .....	29

Care homes.....	30
NHS continuing healthcare.....	31
Safeguarding vulnerable adults and complaints about care .....	32
Mental capacity act, lasting power of attorney (LPoA) and advance decisions to refuse treatment (ADRT), independent mental capacity advocates (IMCAs) and deprivation of liberty safeguards (DoLS) .....	33
End of life .....	34
The Alzheimer’s society and other voluntary organisations.....	36
Appendix 1: Coding - ICD-10, EMIS and SystmOne codes .....	37
Appendix 2: Useful reading and further information .....	38
Appendix 3: Useful scales .....	39
Appendix 4: Anticholinergics and other drugs to be used with caution in Dementia .....	46

Equality and diversity are at the heart of Hardwick CCG’s and NHS England’s values. Throughout the development of any processes cited in this document, we have given due regard of the need to eliminate discrimination, harassment and victimisation, advance equality of opportunity, and foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it.

## INTRODUCTION TO THE FIRST EDITION

**This is intended as an educational tool aimed at GPs and practice nurses who have no previous experience of diagnosing and treating dementia. It is not a protocol or a policy. Primary care is critically placed to take a greater role in assessing and treating dementia and clinicians have a need to expand their knowledge and confidence. Developing a clinical feel for cognitive problems is going to be integral to our care of older patients and their families. Most patients who develop dementia have been known to their GPs for years. Dementia rarely travels alone; it travels with multiple and common co-morbidities with which GPs are very familiar.**

The booklet does not comprise an instruction for primary care to take over everything, but simply to provide the tools for GPs to be able to develop their essential role. There is more than enough work for everyone. The initial ambition was to aim it at assessment and treatment, but no booklet about dementia would be complete without describing the roles of social care and voluntary organisations in supporting patients and carers to build and maintain their resilience. Dementia is seen to criss-cross professional and social boundaries at every stage of the condition.

The booklet refers to people with cognitive problems as 'patients'. Although this term seems inadequate because of the way in which it places people with this profoundly life-changing condition within a medical model, it is hard to find an alternative form of shorthand. Similarly, the term 'carer' is also an inadequate way of describing spouses and families. 'Carers' are co-sufferers whose lives and expectations may be changed irrevocably, and they are often elderly, and sometimes ill, themselves.

Most of what is written here is the pooled knowledge and experience gained from doing two pilot projects in our practice. The first one was a project on the integrated care of older people – which became the 'Virtual Ward'. I realised, during that project, that my social services colleagues knew far more about older people, and far more about dementia, than I did. The second project aimed to explore what could be learned about commissioning for dementia by attaching a CPN for older adults to the primary care team. A key feature of this project was for the CPN to adopt primary care record-keeping and governance. I am grateful to those who allowed us to experiment with this model, and to Phil Smart, our CPN, for patiently teaching me from scratch. I wish to thank Dr Mark Whittingham for his advice and corrections, and Prof Alistair Burns, the National Clinical Director for Dementia for his approval, suggestions and support. Any mistakes are my own.

I dedicate this booklet to my sister-in-law Shirley, who taught me more about living with dementia than she can ever know, and to the Alzheimer's Society who helped her and her husband Tommy, in ways that medicine alone never could.

Dr E Barrett. Shires Health Care. July 2013

## INTRODUCTION TO THE SECOND EDITION

Dementia is a clinical syndrome which affects the intellectual functions of the brain – remembering, thinking, and deciding. Each GP will have about a dozen patients with the disorder. There can be opportunities and challenges at all stages of the illness, whether in relation to prevention, or at the end of life. People may present later in the illness, often in crisis, so timely diagnosis is important in that it can allow support to be provided for people and their families and help to avert emergency admissions to a hospital or a care home. There is a range of drug and other approaches to care.

NICE guidance has been widely interpreted to mean that only specialists can diagnose and treat dementia and this has contributed to a fear of stepping out of line. But no matter how well assessment clinics are run, there are patients who refuse referral to them, and there are other patients who have deteriorated beyond the point where they are able to attend a clinic. Most GPs have patients who are dying of ‘undiagnosed’ dementia.

It is sometimes assumed that patients in care homes will not benefit from an appropriate diagnosis, but this is not necessarily the case. A diagnosis may prompt a review of needs. Sub-typing may help carers to understand certain types of behaviour. Treatment may still help people to feel happier or do more. Carers may be more alert to delirium risk and patients and families may want to express their wishes for future care. A home may be able to acquire increased expertise or support. Better anticipatory care may help prevent hospital admissions. We can raise our game if we have a better understanding.

In the future, some diagnoses will have to be made in primary care if we are to avoid neglecting those who do not engage with an outside service. Assessment is not a mysterious process – it is quite mundane and just needs to be done properly. Drug therapy, particularly with memory drugs, is straightforward and well within the capabilities of GPs. Much of the support we can give to patients and carers is through teamwork and building relationships – it is not technically difficult. There is a vast amount of information available about dementia, but it is in many different places and very little of it is written from a GP perspective. This booklet is an attempt to gather information that seems most relevant to GPs, de-mystify it and put it into one place. It should form a framework for further learning rather than act as a definitive text.

Improving the skills of primary care in relation to cognitive problems may also have a secondary benefit in improving the detection and treatment of depression in older people, and increase referrals to IAPT in the over-65s.

The first edition of this booklet has been very well received and seems to have filled a gap in providing a readily accessible small guide to dementia in primary care.

To make it more widely available, it struck us that it would be useful to have a nationally relevant version that can be widely disseminated. We have made some alterations and added some sections in response to feedback gratefully received. The basis of the guide remains the same. We would encourage practices to add in

bespoke local information as to what is available in their area, both in terms of medical support, and in terms of local social and voluntary services.

We hope this begins to give confidence to colleagues in primary care. Thank you to all our colleagues who have supported us.

**Key points:**

GPs need to build up their capabilities to assess, detect (including diagnosis) 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.

We are aware that this guide may be too detailed to read in one sitting, and that colleagues may want to dip in and out.

<b>Find information on</b>	<b>Page</b>
Preventing dementia	8
Difference between dementia and normal ageing	8
Diagnosing dementia	9
Mild Cognitive Impairment	11
What are the subtypes of dementia?	11
Improving dementia coding in your practice	11
How do you assess someone's memory?	13
When to do a brain scan?	16
Who to refer to a memory clinic?	17
What happens at a memory clinic?	17
Drugs for Alzheimer's disease	18
Managing Agitation	21
Without drugs	21
With drugs	23
Use of antipsychotic drugs	24
Driving and dementia	27
Benefits advice	28
Carers' assessments	29
Continuing care	31
Advance decisions	33
End of life care	34

Dr Elizabeth Barrett, Shires Health Care, April 2014  
 Professor Alistair Burns, NHS England, April 2014

## **WHAT CAN PEOPLE WITH DEMENTIA AND THEIR CARERS EXPECT?**

There are helpful guiding statements as to what a person with dementia, and their carers, should expect. They are derived from the Dementia Action Alliance (DAA) statements. The DAA list also includes the importance of patients having the opportunity to take part in dementia research.

I was diagnosed early

I understand, so I make good decisions and provide for future decision-making

I get the treatment and support that are best for my dementia and my life

Those around me, and looking after me, are well supported

I am treated with dignity and respect

I know what I can do to help myself, and who else can help me

I can enjoy life

I feel part of the community and I'm inspired to give something back

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

I had the opportunity to take part in research

## **PREVENTION OF DEMENTIA**

Until a few years ago, prevention seemed like wishful thinking, but now there is some emerging evidence to suggest that a proportion of new cases of dementia could be prevented by paying attention to vascular risk factors. 'What is good for your heart is good for your head'. Keeping vascular risk factors under control is always going to be worthwhile, as is keeping weight down and exercising. Keeping mentally active and retaining social networks is also good. There is no hard evidence that vitamins can prevent dementia in the setting of a good diet.

## **WHAT IS 'NORMAL'?**

It is normal to have occasional memory lapses and to lose things. It is normal to forget why we have gone upstairs, or to come back from a shopping trip without the very thing we went for. It is normal to have to search our brain for a name, sometimes. Our normal memory may suffer, from time to time, from impaired function through inattention, information overload or mild depression but, unless there is something wrong, we retain a huge store of general (semantic) knowledge, an ability to plan and manage our affairs and, under normal circumstances anyway, we retain our orientation in time and place.



## THE SYNDROME OF DEMENTIA

Think of dementia as 'brain failure'. We talk about liver failure, cardiac failure and respiratory failure, but brain failure feels a step too far. Dementia is the most feared illness in people over the age of 55. The brain is the organ that we least understand. We don't just fear the loss of memory - in a very real way, we fear the loss of who we are.

Dementia is chronic brain failure and delirium is acute brain failure. Dementia is more than just about memory; it is a collection of difficulties that also includes the ability to manage our affairs and to plan things – often referred to as 'executive functions'.

The specialist (ICD-10) classification of dementia is as follows:

- Memory decline. This is most evident in learning new information
- Decline in at least one other domain of cognition such as judging and thinking, planning and organising etc., to a degree that interferes with daily functioning
- Some change in one or more aspects of social behaviour e.g. emotional lability, irritability, apathy or coarsening of social behaviour
- There should be corroborative evidence that the decline has been present for at least 6 months

### Key points:

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.

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 commonest conditions in the differential diagnosis.

## IDENTIFICATION AND DIAGNOSIS OF DEMENTIA

There are compelling arguments against general population screening for dementia. There is no simple test and the condition does not satisfy the WHO population screening criteria. The AMTS (Abbreviated Mental Test Score) is carried out on all patients over the age of 75 who are admitted to hospital for more than 72 hours, and this may be considered a type of screening, but the justification is that it is performed on a high risk population. A lowered AMTS identifies patients at increased risk of developing delirium in hospital, and it also raises awareness in patients and their relatives. The test may open the opportunity for everyone to have important conversations about something they were already concerned about but may not have wanted to discuss.

