Quality in Practice Committee

Dementia: Diagnosis and Management in General Practice

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This quality of care may be dependent on the appropriate allocation of resources to practices involved in its delivery. Resource allocation by the state is variable depending on geographical location and individual practice circumstances. There are constraints in following the guidelines where the resources are not available to action certain aspects of the guidelines. Therefore individual healthcare professionals will have to decide what is achievable within their resources particularly for vulnerable patient groups.

The guide does not however override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or guardian or carer.

Guidelines are not policy documents. Feedback from local faculty and individual members on ease of implementation of these guidelines is welcomed.

EVIDENCE-BASED MEDICINE

Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients.

In this document you will see that evidence and recommendations are attributed a level of evidence (Level 1 – 5) using an adaptation of the revised Oxford Centre 2011 Levels of Evidence.

LEVELS OF EVIDENCE

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

Level 5: Evidence obtained from mechanism-based reasoning

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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 (1).

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.

Dementia prevalence is rising. Ireland is predicted to have the largest growth in the older population of all European countries in the coming decades (2). In 2009, there were an estimated 41,700 people living with some form of dementia in Ireland. It is expected that this figure will rise to 147,000 by 2041 (3). 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 (4). 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 (5).

Calculations suggest that the current cost of dementia care in Ireland is €1.69 billion per annum (3). 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 (3).

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 (6). 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 (7).

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 (7).

Current national and international dementia policy advocates a patient-centred approach enabling persons with dementia to stay living at home for as long as possible (6).

The Irish Government has given a commitment in the Programme of Government for 2011-2016 to develop and implement a National Strategy for Dementia. This will be published in 2014.

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 (8) (9). Timely diagnosis enables planning for the future, the involvement of relevant support organisations and may help to relieve the psychological distress experienced by caregivers (10). 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. Early disclosure of the diagnosis seems to be what people with dementia want to have (11).

However, the hazards of early recognition are well recognized too and 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 (12). There is also a risk that this focus on early diagnosis ignores the lack of capacity within primary care to deal with the demands generated by this policy.

Dementia is a clinical diagnosis made when acquired cognitive deficits in more than one area of cognition interfere with activities of daily living and represent a decline from a previously higher level of functioning (13). Dementia is often preceded by a period of mild cognitive impairment (MCI) in which there are complaints and objective impairments in one or more cognitive domains but with preservation of activities of daily living (14). Young-onset dementia is conventionally considered to include patients with onset of dementia before 65 years of age (15).

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, and Mixed Dementias. These are briefly described in Table 1.

Other sub-types include Parkinson's Disease Dementia, Alcohol Related Dementia, Huntington's Disease 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 (13) (16)

ALZHEIMER'S DISEASE:
Estimated 50% of cases of dementia. Symptoms include, **1.** Cognitive dysfunction - includes memory loss and language difficulties, **2.** Behavioural and psychological symptoms - e.g. apathy, depression, hallucinations, delusions, agitation **3.** Difficulties with performing activities of daily living The average survival period for patients following diagnosis is 8 to 10 years.
VASCULAR DEMENTIA
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 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.
DEMENTIA WITH LEWY BODIES
Estimated 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. Approximately three quarters of older people with Parkinson's disease develop dementia after 10 years.
FRONTO-TEMPORAL DEMENTIA
Represents a significant proportion of people who present with dementia under the age of 65. Pick's disease is included in this subtype. 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.
MIXED DEMENTIAS
Mixtures of two or more of the active dementias can be found in the same person, with one or other usually dominating. Rigid boundaries between subtypes of dementia may be unduly artificial.

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 (17).

Recognition of an emerging dementia syndrome is dependant upon:

- History Taking - including the patient's report and a collateral history
- Physical Examination
- Appropriate Investigations
- Medication Review
- Cognitive Assessment
- Specialist input – for complex cases (e.g. uncertainty about diagnosis, 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. A collateral history from a relative or carer is essential as a person with dementia may not be able to give a fully accurate history.

The differential diagnosis needs to be considered. Treatable causes of cognitive impairment include depression, hypothyroidism and certain vitamin deficiencies.

Delirium**,** a transient usually reversible acute confusional state, develops over a short period (hours to days) and fluctuates; in such cases a search for an acute medical cause is required.

2.3 Physical Examination

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

2.4 Appropriate Investigations

Relevant investigations to perform are included in Table 2.

Table 2: Investigations for Dementia (18)

INVESTIGATIONS IN PRIMARY CARE
Bloods – FBC, ESR, U&E, TFTs, Glucose, Lipids, Calcium & 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. 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)
INVESTIGATIONS IN SECONDARY CARE
• 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.

