

NATIONAL CLINICAL GUIDELINES

THE DIAGNOSIS & TREATMENT OF DEMENTIA

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Valid From: 8th January 2020

Date of Next Revision: 8th January 2022



المبادئ الإرشادية السريرية لدولة قطر
NATIONAL CLINICAL GUIDELINES FOR QATAR



وزارة الصحة العامة
Ministry of Public Health
دولة قطر • State of Qatar

Version History

Version	Status	Date	Editor	Description
1.0	Final	8 th January 2020	Guidelines Team	Final Version for Publication

Citation

Suggested citation style:

Ministry of Public Health Qatar. National Clinical Guideline: The Diagnosis and Treatment of Dementia (2020).

Abbreviations

The abbreviations used in this guideline are as follows:

ACE III	Addenbrooke's Cognitive Examination, 3 rd edition.
6CIT	The 6-item Cognitive Impairment Test
AChE	Acetylcholinesterase
AD	Alzheimer's Disease
ADLs	Activities of Daily Living
BPSD	Behavioural and Psychological Symptoms of Dementia
CADASIL	Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy
CT	Computed Tomography
DWI	Diffusion Weighted Imaging
DLB	Dementia with Lewy Bodies
ECG	Electrocardiography
EEG	Electroencephalogram
FDG-PET	Fluorodeoxyglucose Positron Emission Tomography
FLAIR	Fluid Attenuated Inversion Recovery
FTD	Frontotemporal Dementia
LOD	Late-onset dementia
MCI	Mild Cognitive Impairment
MMSE	The Mini-Mental State Examination
MoCA	Montréal Cognitive Assessment
MRI	Magnetic Resonance Imaging

NICE	The National Institute for Health and Care Excellence
PiB	Pittsburgh B Compound
PML	Progressive Multifocal Leukoencephalopathy
SIS	The 6-item Screener
SPECT	Single Photon Emission Computed Tomography
SSRIs	Selective Serotonin Reuptake Inhibitors
SWI	Susceptibility Weighted Imaging
T2WI	T2-Weight Imaging
VaD	Vascular Dementia
vCJD	Variant Creutzfeldt-Jacob disease
YOD	Young-onset dementia
ZBI	Zarit Burden Interview

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1 Information about this Guideline

1.1 Objective and Purpose of the Guideline

The objective of this guideline is to define the appropriate diagnosis and management of dementia in adults. The purpose is to improve the appropriate prescribing and referral of patients presenting to any provider organisation in Qatar. It is intended that the guideline will be used primarily by healthcare professionals in primary care and outpatient settings.

1.2 Scope of the Guideline

The following aspects of care are included within this Guideline:

- Clinical presentation of different types of dementia, including:
 - Alzheimer’s disease.
 - Vascular dementia.
 - Dementia with Lewy Bodies.
 - Frontotemporal Dementia.
- Generalist and specialist history, examination and investigation of patients presenting with symptoms of dementia.
- Communication of the diagnosis to patients and their caregivers.
- Pharmacological and non-pharmacological treatment options.
- Primary and secondary prevention.
- Considerations for patient preferences.
- Key Performance Indicators.

1.3 Editorial Approach

This guideline document has been developed and issued by the Ministry of Public Health of Qatar (MOPH), through a process which aligns with international best practice in guideline development and localisation. The guideline will be reviewed on a regular basis and updated to incorporate comments and feedback from stakeholders across Qatar.

The editorial methodology, used to develop this guideline, has involved the following critical steps:

- Extensive literature search for well-reputed published evidence relating to the topic.
- Critical appraisal of the literature.
- Development of a draft summary guideline.
- Review of the summary guideline with a Guideline Development Group, comprised of practising healthcare professionals, subject matter experts and patient representatives, from across Qatar.
- Independent review of the guideline by the National Clinical Guidelines & Pathways Committee, appointed by the MOPH, from amongst stakeholder organisations across Qatar.

Whilst the MOPH has sponsored the development of the guideline, the MOPH has not influenced the specific recommendations made within it.

1.4 Sources of Evidence

The professional literature has been systematically queried using specially developed, customised, and tested search strings. Search strategies are developed to allow efficient yet comprehensive analysis of relevant publications for a given topic and to maximise retrieval of articles with certain desired characteristics pertinent to a guideline.

For each guideline, all retrieved publications have been individually reviewed by a member of the Editorial Team and assessed in terms of quality, utility, and relevance. Preference is given to publications that:

1. Are designed with rigorous scientific methodology.
2. Are published in higher-quality journals.
3. Address an aspect of specific importance to the guideline in question.

Further information about the literature search and appraisal process is included in the *Appendix*.

1.5 Evidence Grading and Recommendations

Recommendations made within this guideline are supported by evidence from the medical literature and where possible the most authoritative sources have been used in the development of this guideline. In order to provide insight into the evidence basis for each recommendation, the following evidence hierarchy has been used to grade the level of authoritativeness of the evidence used, where recommendations have been made within this guideline.

Where the recommendations of international guidelines have been adopted, the evidence grading is assigned to the underlying evidence used by the international guideline. Where more than one source has been cited, the evidence grading relates to the highest level of evidence cited:

- **Level 1 (L1):**
 - Meta-analyses.
 - Randomised controlled trials with meta-analysis.
 - Randomised controlled trials.
 - Systematic reviews.
- **Level 2 (L2):**
 - Observational studies, examples include:
 - Cohort studies with statistical adjustment for potential confounders.
 - Cohort studies without adjustment.
 - Case series with historical or literature controls.
 - Uncontrolled case series.
 - Statements in published articles or textbooks.
- **Level 3 (L3):**
 - Expert opinion.
 - Unpublished data, examples include:
 - Large database analyses.
 - Written protocols or outcomes reports from large practices.

In order to give additional insight into the reasoning underlying certain recommendations and the strength of recommendation, the following recommendation grading has been used, where recommendations are made:

- **Recommendation Grade A (RGA):** Evidence demonstrates at least moderate certainty of a net benefit from the recommendation.
- **Recommendation Grade B (RGB):** Evidence is insufficient, conflicting, or poor and demonstrates an incomplete assessment of net benefit vs harm; additional research is recommended.
- **Recommendation Grade C (RGC):** Evidence demonstrates potential harm that outweighs benefit; additional research is recommended.
- **Recommendation of the GDG (R-GDG):** Recommended best practice on the basis of the clinical experience of the Guideline Development Group members.

1.6 Guideline Development Group Members

The following table lists members of the Guideline Development Group (GDG) nominated by their respective organisations and the National Clinical Guidelines & Pathways Committee. The GDG members have reviewed and provided their feedback and approval of the guideline document. Each member has completed a declaration of conflicts of interest, which has been reviewed and retained by the MOPH.

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1.7 National Clinical Guidelines & Pathways Committee Members

The following table lists members of the National Clinical Guidelines & Pathways Committee (NCGPC), appointed by the MOPH. The NCGPC members have reviewed and provided their feedback and approval of the guideline document. Each member has completed a declaration of conflicts of interest, which has been reviewed and retained by the MOPH.

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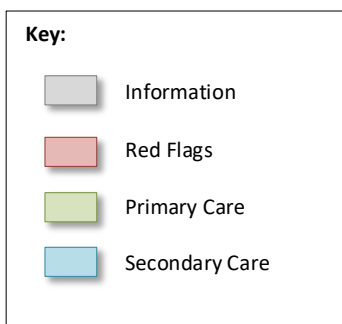
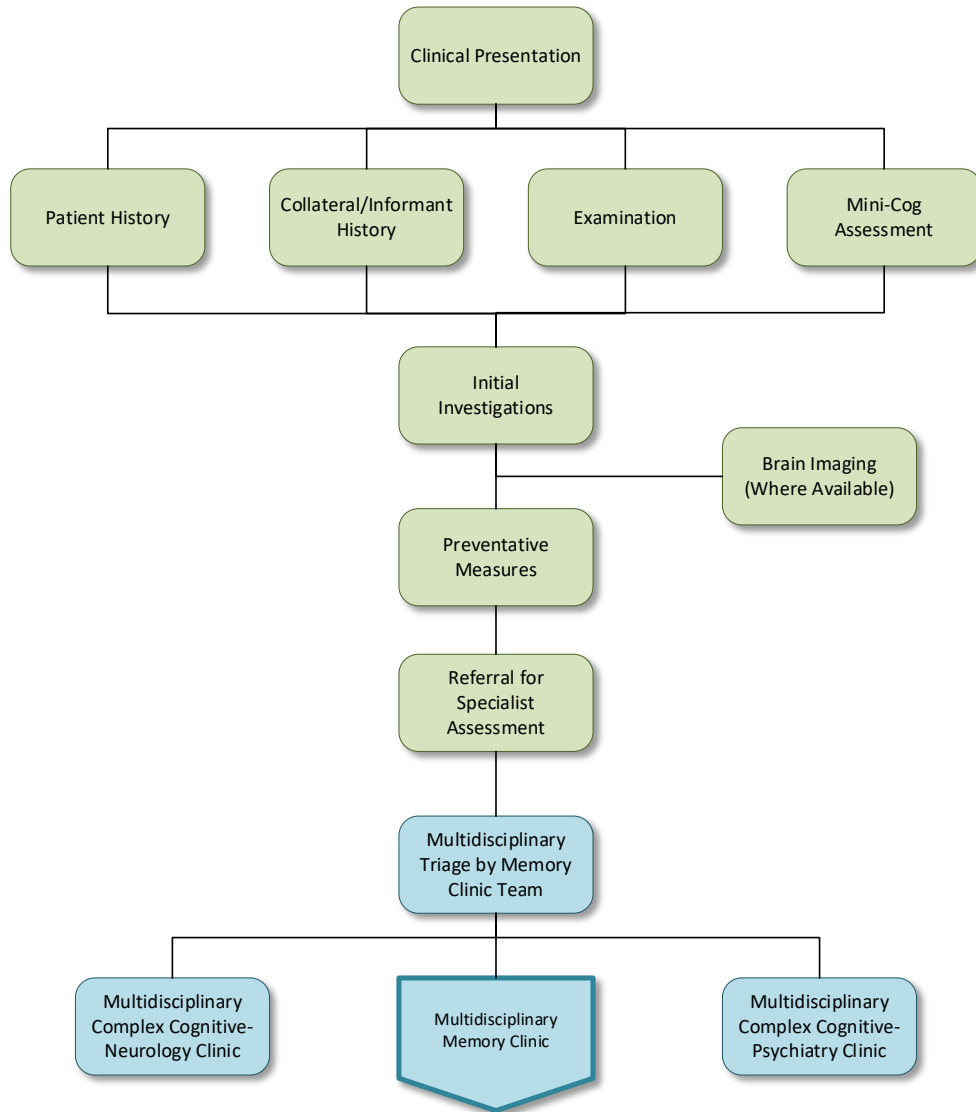
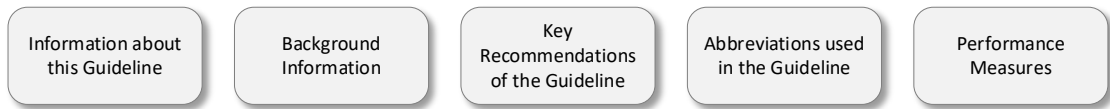
1.8 Responsibilities of Healthcare Professionals