There are arguments for early diagnosis but, like any variable condition with an insidious onset and a slow prodrome, the earlier the diagnosis is attempted the harder it is to be sure about it. It is important to avoid skewing specialist time too far towards early diagnostic conundrums if that means that their time and skills are not available for people with more complex difficulties. There are, however, compelling arguments against delaying or avoiding diagnosis: medication does help many people to become 'more themselves' for a useful period of time; there is an opportunity for individuals and families to maximise enjoyable activities and to plan to mitigate potential difficulties or crises; it is increasingly important that we diagnose and code patients with dementia so that their risk of delirium may be understood when they go into hospital; and, most importantly of all, it seems to be a basic human right for someone to know about their own medical condition. In general, we can raise awareness of dementia among the population. These trends in thinking, and the availability of 'memory drugs', will tend to bring patients to us earlier.

We are moving away from the concept of protecting the patient from the diagnosis because 'nothing can be done', and towards offering 'timely' diagnosis to patients. By this it is meant that diagnosis need not be linked to any particular stage of dementia, and that people and families can be enabled to access the support that helps them when they start to need it. We should respect the decision of patients and families to present themselves at the time that is right for them. We can, gently and sensitively, nudge people towards thinking about their memory, but there is no justification for ambushing them.

There are times when we need to make very finely balanced judgements. For instance, we may have to weigh the risks of not intervening to help a reclusive older person, suspected of self-neglect, against the risks of disturbing their integrity and delicate 'ecosystem' by wading in to inflict unwanted diagnosis or services. Balancing risks and addressing ethical dilemmas are integral parts of our job. Sharing difficult decisions with experienced colleagues is always advisable and can work very well if supportive and educational relationships are built up with specialist colleagues, and advice can be obtained at short notice.

#### **Key points:**

Population screening for dementia is not envisaged.

'Timely' diagnosis is when the patient wants it. In some cases it may be when the carers need it.

The current approach is towards raising awareness, especially in the higher risk population.

#### **Subjective Cognitive Impairment**

There are some patients who have a strong subjective sense that something is wrong with their memory but they perform well on objective tests. Many of these patients suffer from chronic depression and/or anxiety – conditions that are, in themselves, significant risk factors for the development of dementia. These patients

should be offered sensible health advice – especially about exercise, alcohol and vascular risk reduction. Judicious use of anti-depressants may be helpful. Patients may benefit from psychological therapies – including cognitive behaviour therapy. They may accept an offer of periodic cognitive testing. The Alzheimer’s Society will help and advise anyone with a concern about their memory. The person does not need to have a diagnosis of dementia.

### **Mild Cognitive Impairment (MCI)**

MCI has become a more common diagnosis as people present earlier with concerns about memory. Generally speaking, MCI is a heterogeneous group characterised by objective cognitive impairment (but not of such severity as to merit a diagnosis of dementia) but without significant impact on daily activities or discernible progression over time. As with dementia, MCI can affect more than memory. In general, over three years, one third of patients with MCI spontaneously improve (suggesting that their symptoms were caused by depression, anxiety or self-limiting physical illness), one third stay the same, and one third progress to dementia. Patients with MCI need yearly follow-up and the same advice and support as for Subjective Cognitive Impairment.

## **TYPES OF DEMENTIA**

There are many codes for dementia. The first three types on the list below are the ones you will use most often. See Appendix 1 for more information on the codes.

Alzheimer’s Disease  
Vascular Dementia  
Mixed Alzheimer’s/Vascular dementia  
Lewy Body Dementia  
Frontal Lobe Dementia/Pick’s disease/ Progressive Aphasia  
Dementia in Parkinson’s Disease  
Dementia unspecified  
Alcohol related dementias

Sub-typing is important. Anti-psychotics are potentially life-threatening in Lewy Body Dementia (LBD) and in dementia associated with Parkinson’s Disease (PD). Acetylcholinesterase inhibitors do not work in purely vascular dementia. However, the older a person is, the more difficult it can be to draw clear dividing lines between dementia sub-types, and features of all sub-types may be present.

### **Dementia sub-types – key features**

The diagnosis of dementia is a two-stage process; firstly the diagnosis of dementia must be distinguished from depression, delirium, mild cognitive impairment and the

effect of drugs; secondly, it may be possible to elucidate the sub-type. The main dementia sub-types, and their distinguishing features, are as follows:

### ***Alzheimer's Disease***

The key feature is the insidious deterioration in memory and other executive functions (reasoning, flexibility, task sequencing etc). If relatives cannot date when the symptoms started ('probably two or three years ago'), then Alzheimer's Disease (AD) is likely. Patients who complain bitterly about their memory, and are always 'much worse' each time you see them, despite relatively stable cognitive tests, are likely to be depressed.

### ***Vascular Dementia***

There is a step-wise presentation – sometimes noticeable after a 'funny do', an episode of illness, or an operation. If relatives say it started suddenly, then a TIA or small stroke is likely. Vascular dementia can remain static for long periods, and may progress in little jumps.

### ***Mixed Alzheimer's/Vascular Dementia***

It is not always possible to make a clear distinction between AD and vascular dementia. It is helpful to think of the combination as being a bit like 'two and two makes five' – each illness augmenting the other so that the end result is greater than the sum of its parts. Memory drugs can be tried for the Alzheimer's disease component.

### ***Lewy Body Dementia and Dementia in Parkinson's Disease***

These two types of dementia are related but not quite the same. In Lewy Body dementia, dementia comes first and 'Parkinsonism' often develops later - although often without tremor. In dementia in Parkinson's Disease, the Parkinson's Disease comes first, and one in six patients with Parkinson's Disease go on to develop dementia. In Lewy Body Dementia, memory may be well preserved at first, but deteriorates later. The key features are difficulties with attention, arousal at night, marked fluctuation in levels of cognition and confusion, vivid, and often highly developed, hallucinations, sensitivity to neuroleptics and REM sleep disorder.

### ***Focal Dementias***

There are three main types: Frontal Lobe Dementia (FLD), which was previously known as Pick's Disease; Semantic Dementia; and Primary Progressive Aphasia. Frontal Lobe Dementia is particularly difficult because it often presents in a younger age group. In the behavioural variant, it may take several years before the condition is diagnosed. The development of inflexibility and unreasonableness, blunting of social sensitivity and, sometimes, aggression may damage important relationships before the diagnosis is suspected. Semantic dementia affects language, speech is fluent but impoverished, with loss of the store of information and facts (semantic knowledge). In Primary Progressive Aphasia, the meaning of language is maintained

but speech becomes sticky. Other features of Alzheimer's Disease may later develop.

### ***Young onset dementia***

This is generally defined as when the age of onset is under 65. There are a number of particular features of young onset dementia which are important such as: the greater diagnostic difficulty as presentations can be atypical; the higher rate of neurological disorders causing symptoms; the physical fitness of most younger people; and the very different social impact of the diagnosis as young children are often in the home.

### ***Learning Disabilities***

Individuals with learning disability (LD) are at higher risk of developing dementia and the specific association between Down's syndrome and Alzheimer's disease is well recognised. The assessment of cognitive impairment in LD needs special care, paying attention particularly to co-morbid physical and mental health disorders and less reliance of standard tests of cognition. Specialist assessment is usually required.

#### **Key points:**

Sub-typing dementia is important in guiding prescribing decisions.

Most sub-typing can be arrived at by a careful history.

## **ASSESSING COGNITION**

Cognition should be assessed in the context of a patient who is not acutely unwell (when symptoms may be caused by delirium), or suffering from depression. If a patient's cognition has been flagged up during a hospital admission, they need at least a couple of weeks, and sometimes considerably more, to recover and settle down at home before an assessment is done.

Cognitive testing forms just one part of an assessment for dementia, and cannot be considered on its own. It needs to be placed in the context of the history, mental state examination and overall functioning. There is no such thing as a 'dementia test'.

Although some tests are relatively simple, they should not be rushed. This is not good for the examiner or for the patient. It is generally not practical to build a cognitive test into a routine GP consultation. Cognitive testing is best done by someone who can become experienced in using a range of tests and has sufficient time to put patients at ease and observe for clues. Many patients have built up impressive adaptive skills and can present very well, even if they have very significant cognitive problems. Some patients are very keen to do the cognitive tests but some may have a great fear of being 'shown up'. Some may have a fear of

revealing a lifetime of illiteracy, some may not want their family to know how bad their memory has become, so great care needs to be taken in preserving dignity.

Whether the test is done in the surgery or in the patient's home depends on individual circumstances. An AMTS takes a few moments, a GPCOG a few minutes. A MOCA test may only take about 10-15 minutes. A home visit to take a full history from the patient and a relative, and administer an ACE III test, may take up to 90 minutes (this is a much more specialist assessment, much more akin to what a memory clinic would do). The tester needs to ensure that the patient has everything they need – like spectacles and hearing aid - and is in an environment where they can concentrate. A tester should be prepared to abandon a test if a patient refuses or is getting upset or over-tired. It is quite common for patients to refuse to do parts of the test – such as writing.

Cognitive testing includes assessment of recall, reasoning, abstract thinking, visuo-spatial and verbal skills. A stepped approach to the assessment of cognition is available in 'A practical toolkit for clinicians' published by the NHS and Alzheimer's Society (see Appendix 2). It is helpful to be familiar with a short test, such as the AMTS or GPCOG for initial assessment and a more detailed one, such as the MOCA.

All these tests (with the exception of the MMSE) are available to download from the internet, along with their scoring and interpretation. The following scores indicate cognitive difficulties at the time of doing the test:

MOCA: Less than 26/30. It is quite a tough test to do - more difficult than the MMSE although both are scored out of 30.

MMSE: This test is graded by severity and has been used extensively in memory clinics to measure response to medication and guide decisions: 20-26 = mild cognitive impairment; 10-20 = moderate impairment; and less than 10 indicates severe impairment.

ACE III: This is a much more detailed test, scored out of 100. It has good diagnostic value. A score of less than 82 indicates likely dementia. The test gives helpful detail on domains of function:

Attention – marked out of 18,  
Memory – marked out of 26,  
Fluency – marked out of 14,  
Language – marked out of 26,  
Visuospatial – marked out of 16.

