

# Dementia: Diagnosis & Management in General Practice

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# ***Dementia***

## ***Diagnosis & Management***

### ***in General Practice***

## ***Quick Reference Guide***

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Quality and Safety in Practice Committee

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**Level 1:** Evidence obtained from systematic review of randomised trials

**Level 2:** Evidence obtained from at least one randomised trial

**Level 3:** Evidence obtained from at least one non-randomised controlled cohort/follow-up study

**Level 4:** Evidence obtained from at least one case-series, case-control or historically controlled study

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\* Level may be graded down on the basis of study quality, imprecision, indirectness (study PICO does not match questions PICO), because of inconsistency between studies, or because the absolute effect size is very small; Level may be graded up if there is a large or very large effect size. Where possible, systematic review evidence is presented.

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## Summary

### Prevalence

Ireland currently has over 55,000 people with dementia, a figure which is expected to double by 2036. Rising dementia prevalence rates combined with the policy objective of enabling people with dementia to remain living at home, means that there will be a growing demand for primary care-based dementia care in the future.

### Diagnosis

Timely diagnosis enables planning for the future, the involvement of relevant support organisations, appropriate medication management and may help to relieve the psychological distress experienced by caregivers (level of evidence 1).

Dementia is a group of disorders, characterized by a decline in cognition involving one or more cognitive domains (learning and memory, language, executive function, complex attention, perceptual-motor, social cognition). The deficits must represent a decline from previous levels of function and be severe enough to interfere with daily function and independence.

Mild cognitive impairment is generally defined by the presence of memory difficulty and objective memory impairment but is distinguished from dementia by the preserved ability to function in daily life.

Sub-types of dementia include Alzheimer's disease, vascular dementia, dementia with lewy bodies, Parkinson's disease dementia, cortico-basilar dementia, fronto-temporal dementia, normal pressure hydrocephalus and alcohol-related dementias.

Recognition of an emerging dementia syndrome is dependent upon: history taking - including both the patient's report and a detailed collateral history, physical examination, appropriate investigations, medication review, cognitive assessment and specialist input – especially for complex cases.

### Post-Diagnosis Care

**Disclosure:** The majority of people with mild dementia wish to know their diagnosis. Disclosure may facilitate a more patient-centered approach, more pro-active management of dementia and may end the uncertainty for patients and their families.

- Once a diagnosis is received, people with dementia and carers indicate their difficulty in accessing information, navigating the health and social care system and the lack of suitable services and supports.
- Ireland's National Dementia Strategy (INDS) also emphasises the importance of integrated care pathways involving a multidisciplinary response by community based healthcare professionals, as members of a Primary Care Team.
- Medication management in dementia usually focuses on 2 key areas: medications for Alzheimer's Disease cholinesterase inhibitors and memantine and medications for the management of behavioural and psychological symptoms of dementia.

### Behavioural and Psychological Symptoms of Dementia (BPSD)

BPSD is a term used to describe a wide range of behaviours and symptoms that affect patients with dementia. Behavioural symptoms are identified by patient observation and include aggression, agitation, wandering, sexual disinhibition and restlessness. Psychological symptoms are assessed on interviewing patients and carers, and include anxiety, depression, hallucinations and delusions.

Guidelines recommend that non-pharmacological strategies be used first-line for BPSD, unless the person with dementia poses a significant risk to themselves or others (level of evidence 1). Side-effects of antipsychotics include increased risk of falls and drowsiness, hip fractures, pneumonia, reduced motor function, parkinsonism, tardive dyskinesa, accelerated cognitive decline and QT prolongation.

## Driving and Dementia

Dementia may affect driving ability by impacting on perception, attention, judgment and impulsiveness. If in doubt about the patient's ability to drive, referral to an occupational therapist, or on-road testing with a driving assessor, qualified to assess driving among those with disabilities, may be of assistance.

## Legal Issues

The most common legal undertaking for GPs in dementia care involves assessment of the patient's legal capacity to make a will. GPs are also asked to assess patients' capacity to grant an enduring power of attorney. An Advance Healthcare Directive is an advance expression made by a person with capacity, of the person's will and preferences concerning healthcare treatment decisions that may arise if s/he subsequently lacks capacity.

## Dementia and Down Syndrome

The risk for developing dementia for people with Down syndrome by age 50 is 23%, 45% at age 55 and 88% at age 65.

Assessment tools for dementia in the general population are not appropriate for people with Down syndrome. The assessment needs to focus on individual changes in the respective person-compare early assessed baseline with periodic re-assessments.

## Advanced Dementia

The majority of people with dementia die in nursing homes, only around 2% die in a hospice.

Advance care planning and palliative care plans for patients with end stage dementia may help to reduce inappropriate interventions. People with dementia appear to have a significantly increased risk of pain with up to half of people with dementia estimated to be living with chronic pain. Persons with advanced dementia are more likely to be subject to polypharmacy and are at increased risk of inappropriate prescribing and adverse outcomes as a result of medication therapy.

## Section 1: Introduction

### 1.1 Background

Dementia is a syndrome characterised by progressive cognitive impairment and is associated with impairment in functional abilities and in many cases, behavioural and psychological symptoms<sup>1</sup>.

There may be memory loss usually related to short term memory, communication difficulties, changes in personality or mood and problems with spatial awareness. The ability to perform activities of daily living independently may arise, with instances such as forgetting the names of common objects, times and places, missed appointments and issues around drug adherence.

Globally, the prevalence of dementia is rising. Recent estimates suggest that there are currently 46 million people living with dementia worldwide, while this number is estimated to increase to 131.5 million by 2050<sup>2</sup>. Mirroring global estimates and commensurate with its ageing population, the prevalence of dementia in Ireland is projected to rise considerably too in the coming decades. Ireland currently has over 55,000 people with dementia, a figure which is expected to double by 2036, while there are approximately 60,000 informal caregivers, mostly family members<sup>3</sup>. Approximately 60% of people with dementia, i.e. > 30,000 live in their own homes, supported by family carers<sup>4</sup>.

The average GP diagnoses one or two new patients with dementia each year and will have 12 to 15 patients with dementia in an average list size<sup>5</sup>. Primary care dementia workload will inevitably increase as our population ages.

From a global burden of disease perspective, dementia contributes to a greater number of years spent living with a disability in people over the age of 60 years than stroke, cardiovascular disease or cancer<sup>6</sup>.

Calculations suggest that the current cost of dementia care in Ireland is €1.69 billion per annum<sup>4</sup>. There is a significant social cost for families and carers too. Dementia, however, continues to lag behind other chronic diseases in terms of budget allocation and in the share of resources devoted to research on the topic, particularly relative to disease burden<sup>4</sup>.

General Practitioners are often the first healthcare professionals to be consulted when dementia is suspected by patients or their families. Early recognition is not easy because of the insidious and variable onset of symptoms. Confirmation of the diagnosis can take up to 4 years<sup>7</sup>. Irish GPs experience difficulty in diagnosing and disclosing a diagnosis of dementia to their patients citing difficulties differentiating normal ageing from symptoms of dementia, lack of confidence and concerns about the impact of the diagnosis on the patient<sup>8</sup>.

Studies of GP learning needs have highlighted the need for dementia education, in particular around areas including the diagnosis, assessment of carers' needs, quality markers for dementia care in general practice, and assessment of mental capacity<sup>8</sup>. A recent Irish study found that GPs want more training on diagnosis, disclosure and the management of behavioural and psychological symptoms of dementia (BPSD)<sup>9</sup>. In the same study, family carers and people with dementia also emphasised the need for GPs to guide them towards local dementia care services and supports.

Current national and international dementia policy advocates a patient-centered approach enabling persons with dementia to stay living at home for as long as possible<sup>4</sup>.

The Irish National Dementia Strategy, published in 2014, highlights the pivotal role played by GPs in the care of people with dementia, in particular emphasising GPs' central position in the priority action areas of timely diagnosis and intervention, multidisciplinary care and also integrated services and supports. In addition, specific areas of dementia care that involve GPs are addressed, that include palliative care and the management of BPSD<sup>10</sup>. In the UK, GPs have been resourced to improve their diagnostic rates and their management of patients with dementia, through the Quality and Outcomes Framework (QOF). In Ireland, however, the current GP contract lacks a chronic disease management programme and general practice dementia care has remained under-resourced.



## 1.2 Aims of the Document

The aim of this document is to provide an overview of current guidelines and clinical evidence in the management of dementia in general practice. More specifically, its objectives are to explore the key areas around dementia diagnosis, disclosure, management and support of patients and their families.

## 1.3 Key Points

- Dementia prevalence is rising with resultant increase in general practice dementia workload.
- Timely diagnosis and early intervention is advocated by clinical guidelines and national strategies.
- A multidisciplinary approach to the diagnosis and management benefits patients with dementia.
- Education of patients, families and carers and activation of social supports, voluntary and non-voluntary agencies should follow diagnosis.
- Antipsychotics should be used with caution and use should be reviewed at regular intervals.

## Section 2: Diagnosing Dementia

Timely diagnosis of dementia has been recognised as key in the improvement of dementia services and is supported by clinical guidelines and national dementia strategies across Europe<sup>10, 11</sup>. Timely diagnosis enables planning for the future, the involvement of relevant support organisations and may help to relieve the psychological distress experienced by caregivers<sup>12</sup> (level of evidence 1). In patients with dementia who have Alzheimer's disease there is the potential for using cholinesterase inhibitors to modify symptoms and delay the need to seek nursing home care. Under-diagnosis of dementia is common. Approximately 50% of older adults with dementia are either undiagnosed or unaware of the diagnosis, suggesting shortcomings in detection and communication of dementia<sup>13</sup>. Furthermore, while most older persons indicate that they would want a disclosure of the diagnosis<sup>14</sup>, disclosure is frequently omitted by healthcare professionals<sup>9</sup>. The timeliness of the diagnosis is important as the hazards of early recognition are well recognized. These hazards may include an increase in false positive rates, patient trauma on receiving the diagnosis, stigmatization, overloading of specialist services, under-treatment of conditions such as depression and conflict within families<sup>15</sup> (level of evidence 5).

When considering the diagnosis of dementia, it is important to distinguish between case finding and screening. In practice, most assessment of cognitive impairment in primary care involves case finding rather than non-targeted screening. Case finding is the process of establishing a diagnosis where clinical suspicion exists. The aim is to identify a target condition with minimal false negatives. Non-targeted screening of asymptomatic individuals is not recommended, as there is no evidence that screening improves outcomes, may lead to unnecessary investigations and a high rate of false positive diagnoses<sup>16</sup> (level of evidence 1). Case finding by testing high risk groups is more desirable than random screening of patients based on age alone. High risk conditions and groups to consider include: MCI, strong cardiovascular risk factors, post-stroke, positive family history, Down Syndrome, HIV, alcohol excess, nursing home residents and patients with neurodegenerative diseases e.g. Parkinson's disease.

### Diagnostic Criteria

Dementia is a group of disorders, characterized by a decline in cognition involving one or more cognitive domains<sup>17</sup> (learning and memory, language, executive function, complex attention, perceptual-motor, social cognition). The deficits must represent a decline from previous levels of function and be severe enough to interfere with daily function and independence. At a minimum, assistance should be required with complex instrumental activities of daily living, such as paying bills or managing medications. The cognitive deficits do not occur exclusively in the context of a delirium and are not better explained by another mental disorder (e.g., major depressive disorder, schizophrenia).

Young onset dementia is conventionally considered to include patients with onset of dementia before 65 years of age<sup>18</sup>.

Dementia is often preceded by a period of mild cognitive impairment (MCI). However, one-third of MCI cases do not progress to dementia. MCI is generally defined by the presence of memory difficulty and objective memory impairment but is distinguished from dementia by the preserved ability to function in daily life.

Delirium is an acute (hours to days), usually reversible, metabolically induced state of confusion, often with fluctuating consciousness. Patients with delirium have difficulty maintaining attention and concentration. Delirium and dementia can overlap, making the distinction difficult. Dementia itself is the greatest risk factor for developing delirium, adding to the complexity of the assessment.

The latest diagnostic criteria for delirium include the following features;

- A disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (reduced orientation to the environment).
- The disturbance develops over a short period of time (usually hours to a few days), represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.
- An additional disturbance in cognition (e.g. memory deficit, disorientation, language, visuo-spatial ability, or perception).

The disturbances in attention and cognition are not better explained by a pre-existing, established or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma.

There is evidence from the history, physical examination or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal, or exposure to a toxin, or is due to multiple etiologies<sup>17</sup>.

## 2.1 Types of Dementia

The term dementia refers to a group of syndromes characterized by a progressive decline in cognitive function. Over 200 subtypes have been defined.

The main sub-types of dementia include Alzheimer’s Disease (AD), Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), Fronto-temporal dementia (FTD), and Alcohol-related dementias. These are briefly described in Table 1.

Other sub-types include Huntington’s Disease, HIV-dementia, Motor Neurone Disease dementia and Prion Disease (includes Classical Creutzfeldt-Jakob Disease). Identification of dementia sub-type is important because different types of dementia will have different courses, with different patterns of symptoms, and can respond differently to treatments.