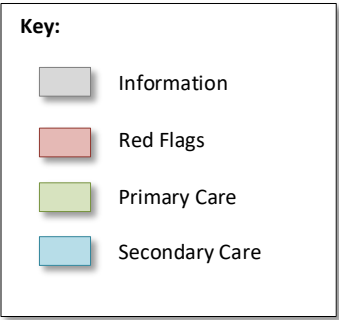
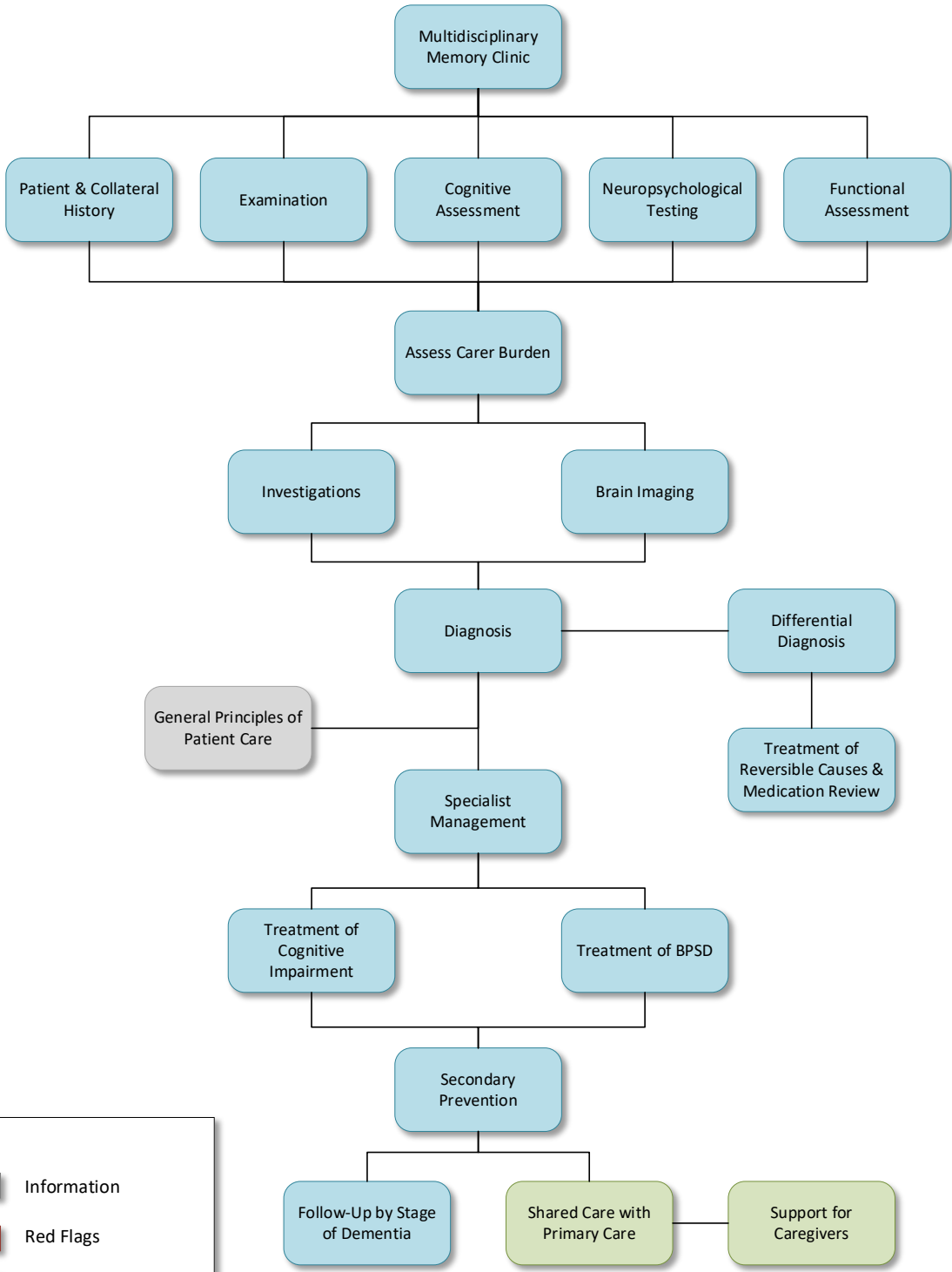
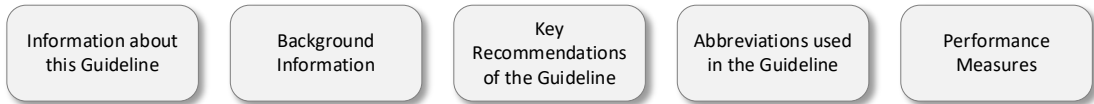
This guideline has been issued by the MOPH to define how care should be provided in Qatar. It is based upon a comprehensive assessment of the evidence as well as its applicability to the national context of Qatar. Healthcare professionals are expected to take this guidance into account when exercising their clinical judgement in the care of patients presenting to them.

The guidance does not override individual professional responsibility to take decisions which are appropriate to the circumstances of the patient concerned. Such decisions should be made in consultation with the patient, their guardians, or caregivers and should consider the individual risks and benefits of any intervention that is contemplated in the patient's care.

2 Dementia Diagnosis & Management Pathway

Click on a box below to see the relevant page of the Pathway.





3 Key Recommendations of the Guideline

The key recommendations of this guideline are as follows:

Initial History (Sections 6.1 & 6.2):

- History taking should be directed to establishing the probability of a dementia diagnosis.
- Ensure identification of medication that may be contributing to cognitive impairment (see Section 9.3).
- A separate history report from a family member or caregiver with the patient absent is obligatory¹ [L2, RGA] as the patient may fail to note some early personal changes that may be noticed by a family member or caregiver.
- Risks of harm to the patient and/or others, identified in the history, should be addressed at the first consultation and appropriate advice given to the patient and caregivers [R-GDG].

Initial Examination (Section 6.3):

- If dementia is suspected, a physical examination and cognitive testing should be conducted which includes assessment of mental health and completion of the Mini-Cog Assessment^{2,3}.
- A normal Mini-Cog score does not exclude dementia and therefore the Mini-Cog Assessment should not be used in isolation to determine whether to refer a patient to a Memory Clinic [R-GDG].

Initial Investigations (Sections 6.4 & 6.5):

- If dementia is suspected, a set of laboratory tests should be ordered to exclude treatable underlying causes^{1,4-6} [L2, RGA] (see Section 6.4).
- Where available, appropriate brain imaging with CT or MRI, should be requested by primary care physicians as part of the initial assessment of dementia [R-GDG].

Referral to Specialist Care (Section 7)

- Where dementia with no underlying cause is suspected, referral to specialist care should be according to the criteria listed in Section 7 [R-GDG].

Specialist Assessment (Section 8):

- If dementia is suspected after initial assessment, a physical examination and cognitive testing should be conducted¹.
- Do not exclude dementia solely because the patient has a normal score on a cognitive instrument² [RGC].
- No one cognitive test is recommended over another¹ [L2, RGB].
- No brief cognitive test has been developed to differentiate between types of dementia, and none can be recommended for this purpose¹ [L2, RGC].
- Repeat the testing on several occasions over several months, to provide convincing evidence of cognitive impairment¹ [RGA].

Functional Assessment (Section 8.4):

- Where available, assessments of ADLs and IADLs should be performed by a specialist occupational therapist working as part of the multi-disciplinary team, using the FAST and FIM assessment tools [R-GDG].

Assessing Carer Burden (Section 8.5):

- The *Zarit Burden Interview* (ZBI) is a reliable instrument to measure caregiving burden in caregivers of patients with dementia^{7,8}.
- Refer family caregivers to their family physician for organisation of additional support and help where appropriate [R-GDG].