Some people develop marked deficits in some domains but function well in others, but it is common to see a global reduction over all domains in dementia. Unusually skewed scores may indicate the need for a specialist opinion and this is where developing experience helps. There are a couple of things to note particularly. Firstly, one of the tests in the ACE III is to ask the patient to draw a clock and put the hands to a certain time. If this is carried out correctly, it virtually excludes dementia because a wide range of cognitive skills are used. Secondly, it is helpful for GPs to understand the distinction between language and fluency. Language may be tested

by asking the patient to point to named objects, whereas verbal fluency tests the number of words beginning with a certain letter that someone can come up with in a minute (actually quite difficult under pressure!). It is quite common to have very different scores for language and fluency.

Care needs to be taken in interpreting any score. Literacy, educational attainment, learning disability and specific learning difficulties will all affect scores. Some content in the ACE III requires usable vision. These questions can be taken out and the scoring measured against a reduced denominator. Inappropriately low scores may be the result of poor engagement or high levels of anxiety and the test may need to be repeated. It is important not to jump to conclusions about the cognition score.

The MMSE has traditionally been the standard Memory Clinic tool. While it is useful, when doing follow up cognitive assessment, to compare like with like, it is advisable to avoid copying or scanning the published MMSE format so as not to fall foul of copyright law. Full details of some of the common scales can be found in Appendix 3.

#### **Key points:**

It is unrealistic to do anything but a brief 'screen' in a normal Primary Care consultation.

It is helpful for someone in the practice to be familiar with a couple of cognition tools.

'A practical guide to the assessment of cognition' is available on the Alzheimer's Society website.

Being able to draw a perfect clock, to all intents and purposes, excludes dementia.

## **ACTIVITIES OF DAILY LIVING (ADLS)**

There are no scores for ADLs that are as readily accepted as those for cognition. The history is as good as any to detect these. For the purposes of nursing assessments these are sometimes divided into personal (PADLs) and domestic (DADLs):

- Difficulties learning new information – like how to use a new phone or cooker.
- Loss of previously familiar skills – such as managing tools and gadgets, cooking a meal, or reading and writing.
- Loss of interest in previously enjoyed hobbies – although this can also be due to depression.
- Difficulties managing money – although this can easily be covered up by trusting a shopkeeper to give the right change, or using a card (PIN numbers can be a challenge). Bills may not be paid and finances may get into a mess.
- As dementia advances, personal care may deteriorate – and self-neglect may become evident especially in people who live alone.

## ECGS AND BRAIN SCANS

An ECG is mainly useful in assessing heart rhythm and rate prior to starting an Acetylcholinesterase Inhibitor (AChEI). They are helpful because AChEIs tend to slow the heart rate and may cause syncope. Ischaemic changes and atrial fibrillation need to be noted. Left bundle branch block indicates ischaemic damage and risk. First or second degree heart block, or a heart rate of less than 60/min are contraindications to AChEIs.

NICE guidelines currently recommend a brain scan as a necessary part of investigation but it is important to exercise judgement in any particular clinical situation. Some patients refuse scans and this should not prevent a diagnosis being made if everything else points to it. It is helpful to chase up a DNA, though, as the patient may have forgotten. Sedating a patient in order to have a scan is not appropriate, unless there are pressing clinical reasons. A scan may support the diagnosis of dementia but a normal scan does not exclude dementia. CT scanning is available by open access in most areas but, if not, have a discussion with your CCG. CT machines and reporting vary. Good clinical information will help the radiologist and will result in a more informative report. CT scans may show up vascular damage and areas of lobar atrophy but, essentially, they exclude brain tumours and normal pressure hydrocephalus. Brain tumours should be considered if the history is unusually short, or there are sudden or fluctuating new or neurological features. Normal pressure hydrocephalus should be suspected if cognitive deterioration is associated with abnormal gait or the onset of a detrusor instability type of incontinence. Patients and relatives are always keen to know the results of a scan even if it has been explained to them that it is not really a diagnostic test.

MRI scanning is more sensitive than CT scans in picking up vascular damage and showing the atrophy associated with Alzheimer's disease. Atrophy around the hippocampus is particularly relevant. However, MRI brain scans are not routinely available for GPs. More advanced scanning, such as Single Photon Emission Tomography and Positron Emission Tomography (PET scans) can show more detail and may be requested by a specialist.

Blood tests: Routine blood tests include FBC, ESR or CRP, TFTs, LFTs, random blood sugar, Vitamin B12 and folate. These need to be done within six months of recording a new diagnosis of dementia (QoF requirement). Blood tests rarely help with diagnosis but it is important to unearth and treat significant pathology. Routine syphilis testing is not necessary but should be done if a risk is identified in the history.

### Key points:

Putting as much clinical information as possible on the CT request form helps the radiologist to provide the most useful report.

Brain scans (CT or MRI) are not essential for a clinical diagnosis of dementia.



## WHO TO REFER

GPs are skilled in judging which patients they should treat and whom they should refer. Referral decisions may be influenced by many factors, including views of patients, local and national guidance, clinical knowledge and experience and the availability of clinical support. Most importantly, it is a decision made in the light of knowledge of the patient and their family. As experience grows, referral practices may change, but the following are likely to remain the situations in which a specialist opinion might reasonably be sought. This is not a protocol and the list may not be complete. Much depends on how easy it is to obtain CPN or consultant support and referral may not be necessary if advice can be obtained through closer working arrangements. Closer working links are very rewarding and deepen skills and knowledge within the team.

- Parkinson's Disease (PD) and suspected Lewy Body Dementia. Dementia in PD can be an extremely challenging clinical problem (the balance of Dopamine and Acetylcholine can be very tricky).
- Suspected Fronto-Temporal lobe dementia (see above).
- Younger people with suspected dementia, where the chances of there being a rarer neurological condition are greater.
- An atypical presentation or course.
- 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 Down's Syndrome patients, who have a particularly high risk of developing dementia). Assessing dementia in patients with LD requires specialist psychological input.
- Suspected alcohol related dementia.

## WHAT HAPPENS IN A MEMORY CLINIC?

Memory services are set up differently in different places. In general, a person is seen for initial assessment (often at home), further investigations are carried out, and a diagnosis is made and shared with the patient and their family. Two thirds of memory clinics do their initial assessment in an average of six weeks. Dementia support workers from voluntary agencies, such as the Alzheimer's Society, are often involved with memory clinics and provide information and may offer carers' assessments at diagnosis. Many clinics have a protocol for initiating treatment with AChEIs or Memantine, and prescribe for the first three months. The prescribing may then be taken over by primary care. This model has its weaknesses, not least that, in order to do proper follow-up, GPs and practice nurses should really have the same level of knowledge and confidence as those who assess patients and commence treatment. Changing and stopping drugs requires just as much knowledge and skill as starting them. The other weakness is that patients with vascular dementia are generally discharged after diagnosis because AChEI drugs are not indicated. It is easy for these patients and their families to lose touch with support agencies and they may feel very alone in their predicament.

## DRUGS USED FOR ALZHEIMER'S DISEASE

### Acetylcholinesterase Inhibitors and Memantine

Before prescribing AChEIs, it is important to look at the drugs the patient already takes. Consider stopping or reducing anticholinergic drugs, in particular. AChEIs work by blocking the enzyme that breaks down acetylcholine, thereby raising its level in the brain. Prices of all these drugs have come down since the patents expired. Donepezil is particularly cost-effective and costs about £1.50 per month.

All AChEIs are licensed for mild to moderate dementia but can be continued into severe dementia if they are deemed helpful. There is very little difference in effectiveness or side-effects between the various drugs and the cheapest is generally used first. Rivastigmine is licensed for dementia in Parkinson's disease, so may be preferred if hallucinations are a prominent presenting feature. If the first AChEI is not tolerated, try a second, but not a third. AChEIs and Memantine may be trialed in severe dementia for improving Behavioural and Psychological Symptoms of Dementia (BPSD).

Drug	Indication	Dosage	Main C/I or S/E
<b>Donepezil</b> (cheapest, long half-life of 70 hours)	Alzheimer's disease, mild and moderate	5mg or 10mg once daily, Start as night time dose but can be taken at any time once patient is used to it	Syncope. Bradycardia, conduction defects.  GI side effects, nausea, diarrhoea
<b>Rivastigmine</b> (short half life, must be twice daily)	Alzheimer's disease mild and moderate and Dementia in PD	1.5mg twice daily to 6mg twice daily, Increase dose at monthly intervals	C/I and S/E as for AChEIs  Must be given twice daily with food to reduce nausea and GI side-effects  Patches are significantly more expensive
<b>Galantamine XL</b>	Alzheimer's disease, mild and moderate	8mg once daily starting dose, increasing monthly to max of 24mg	C/I and S/E as for AChEIs May be better than others for insomnia

Memantine is an NMDA receptor antagonist, licensed for moderate or severe dementia. It may be helpful for BPSD symptoms.

Drug	Indication	Dosage	Main C/I or S/E
<b>Memantine</b>	<p>Alzheimer's disease, moderate to severe</p> <p>Preferred drug if there are cardiac conduction problems or bradycardia.</p> <p>May be trialed in conjunction with an AChEI in later stages of Alzheimer's disease</p>	<p>Ready made starter pack going from 5mg once daily to 20mg once daily within the month.</p>	<p>Check renal function before prescribing</p> <p>constipation hypertension dizziness</p> <p>Metabolised by enzyme 2D6 so it competes for metabolism with other psychiatric drugs</p>

## OTHER TREATMENTS FOR DEMENTIA

There is no specific drug treatment for vascular dementia but GPs are familiar with the lifestyle changes and drug therapies that reduce vascular risk and it is not necessary to detail those interventions in this booklet.

There are a number of herbal remedies available that patients (and their families) may ask about: Ginkgo Biloba (increased risk of stroke in one study) Betrinac and Souvenaid. There is insufficient evidence to prescribe these on the NHS but they can improve symptoms in individuals.

### Key points

There is little to choose between 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 or significant cardiac conduction problems.

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.