*Table 1: Summary of the Main Subtypes of Dementia<sup>19,20</sup>*

Summary of the Main Subtypes of Dementia
<p><b>Alzheimer’s Disease (AD):</b></p> <p>Estimated 50% of cases of dementia.</p> <p>Symptoms include,</p> <ol style="list-style-type: none"> <li>1) Cognitive dysfunction - includes memory loss and language difficulties</li> <li>2) Behavioural and psychological symptoms - e.g. apathy, depression, hallucinations, delusions, agitation</li> <li>3) Difficulties with performing activities of daily living</li> </ol> <p>The average survival period for patients following diagnosis is 8 to 10 years.</p> <p>The neuronal cell death in AD is associated with the build-up of two distinct proteins: beta-amyloid protein in ‘plaques’ outside neurones and tau proteins in ‘tangles’ within neurones. Amyloid Precursor Protein is an important soluble protein that is cleaved by specific enzymes into amyloid. While most amyloid fragments are harmless and remain soluble, fragments of a certain length (42 amino acids = ‘beta amyloid’) have a strong tendency to come together to form clumps in the brain.</p> <p>Approximately 5% of AD cases are familial (Autosomal Dominant), generally of younger onset, many of whom have the Amyloid Precursor Protein. Apart from early onset, familial AD, many other people have a particular form of the e4 apolipoprotein gene (APOE) that slightly increases their susceptibility to sporadic AD.</p>
<p><b>Vascular Dementia:</b></p> <p>Estimated 25% of cases of dementia. Onset may be abrupt or there may be periods of sudden decline followed by relative stability. Patients may present with signs of a prior stroke or other vascular problems, for example, ischaemic heart disease or hypertension. Physical problems such as decreased mobility and balance problems are more commonly seen in people with vascular dementia (VaD) than in people with Alzheimer’s disease.</p> <p>The clinical features depend on the sites of ischaemia. Memory may initially be preserved with deficits in other cognitive domains e.g. visuo-spatial. Heavy frontal ischemia may affect personality and social skills and may be associated with impulsivity or emotional lability.</p>

### **Dementia and Parkinson's:**

(Dementia with Lewy Bodies, Parkinson's Disease Dementia, Corticobasilar Degeneration & Progressive Supranuclear Palsy)

It is estimated that Dementia with Lewy Bodies (DLB) constitutes 15% of cases of dementia. Characterized by fluctuation of awareness from day-to-day and signs of parkinsonism such as tremor, rigidity and slowness of movement or poverty of expression. Visual hallucinations or delusions occur frequently. Falls are also common.

In addition, at least 40% of people with Parkinson's Disease develop Parkinson's Disease Dementia (PDD), especially if older at onset. Clinically, the main distinction between Dementia with Lewy Body and Parkinson's Disease Dementia is temporal. In Dementia with Lewy Body the dementia presents first, before the parkinson's symptoms or the dementia symptoms occur within a year of the Parkinson's Disease symptoms. In Parkinson's Disease Dementia the dementia symptoms develop after a person has had Parkinson's Disease for many years.

Corticobasilar degeneration (CBD) is a rare dementia in which there is progressive dementia, parkinsonism and limb apraxia associated with the build-up of the tau protein.

Progressive Supranuclear Palsy (PSP) often first presents with parkinsonism. A key sign over time is reduced vertical gaze as the pathology affects the mid-brain. People with PSP rarely have typical unilateral tremor or hand bradykinesia but they can have marked truncal rigidity. Later on the dementia becomes more apparent.

### **Fronto-temporal Dementia (FTD):**

Represents a significant proportion of people who present with dementia under the age of 65. Pick's disease is included in this subtype and is caused by Tau protein deposition. Changes in behaviour such as disinhibition, loss of social awareness and loss of insight are much more common than memory problems. Disturbance of mood, speech and continence are frequent. There may be an insidious decline in language skills, known as primary progressive aphasia. A positive family history of dementia is not uncommon.

The two main types of FTD are behavioural variant (bv-FTD), mainly affecting behaviour and Primary Progressive Aphasia Variant, which mainly affects language.

### **Alcohol-related Dementia:**

Korsakoff's dementia is a specific type of dementia, caused by thiamine deficiency, which may present with confabulation.

Alcohol excess is also a risk factor for vascular dementia, falls with head injury and the development of delirium.

### **Normal Pressure Hydrocephalus (NPH):**

A rare cause of dementia, in NPH the cerebral ventricles are larger than expected for the degree of atrophy visible on a brain scan. NPH presents as a triad of early gait disturbance, urinary incontinence and dementia. The diagnostic test involves draining about 50mls of cerebrospinal fluid and video-recording the person's gait pattern, a timed walking test (Get Up and Go) and cognitive tests before and after the drainage. Objective improvement suggests that insertion of a permanent VP shunt may be indicated.

The time between symptom development and diagnosis is characterized by uncertainty for people with dementia and their families. The accurate diagnosis of dementia is a challenge for both GPs and specialists.

In a pan-European study, the average length of time between symptom recognition and formal diagnosis being made is 20 months<sup>21</sup> (level of evidence 4).

Recognition of an emerging dementia syndrome is dependent upon:

- History Taking - including both (a) patient's report and (b) a detailed collateral history
- Physical Examination
- Appropriate Investigations
- Medication Review
- Cognitive Assessment
- Specialist input – especially for complex cases (e.g. uncertainty about diagnosis, atypical presentations, younger people with suspected dementia, rapidly progressive symptoms, challenging behaviour, psychosis, risk to self or others, comorbidities, complex psychopharmacology).

## 2.2 History Taking

Specific attention should be paid to mode of onset, course of progression, pattern of cognitive impairment and presence of non-cognitive symptoms such as behavioural disturbance, hallucinations and delusions. Apart from issues around memory disturbance, the history should also focus on evidence of aphasia (language disturbance), apraxia (motor disturbance) and agnosia (difficulty recognising objects), and complex instrumental activities of daily living, such as shopping, preparing a meal or managing finances. Behavioural disturbance should be explored too, as nearly all patients with AD experience some form of behavioural symptom during the course of their illness, such as apathy, anxiety, agitation and depression.

A detailed collateral history from a relative or carer is essential as a person with dementia may not be able to give a fully accurate history. Some cognitive screening tests e.g. GPCOG, include a standardized collateral as part of the test.

The differential diagnosis needs to be considered. The main differential diagnoses for dementia are depression, delirium and drugs (The three D's). Other treatable causes of cognitive impairment include hypothyroidism and certain vitamin deficiencies. Other differentials to consider include MCI, subjective memory problems, deafness, visual impairment and brain tumours. Exploring the possibility of dementia will often require a number of consultations.

## 2.3 Physical Examination

The focus of the physical examination should be on cardiovascular disease, neurological signs – in particular Parkinsonism, sensory loss, and the exclusion of any possible reversible causes of cognitive decline or delirium.

## 2.4 Appropriate Investigations

There is no single laboratory test that will prove the presence of dementia. Investigations are performed to find potentially reversible causes of cognitive impairment. Patients with an atypical presentation or those with rapidly progressive dementia will require more urgent and extensive investigations. Relevant investigations to perform are included in Table 2.

Table 2: Investigations for Dementia<sup>22</sup>

Investigations for Dementia
<p><b>Investigations in Primary Care</b></p> <p>Bloods – FBC, ESR, U&amp;E, TFTs, Glucose, Lipids, Calcium &amp; B12: (to detect co-morbid conditions such as anaemia due to B12 deficiency or renal disease) and to exclude reversible causes (e.g. hypothyroidism). Syphilis serology and HIV testing is not routinely recommended, unless patients are considered at risk.</p> <p>General Medical Investigations Chest X-Ray and MSU if clinically indicated ECG (Cholinesterase inhibitors may induce sinus bradycardia and aggravate pre-existing sinus node disease and AV block)</p> <p><b>Investigations in Secondary Care</b></p> <p>CT Scan (to exclude intracranial lesions, cerebral infarction and haemorrhage, extra and subdural haematoma, normal pressure hydrocephalus) MRI Scan (a sensitive indicator of cerebrovascular disease) Single-photon emission tomography (to assess regional blood flow) and dopamine scan to detect Lewy Body disease. Carotid ultrasound (if large vessel atherosclerosis suspected) EEGs are not part of routine workup.</p> <p>The use of positron emission tomography (PET) and other functional neuroimaging techniques, to assist in the differential diagnosis and subtyping of dementia, is an area of investigation occasionally utilized by specialists assessing complex cases.</p>

## 2.5 Medication Review

Many drugs may cause or mimic cognitive impairment. In a vulnerable patient, some medications are more commonly associated with confusion<sup>23</sup>:

Table 3: Medications associated with an Increased Risk Of Confusion

Medications Associated with an Increased Risk of Confusion
<ul style="list-style-type: none"> <li>• Anticonvulsants – all anticonvulsants impair cognitive function</li> <li>• Antidepressants – risks highest in tricyclics. Withdrawal delirium also occurs</li> <li>• Antipsychotics – those with considerable anticholinergic activity may worsen delirium</li> <li>• Anti-parkinsonian drugs – risk highest in those with anticholinergic activity</li> <li>• Cardiac drugs – including digoxin and calcium antagonists</li> <li>• Corticosteroids – risk is dose related</li> <li>• Hypnotics/Sedatives – more common with long-acting benzodiazepines</li> <li>• Opioid analgesics – risk highest with pethidine</li> <li>• Anticholinergics – drugs used for urinary incontinence, antihistamines, tricyclics</li> </ul>

## 2.6 Cognitive Assessment

Cognitive function testing adds further evidence to the clinical assessment and investigations. There are a number of validated cognitive screening tools used in general practice. A patient's performance may be affected by educational ability, language, hearing and culture. Results of testing should be included in referrals to secondary care<sup>24</sup>.

Over 50% of GPs use the MMSE because of availability and professional habit, however, there are a number of other cognitive assessment tools available that have been developed for use in primary care. A brief overview of commonly used assessment tools is given in Table 4.

Table 4: Cognitive Assessment Tools in Primary Care<sup>25,26,27</sup>

Cognitive Assessment Tools in Primary Care
<p><b>Mini-Mental State Examination (MMSE)</b> – Developed by Folstein, it is the most commonly used tool in general practice, therefore having translatability across healthcare settings. The MMSE measures orientation, immediate memory, attention and calculation, recall, various aspects of language and visuo-spatial skills. However, scores may be difficult to interpret and it shows age, cultural and educational bias. Scored out of 30, a score of &lt; 24 suggests dementia. It may take up to 20 minutes to complete and so may be less practical for primary care. There are copyright restrictions on the use of the MMSE. The MMSE can be purchased from PAR, Inc. by calling (813) 968-3003.</p>
<p><b>*General Practitioner Assessment of Cognition (GPCOG)</b> – This is a 6-item cognitive screening tool, specifically designed for use in primary care. Taking 5 minutes to complete, it appears to perform well within the primary care setting and is psychometrically robust and relatively free of educational bias. It includes time orientation, a clock drawing task, report of a recent event and a word recall task.</p>
<p><b>**Mini-Cognitive Assessment Instrument (Mini-Cog)</b> - A brief screening tool designed for primary care use, it assesses 2 aspects of cognition – short-term recall and clock drawing. It takes 3-5 minutes to complete and performs comparably to the GPCOG, also being relatively free of educational bias.</p>
<p><b>***Memory Impairment Screen (MIS)</b> – This is a 4-item assessment test that takes approximately 4 minutes to complete. The MIS is especially appropriate for use with ethnic minorities, as it does not show educational or language bias.</p>
<p><b>Abbreviated Mental Test Score (MTS)</b> – This is a well-established 10-item screen that samples various cognitive domains. There are only verbal items. Orientation, long-term memory, recognition and short-term memory are assessed.</p>
<p><b>Six Item Cognitive Impairment Tool (6CIT)</b> – Designed for primary care use, this takes approximately 5 minutes to complete. All items are verbally based. Orientation, short-term memory and attention/concentration are assessed.</p>
<p><b>The Montreal Cognitive Assessment (MoCA)</b> – is a short cognitive screening test with high sensitivity for detecting cognitive impairment. It is particularly useful in those with subtle cognitive deficits, such as an MCI. It is however lengthy, taking at least 10 minutes to complete and its specificity is relatively low.</p>
<p><b>The Clock Drawing Test</b> – is a popular, brief (&lt;2 mins), moderately sensitive and specific test used to screen for visuospatial problems and executive function. It is used alone or as part of other cognitive screening tools, including the GPCOG, Mini-Cog, MoCA and Q-mci.</p>
<p><b>The Quick Mild Cognitive Impairment (Qmci) Screen</b> – is a brief cognitive screening instrument designed to detect MCI. It places most emphasis on verbal fluency and episodic memory.</p>

Three well-conducted systematic reviews of cognitive screening tests in primary care have compared the properties of screening tools in use. They concurred that the best three tools for use in primary care were the \*GPCOG, the \*\*Mini-Cog and the \*\*\*MIS<sup>25,26,27</sup>. They were found to be practical, feasible, have wide applicability and were psychometrically robust (Appendix 1) (level of evidence 1).

## 2.7 Specialist Input and Memory Clinics

The diagnosis of dementia usually results following several consultations and the assembly of corroborative evidence. GPs have been found to be as proficient as memory clinics at making the diagnosis<sup>28</sup>. However, identifying the subtype of dementia remains a task for a multidisciplinary group. Furthermore, structural imaging should be used in the assessment of people with suspected dementia to exclude other cerebral pathologies and to help establish the dementia subtype. This accurate diagnosis and subtyping has become more important with the advent of treatments specifically for Alzheimer's Disease, and because of the need to avoid the potentially serious side-effects of antipsychotic use in people with Lewy body dementia.

Where available, referral to specialist services is, therefore, preferable for confirmation of the diagnosis, exclusion of other pathologies, subtyping of the dementia and tailoring of treatments to the specific dementia subtype<sup>20</sup> (level of evidence 5). The decision on whether to refer for a specialist opinion to Old Age Psychiatry, Gerontology, Neurology or a dedicated Memory Clinic is dependent upon resources that are available locally.

### Memory Clinics

Assessment of cognition is useful in both the initial and differential diagnosis of dementia. Further neuropsychological assessment performed by specialist multidisciplinary teams should be used in the diagnosis of dementia, especially in patients where dementia is not clinically obvious<sup>19</sup>. Memory clinics are increasingly being established as specialist centres for such assessments.

Neuropsychological testing also aids in the differential diagnosis of dementia. The provision of neuropsychology services is variable and in places non-existent. Neuropsychological testing helps to distinguish between AD and other age-associated neurodegenerative disorders<sup>29</sup> (level of evidence 5).

National Dementia Strategies have highlighted the role that memory clinics play in the early diagnosis of dementia<sup>10,30,31</sup>. Memory Clinics in Ireland are not available in every HSE area. There is considerable variability across these clinics in relation to the type of service on offer and how such services are resourced and financed. Some employ a full complement of allied health professionals with emphasis both on diagnosis and follow-up supports, whilst others do not. A few employ their own neuropsychologists, whilst many do not have immediate access to this service. These specialist services appear to be highly valued by both patients and family caregivers because of the opportunities they afford for in-depth discussion about the illness and prognosis<sup>32</sup>.