2.5 Medication Review

Many drugs may cause cognitive impairment. In a vulnerable patient, some medications are more commonly associated with confusion. See Table 3.

Table 3: Medications Associated with an Increased Risk of Confusion (19)

- ***Anticonvulsants*** – all anticonvulsants impair cognitive function
- ***Antidepressants*** – risks highest in tricyclics. Withdrawal delirium also occurs
- ***Antipsychotics*** – those with considerable anticholinergic activity may worsen delirium
- ***Anti-parkinsonian drugs*** – risk highest in those with anticholinergic activity
- ***Cardiac drugs*** – including digoxin and calcium antagonists
- ***Corticosteroids*** – risk is dose related
- ***Hypnotics/Sedatives*** – more common with long-acting benzodiazepines
- ***Opioid analgesics*** – risk highest with pethidine

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 (20).

Over 50% of GPs use the MMSE because of availability and professional habit. A brief overview of commonly used screening tools is given in Table 4.

Table 4: Cognitive Screening Tools in Primary Care (21) (22) (23)

Mini-Mental State Examination (MMSE) – Developed by Folstein, it is the most commonly used tool in General Practice. 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 < 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.

***General Practitioner Assessment of Cognition (GPCOG)** – 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 free of educational bias. It includes time orientation, a clock drawing task, report of a recent event and a word recall task. *http://www.patient.co.uk/doctor/general-practitioner-assessment-of-cognition-gpcog-score*

****Mini-Cognitive Assessment Instrument (Mini-Cog)** - 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 free of educational bias. *http://geriatrics.uthscsa.edu/tools/MINICog.pdf*

*****Memory Impairment Screen (MIS)** – 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. *http://nationalmemoryscreening.org/secure/12/nmsd/Screening%20Tools/2012-MIS.pdf*

Abbreviated Mental Test Score (MTS) – 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. *http://www.patient.co.uk/doctor/abbreviated-mental-test-amt*

Six Item Cognitive Impairment Tool (6CIT) – 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. *http://www.patient.co.uk/doctor/six-item-cognitive-impairment-test-6cit*

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 (21) (22) (23). They were found to be practical, feasible, have wide applicability and were psychometrically robust.

2.7 Specialist Input & 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 (24). However, identifying the sub-type 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 subtype diagnosis. 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 a 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 (16). The decision on whether to refer for a specialist opinion to Old Age Psychiatry, Gerontology, Neurology or a dedicated Memory Clinic is dependant 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 (13). 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 (25).

National Dementia Strategies in England and France have highlighted the role that Memory clinics play in the early diagnosis of dementia (26) (27). 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 (28).

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 disclosure of the diagnosis of dementia requires a sensitive individualized approach. GPs find this disclosure difficult, 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 with disclosure practices adopted in countries such as the UK and Norway (7). 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 (29).

Many questions arise for patients and family members following the diagnosis of dementia. Key areas to be considered are included in Table 5.

Table 5: Information Needs Arising from Diagnosis (18)

Offer the person with dementia and their family information about:

- Signs and symptoms, course and prognosis
- Local care and support services, local information and voluntary organisations
- Pharmacotherapy
- Medico-legal issues, including sources of financial and legal advice and advocacy
- Driving

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; *http://www.alzheimer.ie/About-Us/Publications.aspx*.

Patients and their carers may also be entitled to a range of benefits, such as Carer's Benefit and Respite Care Grants. Information is available from the HSE on these; *http://www.hse.ie/eng/services/list/4/olderpeople/benefitsentitlements/*

Details on further educational, legal, financial, and service resources are available in Appendix 1, 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 (12). This is recognized 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 (30).

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 (10).

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 Appendix 1.

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 (29). 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 (31). 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. This 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 (32). Key members of the primary care team who may contribute to the care of a patient with dementia are included in Table 7.

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; *http://www.hse.ie/eng/services/list/4/olderpeople/tipsforhealthyliving/dementia.html*

Table 7: The Primary Care Team and Dementia (3)

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 help, 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. They may also have a role to play in assessing suitability for assistive technology.

Physiotherapists
Their main aim is to maximise the person's abilities regarding mobility to allow the greatest level of independence possible. They have an important role too in falls risk-assessment.

Speech and Language Therapists (SALTs)
SALTs focus on improving quality of life by maximising communication ability and cognitive function. They also assess swallow and advise regarding food and drink consistency.

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.

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*.

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*.