## **TREATMENT - WHEN TO START, WHAT TO EXPECT, HOW TO MONITOR, WHEN TO STOP?**

About 60 per cent of patients with Alzheimer's disease have useful improvement with memory drug treatment. They may be brighter and more interested in things, and capable of doing and enjoying things that they could not do before. Cognitive testing results may improve, but the most important thing is that the patient improves.

Patients are tending to present earlier because of general awareness of dementia, including the potential for drug treatment. The decision to treat with a memory drug is based, firstly, on whether a diagnosis of Alzheimer's disease (or an Alzheimer's component) can reasonably be made. The patient should hit the threshold for dementia on cognitive testing and also satisfy other Alzheimer's disease criteria – namely global deterioration in function with insidious course, corroborated by a relative or carer. Dementia caused solely by vascular disease will generally not respond to AChEIs but even if vascular dementia is suspected, a corroborated history of gradual decline over months or years may swing the balance towards a trial of medication.

### **Follow-up**

Systematic follow-up of patients with dementia, whether on drug treatment or not, presents a logistical challenge for general practice. Follow-up needs to be initiated by the practice and patients who do not attend should be contacted and offered follow-up at home. The patient should have a simple care plan that includes the diagnosis, a treatment and review plan, and sources of information, including where to find local support groups. If an AChEI has been initiated, the first follow-up contact with the patient and carers will be to establish whether there are any significant side-effects. It is useful to do this before the second prescription is due, so an interval of around three weeks is about right. The second follow-up should be about three months later when the patient should be assessed for response to treatment. A cognition test may be done but, especially in more advanced dementia, an assessment of well-being and functioning is more important. It is helpful to offer information about support organisations at every contact as people's receptiveness may be different at different times. An occupational therapy assessment may be helpful at any stage.

Further follow-up may include periodic assessment of cognition, as in a memory clinic, but should be omitted if it upsets or intimidates the patient. Overall functioning, medication issues and carer views will constitute most of the review. Follow-up is well within the remit of a practice nurse with knowledge of dementia and its problems, and who is trained in cognitive testing. There needs to be a regular MDT meeting with the lead GP. Patients whose risk is causing concern may need to be referred to a CPN, social services, or to the practice's Virtual Ward, or its equivalent resource.

## When to stop treatment

### ***When dementia gets worse:***

AChEIs and Memantine have proved to be very safe drugs. The very strict protocols that were put in place in the early days have relaxed as experience has grown and prices have fallen. In the early years of use, AChEIs were stopped when the MMSE reached 10/30 but evidence had emerged that supports their continued usage in severe dementia. The effectiveness of an AChEI becomes more difficult to assess the longer a patient is on it because the baseline will have changed. The only way to know if it is still helping is to stop the drug and be prepared to re-start it if there is a sudden significant deterioration, but this could be unnecessarily disruptive, and current guidance is to continue indefinitely unless there are problems. Increasingly, Memantine is being tried in addition to Donepezil in severe dementia.

### ***When they might not be working:***

AChEIs result in improvement in about 60 per cent of patients with Alzheimer's disease, so there will be some in whom they are not effective. If there is no subjective or objective improvement at the three month review, they can be continued if there are no side-effects, and the patient reassessed in a further six months. There is no difference in effectiveness between AChEIs and the only reason for swapping is to see if a different drug is better tolerated. If two AChEIs have been tried there is no point in trying another.

### ***When they are not tolerated:***

AChEIs should be stopped if they are thought to be causing problems – such as nausea, weight loss or bradycardia. Anxiety or agitation might prompt a trial without AChEIs as they are stimulant drugs. The result might be more apathy but less agitation.

#### **Key points:**

AChEIs and Memantine work in most people and confer a valuable benefit.

Systematic follow-up is needed, but not necessarily in a specialist hospital clinic.

AChEIs can be continued when dementia enters the more severe stages.

## **BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD) – ALSO KNOWN AS 'NEUROPSYCHOLOGICAL SYMPTOMS'**

This is an area in which it is as important to focus on helping carers and careworkers as it is on helping the patient.

Many patients with dementia are placid and sweet-tempered. Apathy and repetition may cause concern or irritation for relatives, although most spouses seem to have almost infinite patience, borne out of a lifetime of mutual commitment. The 'living well' programmes are ideal for helping patients and carers understand the condition and help prepare them for the future. Alzheimer's support workers can do individual

work, and many patients and carers benefit from regular attendance at Memory Cafes and Singing for the Brain. There may be a local Alzheimer's group that arranges trips and holidays.

More than 90 per cent of patients with dementia will experience BPSD difficulties during the course of their illness. These include sleeplessness, wandering, agitation, pacing, aggression (including spitting), and disinhibition (including sexual disinhibition). Emotional lability (uncontrolled outbursts of crying – or, more rarely, laughing) can occur in patients following stroke. Jealousy, especially sexual jealousy, is particularly common in LBD and PD. The sufferer's jealousy may be supported by vivid and explicit hallucinations, which can be deeply upsetting for the sufferer and for the spouse. Behavioural problems can present great difficulties both at home and in residential units. Police may sometimes have to be involved in the case of physical injury, despite the fact that the behaviour is part of someone's illness.

The CPN, OT or Dementia Support Worker will be able to give guidance to carers on how to assess and deal with psychological distress in people with dementia. Careworkers in residential homes may also need guidance and support. It is important to avoid harmless behaviour being seen as 'difficult' or the development of antagonistic or judgemental feelings towards patients. Where staff are finding a situation particularly hard to manage, be prepared to offer CPN or OT intervention. Family carers may also benefit from training and from psychological assessment and support in their own right.

Challenging behaviour needs to be seen as a manifestation of unmet need, which the patient may not be able to express. Boredom, frustration, annoyance and tiredness may be detected using behaviour charts, and carers may need the help of a CPN or dementia support worker to understand these and develop strategies. A session of 'life work' may be very fruitful, exploring and documenting the life of someone before dementia developed.

The expectation is often put on GPs that they should provide a quick drug fix for patients with troublesome BPSD symptoms, and this can lead to inappropriate prescribing. First and foremost, the approach towards psychological symptoms should be an empathetic one – that of discovering what the patient is experiencing, what their needs are and how best to cater for them. It is particularly important to consider pain as a cause of distress. The causes of pain may be quite mundane and respond to very simple measures (More detailed information is in NICE guidance and the Best Practice Guide on the Alzheimer's Society website).

Urinary tract infections are often suspected as a cause of worsening behaviour and sometimes these are easy enough to detect. However, care needs to be taken in interpreting urine dipstick tests; clean catch specimens can be very difficult to obtain, especially if the patient is incontinent, and it is important to know how the specimen was obtained – some specimens are obtained from catheters or commodes and grow multiple organisms. It can be a very difficult balancing act: GPs need to be careful about not causing *Clostridium Difficile* infections or ESBLs (extended spectrum betalactamase organisms) from the overuse of antibiotics on the one hand: on the other hand, uro-sepsis is a common cause of deterioration and death. Pyrexia, and a very good history from an observant carer, may help inform decisions.

Hallucinations are commonly visual, especially in PD and LBD. They often worsen in the late afternoon as part of a phenomenon known as 'sundowning'. Patients are not always frightened by hallucinations and may talk quite calmly about seeing quite shocking things. Many people see dogs or children in the house, but are not frightened and may prepare food for them. It is important to talk in a matter-of-fact way about hallucinations in order to discover how the patient feels and whether they are frightened of them, or want to respond to them. If a patient is not disturbed by hallucinations, do not be in a rush to medicate them away. Think about covering 'hallucinogenic props' like wardrobe mirrors, ensuring curtains are not moving in the wind, and modifying lighting so that it does not throw shadows.

### **Key points:**

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.

Carers and careworkers need guidance and support.

There is useful guidance on managing BPSD on the Alzheimer's Society website.

### **Drugs used for BPSD**

If drugs have to be used, you should use the safest drugs you can, at the lowest doses that work, and set a review date for reducing or stopping them. Most BPSD symptoms settle within a few weeks.

There is not a particularly wide range of drugs that can be used in BPSD, so it is quite within a GP's capabilities to become familiar with the ones there are. Often, BPSD problems create emergencies and then there is pressure to try to manage things quickly, but longer term strategies need also to be considered.

#### ***Anti-depressants***

Depression is common in dementia but can be hard to diagnose. If depression is suspected as a cause of additional misery in a patient, anti-depressants may help by lifting mood. The three preferred anti-depressants are Sertraline, Trazodone and Mirtazapine. Citalopram lengthens the QT interval and should be avoided or only used in very low doses.

*Sertraline* is the SSRI of choice and has a useful dose range.

*Trazodone* is helpfully sedating. Start with a dose of 50mg once or twice a day.

*Mirtazapine* is also helpfully sedating. Note that it has neurotransmitter agonist action and sedation *decreases* as the dose is increased. A sedating dose is 15mg at night but a dose of 45mg may cause agitation and sleeplessness.

### ***Benzodiazepines***

Long-acting benzodiazepines, such as diazepam and nitrazepam, tend to be unhelpful in dementia as they can increase confusion. Avoid starting them if possible. It may be possible to withdraw them gradually.

*Lorazepam*, however, can be useful for agitation. It is quick acting. It should be only used on a PRN basis. Start with a dose of 0.5mg prn and avoid routine administration.

*Temazepam* and *Zopiclone* are often used for chronic insomnia but they increase the incidence of falls. They may be difficult to stop. Avoid starting them if possible.

*Clomethiazole* will be remembered by older GPs as Heminevrin. This can be useful in a controlled environment, like a care home, where the risk of inadvertent overdose can be eliminated. Dose can go up to three capsules a day, with a maximum of six per day.

### ***Memory drugs***

Improving memory may improve cognition sufficiently to help patients feel 'more themselves' and be less disturbed.

*Memantine*. Can be useful in improving BPSD symptoms in severe dementia by improving cognition. It is mildly sedating as well.

*Rivastigmine* may help with hallucinations but it takes several weeks to build up the dose so it is not an immediate fix. Quetiapine may be necessary to reduce hallucinations while Rivastigmine is taking effect (see anti-psychotic drugs, below).