## Section 3: The Initial Management of Dementia

### 3.1 Disclosure

The majority of people with mild dementia wish to know their diagnosis and it is generally recommended that all GPs discuss the diagnosis with the person with dementia, unless there are clear reasons not to do so. The Alzheimer Society of Ireland ([www.asi.ie](http://www.asi.ie)) strongly advocates for disclosure. Disclosure may facilitate a more patient-centered approach, more pro-active management of dementia and may end the uncertainty for patients and their families. The disclosure of the diagnosis of dementia requires a sensitive individualized approach. GPs find this disclosure particularly difficult<sup>9</sup>, however, not conveying the diagnosis and the use of euphemism adds to uncertainty for patients and their families. Irish disclosure rates to patients rank poorly when compared with disclosure practices adopted in countries such as the UK and Norway<sup>8</sup>. Considerable time is needed with the person with dementia and, if the person consents, with their family. Both will need on-going support and this may need to be achieved over a number of consultations. There is an increased risk of depression in non-professional carers of people with dementia<sup>33</sup>.

Many questions arise for patients and family members following the diagnosis of dementia (level of evidence 5). Key areas to be considered are<sup>9,22</sup>:

*Table 5: Information Needs Arising from Diagnosis (level of evidence 5)*

Information Needs Arising from Diagnosis
Offer the person with dementia and their family information about: <ul style="list-style-type: none"><li>• Signs and symptoms, course and prognosis</li><li>• Local care and support services, local information and voluntary organisations</li><li>• Pharmacotherapy</li><li>• Medico-legal issues, including sources of financial and legal advice and advocacy</li><li>• Driving</li></ul>

The Alzheimer's Society of Ireland produces useful publications for patients and carers about financial, legal and care planning as well as practical tips for coping with memory loss.

Patients and their carers may also be entitled to a range of benefits, such as Carer's Benefit and Respite Care Grants.

Details on further educational, legal, financial, and service resources are available in Appendix 2, at the end of this document.

### 3.2 Educational Support

Acquiring a diagnosis of dementia is sometimes said to expose a 'care gap', where people are left with a clinical diagnosis but with little to no useful support<sup>15</sup>. This is recognised as one of the hazards of early diagnosis. Once a diagnosis is received people with dementia and carers indicate their difficulty in accessing information, navigating the health and social care system and the lack of suitable services and supports<sup>9,34</sup>.

GPs are well placed to provide education and to signpost supports available to persons with dementia and their families. Information should not only include issues considered relevant by clinicians, but should be tailored to meet the emerging needs of patients and carers<sup>7</sup> (level of evidence 4).

Many people with early dementia retain some insight, can understand their diagnosis and should be involved in decision-making. Patients and carers should be provided with information about the services and interventions available to them at all stages of the patient's journey of care.

Educational material is available from a number of sources, listed in the resources section in Appendix 2.

### 3.3 Community-Based Health Services

GPs are highly regarded by families of people with dementia because they provide continuity of care, have established relationships of trust, act as advocates and problem-solvers and they open the gates to other sources of help<sup>33</sup>. GPs are crucial in the development of care pathways as they are usually the first point of contact for the individual or for family members worried about the signs and symptoms of dementia and are well placed to refer patients and families to suitable supports and services.

However, GPs have identified a lack of knowledge of local health and support organisations as a key learning need in their care of patients with dementia<sup>9,35</sup>. The uncertainty about referral criteria and the insufficient supports and services for those with dementia, greatly affect post-diagnostic care provision. Services offered may be fragmented, poorly coordinated, inflexible and inequitable. However, provision of information about available supports is crucial.

A Vision for Change, the report from the expert group on mental health policy, advocates that primary care teams should play a major role in the integrated care of patients with dementia and should work in a coordinated manner with GPs and specialist teams to provide high quality care after diagnosis<sup>36</sup>. Ireland's National Dementia Strategy (INDS) also emphasises the importance of integrated care pathways involving a multidisciplinary response by community based healthcare professionals, as members of a Primary Care Team (PCT)<sup>10</sup>. In addition, and in line with national dementia strategies internationally, the INDS advocates better coordination between primary care, secondary care and community services. However, this objective may be hindered by the low levels of functioning PCTs nationally, in which GPs are actively engaged<sup>37</sup>.

Apart from GPs, other key members of the PCT who may contribute to the care of a patient with dementia are included in Table 6.

Information on community based health services including Day Care Centres, Community Hospitals, Community Intervention Teams, The Home Care Package and The Nursing Home Support Scheme may be found on the [HSE website](#).

## The Primary Care Team and Dementia

### Public Health Nurses (PHNs)

The PHN may have a role in the assessment and management of people with dementia and reviewing the need for supports. They act as the gatekeepers to other community care services such as home care, home help, home care packages, meals on wheels, day-care and other respite care.

### Occupational Therapists (OTs)

OTs are concerned with the care of the whole person; their emphasis tends to be on activities of daily living, including dressing, eating and grooming. Their main aim is to restore and reduce the decline in the person's functional ability. Occupational therapy enhances the abilities of individuals to engage in activities of daily living (e.g. eating, bathing, toileting, functional mobility) and instrumental activities of daily living (e.g. meal preparation, shopping, managing one's finances), work and productive activities (e.g. care of others, educational and vocational activities) and leisure<sup>38</sup>. OTs can also have a role to play in assessing patients' suitability for assistive technologies.

### Physiotherapists

Their main aim is to maximise the person's abilities regarding mobility to allow the greatest level of independence possible. In addition to cognitive decline, gait disturbance and impaired balance lead to a greater risk of falls and fractures for people with dementia. It is estimated that people with dementia are approximately three times more likely to fracture their hip than sex and age matched controls<sup>39</sup>.

Furthermore, for people with dementia the recovery following hip fracture is complicated by the interplay of psychological and social factors.

### Speech and Language Therapists (SLTs)

SLTs have a unique role in identifying the specific nature of communication difficulties for a person with dementia and in reducing the impact of the communication difficulties for the person and for their family members. Optimising the skills of the person with dementia as well as their communication partners, is key to their empowerment and their ability to live well with dementia. In addition to communication difficulties, feeding, eating, drinking and swallowing (FEDS) difficulties occur across all dementia types and those with advanced dementia often present with particularly complex needs in relation to oral feeding. Therefore, the need to assess and manage FEDS difficulties and identify potential risks for aspiration and health related consequences is crucial<sup>40</sup>.

### Dietitians

The dietitian's role is to carry out a full nutritional assessment of the person, based upon which they will provide individualised advice to help improve the person's overall health outcomes. Dietitians can provide sample meal plans and advise on how to fortify and supplement the diet if dietary intake is proving difficult for the person with dementia. A resource has been developed by dietitians, called Nutrition and Dementia, which can be provided to family members/carers which suggests practical strategies to help potential difficulties at mealtime; along with taste changes, overeating, weight loss, constipation, dehydration, or loss of interest in food<sup>41</sup>. Another useful website developed by dietitians is at [www.hse.ie/nutritionsupports](http://www.hse.ie/nutritionsupports).

### Social Workers

They have an important role to play in needs assessment, in advising people about their service entitlement; in protecting the rights of people with dementia and safeguarding the health and welfare of primary caregivers.

Table 6: The Primary Care Team and Dementia

### 3.4 Community-Based Social Services

The Alzheimer Society of Ireland (ASI) is a major dementia-specific service provider in Ireland. It provides a range of services and supports throughout the country, including the Alzheimer national helpline, a dementia advisor service, family carer support groups, social clubs, Alzheimer cafes and runs training courses for family members. Further ASI supports include homecare services, respite centres and day-care centres. The ASI is involved in dementia advocacy, fund-raising and research, details at [www.alzheimer.ie](http://www.alzheimer.ie).

The Carers Association is a voluntary organisation for family carers in the home and advocates on behalf of carers. It also provides information, education and support for family carers, details at [www.carersireland.ie](http://www.carersireland.ie).

There are a number of private service providers offering homecare and nursing care. The HSE provides a list of preferred providers on their website [www.HSE.ie](http://www.HSE.ie) or on their helpline 1850 24 1850.

A range of financial supports may be available to patients with dementia and their families. The Citizens Information Service provides full details of these payments and how to apply for them, on 1890 777 121 or on their website [www.citizensinformation.ie](http://www.citizensinformation.ie).

### 3.5 Pharmacotherapy

Medication management in dementia usually focuses on 2 key areas:

- 1) Drugs for Alzheimer's Disease (AD).
- 2) The management of behavioural and psychological symptoms of dementia (BPSD).

Of particular importance is the regular review and monitoring of all medications, as indicated in Table 3.

#### Drugs for Alzheimer's Disease:

##### Acetylcholinesterase Inhibitors (AChEIs)

In AD there are multiple neurotransmitter abnormalities but most prominent are cholinergic with reduced activity of choline acetyltransferase. AChEI (acetylcholinesterase inhibitors) works by enhancing the concentration of acetylcholine (a cholinergic neurotransmitter).

The NICE Guideline recommends the three Acetylcholinesterase inhibitors (AChEIs) donepezil, rivastigmine and galantamine, as options for managing mild to moderate Alzheimer's disease<sup>22</sup>. Evidence has shown that AChEIs are of some benefit in terms of improvements in cognition and ADLs<sup>42</sup> (level of evidence 5). Effect sizes are modest.

Dementia severity is frequently defined by Mini Mental State Examination (MMSE) score:

- Mild Alzheimer's disease: MMSE 21–26
- Moderate Alzheimer's disease: MMSE: 10–20
- Moderately severe Alzheimer's disease: MMSE 10–14
- Severe Alzheimer's disease: MMSE less than 10

However, the NICE guideline further explains that when assessing the need for AChEI treatment, clinicians should not rely on cognition scores alone in circumstances in which it would be inappropriate to do so<sup>22</sup>. These circumstances include if the cognition score is not a clinically appropriate tool for assessing the severity of that patient's dementia. A decision on the initiation and maintenance of medications should be made on therapeutic and clinical grounds.

The most common adverse effects of AChEIs are gastrointestinal, involving nausea, vomiting, diarrhoea and abdominal pains. These effects occur most commonly on initiation and up-titration of the dosage and are usually transient. Adverse effects may be reduced or avoided by increasing the dose slowly or by taking the medicine after food. Patients who do not tolerate one AChEI may tolerate another.

Randomized controlled trials have shown benefits of AChEIs in dementia with Lewy bodies (DLB) and Parkinson’s disease dementia also<sup>42</sup> (level of evidence 5). AChEIs are not effective for the treatment of mild cognitive impairment<sup>22</sup>. AChEIs are not recommended for the treatment of Vascular Dementia, however, many patients in clinical practice have both Alzheimer’s disease and cerebrovascular pathology<sup>43</sup> (level of evidence 5).

Treatment should be continued only when it is considered to be having a worthwhile effect on cognition or function<sup>22</sup>. When to de-prescribe AChEIs can be a difficult decision for clinicians. Circumstances in which a withdrawal of an AChEI would be reasonable include; severe/ end-stage dementia, where the AChEI has been prescribed for >12 months and the person’s cognition or function has significantly worsened over the previous 6 months, or where the AChEI has been prescribed for >12months and there has been no benefit seen during treatment (i.e. no improvement, no stabilization or no decreased rate of decline)<sup>44</sup>. Discontinuing cholinesterase inhibitors may lead to worsening of cognitive functions and greater functional impairment as compared to continued therapy<sup>35</sup>. When a decision has been made to discontinue therapy because of a perceived lack of effectiveness, the dose should be tapered before stopping the treatment and the patient be monitored over the next 1-3 months for evidence of observable decline. If it occurs consideration should be given to reinstating therapy<sup>45</sup>.

The use of anticholinergics and cholinomimetics (e.g. neostigmine, pyridostigmine) should be avoided<sup>23</sup> in all people with dementia. In particular, they should not be co-prescribed with an AChEI. Anticholinergics have an opposing mechanism of action to AChEIs - they decrease the amount of cholinergic neurotransmitters (like acetylcholine). An anticholinergic medication can, therefore, counteract the beneficial effects of AChEIs.

### Memantine

Memantine is a non-competitive N-methyl-D-aspartate receptor antagonist (NMDA). Overstimulation of the N-methyl-D-aspartate (NMDA) receptor by glutamate is implicated in neurodegenerative disorders.

Memantine may be considered as the person’s dementia progresses. It is recommended for the management of moderate Alzheimer’s disease for patients who are intolerant of or have a contraindication to AChEIs and for severe Alzheimer’s disease<sup>22</sup>. It may be used alone or in combination with cholinesterase inhibitors<sup>46</sup> (level of evidence 1). It is generally well tolerated although common undesirable effects are dizziness, headache, constipation, somnolence and hypertension<sup>47</sup>.

When prescribing both AChEIs and memantine guidelines advise that treatment should be initiated and supervised by a physician experienced in the diagnosis and treatment of Alzheimer’s disease<sup>22</sup>.

## 3.6 Regular Review

Needs and management strategies will change as the dementia progresses. The median survival of people with dementia diagnosed at aged 60-69yrs is 6.7 years (interquartile range 3.1-10.8 years), falling to 1.9 years (interquartile range 0.7-3.6 years) for those diagnosed at age 90yrs or over<sup>48</sup>. Once the diagnosis is made, the support needs of patients and carers should be carefully assessed. This will need to be repeated over intervals as needs change. The quality of care provided to patients with dementia can be improved by focusing on key areas at this regular review<sup>49</sup>. These are listed in Table 7.

Table 7: Areas for Discussion at Regular Review<sup>22,49</sup>

Areas for Discussion at Regular Review
<ul style="list-style-type: none"> <li>• Medications – including use of antipsychotics</li> <li>• Mental Health – including screen for depression</li> <li>• Social Care</li> <li>• Assessment of Carer’s Needs</li> </ul>

Regular physical examination should focus on hearing, vision, nutrition, bowel and bladder function<sup>50</sup>. In the later stages of dementia dental hygiene may be poor, leading to gum disease, tooth decay, infection and difficulty eating. Dental review both early and throughout the illness may help to address these problems<sup>51</sup> (level of evidence 5).