Specialist Investigations (Sections 8.6 & 8.7):

- Syphilis serology and HIV tests *are not recommended* as a routine tests, but can be justified if the apparent course of the syndrome or the presentation is atypical or in cases with a suggestive history^{4,5} [RGB].
- Determination of serum homocysteine levels *is not recommended* in older adults with suspected dementia or cognitive decline due to insufficient evidence that treatment of its elevated levels affects cognition¹ [L2, RGB].
- Genetic testing (e.g., screening for the gene apolipoprotein E or levels of amyloid- β) *is not recommended* due to the low positive and negative predictive values^{1,5,9} [L2, RGB].
- Lumbar puncture and EEG may be performed in atypical presentations of dementia [R-GDG].
- MRI, CT, PET-CT and SPECT, can all be used for brain imaging^{1,4}
- Where indicated the multidisciplinary team should liaise with the neuroradiologists to discuss the most appropriate brain imaging modality and the results of scans [R-GDG].
- Do not rule out AD based solely on the results of brain imaging^{2,10} [L2, RGC].

Diagnosis (Section 9):

- If considering diagnosis of a degenerative dementia, it is important to exclude delirium.
- The initial diagnosis of dementia should not be made while the patient is in a delirious state¹ [L2, RGA].
- If unclear whether the patient has delirium, dementia, or delirium superimposed on dementia, delirium must be treated first^{1,2} [L2, RGC].
- People with dementia syndrome have high rates of depression and people with depression often have prominent complaints of memory loss, neuropsychological deficits, and often organic brain changes (“pseudodementia”)⁴.
- Reversible causes of cognitive impairment (listed in Section 9.2), should be considered prior to making a diagnosis of dementia [R-GDG].
- Medication causing cognitive impairment should be considered and, where possible, stopped or changed¹¹ (see Section 9.3).
- The diagnostic criteria listed in Sections 9.4, 9.5 & 9.6 should be used to diagnose MCI, dementia and its types.
- If a diagnosis of dementia is made, patients and their family caregivers should be invited to a post-diagnostic consultation with a senior member of the multi-disciplinary team [R-GDG].
- Communication to patients and their family caregivers should be sensitive, and at a minimum, should cover [R-GDG]:
 - The diagnosis.
 - Treatment options.
 - Prognosis with respect to expected decline in the patient’s cognition and functional status.
 - Supportive information, e.g. patient information leaflets, should also be provided.
 - The *UK Alzheimer’s Society ‘This is Me’* document should be completed and retained in the patient’s medical record and a copy provided to the family.

General Principles of Patient Care (Section 10.2):

- Care should be provided by an integrated and collaborative multidisciplinary team of professionals (listed in Section 10.1)¹².
- Person-centred care should be provided to all patients [R-GDG].
- Confidential information should not be disclosed to other people (including family members) without the consent of the patient, or their legal representative - except as indicated under applicable Qatari law [R-GDG].
- Early after diagnosis, facilitate opportunities for people with dementia, and their caregivers, to discuss their preferences for advocacy, care and end of life^{2,5,13}:
- Facilitate opportunities for the patient to review and change any advance statements and decisions made by the patient in the past².
- Caregivers should not be able to change the patient's advanced directives unless the new decision is in line with the patient's known wishes [R-GDG].
- The majority of the people with dementia should be cared for in their own residence for as long as possible^{12,14,15} [L3, RGA].
- Patients, their family members, and professional caregivers should be routinely asked about instances of suspected abuse and neglect¹⁶.

Non-Pharmacological Management (Section 10.3):

- Offer a range of psychological therapies and practical measures to promote wellbeing of patients at all stages of dementia^{2,5,17-19} [L1, RGA] (listed in Section 10.3.1).

Pharmacological Management of Cognitive Impairment (Section 10.4):

- Medication will not stop dementia getting worse, but it can help reduce some of the symptoms for some people².
- Monotherapies are recommended as options for managing AD^{2,4,5,17} [RGA], but combination therapy using AChE and Memantine can be considered by specialists [R-GDG]:
 - Mild form:
 - AChE inhibitors:
 - Donepezil.
 - Galantamine.
 - Rivastigmine.
 - Moderate and Severe form:
 - AChE inhibitors.
 - Memantine (if intolerant of or have a contraindication to AChE inhibitors).
- Treatment with an AChE inhibitor or memantine, should only be started on the advice of a clinician who has the necessary knowledge and skills².
- Only consider AChE inhibitors or memantine for patients with VaD if they have suspected comorbid AD, Parkinson's disease dementia or DLB [RGB].

Treatment of Depression and Anxiety (Section 10.4.3)

- Consider psychological treatment for patients with mild to moderate dementia who have mild to moderate depression and/or anxiety² [RGA].
- Do not routinely offer antidepressants for patients with mild to moderate dementia, unless they are indicated for a pre-existing severe mental health problem^{2,17} [RGB].
- If antidepressants are required, consider offering SSRIs (e.g. citalopram or sertraline) mirtazapine, or trazadone^{2,4} [L2, RGA]:
- The use of either tricyclic antidepressants or paroxetine, *are not recommended*^{5,20} [L1, RGB].

Treatment of Sleep Disturbance (Section 10.4.3):

- Exclude underlying causes of sleep disturbance e.g. sleep apnoea, restless leg syndrome, pain, hunger etc.²¹. This is especially important where patients are unable to express their needs [**R-GDG**].
- Hypnotic and sedative medications should be used very cautiously due to a risk of sedation, falls, and deterioration in cognitive function [**R-GDG**].

Treatment of Agitation, Aggression, Distress and Psychosis (Section 10.4.3):

- Some antipsychotics can worsen the motor features and cause severe antipsychotic sensitivity reactions in DLB or Parkinson's disease dementia^{2,17} [**RGC**].
- The risk of stroke and mortality is higher in patients taking antipsychotics¹⁷.
- Consider antipsychotics if there is a need to control psychosis and severely challenging behaviour that is putting the patients, and/or others around them, at a significant risk of harm^{4,17,22} [**L3, RGA**].
- If antipsychotics are required, atypical antipsychotics are preferred (over typical antipsychotics)^{2,5,17} [**RGA**].
- Use the lowest effective dose for the shortest possible time^{2,5,17}.
- Reassess the patient at least every 6 weeks, to check whether medication is still needed^{2,5,17}.
- Stop treatment if the person is not benefiting from taking the medication^{2,5,17}.
- Offer psychosocial and environmental interventions (including family education) to reduce distress in patients with dementia² [**RGA**].
- Consider citalopram or escitalopram to manage agitation¹⁷ [**L1, RGA**].

Young Onset Dementia (Section 10.6)

- Young Onset Dementia (YOD) refers to the manifestation of symptoms of dementia before the age of 65 years²³.
- The impact and burden of YOD may be far greater and far more overwhelming for this population than those with LOD²³.
- There is a considerable delay in the diagnosis of YOD compared to LOD^{24,25}.
- On average, it is not until 2-3 years after the onset of symptoms that YOD is diagnosed²⁶.
- A high-index of suspicion and early referral to a neurologist is therefore recommended [**R-GDG**].
- Pharmacological Treatment of YOD is similar to that for LOD^{27,28}.

Considerations for Inpatient Management (Section 11):

- Admission to hospital should be avoided wherever possible [**R-GDG**]:
- The frequency and severity of symptoms increases with the length of stay and results in increased mortality¹⁴ [**L2, RGC**].
- Patients with dementia should be reviewed more frequently than usual [**R-GDG**].
- Patients should be admitted to dementia-specific wards, where possible [**R-GDG**].
- Physical restraints should only be used in exceptional circumstances for the minimum period of time (e.g. pulling intravenous lines) and in accordance with hospital policy.
- Restraints should only be used with the consent of a senior member of the clinical team²⁹.
- At all times, wherever possible, the decision to use restraints should be discussed with the primary caregiver [**R-GDG**].

Primary and Secondary Prevention of Dementia (Section 12):

- Preventive measures help to improve and maintain cognitive function [**R-GDG**].
- Eating a healthy, balanced diet and maintaining a healthy weight have been shown to delay cognitive decline^{30,31}.

- Evidence suggests that recreational physical activity increases cognitive function later in life^{30–32}. It may improve cognition in older adults with normal cognitive function and also in individuals with different levels of cognitive impairment^{30,31} [**L1, RGA**].
- The control of cardiovascular risk factors, such as obesity, diabetes, dyslipidaemia and hypertension, are important targets for dementia prevention^{31,33,34} [**L1, RGA**].
- Mid-life peripheral hearing impairment can increase the risk of dementia and should therefore be actively evaluated and managed¹⁷.
- Maintaining mental and social activity at high levels can reduce the risk of age-related cognitive decline³⁴ [**L2, RGA**].
- Stopping smoking and reducing alcohol consumption, are effective ways of decreasing the risk of vascular dementia^{10,31} [**L2, RGA**].

Supporting Caregivers (Section 13):

- Caregivers of people with dementia are at an increased risk of depression and anxiety, high levels of stress, long-term medical conditions and Burnout Syndrome^{2,4,35}.
- Caregivers' needs should be routinely evaluated using the *Zarit Burden Interview* (see Section 8.5)^{5,7,8} [**L1, RGA**].
- Offer caregivers of people living with dementia, emotional and informational support as well as resources to handle stress³⁵ [**L2, RGA**].
- Offer caregivers a psychoeducation and skills training (see Section 13)².
- Consider respite care for the patient, if necessary^{36,37} [**L2, GRA**].

4 Background Information

4.1 Definition

Dementia is a clinical syndrome characterised by a progressive decline in a range of cognitive and behavioural symptoms and signs that often include difficulties, and loss of, memory. Other common symptoms and signs include disturbances in language, problems with reasoning and communication, change in personality. For dementia to be present there must be impairment of daily activities^{2,4}.