### ***Anti-psychotic drugs***

There is a national drive to reduce anti-psychotic prescribing in dementia because these drugs increase mortality and the incidence of strokes. Nevertheless, sometimes there is no other option, especially if a patient is extremely distressed or aggressive as a result of hallucinations or psychotic symptoms. Anti-psychotic drugs should only be used when all other ways of dealing with the situation have failed. CPN or psychiatrist help should be sought. If these drugs are used, they should be started in small doses and reviewed after six weeks in order to avoid the risk of embarking on a lifelong repeat prescription. Patients who settle down may well remain settled on withdrawal of anti-psychotics, and fear of relapse is no justification for continued prescribing.

*Risperidone* is the only anti-psychotic drug licenced for aggression in Alzheimer's disease. Anti-psychotics (except tiny doses of Quetiapine) are absolutely contraindicated in PD and LBD. They can cause major severe reactions and can



make a patient very flat, with a high mortality risk. Risperidone, if needed, should be started at a low dose of 0.5mg once or twice a day. Do not exceed 1mg twice daily without specialist advice.

*Quetiapine* may be used cautiously if the patient is distressed by troublesome psychotic symptoms, although the evidence base is not strong. If you do need to use it, start with a very small dose of 12.5mg (half a tablet) once a day and do not increase beyond 25mg twice daily without specialist advice. Half of a very small tablet may cause difficulties if medications are blister packed but the alternative is a liquid preparation which is disproportionately expensive and far more difficult for patients to manage on their own.

*Haloperidol* is a drug of choice for acute delirium, usually in a hospital setting, and should not be used for BPSD.

### Key points:

There is a relatively small range of drugs that can be used.

Drugs should not be the first option.

Anti-depressants and anti-Alzheimer drugs may help BPSD.

Quetiapine in low doses is the safest anti-psychotic.

Anti-psychotics are potentially fatal in LBD and Dementia of PD.

If anti-psychotics are used, they should be used for short periods only (up to six weeks and should be reviewed regularly), and not for preventing a relapse.

## DELIRIUM, DEMENTIA AND ANTICHOLINERGICS

Patients with dementia, who have to go into hospital, are particularly vulnerable. It is very helpful for staff to know what a patient's baseline function was, before admission, and to know a patient's likes and dislikes as well as some personal details – like what they like to be called. Patients and carers should be encouraged to complete the 'This is Me' document, available on the Alzheimer's Society website, and bring it with them to hospital and other places.

Patients with cognitive impairment are at risk of developing delirium when ill. This is increasingly recognised as a serious condition that carries a high mortality risk. Falls and injuries occur when patients try to climb out of bed or go wandering. Delirium delays hospital discharge. Patients who have delirium may take several weeks to recover and some will never recover their previous cognition. Between forty and sixty per cent of patients are not fully recovered at the time of discharge. Disturbing vivid hallucinations may be remembered long after the patient is better and may disturb previously trusting relationships. Patients may remain puzzled and shaken about what has happened to them.

GPs have a role in minimising the anticholinergic drug burden in patients with dementia. Unfortunately, some of these drugs are used very commonly in older patients – drugs for bladder instability, for instance. It may be possible to reduce doses or to stop drugs that do not appear to be effective. There is a list of drugs with anticholinergic properties in the Appendix 4.

**Key points:**

Delirium is common and may take far longer to recover from than people realise.

Delirium can damage cognition.

Anticholinergic drugs contribute to delirium risk.

## **DEMENTIA AND ALCOHOL**

Alcohol misuse is probably under-recognised in older people. While many heavy drinkers reduce their alcohol use as they become older, there are some who increase it for a variety of reasons: some patients develop a new liking for alcohol – possibly because it reduces anxiety, blots out loneliness or aids sleep; some people may simply not remember they have already had a drink and increase their alcohol intake almost by accident; some find the previous limits they put on their alcohol intake are eroded by deteriorating judgement. Alcohol excess in a carer, or co-dependence in a couple, may cause safeguarding concerns. Physical tolerance for alcohol diminishes with age, and susceptibility can be further increased if diet is poor or weight drops. Falls are a common complication. It can sometimes be difficult to separate dementia from alcohol as a cause of deteriorating cognition and self-neglect and, if it can be managed, a short spell in a care home, with regular meals and company, sometimes helps to answer that question.

The syndrome of memory loss caused by alcohol (Korsakoff's syndrome) is more common in deprived areas – maybe because income does not stretch to a good diet as well as alcohol, or maybe because alcohol dependence mitigates against upward social mobility. Generally speaking, it produces a pure and dense amnesia and it occurs in a younger age group than Alzheimer's disease. The amnesia is often associated with lack of insight and blunting of behaviour. Apathy is common, as is a sort of cheery confabulation that may reassure the unwary. High doses of Thiamine and abstention from alcohol may halt progress but the damage is usually done by this time. Capacity and safeguarding issues may crop up because of poor insight. Given that many such patients have long since lost their friends and families, Independent Mental Capacity Advocate (IMCA) involvement may be needed in deciding where someone should live (see page 33-34).

**Key points:**

Alcohol problems are more common in older people than we think.

Alcohol may be a cause, an effect, or a complication of dementia.

## COGNITION AND DRIVING

Knowing whether or not someone is able to drive is not always easy, and knowing how to tell them is even less easy because driving can be strongly associated with independence and self-esteem. Concerns are usually raised by the family but, if not, patients and relatives need to be asked about driving. Ask about a history of frequent bumps, near misses or frights, or getting lost on familiar journeys. A good test is whether a relative will allow themselves, or their children or grandchildren, to be driven by the patient.

Patients with a diagnosis of dementia must inform the DVLA *and* their insurance company. It is illegal not to do so. The DVLA will send an enquiry form to the patient and will then contact the doctor. Disqualification is not automatic, and the DVLA may continue to issue a licence – usually for a year at a time. On average, people with dementia give up driving within two or three years of diagnosis, and often limit their driving to short, familiar, journeys before stopping driving completely.

If a doctor advises a patient not to drive, the patient needs to be told that their insurance is not valid in the event of an accident and it is an offence to drive without insurance. A compromise option may be for the patient to voluntarily stop driving until a driving assessment at a local mobility centre can be arranged. If all else fails, and the patient continues to drive against advice, either the doctor or a relative needs to notify the DVLA of their concerns. Some families use subterfuge to disable the car or 'lose' the keys.

MCI is not automatically reportable but the same actions apply if you believe a patient should not be driving.

It costs about £130 to take a driving assessment at a local mobility centre. The patient will bear the cost if they refer themselves. If the DVLA requests the assessment, the patient does not pay. If the patient drives their own car to the assessment, they need to bring someone with them as they will not be allowed to drive home if they do not pass. There is good information on the Alzheimer's Society website.

### Key points:

MCI is not automatically reportable to the DVLA.

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 become unable to drive.

An independent driving assessment may be useful – remember that, 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.

## **FALLS**

Patients with cognitive impairment are prone to falls. There are a number of possible reasons: the condition itself (especially LBD with associated mobility and balance difficulties); house clutter; poor attention or reduced visuo-spatial awareness; not taking essential medication properly; or not eating regularly. Falls prevention assessment is advisable if the patient is at risk. In some areas there are specialised multi-disciplinary falls teams that can intervene urgently, or systems whereby social care staff inform the surgery if a patient has had a fall. All falls should be logged onto GP risk records. Where wandering or falls represent a high risk, telehealth technology may be used. Sensor pads can be fitted that send an alarm through to a warden if a person falls or wanders. Patients at risk of falls should be encouraged to hire and wear pendant alarms.

## **CARERS**

Informal carers do nearly all of the work of caring for patients with dementia, so looking after carers is vital. Most GPs and practice nurses know that taking the time to listen, empathetically, is highly valued by carers and primary care has a key role in supporting carers. For many carers, the development of dementia in someone they love is a deep and long drawn out living bereavement. They may want to talk about it from time to time and some may need formal counselling.

The practice should keep a record of carers and offer annual health checks. Carers can be offered support from a variety of sources and it is helpful for someone on the team to have details of local groups.

## **BENEFITS ADVICE AND CARERS' ASSESSMENTS**

There are a number of agencies that can assist patients and families with benefits. The Local Authority may have Welfare advisors and local Alzheimer's support workers will help patients and carers fill in appropriate applications. It is helpful to have the telephone numbers handy. GPs are familiar with Disability Living Allowance (DLA) and Personal Independence Payment (PIP) forms but there are a couple of other benefits worth noting.

### **Council tax disregard**

The Local Authority may grant relief from Council Tax to a person if they have a diagnosis of dementia AND are in receipt of middle or higher rate DLA (or its equivalent PIP) AND who have a letter signed by their GP to say they have 'severe mental impairment'. This terminology is unfortunately rather strongly worded, and some GPs feel they have to refuse to sign if the patient's dementia is not measured as severe on cognitive testing (e.g. <10 on MMSE). The Alzheimer's Society take the view that it is reasonable for dementia patients to receive this rebate since, if they also receive DLA, it means that their needs are complex and progressive.

## Carers' Assessments

Most carers have a legal right to an assessment of their own needs. The Social Services Department of the Local Authority will examine what help is needed with caring. This may be provided as part of a Community Care Assessment for the patient. It is helpful to ensure that both carer and patient are assessed. The Carer's Assessment covers help required to maintain the carer's own health and balance caring with other aspects of their lives, such as work and family. Social Services Departments will use the Carer's Assessment and the Community Care Assessment to decide what help to provide.

The Carer's Assessment may be used to request care changes and respite care and to inform contingency planning in the event of care arrangements breaking down. Carers may receive breaks through respite care or other arrangements. Carers may also be eligible for a carer's break, sometimes a yearly sum that can be spent by the carer. To be eligible, they need a Carer's Assessment. The allowance may be spent on any item or service that the carer feels they need. Further details can be found on the NHS Choices website:

<http://www.nhs.uk/CarersDirect/yourself/timeoff/Pages/Accessingrespitecare.aspx>

Carers' assessments are also a useful opportunity to put carers in touch with the local Carers' Association. These organisations can provide much-needed information, companionship and support when times are tough. Carers' associations are politically influential and have an important participation role by feeding views to policy-makers through CCGs and Local Authorities via the Health and Well-being Boards. The Care Act 2014 places a new obligation on the Local Authority to put the needs of carers on an equal footing with the people they care for. The Care Act also places new responsibilities on Local Authorities in relation to those who fund their own care ('self-funders').