Immunisation guidelines recommend flu vaccine administration for residents of nursing homes and long stay institutions, as well as in persons aged 65 years and over<sup>52</sup> (level of evidence 5).

Along with this regular review, a risk assessment should be performed, in order to detect risk to self or others. This may include assessment of:

- Inadvertent self-harm e.g. kitchen accidents, medication mistakes etc.
- Deliberate self-harm.
- Risks to others e.g. driving, gun ownership, aggression, child-minding when losing ability to do so safely etc.
- Elder abuse and vulnerability - Abusive behaviour by family carers towards people with dementia is common, with one-third of people with dementia reporting important levels of abuse and a half reporting some abusive behaviour<sup>53</sup>.

## Section 4: The Behavioural and Psychological Symptoms of Dementia (BPSD)

BPSD is a term used to describe a wide range of behaviours and symptoms that affect patients with dementia.

One way of grouping these behaviours and symptoms is as follows:

- Behavioural symptoms identified by patient observation, such as aggression, agitation, wandering, sexual disinhibition and restlessness.
- Psychological symptoms assessed on interviewing patients and carers, including anxiety, depression, hallucinations and delusions.

The majority of people with dementia will experience BPSD at some time, particularly in the middle and later stages<sup>54</sup>. BPSD is associated with increased rates of admission to nursing homes<sup>55</sup> longer in-patient hospital stays<sup>56</sup> and is a major contributor to caregiver stress and depression<sup>57</sup>.

### 4.1 The Assessment of BPSD

Any acute change in behaviour in a person with dementia should be considered to be a delirium until proven otherwise (See section 2 for more information on the diagnosis of delirium). Once a delirium has been out-ruled the next step is to get a clear description of what behaviour/ symptom you are treating. BPSD is often considered to be an attempt by a person with dementia to communicate an unmet need. Identifying what 'need' they are trying to communicate is the key to assessing and ultimately managing BPSD. Assessment requires a thorough history from the patient, family and carers. Identifying when the behaviour began, when it occurs and when it does not occur can all be very useful when attempting to identify a potential trigger. Assessment of BPSD should consider the following<sup>58</sup>.

#### Patient Factors

- Acute medical problem - UTI, pneumonia, dehydration, constipation, medication side effects
- Unmet need – pain, fear, boredom, cold
- Premorbid personality

#### Care-giver Factors

- Stress, burden, depression
- Lack of education about dementia
- Communication issues
- Mismatch of expectations and dementia severity

#### Environmental Factors

- Overstimulation (e.g. excessive noise) and under-stimulation (e.g. isolated in room)
- Lack of activity
- Lack of routine

### 4.2 The Management of BPSD

Guidelines recommend that non-pharmacological strategies be used first-line for BPSD, unless the person with dementia poses a significant risk to themselves or others<sup>22</sup> (level of evidence 1). In practice, implementing non-pharmacological interventions can be challenging, as availability of therapies may be limited and the physical environment may not be optimal.

The essence of the management of BPSD is identifying the trigger of the behaviour. Identifying and treating the 'unmet need' or the acute medical issue should be the cornerstone of the management BPSD. The importance of considering underlying medical causes such as pain or constipation cannot be underestimated. Most mild BPSD behaviours, not due to a medical cause, will self-resolve in 4 weeks without pharmacological intervention so if the symptoms are mild a period of 'watchful waiting' is always appropriate.

## Non-Pharmacological Management of BPSD<sup>22,59</sup>

- Any intervention needs to be personalised to the personality of the person with dementia and the disease stage
- Educate patients, families and carers e.g. communicate with simple words and phrases, importance of routine, match what they do to the stage of the person's disease
- Support the family carer by ensuring they are accessing all the available services and supports e.g. day centres, home help, respite, carer support groups available through the ASI ([www.alzheimer.ie](http://www.alzheimer.ie))
- Optimise the environment e.g. calm, uncluttered environment, avoid TV and radio, provide visual aids to help orientate the person, hide exits
- Consider the following therapies. There may be expertise in the local primary care team or local voluntary organisations to support these therapies.:
  - Physical activity and meaningful recreational activities based on the person's likes
  - Multisensory stimulation, e.g. aromatherapy, massage, light therapy, music therapy
  - Validation therapy – don't challenge the inaccuracies of what the person with dementia says, instead acknowledge and empathise with the person with dementia which ultimately allows you to distract and redirect the patient to a different task
  - Reminiscence therapy, life-story book

## Pharmacological Management of BPSD

### *Antipsychotics*

Antipsychotics are sometimes used to try to manage BPSD. An Irish study found that 32% of patients in a nursing home were on an antipsychotic medication which is broadly in line with similar studies in the UK<sup>60</sup>. However, people with dementia who are prescribed antipsychotics are at an increased risk of a number of serious side-effects. These include; a 3-time increased risk of stroke and a 1.7 times increased risk of all-cause mortality, compared with placebo<sup>61</sup> (level of evidence 1). Additional side-effects of antipsychotics include; increased risk of falls and drowsiness, hip fractures, pneumonia, reduced motor function, parkinsonism, tardive dyskinesia, accelerated cognitive decline and QT prolongation<sup>62</sup>. When used to manage BPSD the benefit of antipsychotics is modest at best - they are only minimally better than placebo at improving symptoms of BPSD<sup>63</sup> (level of evidence 2). Any minor benefits have been consistently shown to be offset by the significant risks associated with using antipsychotics in people with dementia<sup>64</sup> (level of evidence 5).

Despite the risks of antipsychotic it is still possible that, as a result of the severity of the behaviours or symptoms and in the context of inappropriate resources, a certain number of people experiencing BPSD will require antipsychotics. If antipsychotics are prescribed the lowest possible therapeutic dose should be chosen, with slow titration and regular review and a plan made to review and consider discontinuing treatment after six weeks. The risk of adverse effects should be discussed and documented with patients, families and carers.

The harmful side-effects of antipsychotics are dose and duration dependent, therefore, low dose, short-term treatments should be our aim in the subset of people with BPSD who require antipsychotics. Research has shown that antipsychotics can be safely withdrawn in people with dementia who have taken them for prolonged periods<sup>49</sup>. 70% of people with dementia have no worsening of symptoms when antipsychotics are discontinued and for those patients that do have worsening behaviour most of them are effectively managed with watchful waiting<sup>65</sup>.

Risperidone is the only antipsychotic medication licensed for use in patients with dementia<sup>66</sup>. Its license indicates that it should be used for no longer than six weeks before review or specialist referral. A cardiac risk assessment is recommended prior to initiation, as antipsychotics may prolong the QTc interval leading to arrhythmia, even at therapeutic doses. A starting dose of 0.25mg bd is recommended titrating slowly, to a maximum dosage of 1mg bd. Side-effect risks are increased on higher doses. The evidence base for alternative antipsychotics including quetiapine, aripiprazole and olanzapine is limited<sup>66</sup>.



## Other Medications for BPSD

### *Antidepressants*

The SSRI citalopram has been shown to reduce mild-moderate agitation in people with dementia. However, citalopram can cause worsening of cognition, hyponatremia and QT interval prolongation. Unfortunately, trials to date have shown that antidepressants are ineffective at improving depressive symptoms in people with dementia. Tricyclics should be avoided in people with dementia as antimuscarinic activity may lead to a worsening of cognitive impairment.

### *Cholinesterase Inhibitors*

Generally, they do not have a role in the management of BPSD<sup>67</sup> (level of evidence 2) however, it is possible that they may have a minor role in the management of agitation in Lewy Body Dementia or Parkinson's Dementia

### *Memantine*

Memantine has not been shown to improve BPSD<sup>68,69</sup> (level of evidence 2)

### *Hypnotics*

Not recommended in BPSD. Can result in increasing tolerance and adverse effects including over sedation, confusion, agitation and increased risks of falls.

### *Anticonvulsants*

In some trials carbamazepine has been found to reduce agitation, restlessness and anxiety, however, the evidence is limited and the efficacy and tolerability of long term use of this drug is yet to be established<sup>70</sup>. Valproate has been found to be ineffective at treating agitation and is associated with unacceptable rates of adverse effects<sup>71</sup>. Overall the evidence available is limited.

All psychoactive medication prescribed to treat BPSD should be reviewed at regular intervals and attempts made at drug withdrawal when clinically appropriate.

## Section 5: Driving and Dementia

Driving is an important life skill for most people enhancing independence and freedom. It is a complicated task that requires a combination of complex thought processes and manual skills.

Someone who is diagnosed with mild cognitive impairment or early dementia may be able to continue driving safely for some time, retaining learned skills. However, dementia may affect driving ability by impacting on perception, attention, judgment and impulsiveness. Certain medications including sedatives and antidepressants may affect driving ability also.

The Road Safety Authority publication, *Sláinte agus Tiomáint*, provides guidance on medical fitness to drive<sup>72</sup>. It also outlines the roles and responsibilities for patients, healthcare professionals and the Driving License Authority. The dementia specific guidelines are summarized in Table 8.

Upon diagnosis of dementia the driver must notify the Driving License Authority. They are also obliged to notify their car insurance company<sup>72</sup>.

Healthcare professionals have an ethical and potentially legal obligation to give clear advice to patients in cases where an illness may affect safe driving ability<sup>72</sup>. If in doubt about the patient’s ability to drive, referral to a further specialist and associated multi-disciplinary team (i.e. physiotherapy, occupational therapy, psychology, optometrist) and/or on-road testing with a driving assessor qualified to assess driving among those with disabilities may be of assistance.

*Table 8: Dementia and Driving Guidelines<sup>72</sup>*

Mild Cognitive Impairment (MCI):	<p>Where there is <b>no</b> objective impairment of function MCI does not need to be notified to Driving Licensing Authority.</p> <p>Where there <b>is</b> objective impairment of function or specific treatment is required then the doctor should clarify the cause and apply the relevant section of <i>Sláinte agus Tiomáint</i>.</p>
Dementia or any Organic Brain Syndrome:	<p>It is extremely difficult to assess driving ability in those with dementia. Those who have poor short-term memory, disorientation, lack of insight and judgment are almost certainly not fit to drive.</p> <p>The variable presentations and rates of progression are acknowledged. Disorders of attention will also cause impairment. A decision regarding fitness to drive is usually based on specialist medical assessment, further assessment by occupational therapy and/or neuropsychology, with a low threshold for an on-road driving assessment.</p> <p>In early dementia when sufficient skills are retained and progression is slow, a license may be issued subject to annual review. A formal driving assessment may be necessary.</p> <p><i>Driver must notify Driving Licensing Authority*</i></p>

An Irish study that explored both patients’ and GPs’ experiences of the fitness to drive consultation found that while discussions on driving may be challenging, GPs can use their long-term relationship with patients to lessen the potential for distress, to proactively revisit the topic of driving over multiple consultations, and help patients prepare for adjustments in their driving status before a crisis develops<sup>73</sup>.

Key recommendations arising from this study are:

- 1) this sensitive topic is not suitable for review by locum doctors, but requires the full strength of relational continuity that primary care has the potential to offer. The authors recommend that it is preferable that patients see their regular GP for fitness to drive (FtD) assessments, and practice policy is put in place to facilitate this happening<sup>73</sup>.
- 2) The discussion around driving ability should be introduced into routine consultations for all patients with cognitive impairment, even in the absence of apparent functional impairment.
- 3) For patients with established dementia, fitness to drive discussions should be incorporated into routine post-diagnosis management, along with discussion of other legal issues, such as will-making, advanced care directives etc.
- 4) When decisions about driving cessation have been made, it was recommended that it be discussed by GPs with the same sensitivity as breaking bad news.

A recent scoping review of 18 studies has synthesized the evidence on consultations on fitness to drive in people with cognitive impairment in primary care<sup>74</sup>. While the review highlights the many difficulties GPs encounter during these discussions, useful recommendations are made which may support GPs' approach to the topic within the consultation (Table 9).

*Table 9: Communication strategies for GPs within the fitness to drive consultation<sup>74</sup>*

Study	
Byszewski et al. (2003) <sup>75</sup>	<p>Questions to ask patients:</p> <ul style="list-style-type: none"> <li>• do you think you are a safe driver?</li> <li>• do you restrict driving to familiar areas/routes?</li> <li>• do other drivers honk at you or show irritation?</li> <li>• have you noticed any change in your driving skills?</li> </ul> <p>Questions to ask caregivers:</p> <ul style="list-style-type: none"> <li>• does the patient avoid driving at night?</li> <li>• has the patient received any traffic violations?</li> <li>• does the person need a co-pilot to alert them of potentially hazardous events or conditions?</li> <li>• do you feel uncomfortable being a passenger when the patient is driving?</li> </ul>
Carmody et al. (2014) <sup>76</sup>	Move focus away from assessment of fitness to drive, to focus instead on facilitating planning for driving retirement with patients recently diagnosed with dementia. Aim to engage and assist people recently diagnosed with dementia in their decisions and plans for driving retirement, thereby protecting patient agency while also maintaining public road safety.
Hill et al. (2013) <sup>77</sup>	Promote general health and ensure optimal medication use to best support on-going driving (i.e. vision, range of motion, use lowest effective dose of medications etc.). Be familiar with local resources and regional legal requirements
Meuser et al. (2006) <sup>78</sup>	<p>Where impairment is very mild, advise the person and family that driving cessation will be required eventually. Follow up every 6-12 months. Where mild, educate the patient and family that the advancing impairment will likely necessitate retirement from driving in 6-18 months. Recommend common sense restrictions to reduce risk e.g. avoiding bad weather, night-time, rush hour driving and recommend that they begin to develop an alternate transport plan.</p> <p>Moderate to Severe: Recommend immediate retirement from driving. Work with patient and family to develop and implement a plan for driving cessation and alternate transportation. Enlist help of others to ensure active acceptance of the plan.</p>
Moorhouse and Hamilton (2014) <sup>79</sup>	Increasing familiarity with local resources for driving assessment and supports for patients and caregivers can facilitate discussions about driving.
Reuben et al. (2010) <sup>80</sup>	Consider referral of all patients with dementia to local Alzheimer Associations for provision of support and information regarding driving cessation.