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* 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*.

3.5 Pharmacotherapy

Medication management in dementia usually focuses on 2 key areas.

1. Drugs for Alzheimer's Disease.
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:

a. Cholinesterase Inhibitors

In AD there are multiple neurotransmitter abnormalities but most prominent are cholinergic with reduced activity of choline acetyltransferase, AChEIs act by increasing cholinergic transmission via inhibition of the breakdown of acetylcholine.

The NICE Guideline recommends the three Acetylcholinesterase inhibitors (AChEIs) donepezil, rivastigmine and galantamine, as options for managing mild to moderate Alzheimer's disease (18). Evidence has shown that AChEIs are of some benefit in terms of improvements in cognition, ADL and behavioural symptoms (33). Effect sizes are modest.

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 (18). 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 (33). AChEIs are not recommended for the treatment of cognitive decline in Vascular Dementia or mild cognitive impairment (18), however many patients in clinical practice have both Alzheimer's disease and cerebrovascular pathology (34).

Treatment should be continued only when it is considered to be having a worthwhile effect on cognitive, global, functional

or behavioural symptoms (18). The use of anticholinergics and cholinomimetics (e.g. neostigmine, pyridostigmine) should be avoided (19).

Discontinuing cholinesterase inhibitors may lead to worsening of cognitive functions and greater functional impairment as compared to continued therapy (35). 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 (35).

b. 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 (18). It may be used alone or in combination with cholinesterase inhibitors (36). It is generally well tolerated although common undesirable effects are dizziness, headache, constipation, somnolence and hypertension (37).

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 (18).

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 (38). 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 (39). These are listed in Table 6.

Table 6: Areas for Discussion at Regular Review (18) (39)

- Medications – including use of antipsychotics
- Mental Health – including screen for depression
- Social Care
- Assessment of Carer's Needs

Regular physical examination should focus on hearing, vision, nutrition, bowel and bladder function (40).

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 (41).

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 (42).

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 a third reporting important levels of abuse and half some abusive behavior (43).

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

BPSD is a general term used to describe a range of behavioural and psychological symptoms experienced by patients with dementia.

BPSD may be grouped into

- 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.

People with dementia are more likely to be referred for specialist assessment when BPSD is identified. The majority of people with dementia will experience BPSD at some time, particularly in the middle and later stages (44).

4.1 The Assessment of BPSD

The assessment of BPSD should include a thorough history from the patient, family and carers with careful consideration of the following (45) (18):

- the person's physical health, including pain, infection and constipation. Need to consider and rule out delirium.
- the person's mental health, including depression and anxiety
- side-effects of medication (especially those with a psychotropic effect)
- premorbid personality, individual biography, including religious and cultural identity
- psychosocial factors
- physical environmental factors

4.2 The Management of BPSD

Guidelines urge non-pharmacological management for BPSD (18). In practice, complete resolution of BPSD may be very difficult to achieve with non-pharmacological interventions, as availability of therapies may be limited and the physical environment may not be optimal. A recent 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 (46).

a. Non-Pharmacological Management of BPSD (45)(18)

- Define BPSD treatment targets, e.g. relief of psychotic symptoms, safe containment of wandering
- Educate patients, families and carers
- Optimise the environment
- Treat pain, infection, constipation
- Consider non-medication therapies, depending on availability:
- Physical activity and Recreational activities
- Multisensory stimulation, e.g. aromatherapy, massage, light therapy, music therapy
- Reality orientation therapy
- Validation therapy

b. Pharmacological Management of BPSD

(i) Antipsychotics

There has been increasing concern regarding the safe use of antipsychotics for BPSD, with significantly increased risk of stroke and a 1.7 times increased risk of all-cause mortality, compared with placebo (47). Antipsychotics are frequently prescribed for the management of BPSD; however, the main licensed use for antipsychotics is for the treatment of schizophrenia or bipolar disorder where there is a psychosis (48). A review of the evidence shows that antipsychotics have a limited positive effect in the management of BPSD and may cause considerable harm (48).

Adverse effects of antipsychotics include over-sedation, accelerated cognitive decline, gait disturbance, involuntary movements, Parkinsonism, neuroleptic malignant syndrome, cardio-toxicity and other thromboembolic events.

Older people with dementia, especially those with coexistent comorbidities, are more sensitive to the adverse effects of antipsychotics. Research has shown that antipsychotics can be safely withdrawn in people with dementia who have taken them for prolonged periods (49). Antipsychotic prescribing should be time-limited and reserved for severe and distressing symptoms after careful assessment of the risks and benefits of their use and consideration of the type of dementia (16).