### Key points:

Carers are the most valuable resource in dementia care and we should have a high level of awareness of their needs.

Carers often neglect their own health because of their caring responsibilities.

Carers may be referred for a carer's assessment and benefit check. Carers' groups provide support and information.

Alzheimer's Society can help with counselling, social support, benefit forms and grant applications.

## SOCIAL SERVICES

### Working with Social Services in primary care

There are various tools for risk stratification of vulnerable, older patients at risk of repeated hospital admissions. Some primary care teams have an attached social

worker, or authorised read-only access to social care data. This type of wraparound care is particularly important when looking after patients whose long-term conditions are complicated by deteriorating cognition.

## **Home care and day services**

Social care sits within the Local Authority and commissions services to help look after people in their homes. The Local Authority also commissions and provides day services and residential care. It is best for clinicians not to promise particular social services to patients because they need to meet eligibility criteria and these will differ slightly across Local Authorities. In general, as Local Authority cuts bite, eligibility criteria for social care are being forced up. Some aspects of dementia care sit awkwardly between social care and health. Managing medication is a particular issue and joint working can be helpful. It is often possible to simplify complex regimes to once or twice daily, so that visiting carers can prompt the patient. Agency carers will need administration sheets and blister packs, if they are to help by prompting medication. Patients with dementia often have a health-related need for monitoring, stimulation and companionship, but may not hit the social care threshold for day services or home care. It is hoped that joint commissioning, via the Better Care Fund, will bridge some of the gaps between health and social care for older people. Influencing policy in this regard is an important responsibility.

All patients who seek services or care budgets from the Local Authority must have a financial assessment as well as a needs assessment. Patients often refuse services because they do not wish to contribute financially; some refuse for other reasons. If someone refuses the services they are assessed as needing, it may cause concern and it is important for health professionals to be aware. Intermediate care services may be provided free of charge, as part of an assessment process or an admission avoidance or discharge scheme, but they are only funded for a few weeks.

Social Services do not often directly provide home care. They commission home care from a variety of agencies. These agencies are registered with, and inspected by Social Services and the Care Quality Commission (CQC). Patients and families may prefer to pay their own private carers and they can do this if they use their own money. Sometimes private arrangements cause concerns about financial exploitation, especially if the patient seems neglected, despite paying for care. This can be difficult to deal with. Personal social care budgets may also be awarded, if patients and carers are prepared to manage the employment issues. In this instance, the care managers will ensure that the allocated personal budgets are used appropriately. Monitoring quality across an economy of numerous private providers is a challenge. If you are made aware of concerns about quality, you should discuss them with Social Services.

## **CARE HOMES**

To seek funding for residential care, patients need to be assessed as having needs that cannot be met through care in their own home. This usually means that the maximum level of home care has been tried and found to be inadequate. Cognition difficulties are one of the key reasons for deterioration in self-care, which is why they are present in around 80 per cent of care home residents.

Patients need to have a financial assessment if they are seeking care home funding through the Local Authority. This assessment takes into account income, savings and (in certain circumstances) the value of the property. There are regulations about substantial transfer of assets to family members if it seems that this has been done to avoid paying care costs. The Local Authority can claim against the estate after the patient's death. There are obvious tensions between paying for care and preserving inheritance for families. The question of how to fund the care of older people is a difficult political issue and is likely to remain so.

#### **Key points:**

Social care is based on eligibility criteria and is means tested.

It is helpful for the practice to know if patients have refused services they are assessed as needing.

## **NHS CONTINUING HEALTHCARE**

Clinical Commissioning Groups (CCGs) hold legal responsibility for assessing and delivering NHS Continuing Healthcare (CHC) to their patients. This can be a difficult area for GPs because they are not usually involved in funding decisions. Nevertheless, they need to know something about it. Long-term care costs have an impact on families and sometimes they want advice or support. The following is a brief overview.

NHS CHC means a package of care that is arranged and funded solely by the NHS. Unlike social care funding, it is not means tested so it doesn't affect savings. The patient must be assessed as having a 'primary health need', the definition of which is on the DH website. There is a two-stage assessment process. An initial checklist is done and, if health needs hit the threshold, a full assessment using the NHS CHC decision support tool (DST) follows. NHS CHC is sometimes delivered in a patient's home, but it is more likely to be delivered in a care home. Fast-track funding skips some of the steps. It may be sought if a patient is expected to die within a short time. GPs may be asked to provide medical information for fast-track applications.

A patient, who is not eligible for full NHS CHC, may be assessed as needing some registered nursing care in a care home. In that event, they will receive NHS-Funded Nursing Care (FNC), which is a flat-rate payment towards the cost of nursing care. The care home must have nursing beds but exceptions are sometimes made if a patient is fast-tracked at the end of life and it is inappropriate to move a patient from their long-standing residential placement.

If relatives seek GP support or advice on NHS CHC, there are a couple of particular points to note. If a person with dementia is assessed as needing 24-hour care, it does not follow that they will be eligible for NHS CHC; a patient's nursing needs must satisfy the 'primary health need' criteria. Furthermore, NHS CHC care needs are reviewed regularly and eligibility is not necessarily life-long, even in a progressive condition like dementia. Challenging behaviour, for instance, may

reduce as dementia progresses and, if this happens, nursing needs may no longer hit the threshold for funding through CHC.

It is usual for a social worker and an NHS CHC health assessor to do joint assessments. A large number of assessments are done while patients are in hospital. Good joint working helps to minimise potential delays in discharge.

#### **Key points:**

Most care for patients with dementia is classed as social. To qualify for NHS Continuing Care, a patient must be assessed as having a 'primary health need'.

NHS Continuing Care funding is reviewed regularly and can be withdrawn if a patient's needs change.

FNC (Funded Nursing Care) may be awarded to pay for a nursing care component if needed.

## **SAFEGUARDING VULNERABLE ADULTS AND COMPLAINTS ABOUT CARE**

Adult safeguarding sits within Social Services. It is not uncommon to have concerns about financial abuse of people who are vulnerable as a result of cognitive problems. If suspected, it must be investigated. Other abuses include verbal and sexual abuse, neglect and cruelty.

The Winterbourne and Francis enquiries have raised everyone's awareness about quality, culture and compassion in organisations that look after vulnerable people. While uncaring or cruel people must be prevented from looking after vulnerable people, the enquiries have shown that this is not just about the odd 'bad apple'. There is also a need to understand how cultures determine behaviour and why good people may provide bad care. It is important to be aware of the systemic nature of some of these issues, rather than to focus only on the behaviour of individuals.

Relatives sometimes approach GPs with complaints about care home standards. They can be advised to bring their concerns to the management of the care home, the Local Authority or to the Care Quality Commission. In addition some nursing beds are purchased by the CCG (or another CCG on their behalf), so these nursing concerns should be raised with the Director of Nursing of the CCG.

GPs and community nurses go in and out of care homes on an almost daily basis and have a duty to report upwards if they are concerned about poor care. Community nurses should report concerns to their own management. GPs should discuss nursing concerns with the Director of Nursing in their own CCG or the Local Authority. It is not always easy to raise concerns and it is important to consult with trusted colleagues and keep good records.



### **Key points:**

Adult safeguarding has an increasingly high profile.

There needs to be an adult safeguarding lead in the practice, who is appropriately trained.

## **MENTAL CAPACITY ACT, LASTING POWER OF ATTORNEY (LPoA) AND ADVANCE DECISIONS TO REFUSE TREATMENT (ADRT), INDEPENDENT MENTAL CAPACITY ADVOCATES (IMCAs) AND DEPRIVATION OF LIBERTY SAFEGUARDS (DoLS)**

### **Mental Capacity Act (MCA)**

The principles of capacity are simple; can a person take in the information, retain it for sufficient time, use it to help make a decision and then express that decision? Despite this simplicity, capacity assessments are not always easy. Assessing whether someone fully understands the consequences of an unwise decision can be quite difficult and it may help to discuss it with a CPN or an experienced social worker. There are two common misconceptions about assessments: one is that they have to be done by a professional; and the other is that people can be deemed to have lost capacity generally. Capacity varies over time so do not make the mistake of writing a capacity assessment on a person you might have seen three months ago. Capacity is issue specific and should be assessed by the person who needs the answer to the question that is being asked. A lawyer, drawing up a will, for instance, is the correct person to assess the patient's capacity in this matter but may ask for corroborative medical information to assist their assessment. People have the right to make unwise decisions – capacity assessment is about the process of decision making, not about the decision itself.

### **Lasting Power of Attorney (LPoA)**

Lasting Power of Attorney sits within the Mental Capacity Act 2005. It is a legal arrangement to allow someone to appoint another person to make decisions on their behalf, in the event of them losing relevant capacity. There are two components – Health and Wellbeing and Finance and Property. It is, therefore, a form of advance planning and it has to be done while a person is still able to understand who it is they want to act for them, and what it is they want them to do. A GP may be asked for an opinion as to whether a person has capacity to appoint someone as LPoA. Once a patient loses capacity, it is too late, and a deputy needs to be appointed through the Court of Protection. This is much more expensive. LPoA can cover financial affairs or decisions about care, or both. It is quite easy to do, and a lawyer does not necessarily have to be involved. Forms are available from the internet and the Alzheimer's Society has useful information.

### **Advance Decisions to Refuse Treatment (ADRT)**

Under the Mental Capacity Act, any patient can write an ADRT. In order to be used, this needs to be kept in a place where it can be found when needed. It is best for

patients to send copies to relatives and for the existence of the document to be on the patient record. As long as the patient retains capacity they can rescind the document at any point. The patient can only dictate what medical care is NOT to be done in the event of them losing capacity. Common requests are not to be resuscitated, ventilated or artificially fed. CQC has standard forms. Information can also be obtained from the Alzheimer's Society website and from [www.patient.co.uk](http://www.patient.co.uk)

### **Independent Mental Capacity Advocates (IMCAs)**

The main roles of the IMCA are in relation to the Mental Capacity Act and in safeguarding of vulnerable adults. People making important decisions about someone who lacks capacity are required to consult with relatives or carers when reaching a best interests decision. If a patient has no-one who can speak for them, an IMCA will be appointed. IMCA involvement is required in safeguarding decisions for vulnerable adults in order to ensure that every opportunity has been taken to understand the patient's needs, and the patient has had appropriate help to express their wishes and views.