## Section 6: Legal Issues

One of the advantages of timely diagnosis is that it may give an individual the opportunity to make plans for the future while he/she retains the capacity to do so. For GPs the most common legal undertaking in dementia care involves assessment of the patient's legal capacity to make a will (testamentary capacity). GPs are also asked to assess patients' capacity to grant an enduring power of attorney (EPA).

### 6.1 Capacity

This is likely to change substantially in 2019, when the Assisted Decision Making (Capacity) Act is expected to be enacted, changing towards universal supported mental capacity. The Government's Assisted Decision Making (Capacity) Act 2015 proposes a modern legal framework for people with impaired capacity in Ireland<sup>81</sup>. When enacted it will replace the Lunacy Regulation Act of 1871.

The Bill introduces the concept of decision-assistance and co-decision making, which will require the involvement of another person (a 'decision-making assistant' or a 'co-decision-maker'). The most likely person to fulfill the role will be a carer or family member. This will provide access for persons with impaired capacity to the support they may require in exercising their legal capacity. An important provision from a carer's perspective is the allowance for an "informal decision-maker" to make decisions in respect of 'personal welfare' (including healthcare and treatment)<sup>82</sup>.

Capacity refers to a person's ability in law to make a decision with legal consequences, and the relevant test depends on what decision the patient is trying to make.

All persons are considered to have capacity, unless proven otherwise. People may suffer from transitory loss of capacity. The "test" should be revisited and reconsidered as appropriate. The assessment of capacity is task specific. It focuses on the specific decision that needs to be made at the specific time the decision is required. One of the relevant factors to be considered is the effect of the decision being made. For example, if a significant irrevocable decision is being considered the resulting responsibility attaching to the practitioner in assessing capacity is greater. Incapacity to manage one's financial affairs does not necessarily imply, for example, incapacity to consent to clinical treatment.

A person is considered unable to make a decision for himself or herself if one or more of the following criteria are met. He/she is unable to:

- Understand the information relevant to the decision
- Retain the information
- Use or weigh the information as part of the process of making the decision
- Communicate his or her decision (whether by talking, using sign language or any other means)<sup>56</sup>

Testamentary capacity relates to a person's capacity to make a will. An old and tested legal authority on testamentary capacity is the judgment in the case of *Banks v Goodfellow*.

The test for testamentary capacity is outlined in Table 10.

Table 10: Assessing Testamentary Capacity: The Tests<sup>83</sup>

Assessing Testamentary Capacity: The Tests
<p>What the testator (the person making the will) must be capable of understanding:</p> <ul style="list-style-type: none"> <li>• The nature and effect of making a will</li> <li>• The extent of his or her estate</li> <li>• The fact that those who might expect to benefit from the testator's will (both those being included in, and being excluded from, the will) might bring a claim.</li> </ul> <p>What the testator should not have:</p> <ul style="list-style-type: none"> <li>• A mental illness that influences the testator to make bequests (dispositions) in the will that he or she would not otherwise have included.</li> </ul>

Before assessing testamentary capacity, a GP should insist on a letter of instruction from the patient's solicitor confirming that the patient has consented to examination by the GP and disclosure of the results to the solicitor<sup>84</sup>.

An explanation should be given to the patient that this is an examination for legal purposes, not the usual doctor-patient consultation. Findings of a mental state examination including the patient's appearance, behaviour, mood, form and insight may be recorded. An MMSE may be performed and recorded but this is for medical records and does not need to appear on your opinion for the solicitor, but it will inform your opinion<sup>85</sup>. Answers to the questions mentioned above in Table 10, should be recorded in as detailed a fashion as possible.

Other essential components of a certificate of mental capacity are included in Table 11.

Table 11: Information to include in a Certificate of Mental Capacity<sup>84</sup>

Information to include in a Certificate of Mental Capacity
<ul style="list-style-type: none"> <li>• Identification of self</li> <li>• Identification of the subject</li> <li>• The date, time and duration and basis for the examination</li> <li>• The diagnosis</li> <li>• The opinion and the grounds for the opinion</li> <li>• The part/parties with whom the opinion will be shared/passed</li> </ul>

If in doubt about capacity, a second opinion should be sought from an old age psychiatrist or other relevantly experienced professional. Where capacity to make a will is lacking, this may lead to reversion to an earlier will or the patient dying intestate.

A summary of the process of assessing testamentary capacity is given in Table 12.

Table 12: Process for Assessing Testamentary Capacity<sup>84</sup>

Process for Assessing Testamentary Capacity
<ul style="list-style-type: none"><li>• Get a letter from the solicitor detailing legal tests</li><li>• Set aside enough time</li><li>• Assess (in the standard way) whether the patient has dementia</li><li>• Check that the patient understands each of the Banks v Goodfellow points (Table 10)</li><li>• Record the patient's answers in as detailed a manner as possible</li><li>• Check facts, such as the extent of the estate, with the solicitor</li><li>• Ask about and review material changes from previous wills, such as why potential beneficiaries are included or excluded</li></ul>

## 6.2 Enduring Power of Attorney (EPA)

A Power of Attorney is a document appointing an agent. An Ordinary Power of Attorney is automatically revoked during the period of incapacity of the donor (and is obviously revoked completely on the death of the donor).

An Enduring Power of Attorney is one made by a patient at a time when they have full capacity appointing some person, usually a member of their family but sometimes their solicitor, to manage their affairs. The form of Power of Attorney is a statutory form and requires the donor's solicitor and doctor to confirm that they are satisfied that the patient has capacity. An Enduring Power is not effective until it has been registered and it cannot be registered until the patient has lost capacity. It is therefore less open to abuse and the duty of care to assess capacity is at the lowest end of the scale. Ideally the statement of capacity should be signed as soon as possible after the signing of the Enduring Power by the patient but must be signed within 30 days

The legal test for an EPA is that the donor understands that the Attorney will be able to assume authority over their affairs

- (a) once the donor becomes "incapable" and
- (b) once the EPA is registered, thereafter the power is irrevocable.

An Attorney has the power to make decisions relating to property, financial and business affairs of the donor, or decisions regarding the personal care of the patient. They cannot make decisions in relation to medical treatment. The Assisted Decision Making (Capacity) Bill 2013 seeks to address this deficiency.

A GP may be asked to evaluate whether their patient has the capacity to make an enduring power of attorney. The patient must notify at least two persons of the EPA. When the donor becomes "incapable" the Attorney applies to have the EPA registered so that it can come into force.

## 6.3 Ward of Court

The procedures described below regarding Wardship will be changed when the Assisted Decision Making (Capacity) Bill 2013 is implemented.

If it is too late in the advancement of dementia for a person to grant an EPA, then an application to the High Court might be considered to have the person made a Ward of Court. If the person has been declared a "ward of court" then all consent issues must be directed to the Offices of the Ward of Court and in a timely manner.

The ward of court procedure allows for the financial affairs and property of a person without capacity to be dealt by an appropriate "committee".

This is an expensive, cumbersome and lengthy process. It tends to be used only where the person involved has substantial financial assets.

Further information on Wardship is available from The Office of Wards of Courts at [www.courts.ie](http://www.courts.ie).

## 6.4 Advance Care Directives

**Advance healthcare planning** can be described as a process of discussion and reflection about the goals, values, will and preferences for healthcare treatment, occurring in the context of an anticipated deterioration in the person's condition.

Research indicates that advance care planning may improve end of life care, patient and family satisfaction, and also reduces stress, anxiety, and depression in surviving relatives<sup>86</sup>. GPs may have a role in discussing advance decisions before being drafted, explaining the advantages and disadvantages of refusing or choosing medical procedures in advance.

**An Advance Healthcare Directive** is an advance expression made by a person with capacity, of the person's will and preferences concerning healthcare treatment decisions that may arise if s/he subsequently lacks capacity. An advance care directive, also known as a living will, seeks to permit a patient to participate/inform in clinical decision making after they have lost the power to communicate their preferences or views and/or have become clinically incompetent<sup>87</sup>. It may emerge in the context of mental illness or end-of-life decision making.

To be effective and binding an advanced care directive must be in writing, signed, dated, witnessed and certified by a medical practitioner that the patient has the capacity to draft the advance directive<sup>88</sup>.

Further useful information on advance care directives for patients is available from The Irish Hospice Foundation at [www.thinkahead.ie](http://www.thinkahead.ie).

## Section 7: Dementia and Down Syndrome

By the age of 40, practically all people with Down syndrome will have the neuropathology of Alzheimer’s disease, although not all will show clinical symptoms<sup>89</sup>. The risk for developing dementia for people with Down syndrome by age 50 is 23%, 45% at age 55 and 88% at age 65<sup>90</sup>.

### Dementia Symptoms in Persons with Down Syndrome

The clinical presentation of dementia for people with Down syndrome presents differently compared to the general population. The earliest symptoms of dementia in people with Down syndrome appear to be in personality and behaviour associated with executive dysfunction and frontal-like symptoms, which can be misdiagnosed as behavioural disorder or depression<sup>91,92</sup>. To detect early signs of dementia it is widely recommended to compare an early, assessed baseline with periodic re-assessments<sup>90,93</sup>. Common symptoms of dementia in people with Down syndrome are detailed in Table 13.

Table 13: Common symptoms of dementia in persons with Down syndrome<sup>94,95,96</sup>

Early Stage	Middle Stage	Late Stage
<p>At this stage, the person is showing signs of decline from their usual level of functioning in the following areas:</p> <p>Subtle changes in behaviour and mood.</p> <p>Performance at day placements deteriorate.</p> <p>Memory problems, particularly for recent events.</p> <p>Ability to learn new information is affected.</p> <p>Language and word finding problems.</p> <p>Decline in social, community and daily living skills.</p> <p>Disorientation.</p> <p>Difficulties with steps, stairs and kerbs due to depth perception problems.</p>	<p>Memory loss become more pronounced- forgetting personal information or the names of familiar people.</p> <p>Language problems become more evident.</p> <p>Confusion and disorientation around time, place and may have problems finding their way around familiar environments.</p> <p>Increasing difficulties with activities of daily living and then loss of self-care skills.</p> <p>More severe changes in personality and social behaviour: e.g. mood changes, inactivity or apathy, behavioural disturbances such as wandering, sleep problems, agitation, hallucinations and delusions.</p> <p>Disturbed sleep patterns.</p>	<p>New onset epilepsy- 70-80% of cases</p> <p>Incontinence (bladder and bowels).</p> <p>Loss of eating/drinking skills.</p> <p>Problems with walking and balance, individuals become chair- or bed-bound.</p> <p>Problems with recognising people.</p> <p>Often require 24-hour care.</p> <p>Will become bedridden and inactive.</p> <p>Greater risk of infections, particularly pneumonia.</p>

### Assessment Approach

Assessment is challenging with this population due to communication difficulties, and difficulty in identifying decline due to dementia, rather than pre-existing intellectual disability. Because of this, there is a need for annual baseline screening for persons with Down syndrome over the age of 35 years<sup>97</sup>.

Table 14: Differential diagnosis of functional and cognitive decline in persons with Down Syndrome<sup>95,98</sup>

Differential Diagnosis of Functional and Cognitive Decline in Persons with Down Syndrome
<ul style="list-style-type: none"> <li>• Depression or other mental illness</li> <li>• Sensory impairment: vision/hearing</li> <li>• Thyroid impairment, B12, folate deficiency</li> <li>• Medical problem- drugs, acute, chronic, infection, pain, epilepsy</li> <li>• Major life events: Separation, bereavement, environmental changes</li> </ul>



## Assessment Instruments

Assessment tools for dementia in the general population are not appropriate for people with Down syndrome. Always look for evidence from previous assessments on file that might indicate premorbid functioning.

The assessment needs to focus on individual changes in the respective person - compare early assessed baseline with periodic re-assessments. There are a number of tools available with varying degrees of reliability and validity (Table 15). No one approach or instrument has been conclusively agreed upon. A combination of informant and direct assessment is generally recommended. The performance of assessments will vary depending on the individual, and is influenced by age, level of intellectual disability and premorbid functioning. The same test can then be repeated for comparison.

*Table 15: Useful cognitive screening tools for persons with dementia<sup>96</sup>*

Useful Cognitive Screening Tools for Persons with Dementia
<ul style="list-style-type: none"><li>• Dementia Scale for Down Syndrome (DSDS)</li><li>• Dementia Questionnaire for people with learning disabilities (DLD)</li><li>• Cambridge Examination for Mental Disorders of Older People with Down Syndrome (CAMDEX-DS)</li><li>• Down Syndrome Mental State Examination (DSMSE)</li><li>• Test for Severe Impairment (TSI)</li></ul>

### *Important Considerations*

For individuals with profound intellectual disabilities changes may not be detected through standardised testing. Caregiver reports may take precedence. Numerous components of executive function and behaviour seem to be affected before memory skills begin to decline, which suggests that dementia in Down syndrome mainly manifests as BPSD, only later to be followed by changes in cognition. Current diagnostic procedures for the general population (ICD-10, DSM-V criteria) that focus on decline in memory functions, fail to facilitate early detection and diagnosis in people with Down syndrome.

## Section 8: Advanced Dementia

### 8.1 The Nursing Home

Dementia is common in patients in nursing homes, though it is likely under-diagnosed<sup>3</sup>. A Department of Health and Children report stated that 26% of these people in residential care were reported as having dementia<sup>99</sup>. This is likely to be a gross underestimation<sup>4</sup>. In the USA and Europe, between one-half and two-thirds of nursing homes residents are said to have dementia<sup>100</sup>. A study in the Dublin area to assess cognitive impairment found that 89% of participants surveyed were cognitively impaired, of whom 42% were severely and 27% moderately impaired. However, only one third of the participants surveyed had a recorded clinical diagnosis of dementia<sup>101</sup>.

Studies have found that over a one-year period having a co-resident caregiver made admission to residential care twenty times less likely for a person with dementia, thus emphasising the pivotal role played by family caregivers<sup>102</sup>.

Irish research has shown that the key factors influencing family caregivers' decision to move their relatives with dementia into residential care are complex and interrelated<sup>103</sup>. Professionals were found to play a key role in prompting this discussion about placement with carers.