In severe cases of BSPD, when all other management options have been exhausted and when the safety of the patient or caregiver is at risk, antipsychotic use may be justified. The lowest possible therapeutic dose should be chosen, with slow titration and regular review and a plan made to review and consider discontinuing treatment where possible, after six weeks (45). The risk of adverse effects should be discussed and documented with patients, families and carers.

Risperidone is the only antipsychotic medication licensed for use in patients with dementia (50). 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 (50).

(ii) Other medications for BPSD (46)(51)

- Antidepressants – should be considered if evidence of depression or anxiety. Tricyclics should be avoided as antimuscarinic activity may lead to a worsening of cognitive impairment.
- Cholinesterase Inhibitors and Memantine – May be of some benefit for the symptoms of BPSD.

- Hypnotics – May be of limited benefit, especially for night-time disturbance. However increasing tolerance and adverse effects including oversedation, confusion, agitation and risks of falls needs to be considered.
- Valproate and Carbamazepine – In some trials carbamazepine has been found to reduce agitation, restlessness and anxiety however the efficacy and tolerability of long term use of this drug is yet to be established (52).

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 to 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.

A recently published document by the Road Safety Authority provides guidance on medical fitness to drive (53). 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 (53).

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 (53). 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 (53)

MILD COGNITIVE IMPAIRMENT (MCI)
Where there is **no** objective impairment of function MCI does not need to be notified to Driving Licensing Authority. Where there **is** objective impairment of function or specific treatment is required then the doctor should clarify the cause and apply the relevant section of Sláinte agus Tiomáint.
DEMENTIA OR ANY ORGANIC BRAIN SYNDROME
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. 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. 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. *Driver must notify Driving Licensing Authority*

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

The Government's Assisted Decision Making (Capacity) Bill 2013 was published in July 2013 proposing a modern legal framework for people with impaired capacity in Ireland (54). If enacted in its current form it will replace the Lunacy Regulation Act of 1871.

See *http://www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf*.

The Bill seeks to introduce 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) (55).

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) (56)

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 9.

Table 9: Assessing Testamentary Capacity: The Tests (56)

What the testator (the person making the will) must be capable of understanding:

- The nature and effect of making a will
- The extent of his or her estate
- 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

What the testator should not have:

- A mental illness that influences the testator to make bequests (dispositions) in the will that he or she would not otherwise have included

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 (57).

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 (58). Answers to the questions mentioned above in Table 9, should be recorded in as detailed a fashion as possible.

Other essential components of a certificate of mental capacity are included in Table 10.

Table 10: Information to include in a Certificate of Mental Capacity (57)

- Identification of self
- Identification of the subject
- The date, time and duration and basis for the examination
- The diagnosis
- The opinion and the grounds for the opinion
- The part/parties with whom the opinion will be shared/passed

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 11.

Table 11: Process for Assessing Testamentary Capacity (57)

- Get a letter from the solicitor detailing legal tests
- Set aside enough time
- Assess (in the standard way) whether the patient has dementia
- Check that the patient understands each of the Banks v Goodfellow points (Table 9)
- Record the patient's answers in as detailed a manner as possible
- Check facts, such as the extent of the estate, with the solicitor
- Ask about and review material changes from previous wills, such as why potential beneficiaries are included or excluded

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

- once the donor becomes "incapable" and
- 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 if 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 @ *www.courts.ie*

6.4 Advance Care Directives

- 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 (59). 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 care directive/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 (60). It may emerge in the context of mental illness or end-of-life decision making.
- The Law Reform Commission has recommended that advance care directives be made legally binding in Ireland (61). The Assisted Decision Making (Capacity) Bill 2013 if enacted, will address this area.
- To be effective 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.

Further useful information on advance care directives for patients is available from The Irish Hospice Foundation at *www.thinkahead.ie* and in the publication 'Let Me Decide' (62).

Section 7: Advanced Dementia

7.1 The Nursing Home

Dementia is common in patients in nursing homes, though is likely to be under-diagnosed (3). A Department of Health and Children report stated that 26% of these people in residential care were reported as having dementia (63). This is likely to be a gross underestimation (3). In the USA and Europe, between one-half and two-thirds of nursing homes residents are said to have dementia (64). A recent 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 (65).

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 (66).

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 (67). 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 (3).