### **Deprivation of Liberty Safeguards (DoLS)**

A 2014 Supreme Court judgment has had particularly important implications in relation to DoLS.

In essence, DoLS legislation is about ensuring that a patient who lacks capacity has the benefit of a formal process if a decision is made to care for them in a place from which they cannot leave. This pertains even if the patient is content in their placement and is not trying to leave, so it applies to care homes where the door is locked to prevent patients wandering and getting into danger. An application to the Court of Protection is required. Temporary DoLS arrangements can be applied in an emergency but all longer term DoLS placements need to go through the Court.

#### **Key points:**

Mental Capacity is issue specific and must be based on a current assessment.

Separate 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.

DoLS practices have recently changed.

### **END OF LIFE**

Advanced dementia is a terminal condition and end of life plans should be put in place to support palliative care. These should be individualised and discussed with relatives.

End of life care can pose difficulties because the condition is not always predictable. Ideally, patients with dementia should be asked about their end of life wishes before they lose capacity, but these are not easy conversations. Relatives and carers continue to have a very important role if a patient is in hospital or has gone into care and need to be listened to carefully. Relationships between relatives and professional carers can quite easily become fraught. An end of life plan, incorporating the known wishes of the patient, is especially helpful if relatives disagree among themselves about how much intervention should occur in the event of deterioration. 'The Triangle of Care' – a document published by the RCN and The Carers' Trust is a helpful read.

A special mention needs to be made of nutrition because it can become a serious concern at the end of life, and care home staff need to report weight loss to GPs. Nutritional neglect in hospitals and care homes is a common cause of complaint from relatives. The Coroner must be informed if relatives complain about neglect in relation to a death. The common causes of Coroner involvement are nutrition, pressure sores and injuries.

Patients with dementia lose weight for various reasons but the main reasons, in the later stages of dementia, are difficulties coordinating, chewing and swallowing, or just, simply, inability or unwillingness to eat enough. Dietician and Speech and Language Therapy assessment (SaLT) should be sought where weight loss is persistent or aspiration is observed. Care homes should ensure that staff are offering the right food to patients, are taking time to assist with eating and are presenting food safely following SaLT advice. Good records need to be kept. Despite everyone's best efforts, patients with end-stage dementia may continue to lose weight and may eventually stop eating and drinking as part of terminal decline.

Relatives sometimes ask about PEG feeding for patients with dementia. In general, insertion of a PEG is not advised in patients who have severe dementia, as this has not been shown to improve or prolong life. A sudden event, such as a CVA, might be an indication and would require careful specialist consideration.

'Dementia' as the sole cause of death, will not be accepted on a Cause of Death certificate or a Cremation certificate. You need to specify severity. The registrar will accept 'Severe Dementia' for 1a.

## **Place of death**

Hospitals are highly detrimental environments for people with dementia. Inevitably, there will be changes of wards and changes of staff. The benefits and risks of hospital admission in late stages of dementia require careful conversations with relatives, and knowledge of a patient's prior wishes can be very helpful. There needs to be a discussion of what can realistically be achieved by hospital admission, and decisions may be complicated by feelings of guilt on the part of relatives, or fear of allegations of neglect on the part of care home staff. However, many relatives do take the view that the interests of the patient are not best served by another admission, and that they would prefer that their relative is treated palliatively at home. Out of hours services need care plans that specify that the patient should be offered appropriate care at home, and that CPR should not be attempted when the

patient dies. Relatives should be made aware of these documents. It is important for someone to explain to relatives that CPR is futile at the end of life and that they are not being asked to shorten their relative's life in any way.

### **Key points:**

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.

Relatives of residents in care homes often feel guilty and distressed. They are important monitors of the quality of care.

Bereavement reactions, following a death from dementia can be complex.

## **THE ALZHEIMER'S SOCIETY AND OTHER VOLUNTARY ORGANISATIONS**

Voluntary associations provide huge resources for patients and carers. The Alzheimer's Society has a vast website and contains virtually all the resources that may be needed. The Alzheimer's Society may hold contracts for local Memory Cafes and support workers in some places, although there are other charities who do this work as well. Support workers are able to help anyone with a memory problem – they do not need to have a diagnosis of dementia to receive help. Dementia charities run Dementia Awareness sessions for organisations, and 'Living with Dementia' education courses for patients and carers. Anyone can become a Dementia Friend by attending a short local session and signing up. Carers' Associations are also very active and helpful.

Dementia cafes, peer support groups and assistive technology have key roles in the support of people with dementia and their carers. On the whole charitable organisations play a far greater role in enhancing people's lives than the medical profession does. Singing for the Brain is particularly well received. There is also a growing experience of using art therapy for people with dementia, with impressive results, demonstrating the untapped potential that many people have, and their ability to enjoy new things and to develop, even while living with dementia.

## APPENDIX 1: CODING - ICD-10, EMIS and SystemOne codes

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. SystemOne practices) & description	
F00	Dementia in Alzheimer's disease	Eu00z	Dementia in Alzheimer's disease, unspecified	F110.	Alzheimer's disease
F01	Vascular dementia	Eu01z	Vascular dementia, unspecified	XE1XS	Vascular dementia
F00.2	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	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	Eu02y	Dementia in other diseases specified elsewhere	X0034	Frontotemporal dementia
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	XaKyY	Lewy body dementia
F10.7	Residual and late onset psychotic disorder due to alcohol Including: Alcoholic dementia Other alcoholic dementia Chronic alcoholic brain syndrome	Eu107	Residual and late onset psychotic disorder due to alcohol	Xa25J	Alcoholic dementia

*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.*

Author - Kim Thompson, Regional Medical Manager, NHS England North 10.11.14

## APPENDIX 2: USEFUL READING AND FURTHER INFORMATION

**For assessment of Cognition:** a handy guide to the major scales

[www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1045](http://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](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=609)

**Specific alternatives to medication for agitation**

[www.bps.org.uk/content/alternatives-antipsychotic-medication-psychological-approaches-managing-psychological-and-be](http://www.bps.org.uk/content/alternatives-antipsychotic-medication-psychological-approaches-managing-psychological-and-be)

**How to improve coding of dementia in your practice**

[www.dementiapartnerships.com/?s=coding](http://www.dementiapartnerships.com/?s=coding)

**The dementia prevalence calculator** – a guide to your local dementia prevalence rate

[www.dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/](http://www.dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/)

**Dementia partnerships**

A very useful source of information on all aspects of dementia

[www.dementiapartnerships.com](http://www.dementiapartnerships.com)

**Books**

David Ames, Edmond Chiu, James Lindesay and Kenneth I. Shulman (2010) *Guide to the Psychiatry of Old Age*. Cambridge: Cambridge University Press.

John Ballatt and Penelope Campling (2011) *Intelligent Kindness: Reforming the Culture of Healthcare*. London: RC Psych publications.

**The Alzheimer's Society**

A wealth of detail and information sheets about dementia with details of locally available services. A very useful source for people with dementia and their carers

[www.alzheimers.org.uk/](http://www.alzheimers.org.uk/)

## APPENDIX 3: USEFUL SCALES

Common cognition tests are:

- Abbreviated Mental Test Score (AMTS). It is easy to use. There are 10 questions with one mark for each answer. It largely measures memory and concentration and is used for screening in hospitals.

Qureshi KN, Hodkinson HM. (1974) Evaluation of a ten-question mental test in the institutionalized elderly. *Age & Ageing*. 3, 152–157

- Montreal Cognition Assessment (MOCA). A 'MOCA blind' is available for visually impaired patients.

[www.mocatest.org/](http://www.mocatest.org/)

- GPCOG. It contains cognitive tests and elements of the history

The General Practitioner Assessment of Cognition [www.gpcog.com.au/](http://www.gpcog.com.au/)

- MMSE The gold standard of cognitive tests but now subject to copyright issues.

Folstein, M. F., Folstein, S.E., Mchugh, P.R. (1975) Mini-mental state. A practical method for grading the cognitive state of patients for the clinician, *Journal of Psychiatric Research*, 12, 3, 189-198

- ACE III (this is a modified Addenbrooke's test - the MMSE questions that are subject to copyright have been removed. Lengthy and probably not that suitable for General Practice. )

[www.neura.edu.au/frontier/research/test-downloads/](http://www.neura.edu.au/frontier/research/test-downloads/)

Depression:

- Geriatric Depression Scale (can be helpful in younger people despite its name)

*4 item* - H W van Marwijk, P Wallace, G H de Bock, J Hermans, A A Kaptein, and J D Mulder (1995) Evaluation of the feasibility, reliability and diagnostic value of shortened versions of the geriatric depression scale, *British Journal of General Practice*, 45:195-199; Almeida OP, Almeida SA (1999) Short versions of the geriatric depression scale: a study of their validity for the diagnosis of a major depressive episode according to ICD-10 and DSM-IV . *International Journal of Geriatric Psychiatry*. 14(10):858-65.

*15 item*: Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey MB, Leirer VO: Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research* 17: 37-49, 1983; Sheikh JA, Yesavage JA. 1986. Geriatric Depression Scale (GDS): recent findings and development of a shorter version. In *Clinical Gerontology: A Guide to Assessment and Intervention*, Brink TL (ed) Howarth Press: New York.