Reasons for choosing placement included:

- The excessive demands of caring, especially night-time caring and continence issues
- A decline in physical and mental health of both the carer and the person with dementia
- Lack of formal and informal support
- Conflicting roles and responsibilities, especially for adult children carers with conflicting demands
- Financial sacrifice and hardship of carers

Many of the National Dementia Strategies in other countries (Northern Ireland, England, France, Scotland and Australia) have targeted training for health service professionals and have recognised that quality of care for people with dementia in residential care settings can be enhanced through training, knowledge and commitment of staff<sup>4</sup>.

Suggested strategies to improve the quality of care in nursing homes include the following<sup>30</sup>:

- Identification of a senior staff member within the care home to take the lead for quality improvement in the care of persons with dementia in the care home.
- Development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member.
- Appropriate use of anti-psychotic medication for people with dementia.
- The commissioning of specialist in-reach services from older people's community mental health teams to work in care homes.
- The specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry, etc.

International consensus on design features that underpin best practice in dementia care include<sup>4</sup>:

- Small scale
- Familiar, domestic, homely in style
- Plenty of scope for ordinary activities (unit kitchens, washing lines, garden sheds)
- Unobtrusive concern for safety
- Different rooms for different functions
- Age-appropriate furniture and fittings
- Safe outside space
- Single rooms big enough for lots of personal belongings
- Good signage and multiple cues where possible, e.g. sight, smell, sound
- Use of objects rather than colour for orientation
- Enhanced visual access
- Controlled stimuli, especially noise

## 8.2 Palliative Care

The majority of people with dementia die in nursing homes, only around 2% die in a hospice<sup>24</sup>. Early recognition of the advanced stages of dementia with timely referral to a community palliative care team and use of end of life care pathways, may improve quality of care. The need to address end of life care for people with dementia and the lack of resources available has been explored in Building Consensus for the Future 2012, produced by The Irish Hospice Foundation and The Alzheimer Society of Ireland<sup>104</sup>.

Advance care planning and palliative care plans for patients with end stage dementia may help to reduce inappropriate interventions, such as antibiotics for fever, artificial feeding and cardiopulmonary resuscitation<sup>105</sup>.

As part of The Irish Hospice Foundation's Changing Minds programme in 2013, a suite of seven guidance documents was developed to support healthcare staff working with people with dementia from all care settings in addressing specific aspects of dementia palliative care. These documents cover areas including pain management, advance care planning, hydration and nutrition, ethical decision-making and medication management. Each guidance document is accompanied by a factsheet, all of which are available to download from the Irish Hospice Foundation website, <https://hospicefoundation.ie/>.

Further guidance for the palliative care management of patients with dementia is given in Table 16.

Table 16: Dementia Palliative Care<sup>22</sup>

Dementia Palliative Care
<ul style="list-style-type: none"><li>• Dementia care should incorporate a palliative care approach considering physical, psychological, social and spiritual needs of the patient.</li><li>• Advance care planning should be utilized by health and social care professionals</li><li>• Palliative care services should be available to people with dementia in the same way they are available to people who do not have dementia.</li><li>• People with dementia should be encouraged to eat and drink by mouth for as long as possible. Specialist assessment and advice concerning swallowing and feeding in dementia should be available. Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity. Ethical and legal principles should be applied when making decisions about withholding or withdrawing nutritional support.</li><li>• Policies in hospitals and long-stay residential, nursing or continuing care units should reflect the fact that cardiopulmonary resuscitation is unlikely to succeed in cases of cardiopulmonary arrest in people with severe dementia.</li><li>• If people with dementia have unexplained changes in behaviour they should be assessed to see whether they are experiencing pain, potentially by the use of an observational pain assessment tool.</li></ul>

### Pain

People with dementia appear to have a significantly increased risk of pain with up to half of people with dementia estimated to be living with chronic pain<sup>106,107</sup>. In one study of nursing home residents the prevalence of chronic pain in residents with dementia was almost double that of residents without dementia<sup>108</sup>. However, pain in people with dementia is often under-diagnosed, underestimated and undertreated<sup>109</sup>. Untreated pain can worsen cognitive function, leading to depressive symptoms, reduced quality of life and may trigger or exacerbate BPSD<sup>110</sup>. Therefore, the management of any change in mood or behaviour should include a careful clinical assessment for signs of pain and a review of regular analgesia. Pain assessment tools for persons with dementia have been developed in order to standardise pain assessment, helping to rate patients' levels of pain.

Examples of commonly used pain assessment tool for persons with dementia include the Abbey Pain Scale, PAINAD and the DOLOPLUS 2 Scale<sup>111</sup>.

### *Prescribing*

Persons with advanced dementia are more likely to be subject to poly-pharmacy than healthier persons with a longer life expectancy and are at increased risk of inappropriate prescribing and adverse outcomes as a result of medication therapy<sup>112</sup>. Inappropriate prescribing pertains to the mis-prescribing, over-prescribing and under-prescribing of medications in the context of a person's co-morbidities, full medication regime, functional and cognitive status as well as treatment goals and life expectancy<sup>112</sup>.

Helpful tools have been developed to assist clinicians with appropriate prescribing decisions and with the de-prescribing of medications. STOPPFrail comprises 27 criteria relating to medications that are potentially inappropriate in frail older patients with limited life expectancy<sup>113</sup>, while an expert consensus group has categorised the appropriateness of medications for patients with advanced dementia who are nearing the end of life<sup>114</sup>.

## References

1. Royal College of Psychiatrists. Dementia and Memory Problems. Available at: <https://www.rcpsych.ac.uk/mental-health/problems-disorders/dementia-and-memory-problems>
2. Prince M. World Alzheimer Report 2015: The Global Impact of Dementia: an analysis of prevalence, incidence, cost and trends. Alzheimer's Disease International (ADI): London; 2015.
3. O'Shea E, Cahill S, Pierce M. (eds) Developing and implementing dementia policy in Ireland. NUI Galway, Centre for Economic and Social Research on Dementia: Galway; 2017. Available at: <http://www.lenus.ie/hse/handle/10147/622755>
4. Cahill S, O'Shea E, Pierce M. Creating Excellence in Dementia Care: a research review for Ireland's National Dementia Strategy. Dementia Services Information and Development Centre: Dublin; 2012. Available at: [http://dementia.ie/images/uploads/site-images/creating\\_excellence\\_in\\_dementia\\_care\\_2012.pdf](http://dementia.ie/images/uploads/site-images/creating_excellence_in_dementia_care_2012.pdf)
5. Iliffe S, Robinson L, Brayne C, Goodman C, Rait G, Manthorpe J, et al. Primary care and dementia: 1. diagnosis, screening and disclosure. *Int J Geriatr Psychiatry* 2009 Sep; 24(9):895-901.
6. World Health Organization, Alzheimer's Disease International. Dementia: a public health priority. WHO; Geneva: 2012. Available at: [https://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/](https://www.who.int/mental_health/publications/dementia_report_2012/en/)
7. Bamford C, Eccles M, Steen N, Robinson L. Can primary care record review facilitate earlier diagnosis of dementia? *Fam Pract* 2007 Apr; 24(2):108-116.
8. Cahill S, Clark M, Walsh C, O'Connell H, Lawlor B. Dementia in primary care: the first survey of Irish general practitioners. *Int J Geriatr Psychiatry* 2006 Apr; 21(4):319-324.
9. Foley T, Boyle S, Jennings A, Smithson WH. "We're certainly not in our comfort zone": a qualitative study of GPs' dementia-care educational needs. *BMC Fam Pract* 2017 May 22; 18(1):66-017-0639-8.
10. Department of Health. The Irish National Dementia Strategy. Dublin: Department of Health; 2014. Available at: <https://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>
11. The Scottish Government. Scotland's National Dementia Strategy. Edinburgh: The Scottish Government; 2010. Available at: <https://www2.gov.scot/Publications/2010/09/10151751/17>
12. Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J. Disclosing a diagnosis of dementia: a systematic review. *Int J Geriatr Psychiatry* 2004 Feb; 19(2):151-169.
13. Amjad H, Roth DL, Sheehan OC, Lyketsos CG, Wolff JL, Samus QM. Underdiagnosis of Dementia: an Observational Study of Patterns in Diagnosis and Awareness in US Older Adults. *J Gen Intern Med* 2018 Jul; 33(7):1131-1138.
14. Jha A, Tabet N, Orrell M. To tell or not to tell-comparison of older patients' reaction to their diagnosis of dementia and depression. *Int J Geriatr Psychiatry* 2001 Sep; 16(9):879-885.
15. Iliffe S, Manthorpe J. The hazards of early recognition of dementia: a risk assessment. *Aging Ment Health* 2004 Mar; 8(2):99-105.
16. Lin JS, O'Connor E, Rossom RC, Perdue LA, Eckstrom E. Screening for cognitive impairment in older adults: A systematic review for the U.S. Preventive Services Task Force. *Ann Intern Med* 2013 Nov 5; 159(9):601-612.
17. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. Arlington, VA: American Psychiatric Association Publishing; 2013.
18. Rossor MN, Fox NC, Mummery CJ, Schott JM, Warren JD. The diagnosis of young-onset dementia. *Lancet Neurol* 2010 Aug; 9(8):793-806.
19. SIGN. Clinical Guideline 86: Management of patients with dementia: a national clinical guideline. Scottish Intercollegiate Guidelines Network: Edinburgh; 2006. Available at: <https://www.sign.ac.uk/archived-guidelines.html>
20. Burns A, Iliffe S. Dementia. *BMJ* 2009 Feb 5; 338:b75.
21. Bond J, Stave C, Sganga A, O'Connell B, Stanley RL. Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey. *Int J Clin Pract Suppl* 2005 Mar; (146):8-14.
22. NICE. Clinical Guideline (NG97): Dementia: assessment, management and support for people living with dementia and their carers. London: National Institute for Clinical Excellence; 2018. Available at: <https://www.nice.org.uk/guidance/ng97>
23. National Medicines Information Centre. Management of dementia. *NMIC Bulletin* 2011; 17(2). Available at:

- <http://www.stjames.ie/GPsHealthcareProfessionals/Newsletters/NMICBulletins/NMICBulletins2011/Dementia%202011.pdf>
24. Robinson L, Tang E, Taylor JP. Dementia: timely diagnosis and early intervention. *Bmj*. 2015 Jun 16;350:h3029.
  25. Milne A, Culverwell A, Guss R, Tuppen J, Whelton R. Screening for dementia in primary care: a review of the use, efficacy and quality of measures. *Int Psychogeriatr* 2008 Oct; 20(5):911-926.
  26. Lorentz WJ, Scanlan JM, Borson S. Brief screening tests for dementia. *Can J Psychiatry* 2002 Oct; 47(8):723-733.
  27. Brodaty H, Low LF, Gibson L, Burns K. What is the best dementia screening instrument for general practitioners to use? *Am J Geriatr Psychiatry* 2006 May; 14(5):391-400.
  28. van Hout H, Vernooij-Dassen M, Poels P, Hoefnagels W, Grol R. Are general practitioners able to accurately diagnose dementia and identify Alzheimer's disease? A comparison with an outpatient memory clinic. *Br J Gen Pract* 2000 Apr; (453):311-312.
  29. Salmon DP, Bondi MW. Neuropsychological assessment of dementia. *Annu Rev Psychol* 2009; 60:257-282.
  30. Department of Health UK. Living well with dementia: a national dementia strategy. London: Department of Health; 2009. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf)
  31. Alzheimer Europe. French neurodegenerative diseases plan for 2008 - 2012. Available at: <https://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies/France#fragment3>
  32. Cahill S, Gibb M, Bruce I, Headon M, Drury M. The subjective experiences of new patients and their primary caregivers attending a National Memory Clinic. *Dementia: The International Journal of Social Research and Practice* 2008; 7(2):175-189.
  33. Downs M, Ariss SMB, Grant E, Keady J, Turner S, Bryans Mea. Family carers' accounts of general practice contacts for their relatives with early signs of dementia. *Dementia* 2006; 5(3):353-373.
  34. Alzheimer Society of Ireland. Report National Dementia Summit 16 June 2011. Dublin: Alzheimer Society of Ireland; 2011.
  35. Iliffe S, Koch T, Jain P, Lefford F, Wong G, Warner A, et al. Developing an educational intervention on dementia diagnosis and management in primary care for the EVIDEM-ED trial. *Trials* 2012 Aug 22; 13:142-6215-13-142.
  36. Department of Health and Children. A Vision for Change: Report of the expert group on mental health policy. Dublin: Department of Health and Children; 2006.
  37. O'Riordan M. Primary Care Teams: a GP perspective. Dublin: Irish College of General Practitioners; 2011.
  38. Miller PA, Butin D. The role of occupational therapy in dementia-C.O.P.E. (Caregiver options for practical experiences). *Int J Geriatr Psychiatry* 2000 Jan; 15(1):86-89.
  39. Hall AJ, Watkins R, Lang IA, Endacott R, Goodwin VA. The experiences of physiotherapists treating people with dementia who fracture their hip. *BMC Geriatr* 2017 Apr 20; 17(1):91-017-0474-8.
  40. Irish Association of Speech & Language Therapists. Speech and Language Therapy Provision for People with Dementia. IASLT Position Statement, 2016. Dublin: Irish Association of Speech & Language Therapists; 2016. Available at: <http://www.iaslt.ie/documents/public-information/Adult%20Speech%20and%20Language/IASLT%20Position%20Statement%20SLTServiceProvisionDementia2016.pdf>
  41. Irish Nutrition and Dietetic Institute. Nutrition and dementia: A practical guide when caring for a person with dementia. Dublin: Irish Nutrition and Dietetic Institute; 2016. Available at: [https://www.indi.ie/images/Dementia\\_Booklet\\_.pdf](https://www.indi.ie/images/Dementia_Booklet_.pdf)
  42. Rodda J, Walker Z. Ten years of cholinesterase inhibitors. *Int J Geriatr Psychiatry* 2009 May; 24(5):437-442.
  43. Rodda J, Carter J. Cholinesterase inhibitors and memantine for symptomatic treatment of dementia. *BMJ* 2012 May 1; 344:e2986.
  44. Reeve E, Farrell B, Thompson W, Herrman N, Sketris I, Magin Pea. Evidence-based Clinical Practice Guideline for Deprescribing Cholinesterase Inhibitors and Memantine: Recommendations. Sydney: The University of Sydney; 2018.
  45. Herrmann N, Black SE, Li A, Lanctot KL. Discontinuing cholinesterase inhibitors: results of a survey of Canadian dementia experts. *Int Psychogeriatr* 2011 May; 23(4):539-545.