The following cognitive domains may be affected³⁸:

- Complex attention.
- Executive function.
- Learning and memory.
- Language.
- Perceptual-motor.
- Social cognition.

4.2 Types of Dementia

The most common types of dementia are^{2,4,31}:

- Alzheimer's disease (AD)
- Vascular dementia (VaD).
- Mixed dementia (AD and VaD).
- Dementia with Lewy bodies (DLB).
- Frontotemporal dementia (FTD).

Other types (frequencies <1%) include focal dementias (such as progressive aphasia), subcortical dementias (such as Parkinson's disease dementia), and secondary causes of dementia syndrome (such as intracranial lesions)^{4,39}.

4.3 Aetiology

Dementia comprises a range of neurodegenerative disorders with different aetiologies. Most changes in the brain that cause dementia are permanent⁴. However, a small subset of treatable disorders presenting as memory loss (<1% of all cases) and should not be missed.

AD is the commonest cause of dementia (estimated to be 50-60% of cases in Qatar^{39,40}. VaD is the second most common dementia type (40%)⁴¹. However, it is very common as a mixed pathology in older individuals. The typical onset of dementia is late onset, sporadic AD, with symptoms that appear at age 65 or older.

4.4 Risk Factors for Development of Dementia

Non-modifiable^{17,41,42}:

- Age ≥65 years.
- Genetic risks (i.e. Downs Syndrome).
- Gender:

- Females are in higher risk of dementia than males.
- Female are at higher risk of AD.
- Males are at higher risk of VaD.

Modifiable risk factors^{1,10,17,30,41–43}:

- Repetitive head trauma.
- Brain tumour.
- Diabetes.
- Overweight/obesity.
- Smoking history.
- Heavy alcohol use.
- Psychological conditions, e.g.:
 - Anxiety.
 - Depression.
- Vascular events and conditions, e.g.:
 - Stroke.
 - Hypertension.
 - Hypercholesterolaemia.
 - Atherosclerosis.
 - Hyperhomocysteinaemia.
- Hearing loss.
- Family history of:
 - Dementia.
 - Stroke.
 - Hypercholesterolaemia.
- Social isolation.
- Lack of exercise.

Factors such as high education level, physical exercise, and good social networks are considered protective^{1,43}.

4.5 Prognosis

Dementia is a progressive condition. The symptoms will gradually get worse over time, but the progression varies from person to person². However, people can live for many years after being diagnosed with dementia⁴².

The estimated survival time is shorter in men than in women across all age groups⁴². Married individuals with dementia tend to show a longer survival; widowed men have the shortest survival⁴². DLB patients tend to have shorter survival times than AD patients⁴⁴.

4.6 Barriers to Early Diagnosis

The major barriers to the early diagnosis of dementia are^{1,4,36,45}:

- Difficulties in recognising the symptoms and signs of dementia^{1,41}.
- Societal stigma and lack of public awareness [R-GDG].
- The complexity of the diagnostic process:

- Insidious and variable onset of the syndrome, which emerges through changes in the personality of the individual, sometimes without a clear demarcation until late in the disease process.
- In the early stage symptoms, people with dementia do not necessarily present themselves with memory problems.
- Psychological aspects:
 - Patients, families, and physicians may be reluctant to diagnose dementia because it is a serious and largely unmodifiable disease.
 - Patient's and/or family's fear of the diagnosis [R-GDG].
- Lack of simple diagnostic test for dementia.
- Lack of consultation time or lack of access to appropriate services. The diagnostic process requires multiple visits with a multi-disciplinary team and should include family members or caregivers.

5 Clinical Presentation

There is considerable heterogeneity in the presentation of dementia, however the cognitive or behavioural impairment includes but is not limited to^{16,17}:

- The inability to acquire and remember new information.
- Impairment of reasoning and handling of complex tasks and/or impaired judgement.
- Changes in personality or behaviour.
- Impairment of visuospatial abilities.
- Impairment of language functions (speaking, reading, writing).
- Disrupted sleep and circadian rhythms.

See *Section 9.6* for diagnostic criteria.

6 Initial Assessment

6.1 Patient History

History taking should be directed to establishing the probability of a dementia diagnosis.

Important points in the history to elicit from the patient include^{1,4}:

- The onset of cognitive, behavioural, and psychological symptoms and their progression, including:
 - Cognitive decline.
 - Psychological and behavioural symptoms, including:
 - Anxiety.
 - Depression.
 - Hallucinations and delusions.
 - Personality change.
 - Agitation and/or aggression.
 - Wandering and getting lost.
- Difficulties in managing daily activities, including:
 - Self-care.
 - Managing bank account.
 - Driving.
 - Using public transport.
 - Learning to use new machines or appliances.
 - Shopping.

- Cooking.
- Reading.
- Mixing up prayer times [R-GDG]
- Sleep disturbance.
- Smoking and alcohol consumption.
- Past Medical History and risk factors, including:
 - Vascular diseases (e.g. hypertension).
 - Vascular events (e.g., stroke).
 - Renal disease.
 - Diabetes.
 - Head injury.
- Medication history:
 - Identify medication that may be contributing to cognitive decline (see *Section 9.3*).
 - Consider stopping or changing such medication to appropriate alternatives [R-GDG].

6.2 Collateral/Informant History

A separate history report from a family member or caregiver with the patient absent is obligatory¹ [L2, RGA] as the patient may fail to note some early personal changes that may be noticed by a family member or caregiver.

Important points in the history to elicit during a collateral/informant interview, include¹:

- Identification of the primary caregiver and wellbeing of the caregiver [R-GDG].
- Assess the adequacy of the family and other caregivers to provide accurate reporting and care [R-GDG]:
 - Some caregivers may be reluctant to share information honestly on the patient's condition and therefore additional informant histories should be sought.
- Cognitive, behavioural, and psychological symptoms.
- Ability to complete activities of daily living.
- Onset and progression of symptoms.
- Risk assessment of the patient, including:
 - Ability of patient to handle medication.
 - Driving.
 - Home safety (e.g. fire risk).

Note:

- Family members may protect the patient from difficulties in daily life. They may gradually take over social roles from the patient, delaying the conscious recognition of the disorder by offsetting impairments⁴.
- Safety issues and risks of harm to the patient and/or others, identified in the history, should be addressed at the first consultation and appropriate advice given to the patient and caregivers [R-GDG].

6.3 Initial Examination

If dementia is suspected, a physical examination and cognitive testing should be conducted as follows [R-GDG]:

- Measure the blood pressure.
- Exclude a physical cause for cognitive impairment.

- Exclude a mental health cause for the cognitive impairment (e.g. depression, anxiety):
 - Perform the GAD-2 and PHQ-2 scores to screen for anxiety and depression, respectively.
 - If either score is positive follow the recommendations of the National Clinical Guidelines on Generalised Anxiety Disorder and Depression.
- Neurological examination, including hearing and vision assessment.
- The Mini-Cog Assessment^{2,3}:
 - Minimal language content reduces cultural and educational bias.
 - Comprised of two components:
 - A 3-item recall test for memory.
 - Clock drawing test.
 - A normal score does not exclude dementia and therefore the Mini-Cog Assessment should not be used in isolation to determine whether to refer a patient to a Memory Clinic [**R-GDG**].

6.4 Initial Investigations

If dementia is suspected, the following set of laboratory tests should be ordered to exclude treatable underlying causes^{1,4-6} [**L2, RGA**]:

- Complete blood count^{1,4,5}.
- Serum calcium^{1,5}.
- Serum fasting glucose or HBA_{1c}^{1,5,6}.
- Serum lipid profile [**R-GDG**].
- Electrolytes^{1,4,5}.
- Renal function tests^{1,4,6}.
- Thyroid function tests^{1,4-6}.
- Liver function tests⁶.
- Serum vitamin B₁₂ level and folic acid^{1,4-6}.

6.5 Brain Imaging

Where available, appropriate brain imaging with CT or MRI, should be requested by primary care physicians as part of the initial assessment of dementia [**R-GDG**].

7 Referral Criteria

Treatments and referrals to specialist care should be directed according to the underlying cause, if any is identified. Where dementia with no underlying cause is suspected, referral to specialist care should be according to the following criteria **[R-GDG]**.

Criteria for referral to the Memory Clinic **[R-GDG]**:

- Any patient with suspected cognitive impairment based on initial assessment and informant history, supported by the results of the Mini-Cog Assessment.
- Patients who fail to improve after an underlying cause is treated.

On the basis of the referral from Primary Care, the Memory Clinic Team will determine referral to the following subspecialist clinics **[R-GDG]**:

- Criteria for referral to Complex Cognitive-Neurology:
 - Rapid progression of cognitive impairment.
 - Focal neurological signs.
 - Seizures.
 - Patients with a younger age of onset, or atypical presentation.
- Criteria for referral to Complex Cognitive-Psychiatry:
 - Severe behavioural problems.
 - Patients at risk of self-harm or harm to others.
 - Severe depression, refractory to treatment.
 - Severe anxiety, refractory to treatment.
- Criteria for referral to Speech and Language Therapy^{2,46,47}:
 - Difficulty speaking, writing, and calculating.
 - Difficulty eating and drinking.
 - Difficulty swallowing.
 - Suspected aspiration pneumonia.

All patients should remain under shared care with their primary care physicians with regular communication from specialists back to primary care (see also *Section 15.3*) **[R-GDG]**.

8 Specialist Assessment

8.1 History Taking

Refer to *Sections 6.1* and *6.2* above.