Delirium:

- AT4: a useful screening test for delirium

4AT Score: [www.the4at.com/](http://www.the4at.com/)

## ABBREVIATED MENTAL TEST SCORE

1. Age?

0 points–incorrect 1 point- correct
--

2. Time? (to nearest hour)

0 points–incorrect 1 point- correct
--

3. Address for recall at end of test

*(this should be repeated by the patient to ensure it has been heard correctly)*

"42 West Street"

4. Year?

0 points–incorrect 1 point- correct
--

5. Name of this place?

0 points–incorrect 1 point- correct
--

6. Identification of two persons (doctor, nurse etc.)?

0 points–incorrect 1 point- correct
--

7. Date of birth?

0 points–incorrect 1 point- correct
--

8. Year of First World War?

0 points–incorrect 1 point- correct
--

9. Name of present Monarch?

0 points–incorrect 1 point- correct
--

10. Count backwards 20 to 1

0 points–incorrect 1 point- correct
--

Address recall correct?

0 points–incorrect 1 point- correct
--

Abbreviated mental test score =  /10

--

AMT Score: Qureshi KN, Hodkinson HM. (1974) Evaluation of a ten-question mental test in the institutionalized elderly. *Age & Ageing*. 3, 152–157

## MONTREAL COGNITION ASSESSMENT (MOCA)

MOCA: [www.mocatest.org/](http://www.mocatest.org/)



# GENERAL PRACTITIONER ASSESSMENT OF COGNITION (GPCOG)

## GPCOG Patient Examination

Unless specified, each question should only be asked once

### Name and address for subsequent recall

*"I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington"*

*(Allow a maximum of 4 attempts but do not score yet)*

### Time Orientation

What is the date? (accept exact only)

0 points—incorrect  
1 point- correct

### Clock Drawing (visuospatial functioning) use a paper with a printed circle.

Please mark in all the numbers to indicate the hours of a clock (correct spacing required).

0 points—incorrect  
1 point- correct

*For a correct response (above), the numbers 12, 3, 6, and 9 should be in the correct quadrants of the circle and the other numbers should be approximately correctly placed.*

Please mark in hands to show 10 minutes past eleven o'clock (11:10).

0 points—incorrect  
1 point- correct

*For a correct response (above), the hands should be pointing to the 11 and the 2 but do not penalise if the respondent fails to distinguish the long and short hands.*

### Information

Can you tell me something that happened in the news recently? (recently = in the last week)

0 points—incorrect  
1 point- correct

*Respondents are not required to provide extensive details, as long as they demonstrate awareness of a recent news story.*

*If a general answer is given, such as "war", "a lot of rain", ask for details.*

*If unable to give details, the answer should be scored as incorrect.*

### Recall

What was the name and address I asked you to remember?

*Score for each of the 5 components - John, Brown, 42, West Street, Kensington.*

John	0 points—incorrect / 1 point- correct
Brown	0 points—incorrect / 1 point- correct
42	0 points—incorrect / 1 point- correct
West Street	0 points—incorrect / 1 point- correct
Kensington	0 points—incorrect / 1 point- correct

GPCOG Patient Score=  /9

## GPCOG Informant Interview

Ask the informant: "Compared to a few years ago"

Does the patient have more trouble remembering things that have happened recently?

Yes / No

Does he or she have more trouble recalling conversations a few days later?

Yes / No

When speaking, does the patient have more difficulty in finding the right word or tend to use the wrong words more often?

Yes / No

Is the patient less able to manage money and financial affairs (e.g., paying bills, budgeting)?

Yes / No

Is the patient less able to manage his or her medication independently?

Yes / No

Does the patient need more assistance with transport (either private or public)?

Yes / No

Score 1 point for each "no" answer.

Informant Score=  /6

Combined (overall) score=  /15

Overall

**Patient name:** \_\_\_\_\_ **Date:** \_\_\_\_\_

© University of New South Wales as represented by the Dementia Collaborative Research Centre – Assessment and Better Care; Brodaty, H., Pond, D., Kemp, N., Luscombe, G., Harding, L., Berman, K. and Huppert, F. (2002) The GPCOG: A New Screening Test for Dementia Designed for General Practice, *Journal of the American Geriatrics Society*, 50, 530-534

## ADDENBROOKE'S COGNITIVE EXAMINATION – ACE-III

ACE III: [www.neura.edu.au/frontier/research/test-downloads/](http://www.neura.edu.au/frontier/research/test-downloads/)

## GERIATRIC DEPRESSION SCALE

There are four and 15 item versions

### 4 Item Geriatric Depression Scale (GDS-4)

Are you basically satisfied with your life?	Yes NO
Do you feel that your life is empty?	YES No
Are you afraid that something bad is going to happen to you?	YES No
Do you feel happy most of the time?	Yes NO
4 Item GDS score <input type="text"/> /4	<input type="text"/>

(Score 1 for answers in block capitals: 2-4=Depressed, 1=uncertain, 0=Not depressed)

### 15 Item Geriatric Depression Scale (GDS-15)

Are you basically satisfied with your life?	Yes NO
Have you dropped many of your activities and interests?	YES No
Do you feel that your life is empty?	YES No
Do you often get bored?	YES No
Are you in good spirits most of the time?	Yes NO
Are you afraid that something bad is going to happen to you?	YES No
Do you feel happy most of the time?	Yes NO
Do you often feel helpless?	YES No
Do you prefer to stay at home, rather than go out and do new things?	YES No
Do you feel you have more problems with memory than most?	YES No
Do you think it is wonderful to be alive?	Yes NO

Do you feel pretty worthless the way you are now?

YES  
No

Do you feel full of energy?

Yes  
NO

Do you feel that your situation is hopeless?

YES  
No

Do you think that most people are better off than you are?

YES  
No

15 Item GDS score

(Score 1 for answers in block capitals: 0-4 normal, 5-9 Mild depression, 10-15 More severe depression)

*4 item* - H W van Marwijk, P Wallace, G H de Bock, J Hermans, A A Kaptein, and J D Mulder (1995) Evaluation of the feasibility, reliability and diagnostic value of shortened versions of the geriatric depression scale, *British Journal of General Practice*, 45:195-199; Almeida OP, Almeida SA (1999) Short versions of the geriatric depression scale: a study of their validity for the diagnosis of a major depressive episode according to ICD-10 and DSM-IV . *International Journal of Geriatric Psychiatry*. 14(10):858-65.

*15 item*: Yesavage JA, Brink TL, Rose TL, Lum O, Huang V, Adey MB, Leirer VO: Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research* 17: 37-49, 1983; Sheikh JA, Yesavage JA. 1986. Geriatric Depression Scale (GDS): recent findings and development of a shorter version. In *Clinical Gerontology: A Guide to Assessment and Intervention*, Brink TL (ed) Howarth Press: New York.

## 4AT SCORE

### 1 Alertness

*This includes patients who may be markedly drowsy (eg. difficult to rouse and/or obviously sleepy during assessment) or agitated/hyperactive. Observe the patient. If asleep, attempt to wake with speech or gentle touch on shoulder. Ask the patient to state their name and address to assist rating.*

Normal (fully alert, but not agitated, throughout assessment) **0**

Mild sleepiness for <10 seconds after waking, then normal **0**

Clearly abnormal **4**

### 2 AMT4

*Age, date of birth, place (name of the hospital or building), current year.*

No mistakes **0**

1 mistake **1**

2 or more mistakes/untestable **2**

### 3 Attention

*Ask the patient: "Please tell me the months of the year in backwards order, starting at December."*

*To assist initial understanding one prompt of "what is the month before December?" is permitted.*

Months of the year backwards Achieves 7 months or more correctly **0**

Starts but scores <7 months/refuses to start **1** Untestable (cannot start because unwell, drowsy, inattentive) **2**

### 4 Acute change or fluctuating course

*Evidence of significant change or fluctuation in: alertness, cognition, other mental function (e.g. paranoia, hallucinations) arising over the last 2 weeks and still evident in last 24hrs*

No **0**

Yes **4**

**4 or above:** possible delirium +/- cognitive impairment

**1-3:** possible cognitive impairment

**0:** delirium or severe cognitive impairment unlikely (but delirium still possible if [4] information incomplete)

## 4AT SCORE

**GUIDANCE NOTES** Version 1.1. Information and download: [www.the4AT.com](http://www.the4AT.com)

The 4AT is a screening instrument designed for rapid initial assessment of delirium and cognitive impairment. A score of 4 or more *suggests* delirium but is not diagnostic: more detailed assessment of mental status may be required to reach a diagnosis. A score of 1-3 suggests cognitive impairment and more detailed cognitive testing and informant history-taking are required. A score of 0 does not definitively exclude delirium or cognitive impairment: more detailed testing may be required depending on the clinical context. Items 1-3 are rated *solely on observation of the patient at the time of assessment*. Item 4 requires information from one or more source(s), eg. your own knowledge of the patient, other staff who know the patient (eg. ward nurses), GP letter, case notes, carers. The tester should take account of communication difficulties (hearing impairment, dysphasia, lack of common language) when carrying out the test and interpreting the score.

**Alertness:** Altered level of alertness is very likely to be delirium in general hospital settings. If the patient shows significant altered alertness during the bedside assessment, score 4 for this item. **AMT4 (Abbreviated Mental Test - 4):** This score can be extracted from items in the AMT10 if the latter is done immediately before. **Acute Change or Fluctuating Course:** Fluctuation can occur without delirium in some cases of dementia, but marked fluctuation usually indicates delirium. To help elicit any hallucinations and/or paranoid thoughts ask the patient questions such as, “Are you concerned about anything going on here?”; “Do you feel frightened by anything or anyone?”; “Have you been seeing or hearing anything unusual?”

4AT Score: [www.the4at.com/](http://www.the4at.com/)

## APPENDIX 4: ANTICHOLINERGICS AND OTHER DRUGS TO BE USED WITH CAUTION IN DEMENTIA

Drugs for bladder instability	Avoid if possible. If not, Solifenacin is preferred to Tolterodine or Oxybutynin
Antiemetics	Domperidone and Ondansetron preferred to Cyclizine, Metoclopramide, Prochlorperazine (and other phenothiazines).
Antihistamines	Avoid if possible. If not, Loratadine and Fexofenadine preferred to Chlorpheniramine, Promethazine, Hydroxyzine
Tricyclics generally	Includes the very commonly used Amitriptyline
Analgesics	Avoid Tramadol and Pethidine in particular
Sedation	All sedation to be used with caution – long-acting benzodiazepines and anti-psychotics especially