46. McShane R, Areosa Sastre A, Minakaran N. Memantine for dementia. *Cochrane Database Syst Rev* 2006 Apr 19; (2):CD003154. doi(2):CD003154.
47. McKeage K. Memantine: a review of its use in moderate to severe Alzheimer's disease. *CNS Drugs* 2009 Oct; 23(10):881-897.
48. Rait G, Walters K, Bottomley C, Petersen I, Iliffe S, Nazareth I. Survival of people with clinical diagnosis of dementia in primary care: cohort study. *BMJ* 2010 Aug 5; 341:c3584.
49. Connolly A, Iliffe S, Gaehl E, Campbell S, Drake R, Morris J, et al. Quality of care provided to people with dementia: utilisation and quality of the annual dementia review in general practice. *Br J Gen Pract* 2012 Feb; 62(595):e91-8.
50. WHO. For people with dementia, what is the role of a medical review (including comorbid physical and mental conditions and medication use)? 2012; Available at: [https://www.who.int/mental\\_health/mhgap/evidence/resource/dementia\\_q8.pdf](https://www.who.int/mental_health/mhgap/evidence/resource/dementia_q8.pdf)
51. Alzheimer's Society UK. Dental care and dementia. 2018; Available at: <https://www.alzheimers.org.uk/get-support/daily-living/dental-care?documentID=138>
52. National Immunisation Advisory Committee. Immunisation Guidelines for Ireland. Dublin: HSE; 2018. Available at: <https://www.hse.ie/eng/health/immunisation/hcpinfo/guidelines/immunisationguidelines.html>
53. Cooper C, Selwood A, Blanchard M, Walker Z, Blizard R, Livingston G. Abuse of people with dementia by family carers: representative cross sectional survey. *BMJ* 2009 Jan 22; 338:b155.
54. Savva GM, Zaccai J, Matthews FE, Davidson JE, McKeith I, Brayne C, et al. Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *Br J Psychiatry* 2009 Mar; 194(3):212-219.
55. Toot S, Swinson T, Devine M, Challis D, Orrell M. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *Int Psychogeriatr* 2017 Feb; 29(2):195-208.
56. Wancata J, Windhaber J, Krautgartner M, Alexandrowicz R. The consequences of non-cognitive symptoms of dementia in medical hospital departments. *Int J Psychiatry Med* 2003; 33(3):257-271.
57. Van Den Wijngaert MA, Vernooij-Dassen MJ, Felling AJ. The influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging & Mental Health*. 2007 Nov 1;11(6):626-36.
58. Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioural and psychological symptoms of dementia. *BMJ* 2015 Mar 2; 350:h369.
59. O'Connell H. Clinical Focus: Alzheimer's disease: management dilemmas tackling behavioural problems. *Forum Journal of the Irish College of General Practitioners Clinical Focus* 2012; 12(3):11-15.
60. Shortall E. Antipsychotic prescribing for dementia prescribing. *Forum Journal of the Irish College of General Practitioners* 2012; 29(12):51-52.
61. Schneider LS, Dagerman KS, Insel P. Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA* 2005 Oct 19; 294(15):1934-1943.
62. Schneider LS, Dagerman K, Insel PS. Efficacy and adverse effects of atypical antipsychotics for dementia: meta-analysis of randomized, placebo-controlled trials. *Am J Geriatr Psychiatry* 2006 Mar; 14(3):191-210.
63. Schneider LS, Tariot PN, Dagerman KS, Davis SM, Hsiao JK, Ismail MS, et al. Effectiveness of atypical antipsychotic drugs in patients with Alzheimer's disease. *N Engl J Med* 2006 Oct 12; 355(15):1525-1538.
64. Banerjee S. The use of antipsychotic medication for people with dementia: Time for action. London: Department of Health, UK; 2009.
65. Alzheimer's Society UK. Optimising treatment and care for people with behavioural and psychological symptoms of dementia: a best practice guide for health and social care professionals. London: Alzheimer's Society; 2011.
66. Ballard C, Lana MM, Theodoulou M, Douglas S, McShane R, Jacoby R, et al. A randomised, blinded, placebo-controlled trial in dementia patients continuing or stopping neuroleptics (the DART-AD trial). *PLoS Med* 2008 Apr 1; 5(4):e76.
67. Howard RJ, Juszcak E, Ballard CG, Bentham P, Brown RG, Bullock R, et al. Donepezil for the treatment of agitation in Alzheimer's disease. *N Engl J Med* 2007 Oct 4; 357(14):1382-1392.
68. Fox C, Crugel M, Maidment I, Auestad BH, Coulton S, Treloar A, et al. Efficacy of memantine for agitation in Alzheimer's dementia: a randomised double-blind placebo-controlled trial. *PLoS One* 2012; 7(5):e35185.



69. Ballard C, Thomas A, Gerry S, Yu LM, Aarsland D, Merritt C, et al. A double-blind randomized placebo-controlled withdrawal trial comparing memantine and antipsychotics for the long-term treatment of function and neuropsychiatric symptoms in people with Alzheimer's disease (MAIN-AD). *J Am Med Dir Assoc* 2015 Apr; 16(4):316-322.
70. Hersch EC, Falzgraf S. Management of the behavioral and psychological symptoms of dementia. *Clin Interv Aging* 2007; 2(4):611-621.
71. Lonergan E, Luxenberg J. Valproate preparations for agitation in dementia. *Cochrane Database Syst Rev* 2009 Jul 8; (3):CD003945. doi(3):CD003945.
72. Road Safety Authority. Sláinte agus Tiomáint; Medical Fitness to Drive Guidelines (Group 1 and 2 Drivers). 7<sup>th</sup> Ed. Dublin: Road Safety Authority; 2018. Available at: <http://www.rsa.ie/Documents/Licensed%20Drivers/Sla%CC%81inte%20agus%20%20Tioma%CC%81int%202018.pdf>
73. Sinnott C, Foley T, McLoughlin K, Sheehan C, Horgan L, Bradley C. Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment. [In Press]
74. Sinnott C, Foley T, Forsyth J, McLoughlin K, Horgan L, Bradley CP. Consultations on driving in people with cognitive impairment in primary care: A scoping review of the evidence. *PLoS One* 2018 Oct 15; 13(10):e0205580.
75. Byszewski AM, Graham ID, Amos S, Man-Son-Hing M, Dalziel WB, Marshall S, et al. A continuing medical education initiative for canadian primary care physicians: the driving and dementia toolkit: a pre- and postevaluation of knowledge, confidence gained, and satisfaction. *J Am Geriatr Soc* 2003 Oct; 51(10):1484-1489.
76. Carmody J, Potter J, Lewis K, Bhargava S, Traynor V, Iverson D. Development and pilot testing of a decision aid for drivers with dementia. *BMC Med Inform Decis Mak* 2014 Mar 19; 14:19-6947-14-19.
77. Hill LL, Rybar J, Styer T. Evaluation of curriculum to improve health professionals' ability to manage age-related driving impairments. *Accid Anal Prev* 2013 Dec; 61:222-232.
78. Meuser TM, Carr DB, Berg-Weger M, Niewoehner P, Morris JC. Driving and dementia in older adults: Implementation and evaluation of a continuing education project. *Gerontologist* 2006 Oct; 46(5):680-687.
79. Moorhouse P, Hamilton LM. Not if, but when: impact of a driving and dementia awareness and education campaign for primary care physicians. *Can Geriatr J* 2014 Jun 3; 17(2):70-75.
80. Reuben DB, Roth CP, Frank JC, Hirsch SH, Katz D, McCreath H, et al. Assessing care of vulnerable elders--Alzheimer's disease: a pilot study of a practice redesign intervention to improve the quality of dementia care. *J Am Geriatr Soc* 2010 Feb; 58(2):324-329.
81. Assisted Decision Making (Capacity) Act 2015. Available at: <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>
82. Revaluing Care Research Network. Publication of the Irish Assisted Decision-Making (Capacity) Bill: Implications for Carers. 2013. Available at: <http://revaluingcare.net/publication-of-the-irish-assisted-decision-making-capacity-bill-implications-for-carers/>.
83. British Medical Association (BMA). Mental capacity. Available at: <https://www.bma.org.uk/advice/employment/ethics/mental-capacity/assessing-mental-capacity>
84. Jacoby R, Steer P. How to assess capacity to make a will. *BMJ* 2007 Jul 21; 335(7611):155-157.
85. Hanley K. Mental capacity - not so straightforward. *Forum Journal of the Irish College of General Practitioners* 2011; 28(6):10-11.
86. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010 Mar 23; 340:c1345.
87. Doran K. What is in the Advanced Healthcare Decisions Bill? *Forum Journal of the Irish College of General Practitioners* 2013; 30(3):15-16.
88. Advance Healthcare Decisions Bill 2012. Available at: <https://www.oireachtas.ie/en/bills/bill/2012/2/>
89. Lamar M, Foy CML, Beacher F, Daly E, Poppe M, Archer N, et al. Down syndrome with and without dementia: an in vivo proton Magnetic Resonance Spectroscopy study with implications for Alzheimer's disease. *Neuroimage* 2011 Jul 1; 57(1):63-68.
90. McCarron M, McCallion P, Reilly E, Dunne P, Carroll R, Mulryan N. A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *J Intellect Disabil Res* 2017 Sep; 61(9):843-852.
91. Lautarescu BA, Holland AJ, Zaman SH. The Early Presentation of Dementia in People with Down Syndrome: a Systematic Review of Longitudinal Studies. *Neuropsychol Rev* 2017 Mar; 27(1):31-45.
92. McCarron M, McCallion P, Reilly E, Mulryan N. Responding to the challenges of service development to address dementia needs for people with an intellectual disability and caregivers. In: Watchman K,



- editor. *Intellectual Disability and Dementia: Research into Practice* London: Jessica Kingsley Publishers; 2014. p. 241-270.
93. Firth NC, Startin CM, Hithersay R, Hamburg S, Wijeratne PA, Mok KY, et al. Aging related cognitive changes associated with Alzheimer's disease in Down syndrome. *Ann Clin Transl Neurol* 2018 May 20; 5(6):741-751.
  94. McCarron M, McCallion P, Coppus A, Fortea J, Stemp S, Janicki M, et al. Supporting advanced dementia in people with Down syndrome and other intellectual disability: consensus statement of the International Summit on Intellectual Disability and Dementia. *J Intellect Disabil Res* 2018 Jul; 62(7):617-624.
  95. British Psychological Society, Royal College of Psychiatrists, Division of Clinical Psychology. *Dementia and people with intellectual disabilities: Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia*. Leicester: The British Psychological Society; 2015. Available at: [https://www1.bps.org.uk/system/files/Public%20files/rep77\\_dementia\\_and\\_id.pdf](https://www1.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf)
  96. McCarron M, Reilly E. *Supporting persons with intellectual disability and dementia: Quality Dementia Care Standards. A guide to practice*. Dublin: Daughters of Charity Services; 2010.
  97. Aylward EH, Burt DB, Thorpe LU, Lai F, Dalton A. Diagnosis of dementia in individuals with intellectual disability. *J Intellect Disabil Res* 1997 Apr; 41 (Pt 2):152-164.
  98. McCarron M, Lawlor BA. Responding to the challenges of ageing and dementia in intellectual disability in Ireland. *Aging Ment Health* 2003 Nov; 7(6):413-417.
  99. Department of Health and Children. *Long Stay Activity Statistics 2008*. Dublin: Department of Health and Children; 2009.
  100. Magaziner J, German P, Zimmerman SI, Hebel JR, Burton L, Gruber-Baldini AL, et al. The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older: diagnosis by expert panel. *Epidemiology of Dementia in Nursing Homes Research Group. Gerontologist* 2000 Dec; 40(6):663-672.
  101. Cahill S, Diaz-Ponce AM, Coen RF, Walsh C. The under detection of cognitive impairment in nursing homes in the Dublin area. The need for on-going cognitive assessment. *Age Ageing* 2010 Jan; 39(1):128-131.
  102. Banerjee S, Murray J, Foley B, Atkins L, Schneider J, Mann A. Predictors of institutionalisation in people with dementia. *J Neurol Neurosurg Psychiatry* 2003 Sep; 74(9):1315-1316.
  103. Argyle E, Downs M, Tasker J. *Continuing to Care for People with Dementia: Irish Family Carers' Experience of their Relative's Transition to a Nursing Home*. Bradford: Bradford University; 2010.
  104. The Irish Hospice Foundation, The Alzheimer Society of Ireland. *Building consensus for the future. Report of the feasibility study on palliative care services for people with dementia*. Dublin: The Alzheimer's Society of Ireland, Dublin; 2012. Available at: <http://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/DPC-Feasibility-Study-report-FINAL.pdf?ext=.pdf>
  105. Harris D. Forget me not: palliative care for people with dementia. *Postgrad Med J* 2007 Jun; 83(980):362-366.
  106. Corbett A, Husebo B, Malcangio M, Staniland A, Cohen-Mansfield J, Aarsland D, et al. Assessment and treatment of pain in people with dementia. *Nat Rev Neurol* 2012 Apr 10; 8(5):264-274.
  107. Zwakhalen SM, Koopmans RT, Geels PJ, Berger MP, Hamers JP. The prevalence of pain in nursing home residents with dementia measured using an observational pain scale. *Eur J Pain* 2009 Jan; 13(1):89-93.
  108. Malara A, De Biase GA, Bettarini F, Ceravolo F, Di Cello S, Garo M, et al. Pain Assessment in Elderly with Behavioral and Psychological Symptoms of Dementia. *J Alzheimers Dis* 2016; 50(4):1217-1225.
  109. Reynolds KS, Hanson LC, DeVellis RF, Henderson M, Steinhauer KE. Disparities in pain management between cognitively intact and cognitively impaired nursing home residents. *J Pain Symptom Manage* 2008 Apr; 35(4):388-396.
  110. Habiger TF, Flo E, Achterberg WP, Husebo BS. The Interactive Relationship between Pain, Psychosis, and Agitation in People with Dementia: Results from a Cluster-Randomised Clinical Trial. *Behav Neurol* 2016; 2016:7036415.
  111. Lichtner V, Dowding D, Esterhuizen P, Closs SJ, Long AF, Corbett A, et al. Pain assessment for people with dementia: a systematic review of systematic reviews of pain assessment tools. *BMC Geriatr* 2014 Dec 17; 14:138-2318-14-138.
  112. Laroche ML, Charmes JP, Bouthier F, Merle L. Inappropriate medications in the elderly. *Clin Pharmacol Ther* 2009 Jan; 85(1):94-97.
  113. Lavan AH, Gallagher P, Parsons C, O'Mahony D. STOPPFrail (Screening Tool of Older Persons

- Prescriptions in Frail adults with limited life expectancy): consensus validation. *Age Ageing* 2017 Jul 1; 46(4):600-607.
114. Parsons C, McCann L, Passmore P, Hughes C. Development and application of medication appropriateness indicators for persons with advanced dementia: a feasibility study. *Drugs Aging* 2015 Jan; 32(1):67-77.