8.2 Examination

If dementia is suspected after initial assessment, a physical examination and cognitive testing should be conducted¹.

Physical examination must include¹:

- A general examination.
- A comprehensive neurological examination, including:
 - Assessment of gait and balance.

For cognitive testing, the following instruments can be used [**L1, RGA**]:

- Montréal Cognitive Assessment (MoCA)^{1,51}:
 - Time to administer: 15-25 minutes.
 - More sensitive than the mini-mental state examination (MMSE) in detecting AD.
 - More sensitive in detecting mild cognitive impairment.
 - Validated Arabic version is available.
- Addenbrooke's Cognitive Examination (ACE III)⁵²:
 - Sensitive to the early stages of dementia.
 - Version in Arabic is available.
 - Age, education, and IQ should be taken into account when interpreting results.
- Other tests of cognition include:
 - MMSE^{1,4}.
 - Modified MMSE¹.
 - The 6-item cognitive impairment test (6CIT)^{2,4}.
 - CAMCOG Assessment^{53,54}.

Healthcare professionals should not rely solely on cognition scores in circumstances in which it would be inappropriate to do so² [**L2, RGC**], including:

- If the patient has learning difficulties or other disabilities (e.g., sensory impairments).
- If the patient has linguistic or other communication difficulties.
- If the patient's level of education is inappropriate for the test.
- If it is not possible to apply the tool in a language in which the patient is sufficiently fluent.

In such cases another appropriate method of assessment should be determined [**L2, RGA**].

Note:

- Do not exclude dementia solely because the patient has a normal score on a cognitive instrument² [**RGC**].
- No one cognitive test is recommended over another¹ [**L2, RGB**].
- No brief cognitive test has been developed to differentiate between types of dementia, and none can be recommended for this purpose¹ [**L2, RGC**].
- Repeat the testing on several occasions over several months, to provide convincing evidence of cognitive impairment¹ [**RGA**].
- Some commonly prescribed medicines are associated with increased anticholinergic burden, and therefore cognitive impairments² [**RGA**] (see *Section 9.3*).

8.3 Neuropsychological Testing

Neuropsychological testing has demonstrated utility in distinguishing between dementia types but it cannot be used alone for the diagnosis of dementia^{1,2}. Neuropsychological testing should be used in appropriate patients^{1,2}.

Neuropsychological testing:

- Addresses the distinction between [**L2, RGB**]:
 - Normal ageing.
 - Mild cognitive impairment (MCI) or cognitive impairment without dementia.
 - Early dementia.
- Addresses the risk of progression from mild cognitive impairment or cognitive impairment without dementia to dementia or AD [**L2, RGB**].
- Assist in the differential diagnosis of dementia and other syndromes of cognitive impairment [**L2, RGB**].

8.4 Functional Assessment

Assessment of ADLs and Instrumental Activities of Daily Living (IADLs) are necessary to determine the patient's functional status. The following assessment tools may be used to assess function [**R-GDG**]:

- Functional Assessment Staging Tool (FAST).
- Functional Independence Measure (FIM).

Where available, the above assessments should be performed by a specialist occupational therapist working as part of the multi-disciplinary team [**R-GDG**].

8.5 Assessing Carer Burden

The *Zarit Burden Interview* (ZBI) is a reliable instrument to measure caregiving burden in caregivers of patients with dementia^{7,8}. The survey provides a comprehensive assessment of both objective and subjective burden⁸ and should be performed in all family caregivers at regular intervals.

The short 12-item version⁵⁵ performs as good as the full version⁵⁶. The 4-item version⁵⁵ can be used for a brief screening⁵⁶.

Alternative measure tools include⁸:

- Burden Assessment Scale (BAS).
- the General Health Questionnaire (GHQ-28).
- the Dementia Management Strategies Scale (DMSS).
- the Revised Memory and Behaviour Problems Checklist (RMBPC).

Note:

- Refer family caregivers to their family physician for organisation of additional support and help where appropriate [**R-GDG**]
- When available, refer to additional support services such as *Qatar Alzheimer's Society* and the *National Dementia Support Helpline* [**R-GDG**].

8.6 Specialist Investigations

If not already conducted, an electrocardiography (ECG) may be indicated⁴ [L2], especially if treatment with a cholinesterase drug is being considered.

Note:

- Syphilis serology and HIV tests *are not recommended* as a routine tests, but can be justified if the apparent course of the syndrome or the presentation is atypical or in cases with a suggestive history^{4,5} [RGB].
- Determination of serum homocysteine levels *is not recommended* in older adults with suspected dementia or cognitive decline due to insufficient evidence that treatment of its elevated levels affects cognition¹ [L2, RGB].
- Genetic testing (e.g., screening for the gene apolipoprotein E or levels of amyloid- β) *is not recommended* due to the low positive and negative predictive values^{1,5,9} [L2, RGB].
- The following additional investigations may be performed in atypical presentations of dementia [R-GDG]:
 - Lumbar puncture.
 - Electroencephalogram (EEG).

8.7 Brain Imaging

For brain imaging, the following methods can be used^{1,4}:

- Magnetic resonance imaging (MRI).
- Cranial computed tomography (CT).
- Positron Emission Tomography (PET-CT).
- Single photon emission computed tomography (SPECT).
- Da TScan

Where indicated the multidisciplinary team should liaise with the neuroradiologists to discuss the most appropriate brain imaging modality and the results of scans [R-GDG].

NB: Do not rule out AD based solely on the results of brain imaging^{2,10} [L2, RGC].

9 Diagnosis

9.1 Differential Diagnosis

If considering diagnosis of a degenerative dementia, it is important to exclude delirium (see *Table 9.1(1)* and detailed diagnostic criteria for dementia in *Sections 9.5 & 9.6*). The initial diagnosis of dementia should not be made while the patient is in a delirious state¹ [**L2, RGA**].

Dementia	Delirium
Gradual onset with further progression.	Abrupt onset.
Long term (months to years).	Short term (hours to days).
Normal attention (except in severe dementia).	Reduces ability to focus, sustain or shift attention.
Generally intact consciousness.	Reduced level on consciousness and disorientation.
Coherent speech, anomia or aphasia.	Incoherent and disorganized speech.
Neurological causes.	Medical causes, substance intoxication or side-effect of drugs.
Other symptoms vary depending on the underlying pathology.	Hyperactive, hypoactive and mixed forms are possible (determined by the type of psychomotor disturbances); sleep impairments and perceptual disturbances may be present.

Table 9.1(1): Differentiation between dementia and delirium⁵⁷.

If unclear whether the patient has delirium, dementia, or delirium superimposed on dementia, delirium must be treated first^{1,2} [**L2, RGC**].

Main differences between dementia and mild cognitive impairment (MCI) (see *Section 9.4*) are shown below in *Table 9.1(2)*. Detailed diagnostic criteria for dementia are given in *Sections 9.5 & 9.6*.

Dementia	Mild Cognitive Impairment
Significant cognitive decline in one or more domains (see <i>Section 4.1</i>).	Impaired cognition in one or more domains but to a lesser extent than in dementia.
Substantially impaired cognition.	Mild impairments in complex aspects of daily activities.
Impairments on daily activities.	No significant impairment on daily activities.
Clinical features include: <ul style="list-style-type: none"> • Severe memory loss. • Visuospatial dysfunction. • Language problems. • Articulating problems. • Personality problems. 	Clinical features include: <ul style="list-style-type: none"> • Difficulties in solving complex problems. • Difficulties in performing more than one task at a time.

Table 9.1(2): Differentiation between dementia and MCI⁵⁷.

People with dementia syndrome have high rates of depression and people with depression often have prominent complaints of memory loss, neuropsychological deficits, and often organic brain changes (“pseudodementia”). To diagnose patients with dementia when they are depressed is one of the great errors of clinical practice⁴.

Main differences between dementia and depression are shown below in *Table 9.1(3)*. Detailed diagnostic criteria for dementia are given in *Sections 9.5 & 9.6*.

Dementia	Depression
Significant cognitive decline in one or more domains (see <i>Section 4.1</i>).	Impaired cognition in one or more domains but to a lesser extent than in dementia.
Substantially impaired cognition, with denial or no concern about the symptoms.	Mild impairments in complex aspects of daily activities, with excessive preoccupation with symptoms.
Mood is usually normal but may fluctuate based on the circumstances. Tends to improve with stimulation and support.	Mood is usually depressed and rarely improves with stimulation and support
Suicidal thoughts and actions are uncommon	Suicide thoughts and actions are usually common
Feelings of guilt or worthlessness are relatively uncommon.	Guilt or worthlessness is usually common in severe depression.
Clinical features include ⁵⁸ : <ul style="list-style-type: none"> • Severe memory loss may be accompanied by gradual loss of interest or initiatives, weight loss, disrupted sleep patterns and rarely psychomotor retardation. • Energy level and concentration are usually normal but reduced in late dementia. • Visuospatial dysfunction. • Language and articulating problems. • Personality problems 	Clinical features occur sub-acutely over weeks including: <ul style="list-style-type: none"> • loss of interest and pleasure. • Loss of appetite with increased or decreased weight. • Decreased or increased sleep. • Psychomotor retardation • Loss of energy • Loss of concentration and focus

Table 9.1(3): Differentiation between dementia and depression^{57,58}.

9.2 Reversible Causes of Dementia

The following illnesses are associated with a potentially reversible cognitive impairment and should be considered in all cases [R-GDG]. These include^{57,59}:

- Space occupying lesions:
 - Benign tumours, especially subfrontal meningiomas.
 - Subdural haematoma.
- Hydrocephalus.
- Deficiency states:
 - Vitamin B12, B1 (Wernicke-Korsakoff), B6.
 - Niacin (pellagra).
- Endocrine disease and metabolic disorders:
 - Hypothyroidism.
 - Chronic hypocalcaemia.
 - Recurrent hypoglycaemia.
 - Cushing’s disease.