Suggested strategies to improve the quality of care in nursing homes include the following (26):

- 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.
- Only 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 (3):

- 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

HIQA (Health Information and Quality Agency) has developed specific standards for the operation of nursing homes and residential centres (68). Some of the areas specifically related to GP care include:

- Medication management
- Medication monitoring and review
- Use of psychotropic medication
- End of life care

7.2 Palliative Care

The majority of people with dementia die in nursing homes, only around 2% die in a hospice (20). 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 (69).

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 (70).

Guidance for the palliative care management of patients with dementia is given in table 13.

Table 13: Dementia Palliative Care (18)

- Dementia care should incorporate a palliative care approach considering physical, psychological, social and spiritual needs of the patient.
- Advance care planning should be utilized by health and social care professionals
- Palliative care services should be available to people with dementia in the same way they are available to people who do not have dementia.
- 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.
- 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.
- 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.

Examples of pain assessment tools for patients with dementia include:

- The Abbey Pain Scale: *http://www.bcf.nhs.uk/docs/19354_8582738196.pdf?_ts=1&_ts=1*
- DOLOPLUS 2 Scale: *http://prc.coh.org/PainNOA/Doloplus%202_Tool.pdf*

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Appendix:

(1) Dementia Resources

a. Information about Dementia

- **The Alzheimer Society of Ireland**
- Contact the Alzheimer National Helpline Monday to Friday, 10 am - 4 pm. Freephone 1800 341 341. Email: *helpline@alzheimer.ie* Visit *www.alzheimer.ie*
- **Alzheimer Society UK** provide an online forum for carers called Talking Point at *http://forum.alzheimers.org.uk*
- **The Scottish Dementia Working Group** is run by people with dementia and provides information for people with dementia at *www.sdwg.org.uk*
- **The Dementia Advocacy & Support Network International (DASNI)** provides an online support network for people with dementia at *www.dasninternational.org*

Primarily 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 (1) Education and Training, (2) Information and Consultancy, (3) Research. Phone: 01 4162035, email: dsidc@stjames.ie or see website: *http://dementia.ie*.
- **Living with Dementia,** Trinity College Dublin. Hosted by The School of Social Work and Social Policy, TCD, it has research, education and information dissemination components. Phone: 01 8962914, visit website: *http://livingwithdementia.tcd.ie*
- **Bradford Dementia Group** runs undergraduate and postgraduate courses on dementia for healthcare professionals: *http://www.brad.ac.uk/health/career-areas/bradford-dementia-group/*
- **The Dementia Centre at Stirling University** DSDC is an international centre of knowledge and expertise in dementia care: *http://dementia.stir.ac.uk*

b. Service Providers

- **The Alzheimer Society of Ireland**
  For dementia-specific specialist services such as day care, home care, social clubs, family carer support groups and training across Ireland contact: Alzheimer National Helpline Freephone 1800 341 341, Email: helpline@alzheimer.ie or visit *www.alzheimer.ie*
  - Alzheimer Cafés:
    The Alzheimer Café is a safe and relaxed place where people with dementia and their families can meet to share experiences and talk about dementia. www.alzheimercafe.ie
    Alzheimer Society Social Clubs: Drop-in centres for carers and people with dementia.
    Alzheimer Society of Ireland Home Care Service
    Specialist home care/home support service that use trained dementia care workers to provide support and care in a persons home for a designated number of hours per week.
- **Private Home Care Agencies**
  Several agencies now provide home care services. Lists of approved, fully insured, agencies are available from Local Health Centre's and Social Work Teams.
  Costs may vary.
- **The Carer's Association**
- For services such as home respite, carer training and support groups around Ireland; Call 1800 24 07 24 / visit *www.carersireland.ie*
- **Caring for Carers Ireland**
  Contact 065 6866515 / *www.caringforcarers.ie*
- **The Health Service Executive (HSE)**
  To find out where your local HSE Health Centre is or to ask about services that may be available in your area; Call 1850 24 1850, visit *www.hse.ie*

c. Legal Services

- **The Law Society of Ireland**
- For a list of solicitors working in Ireland, call 01 672 4800 or visit *http://www.lawsociety.ie*
  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 or *www.legalaidboard.ie*
- **FLAC – Free Legal Advice Centres**
  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 or visit *http://www.flac.ie*

d. 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 or Visit: *www.citizensinformation.ie*.
- **The Department of Social Protection**
  The Department charged with the delivery of income supports such as the Carer's Allowance, to find out about these supports and where your local welfare office is visit *https://www.welfare.ie*

(Much of the information in the appendix is adapted from leaflets from Dementia Services Information & Development Centre http://www.dementia.ie & The Alzheimer Society of Ireland www.alzheimer.ie)