## Appendix 1: Cognitive Screening Tools

### Appendix 1A: Memory Impairment Screen (MIS)

#### Instructions for Administration

1. Show patient a sheet of paper with the 4 items to be recalled in 24-point or greater uppercase letters (on other side), and ask patient to read the items aloud.
2. Tell patient that each item belongs to a different category. Give a category cue and ask patient to indicate which of the words belongs in the stated category (eg, "Which one is the game?"). Allow up to 5 attempts. Failure to complete this task indicates possible cognitive impairment.
3. When patient identifies all 4 words, remove the sheet of paper. Tell patient that he or she will be asked to remember the words in a few minutes.
4. Engage patient in distractor activity for 2 to 3 minutes, such as counting to 20 and back, counting back from 100 by 7, spelling WORLD backwards.
5. FREE RECALL — 2 points per word: Ask patient to state as many of the 4 words he or she can recall. Allow at least 5 seconds per item for free recall. Continue to step 6 if no more words have been recalled for 10 seconds.
6. CUED RECALL — 1 point per word: Read the appropriate category cue for each word not recalled during free recall (eg, "What was the game?").

Word	Cue	Free recall (2 pts.)	Cued Recall (1 pts)
Checkers	Game		
Saucer	Dish		
Telegram	Message		
Red Cross	Organization		

#### Scoring

The maximum score for the MIS is 8:

- 5-8 = no cognitive impairment
- $\leq 4$  = possible cognitive impairment

#### Word List:

- CHECKERS
- SAUCER
- TELEGRAM RED
- CROSS

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## Appendix 1B: Mini-Cog Test

### Instructions for the Mini-Cog Test

#### Administration

The Mini-Cog test is a 3-minute instrument to screen for cognitive impairment in older adults in the primary care setting. The Mini-Cog uses a three-item recall test for memory and a simply scored clock-drawing test (CDT). The latter serves as an “informative distractor,” helping to clarify scores when the memory recall score is intermediate. The Mini-Cog was as effective as or better than established screening tests in both an epidemiologic survey in a mainstream sample and a multi-ethnic, multilingual population comprising many individuals of low socioeconomic status and education level. In comparative tests, the Mini-Cog was at least twice as fast as the Mini-Mental State Examination. The Mini-Cog is less affected by subject ethnicity, language, and education, and can detect a variety of different dementias. Moreover, the Mini-Cog detects many people with mild cognitive impairment (cognitive impairment too mild to meet diagnostic criteria for dementia).

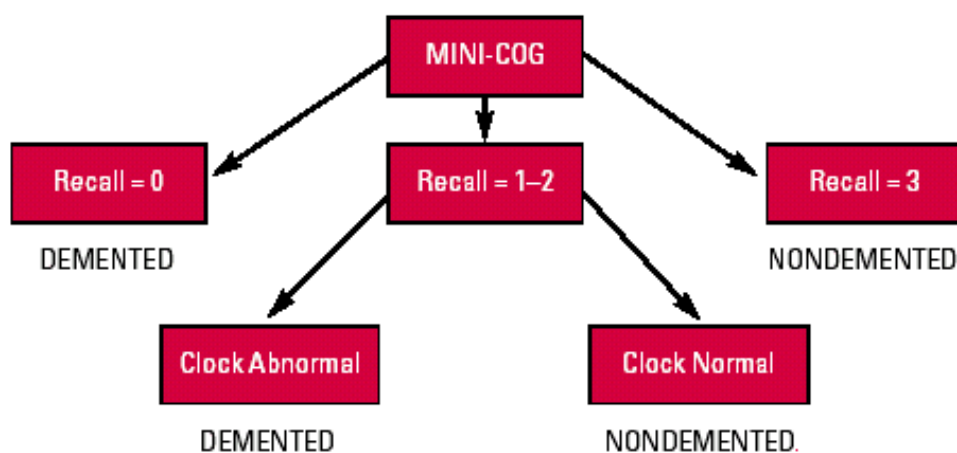
#### Scoring

One point for each recalled word.

Score clock drawing as normal (the patient places the correct time and the clock appears grossly normal) or abnormal.

Score	
0	Positive for cognitive impairment
1 - 2	Abnormal CDT then positive for cognitive impairment
1 - 2	Normal CDT then negative for cognitive impairment
3	Negative screen for dementia (no need to score CDT)

**Figure 1. The Mini-Cog scoring algorithm. The Mini-Cog uses a three-item recall test for memory and the intuitive clock-drawing test. The latter serves as an “informative distractor,” helping to clarify scores when the memory recall score is intermediate.**



#### Reference

Borson S. The mini-cog: a cognitive “vitals signs” measure for dementia screening in multi-lingual elderly. *Int J Geriatr Psychiatry* 2000; 15(11):1021.

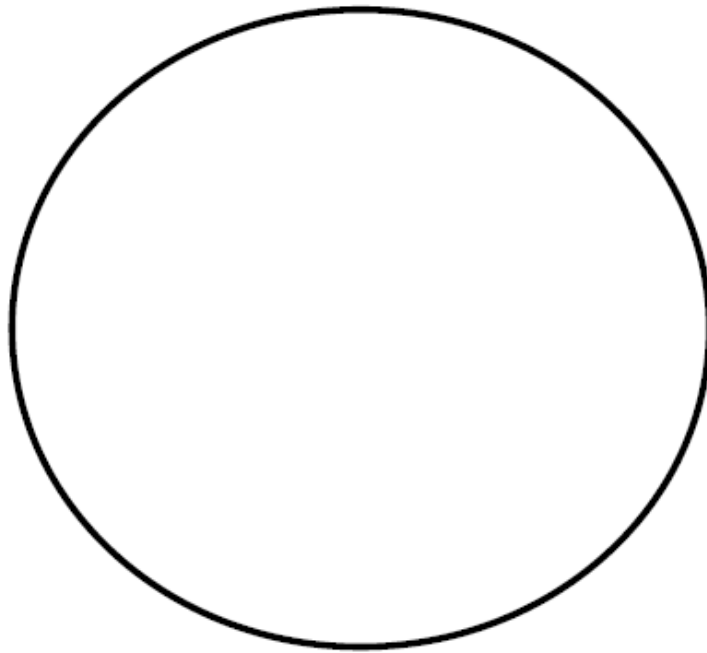
Pt. Name: \_\_\_\_\_ DOB: \_\_\_\_\_  
Date: \_\_\_\_\_

**Instructions**

Inside the circle draw the hours of a clock as if a child would draw them  
Place the hands of the clock to represent the time “forty five minutes past ten  
o’clock”

**Instrucciones**

Dentro del círculo dibuje las horas del reloj como si lo haría un niño.  
Ponga las manos del reloj para representar el tiempo “cuarenta y cinco  
minutos despues de las diez”



## THE MINI-COG

1. Instruct the patient to listen carefully and repeat the following

APPLE WATCH PENNY  
MANZANA RELOJ PESETA

2. Administer the Clock Drawing Test

3. Ask the patient to repeat the three words given previously

\_\_\_\_\_

### Scoring

Number of correct items recalled \_\_\_\_\_ [if 3 then negative screen. STOP]

If answer is 1-2

Is CDT Abnormal?      No      Yes

If No, then negative screen

If Yes, then screen positive for cognitive impairment

## Appendix 1C: The GPCOG

Patient name: \_\_\_\_\_

Testing date: \_\_\_\_\_



### STEP 1 – PATIENT EXAMINATION

Unless specified, each question should only be asked once.

#### Name and address for subsequent recall test

*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.)*

#### Time orientation

1. *What is the date? (exact only)*

Correct Incorrect



#### Clock drawing (use blank page)

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



3. *Please mark in hands to show 10 minutes past eleven o'clock. (11.10)*



#### Information

4. *Can you tell me something that happened in the news recently? (Recently = in the last week. If a general answer is given, e.g. "war", "lot of rain", ask for details. Only specific answer scores.)*



#### Recall

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

John



Brown



42



West (St)



Kensington



Add the number of items answered correctly:

Total score:

out of 9

9	<b>No significant cognitive impairment</b> Further testing is not necessary
5 – 8	<b>More information required</b> Proceed with informant interview in step 2 on next page
0 – 4	<b>Cognitive impairment is indicated</b> Conduct standard investigations

Patient name: \_\_\_\_\_

Testing date: \_\_\_\_\_



## STEP 2: INFORMANT INTERVIEW

Informant name: \_\_\_\_\_

Relationship to patient, i.e. informant is the patient's: \_\_\_\_\_

Ask the informant:

Compared to 5–10 years ago,

	YES	NO	Don't know	N/A
1. Does the patient have more trouble remembering things that have happened recently than s/he used to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2. Does s/he have more trouble recalling conversations a few days later?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3. When speaking, does s/he have more difficulty in finding the right word or tend to use the wrong words more often?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4. Is s/he less able to manage money and financial affairs (e.g. paying bills and budgeting)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is s/he less able to manage his or her medication independently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Does s/he need more assistance with transport (either private or public)? (If the patient has difficulties only due to physical problems, e.g. bad leg, tick 'no'.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Add the number of items answered with 'NO', 'Don't know' or 'N/A':

Total score:  out of 6

4 – 6 No significant cognitive impairment  
Further testing is not necessary

0 – 3 Cognitive impairment is indicated  
Conduct standard investigations

When referring to a specialist, mention the individual scores for the two GPCOG test steps:

STEP 1 Patient examination: \_\_\_ / 9

STEP 2 Informant interview: \_\_\_ / 6 or N/A



## Appendix 2: Dementia Resources

### Online Resources and Information about Dementia

- **The Alzheimer Society of Ireland:** Contact the Alzheimer National Helpline Monday to Friday, 10 am - 4 pm. Freephone 1800 341 341. Visit [www.alzheimer.ie](http://www.alzheimer.ie)
- **Understand Together Campaign:** Understand Together is a public support, awareness and information campaign led by HSE, working with The Alzheimer Society of Ireland and Genio and also hosts an online searchable directory of services.
- **Trinity Brain Health:** 'Freedom' films address your fears about memory loss and dementia and provide practical advice about brain health.
- **Alzheimer Society UK:** provide an online forum for carers called [Talking Point](#).
- **Dementia UK:** has free resources and information.

### Educational Resources for Healthcare Professionals

- **The Dementia Services Information and Development Centre (DSIDC):** St James's Hospital, is a National Centre for excellence in dementia, offering services in education and training, information and research. Contact 01 4162035.
- **The Primary Care Research, Education and Pathways of Dementia (PREPARED) project:** Department of General Practice, UCC. Provides clinical educational resources and a range of dementia workshops, online training and accredited CPD modules directed at GPs and healthcare professionals who are managing people with dementia in primary care.
- **Bradford Dementia Group:** runs undergraduate and postgraduate courses on dementia for healthcare professionals.
- **The Dementia Centre at Stirling University (DSDC):** is an international centre of knowledge and expertise in dementia care.

### Service Providers

- **The Health Service Executive (HSE):** The HSE is responsible for the delivery of both community and hospital based services to people living in Ireland. Your local health office will be able to provide you with details of the services that may be available. Services can vary from county to county so it is important to check with your local office. Contact 1850 24 1850
- **The Alzheimer Society of Ireland:** For dementia-specific specialist services such as day care, home care, home support, social clubs, family carer support groups, Alzheimer Cafés and training events across Ireland. The Alzheimer Society of Ireland also operates the Alzheimer National Helpline Freephone 1800 341 341.
- **Private Home Care Agencies:** Other companies and individuals also offer private home care and nursing care. Home and Community Care Ireland represents registered private home care providers in Ireland and have a [list of registered providers](#) or call 01 484 7499. The HSE also holds a [list of approved home help agencies](#).
- **Family Carers Ireland:** for support for family carers. Contact 1800 240724

### Legal Services

- **The Law Society of Ireland:** For a list of solicitors working in Ireland, call 01 672 4800. The Law Society is the educational, representative and regulatory body of the solicitors' profession in Ireland.
- **The Legal Aid Board:** The board provides legal aid and advice on matters of civil law. There is a means test to access this service. A list of law centres operating around the country is available at 1890 615200.
- **Free Legal Advice Centres (FLAC):** Voluntary organisation which provides information and referral on legal issues over the phone and at a number of part-time clinics. There is no means test for the service but they do not provide legal representation or undertake legal work. Contact the Information and Referral Line at 17890 350 25.

## Information about Financial Grants and Entitlements

- **[The Citizen's Information Service](#)**: This is a statutory body and provides information about public services and the entitlements of the citizens of Ireland. For information about grants and income supports, how to apply for these supports or to locate the nearest office to you; Phone: 0761 07 4000 or LoCall: 1890 777 121.
- **[The Department of Social Protection](#)**: The Department charged with the delivery of income supports such as the carer's allowance.
- **[The Health Service Executive](#)**: is responsible for administering the Nursing Home Support Scheme Act 2009 (also known as the Fair Deal scheme)

**Please note:** Much of the information in the appendix is adapted from leaflets from [Dementia Services Information & Development Centre](#) and [The Alzheimer Society of Ireland](#).