- Addison's disease.
- Uraemia.
- Hepatic encephalopathy.
- Infections:
 - AIDS dementia complex.
 - Lyme disease.
 - Tuberculosis.
 - Syphilis.
- Inflammatory and vasculitides:
 - Systemic lupus erythematosus.
 - Giant cell arteritis.
 - Polyarteritis nodosa.
 - Bechet's disease.
 - Neurosarcoidosis.
- Alcoholic dementia.
- Chronic intoxications:
 - Heavy metals.
 - Drugs (see *Section 9.3*).
 - Carbon monoxide poisoning.
- Wilson's disease.
- Whipple's disease.
- Limbic encephalitis.

9.3 Medication Causing Cognitive Impairment

Medications that cause cognitive impairment and should thus be avoided in older patients, include¹¹.

- Anticholinergics.
- Benzodiazepines.
- Benzodiazepine receptor agonists (Z-drugs).
- Corticosteroids.
- Antipsychotics.

9.4 Mild Cognitive Impairment

Dementia is usually preceded by MCI and the boundary between the two is often not clear^{12,17}. MCI sometimes reverts to healthy cognition¹⁷. Patients with MCI demonstrate impairments in one or more domains (usually memory difficulties), but they can still be engaged in complex activities, such as paying bills or taking medications^{12,17}.

The following diagnostic criteria should be used to diagnose MCI and where possible If possible the cause of MCI should be specified³⁸:

- **Modest** cognitive decline from a previous level of performance in one or more cognitive domain is evident based on:
 - Concern of the patient, caregiver or clinician that there has been a **mild** decline; and
 - A **modest** impairment in cognitive performance, preferably documented by neuropsychological testing or another quantified clinical assessment.
- The cognitive decline does not interfere with independence in ADLs.
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits are not better explained by another mental disorder.

9.5 Dementia

The following criteria should be used to diagnose dementia³⁸:

- **Significant** cognitive decline from a previous level of performance in one or more cognitive domain is evident based on:
 - Concern of the patient, caregiver or clinician that there has been a **significant** decline; and
 - A substantial impairment in cognitive performance, preferably documented by neuropsychological testing or another quantified clinical assessment.
- The cognitive decline interferes with independence in ADLs.
- The cognitive deficits do not occur exclusively in the context of a delirium.

If possible specify³⁸:

- With or without behavioural disturbances.
- Severity level: mild, moderate, severe.

9.6 Types of Dementia

Differentiate between dementia types using *Table 9.6* below⁵⁷ and DSM-V diagnostic criteria³⁸.

Types	Clinical features	Neuropathology
AD ^{57,60}	<ul style="list-style-type: none"> • Impaired memory. • Apathy. • Depression. • Gradual onset. 	<ul style="list-style-type: none"> • Cortical amyloid plaques. • Cerebral amyloid angiopathy. • Neurofibrillary tangles. • Synaptic loss.
VaD ^{57,61}	<ul style="list-style-type: none"> • Similar to AD. • Memory is less affected than in AD. • Physical frailty. • Prominent mood fluctuations. • Stepwise progression. 	<ul style="list-style-type: none"> • Cerebrovascular disease. • Single infarcts. • Multi-infarct diseases.
DLB ^{57,62}	<ul style="list-style-type: none"> • Fluctuations in cognitive ability. • Parkinsonism. • Hallucinations. 	Cortical Lewy Bodies.
FTD ^{18,57}	<ul style="list-style-type: none"> • Changes in personality. • Mood changes. • Language impairments. 	No single pathology. Damage of frontal and temporal zones.

Table 9.6: Key clinical and neuropathology features to differentiate between dementia types.

9.6.1 Diagnostic Criteria: AD

The following criteria should be used to diagnose **definite AD**³⁸:

- The general criteria for dementia or MCI are met.
- There is insidious onset and gradual progression of impairment on at least two domains (see *Section 4.1*)
- Criteria are met for either probable or possible AD.
- The cognitive deficits are not better explained by cerebrovascular or another neurodegenerative disease, the effects of a substance, or another mental, neurological, or systemic disorder.

Probable AD is diagnosed if any of the following is present; otherwise, **possible AD** should be diagnosed³⁸:

- Evidence of a causative AD genetic mutation (family history or genetic testing).
- The three of the following are present
 - Clear evidence of decline in memory and learning and at least one other cognitive domain.
 - Progressive and gradual decline in cognition, without extended plateaus.
 - No evidence of mixed aetiology.

9.6.2 Diagnostic Criteria: VaD

The following criteria should be used to diagnose **definite VaD**³⁸:

- The general criteria for dementia or MCI are met.
- The clinical features are consistent with a vascular aetiology, as suggested by either of the following:
 - The onset of the cognitive decline is temporally related to a cerebrovascular event.
 - Evidence for decline is prominent in complex attention and frontal-executive function.
- There is evidence of the presence of cerebrovascular disease from history, physical examination, and/or neuroimaging considered sufficient to account for the neurocognitive decline.
- The cognitive deficits are not better explained by another brain disease or systemic disorder.

Probable VaD is diagnosed if one of the following is present; otherwise, **possible VaD** should be diagnosed³⁸:

- Clinical criteria are supported by neuroimaging evidence of significant parenchymal injury attributed to cerebrovascular events.
- The neurocognitive syndrome is temporally related to a documented cerebrovascular event.
- Both clinical and genetic evidence of cerebrovascular disease is present.

Possible VaD should also be diagnosed if the clinical criteria are met but neuroimaging is not available and the temporal relationship is not established³⁸.

9.6.3 Diagnostic Criteria: DLB

The following criteria should be used to diagnose **definite DLB**³⁸:

- The general criteria for dementia or MCI are met.
- There is insidious onset and gradual progression.
- Criteria are met for either probable or possible DLB.
- The cognitive deficits are not better explained by cerebrovascular or another neurodegenerative disease, the effects of a substance, or another mental, neurological, or systemic disorder.

Probable DLB is diagnosed if the patient has two core features or, at least one core and one suggestive feature:

- Core diagnostic features:
 - Fluctuating cognition with pronounced variations in attention and alertness.
 - Recurrent visual hallucinations (well-formed and detailed).
 - Spontaneous features of Parkinsonism, with onset subsequent to the development of the cognitive decline.
- Suggestive diagnostic features:
 - Meets criteria for Rapid Eye Movement Sleep Behaviour Disorder.
 - Severe neuroleptic sensitivity.

Possible DLB should be diagnosed if the patient has only one core feature and one or more suggestive features³⁸:

9.6.4 Diagnostic Criteria: FTD

The following criteria should be used to diagnose FTD³⁸:

- The general criteria for dementia or MCI are met.
- There is insidious onset and gradual progression.
- Relative sparing of learning and memory and perceptual-motor function.
- Criteria are met for either behavioural or language variant:
 - Behavioural variant:
 - At least three of the following behavioural symptoms:
 - Behavioural disinhibition.
 - Apathy or inertia.
 - Loss of sympathy or empathy.
 - Perseverative, stereotyped or compulsive/ritualistic behaviour.
 - Hyperorality and dietary changes.
 - Prominent decline in social cognition and/or executive abilities.
 - Language variant:
 - Prominent decline in language ability (speech production, word finding, object naming, grammar, word comprehension).
- The cognitive deficits are not better explained by cerebrovascular or another neurodegenerative disease, the effects of a substance, or another mental, neurological, or systemic disorder.

9.7 Communication of the Diagnosis

If a diagnosis of dementia is made, patients and their family caregivers should be invited to a post-diagnostic consultation with a senior member of the multi-disciplinary team [R-GDG].

Communication to patients and their family caregivers should be sensitive, and at a minimum, should cover [R-GDG]:

- The diagnosis.
- Treatment options.
- Prognosis with respect to expected decline in the patient's cognition and functional status.
- Supportive information, e.g. patient information leaflets, should also be provided.
- The *UK Alzheimer's Society 'This is Me'* document should be completed and retained in the patient's medical record and a copy provided to the family.

10 Specialist Management

10.1 Multidisciplinary Approach

Care should be provided by an integrated and collaborative multidisciplinary team, which may include the following¹²:

- Geriatrician.
- Old age psychiatrist.
- Neurologist with special interest in dementia.
- Neuropsychologists.
- Clinical psychologists
- Nurses.
- Clinical pharmacist.
- Physiotherapists.
- Occupational therapists.
- Nutritionists.
- Social workers.
- Speech and language therapist.

However, patients should remain under the care of their primary care physician who must retain overall responsibility for the patient's overall care [R-GDG].

10.2 General Principles of Patient Care

10.2.1 Person-Centred Care

Person-centred care should be provided to all patients [R-GDG]. Person-centred care is sociopsychological treatment approach that recognises people using health and social services as equal partners in planning, developing and monitoring care to ensure it meets their needs^{63,64}.

Person-centred care interventions help to^{2,64,65} [L1, RGA]:

- Alleviate fears of other people “finding out” the diagnosis.
- Reduce behavioural and psychological symptoms.
- Reduce rapid decline in functional abilities.

10.2.2 Confidentiality

Confidential information should not be disclosed to other people (including family members) without the consent of the patient, or their legal representative - except as indicated under applicable Qatari law [R-GDG].

If it has not been documented earlier, ask the patient and document the following²:

- For their permission to share information.
- Which people they would like to share information with.
- What information they would like to share.

10.2.3 Decision Making

Involve patients with dementia in the decision-making process^{2,43,66}. Excluding the patient from taking part in decisions, can result in depression, frustration, and anger. Involve significant and trusted people in supporting decision-making. If there are no significant trusted people, or no-one willing to take on this role, consider involving an advocate⁶⁶. Give the patient time during the decision-making process. Meet more than once if needed⁶⁶. Prepare a written record of the decisions being made and share it with the patient, family members and/or caregivers⁶⁶.

NB: All decisions taken on behalf of the patient should be taken in the patient's best interests.

10.2.4 Coordination and Continuity of Care

All patients with dementia should ideally be assigned a care coordinator to ensure management of the patient's care needs [R-GDG].

A member of the MDT, who is responsible for coordinating care, should²:

- Coordinate care on behalf of the patient, across organisational boundaries [R-GDG].
- Ensure continuity of care as much as possible [R-GDG].
- Arrange an initial assessment of the patient's needs.
- Provide information about available services and how to access them.
- Ensure that patients are aware of their rights.
- Inform about advocacy services and available voluntary support.
- Involve the patient's family members and/or caregivers in support and decision-making.
- Develop a care and support plan in collaboration with the patient and their caregiver and provide a copy to the patient and their caregiver.
- Tell people with diagnosed dementia (at all stages of the condition) about research studies they could participate in.

10.2.5 Advanced Care Planning

Early after diagnosis, facilitate opportunities for people with dementia, and their caregivers, to discuss^{2,5,13}:

- Who should advocate for the patient, if they cannot make decisions for themselves.
- Advance treatment decisions.
- Preferences regarding future care and religious or spiritual beliefs.
- Preferences for place of care and end of life (see also *Section 14*).

Facilitate opportunities for the patient to review and change any advance statements and decisions made by the patient in the past². Caregivers should not be able to change the patient's advanced directives unless the new decision is in line with the patient's known wishes [R-GDG].

10.2.6 Venues of Care

The majority of the people with dementia should be cared for in their own residence for as long as possible^{12,14,15} [L3, RGA]. Day Care and Respite Care are options to enable caregivers to have a break and relief from their duties^{33,66} [L2, RGA].

With the progression of the disease, some patients may require placement in long-term care. These facilities should meet the needs of the patients and adequately address behavioural symptoms¹⁵[L3, RGA].

10.2.7 Safeguarding

The signs and symptoms of dementia make patients highly vulnerable to harm, abuse or neglect^{16,67}. Patients, their family members, and professional caregivers should be routinely asked about instances of suspected abuse and neglect¹⁶.

Safeguarding patients is the responsibility of all clinicians⁶⁷. They should recognise signs of abuse and protect their dementia patients from any harm. All cases of abuse (physical, psychological, sexual, financial, discriminatory) must be reported to the police.

10.2.8 Assessment and Management of Comorbidities

Multiple comorbidities are common amongst older people and people with dementia are no exception. All patients with dementia should therefore have detailed evaluation for the presence of comorbidities and sensory impairments [R-GDG]. Examples of common comorbidities include:

- Type 2 diabetes mellitus.
- Hypertension.
- Cardiovascular disease.
- Osteoarthritis pain.
- Geriatric syndromes, e.g.:
 - Constipation.
 - Incontinence.
 - Increased falls risk.

Evaluation of comorbid conditions will prevent emergence of problems such as delirium, falls, infections, cerebrovascular events etc. Prompt identification and early interventions can thus help to prevent or identify major events early and improve outcomes [R-GDG].

Assessment should be performed by a geriatrician or primary care physician after the diagnosis of dementia is established with appropriate management of any identified comorbid conditions, included within the follow-up plan of care. [R-GDG].

10.3 Non-Pharmacological Management

10.3.1 Psychological Interventions to Promote Cognition

Offer a range of therapies and practical measures to promote wellbeing of patients at all stages of dementia, including^{2,5,17-19} [L1, RGA]:

- Group cognitive stimulation therapy.
- Cognitive rehabilitation to support functional ability.
- Occupational therapy to identify and eliminate problem areas in everyday life (such as getting dressed, etc.).
- Speech and language therapy to help improve communication and/or swallowing problems.
- Physiotherapy to help with movement difficulties.
- Relaxation techniques (such as massage, music or dance therapy).
- Social interaction, leisure activities and other dementia activities (e.g., such as “memory cafés”, which are drop-in sessions for people with memory problems and their caregivers to get support and advice).
- Strategies for challenging behaviour such as:
 - Distraction techniques.

- A structured daily routine.
- Engaging in pre-dementia activities and interests [R-GDG].

Person-engagement strategies that reinforce memory, may be offered, including⁴ [RGA]:

- Setting shorter term goals.
- Maintaining a social circle.
- Useful family roles.

Music therapy:

- Can be offered to patients with dementia as a non-pharmacological intervention to reduce behavioural symptoms and cognitive decline^{5,68}.
- Consider combining music therapy with other cognitive stimulations such as dance, physical exercise, video game, art, etc.⁶⁸.

Aromatherapy:

- Can be provided by either inhalation or skin application can be offered as a complementary therapy for dementia^{5,69,70} [L1, RGA].
- Consider using:
 - Lemon balm (*Melissa officinalis*)⁷¹.
 - Lavender oil (*Lavendula officinalis*)⁷².

Bright light treatment:

- May be offered to reduce restlessness and sleep disturbances^{5,69} [L2, RGA].

Snoezelen room multisensory stimulation:

- May be offered to patients with moderate to severe dementia to^{5,73} [L1, RGA]:
 - Reduce apathy and agitation.
 - Improve activities of daily living.

Animal-assisted therapy:

- May be used to improve social behaviours, physical activity, and dietary intake in dementia patients⁷⁴⁻⁷⁶ [L1, RGA].
- It may positively affect agitation, aggression, and quality of life⁷⁴ [L1, RGA].

Reminiscence therapy⁷⁷ [L1, RGB] may be offered to patients for improved quality of life [R-GDG].

10.4 Pharmacological Management

10.4.1 Cognitive Impairment

Medication will not stop dementia getting worse, but it can help reduce some of the symptoms for some people². Monotherapies are recommended as options for managing AD^{2,4,5,17} [RGA], but combination therapy using AChE and Memantine can be considered by specialists [R-GDG]:

- Mild form:
 - AChE inhibitors:
 - Donepezil.
 - Galantamine.
 - Rivastigmine.
- Moderate and Severe form:
 - AChE inhibitors.
 - Memantine (if intolerant of or have a contraindication to AChE inhibitors).

Medication	Starting dose	Common side effects
Donepezil ^{57,78}	For mild-to-moderate dementia , the initial dose is 5 mg/day. The dose can be increased to 10 mg/day slowly over a period of 4 weeks. For moderate-to-severe dementia , the patient should be continued on 10 mg/day dose. In selected cases doses can be increased up to 20mg/day provided there is no serious safety concern. [R-GDG]	Gastrointestinal problems (nausea, diarrhoea, and vomiting), insomnia, muscle cramps, fatigue, anorexia. These symptoms usually last 1-3 weeks, resolving with the continued use. Other side effects: bradycardia, heart block, weight loss, syncope.
Galantamine ^{57,79}	Start with 4mg b.i.d., increase to 8 mg b.i.d. after 4 weeks, increase to 12 mg b.i.d. after another 4 weeks.	Gastrointestinal problems (nausea, diarrhoea, and vomiting), dizziness, drowsiness, loss of appetite, and weight loss. Cardiac side effects.
Rivastigmine ^{57,80}	Oral: Start with 1.5mg b.i.d., increase to 3 mg b.i.d. after 2 weeks, increase to 6 mg b.i.d. after another 2 weeks. Transdermal: 4.6mg/24h, increase to 9.5mg/24h after a minimum 4 weeks, increase to 13.3mg/24h if needed	Slightly more severe gastrointestinal problems (nausea and vomiting), weight loss. Cardiac side effects.
Memantine ^{57,81}	Start with 5mg/day, increase 5 mg/day weekly until the target dose 20mg/day (10mg b.i.d.) is reached.	Dizziness, headache, confusion, diarrhoea, and constipation.

Table 10.4.1: Medication used to treat cognitive impairment(modified from ⁵⁷).

Treatment with an AChE inhibitor or memantine, should only be started on the advice of a clinician who has the necessary knowledge and skills².

Note²:

- Medication should be started at the lowest dose and slowly titrated, as per protocol.
- Consider the patient's ability to swallow when prescribing.
- A baseline ECG should be performed prior to initiating AChE or memantine treatment.
- Baseline renal function should be assessed prior to initiating treatment with memantine.
- Only consider AChE inhibitors or memantine for patients with VaD if they have suspected comorbid AD, Parkinson's disease dementia or DLB **[RGB]**.

10.4.2 Treatments Not Recommended in Dementia

The following *are not presently recommended* to treat dementia:

- Ginseng, ginkgo biloba, curcumin, or herbal formulations^{2,5,82-85} **[L1, RGB]**.
- Omega-3^{5,30} **[L1, RGB]**.
- Vitamin E supplements^{5,83} **[L2, RGB]**.
- Vitamin B Supplements.
- Huperzine A⁸⁵ **[L1, RGB]**.
- Caprylic acid⁸⁵ **[L1, RGB]**.
- Co-enzyme Q10⁸⁵ **[L1, RGB]**.
- Phosphatidylserine⁸⁵ **[L1, RGB]**.
- Coral calcium⁸⁵ **[L1, RGB]**.
- Tramiprosate⁸⁵ **[L1, RGB]**.
- Acupuncture^{2,86} **[L2, RGB]**.
- Non-invasive brain stimulation (including transcranial magnetic stimulation)² **[RGB]**.

Medication that are not recommended for the treatment of dementia are:

- AChE inhibitors not mentioned in *Section 10.4.1*.
- Selegiline⁸⁷ [L1, RGB].
- Oestrogen replacement therapy⁵ [L1, RGB].
- Statin therapy⁵ [L1, RGB].
- Steroidal and non-steroidal anti-inflammatory drugs^{5,30} [L1, RGB].

See *Section 9.3* for a list of medication that can cause cognitive impairment and should thus be avoided in patients with dementia.

10.4.3 Treatment of Behavioural and Psychological Symptoms of Dementia

Depression and Anxiety

Consider psychological treatment for patients with mild to moderate dementia who have mild to moderate depression and/or anxiety² [RGA].

Antidepressants may help control the loss of inhibitions, overeating, and compulsive behaviours seen in some people but *do not routinely offer* antidepressants for patients with mild to moderate dementia, unless they are indicated for a pre-existing severe mental health problem^{2,17} [RGB].

If antidepressants are required, consider offering^{2,4} [L2, RGA]:

- Selective serotonin reuptake inhibitors (SSRIs) such as:
 - Citalopram.
 - Sertraline.
- Mirtazapine.
- Trazodone.

Note:

- The use of either tricyclic antidepressants or paroxetine, *are not recommended*^{5,20} [L1, RGB].
- Trazodone has benefit in patients with sleep disturbance and those with FTD [R-GDG].

Sleep Disturbance

Exclude underlying causes of sleep disturbance e.g. sleep apnoea, restless leg syndrome, pain, hunger etc.²¹. This is especially important where patients are unable to express their needs [R-GDG].

Consider a personalised multicomponent sleep management approach that includes^{2,21} [L1, RGA]:

- Sleep hygiene education:
 - Sleep at night.
 - Minimizing naps.
 - Minimizing sleep-disrupting substances (alcohol, tobacco, caffeine).
 - Avoiding excessive light at night.
 - Developing a bedtime routine.
- Exposure to daylight.
- Exercise.
- Personalised activities.
- Bright light therapy.

In special cases hypnotics may be prescribed, where available **[R-GDG]**:

- Low dose trazodone 25-50mg daily^{4,17,21}.
- Low dose mirtazapine 7.5-15mg daily^{17,21,88}.
- Low dose melatonin 1-3mg daily²¹.
- Low dose doxepin 3-6mg daily⁸⁹.

Note:

- Hypnotic and sedative medications should be used very cautiously due to a risk of sedation, falls, and deterioration in cognitive function **[R-GDG]**.
- Perform the following²¹ **[RGA]**:
 - Frequent serial assessments of safety.
 - Objective measurements of drug efficacy.
 - Review of medication safety **[R-GDG]**.

Agitation, Aggression, Distress and Psychosis

Antipsychotic drugs can have serious side effects^{2,17}. Some antipsychotics can worsen the motor features and cause severe antipsychotic sensitivity reactions in DLB or Parkinson's disease dementia^{2,17} **[RGC]**. The risk of stroke and mortality is higher in patients taking antipsychotics¹⁷.

Consider antipsychotics if there is a need to control psychosis and severely challenging behaviour that is putting the patients, and/or others around them, at a significant risk of harm^{4,17,22} **[L3, RGA]**.

Before starting antipsychotics, discuss the benefits and harms with the patient, family members, and/or caregivers^{2,5,17} **[L1, RGA]**. If antipsychotics are required, atypical antipsychotics are preferred (over typical antipsychotics)^{2,5,17} **[RGA]**:

- Use the lowest effective dose.
- Use them for the shortest possible time.
- Reassess the patient at least every 6 weeks, to check whether medication is still needed.
- Stop treatment if the person is not benefiting from taking the medication.
- Discuss the decision with the patient and their family members or caregivers² **[RGA]**.

Note:

- Offer psychosocial and environmental interventions (including family education) to reduce distress in patients with dementia² **[RGA]**.
- Consider citalopram or escitalopram to manage agitation¹⁷ **[L1, RGA]**.

Consider using **[R-GDG]**:

- Risperidone.
- Quetiapine.
- Olanzapine.
- Aripiprazole.

Note:

- Patients with DLB are very sensitive to antipsychotics^{1,3}.
- Patients should be routinely assessed for pain^{2,5} **[RGA]**.
- Encourage people with dementia to have eye and hearing tests, every 2 years to minimise agitation and distress from sensory impairment² **[RGA]**.

10.5 Follow-Up by Stage of Dementia

The following patient characteristics, caregiver experience and possible interventions are provided according to the stage of the disease.

Healthcare professionals involved in the care of the patient should anticipate and address patient and caregiver's needs at regular intervals. individualised management plans should be developed in conjunction with patients and their caregivers [R-GDG].

Mild Stage		
Patient Characteristics	Caregiver Experience	Possible Interventions
<ul style="list-style-type: none"> Mild disorientation in time, place or person or forgetfulness. Difficulty with selecting words, complex planning and multistep instructions. Loss of interest in activities which were previously of interest. Social withdrawal, depression and anxiety due to cognitive decline. 	<ul style="list-style-type: none"> Increase in time taken to care for the patient. 	<ul style="list-style-type: none"> Shared care with Specialist. Optimise patient's cognitive function and skills. Manage other acute or long-term health needs, Monitor compliance and adverse drug effects. Regular follow up for cognitive skills, ADLs and needs. Facilitate understanding between patient, caregiver and support services.
Moderate Stage		
Patient Characteristics	Caregiver Experience	Possible Interventions
<ul style="list-style-type: none"> Worsening of language and memory impairment. Disorientation, difficulty in recognising familiar people. Difficulty with self-care, IADLs and some basic ADLs. Behavioural and psychological symptoms e.g. agitation and depression. Wandering, leaving cooker on. Poor financial judgment. 	<ul style="list-style-type: none"> Caregiving displaces time available for work or other activities. Increase burden of care. Frustration and anger. Depression, anxiety and stress. Impaired sleep. 	<ul style="list-style-type: none"> Shared care with Specialist. Review patient and caregiver safety. Assess and refer for behavioural and psychological symptoms as appropriate. Encourage family and friends to participate in care. Review and arrange support services e.g. domiciliary support, homecare nursing, supervise care setting. Refer to caregiver support groups. Review and monitor caregiver's wellbeing.

Severe Stage		
Patient Characteristics	Caregiver Experience	Possible Interventions
<ul style="list-style-type: none"> • Marked impairment of speech, swallowing, recognition of familiar people and basic ADLs. • Incontinence. • Gait impairment, falls or immobility. • Behavioural and psychological symptoms e.g. agitation, delusion. • May require constant care. 	<ul style="list-style-type: none"> • Fatigue which may be severe. • Feelings of guilt especially if patient is institutionalised. • Problems coping with own health needs. 	<ul style="list-style-type: none"> • Shared care with Specialist. • Advise on care and avoidance of complications e.g. safe feeding, avoidance of pressure sores. • Assess and refer for behavioural and psychological symptoms as appropriate. • Encourage use of support groups, respite care, scheduled time away and self-care.
End of Life Stage		
Patient Characteristics	Caregiver Experience	Possible Interventions
<ul style="list-style-type: none"> • May be mute and bedridden. • Symptoms of anorexia, agitation, restlessness, pain, dyspnoea, aspiration, pressure sores. • Completed dependence on caregiver. 	<ul style="list-style-type: none"> • Significant burden of daily care. • Grief and/or relief at time of death. 	<ul style="list-style-type: none"> • Ensure involvement of palliative care specialist, where available. • Follow the patient's advance care directives. • Refer to bereavement support groups. • Follow up with caregivers following the patient's death to review the bereavement process and mood.

Table 10.5: The dementia journey⁹⁰.

10.6 Young-Onset Dementia

The terminologies of 'young-onset dementia' (YOD), 'younger-onset dementia', 'early-onset dementia' and 'younger people with dementia' are often used interchangeably. However, they all refer to the manifestation of symptoms of dementia before the age of 65 years^{23,24,91}.

Although the prevalence of YOD is much lower than of Late Onset Dementia (LOD), a significant number of individuals are affected by the condition²³.

The most frequent causes or aetiology of YOD are^{26,92}:

- Alzheimer's disease (AD) (c.33%).
- Vascular dementia (VaD) (c.15%).
- Frontotemporal dementia (FTD) (10-15%).
- Dementia with Lewy Bodies (DLB) (c.5%).

Unlike in LOD, people with YOD are generally employed at the time of the diagnosis, supporting dependent children and/or ageing parents, and may have significant financial obligations and commitments. The impact and burden of YOD may therefore be far greater and far more overwhelming for this population than those with LOD^{24,91}. Patients with YOD also require different types of support and services than those available for individuals with LOD^{24,26,91}.

10.6.1 Diagnosis of Young-Onset Dementia

There is a considerable delay in the diagnosis of YOD compared to LOD^{24,25}. On average, it is not until 2-3 years after the onset of symptoms that YOD is diagnosed²⁶.

This delay may be due to²⁶:

- Patients and family members may not seek medical advice early on.
- Clinicians may not consider a diagnosis of dementia in young patients.
- The distinction between neurological and psychiatric illness in this age group is often difficult.
 - Prominent psychiatric manifestations and affected non-memory cognitive domains, changes in personality, behaviour and cognition - are often deemed to result from mood disorders such as depression or anxiety.
- YOD has a broad differential diagnosis compared to LOD.
 - Although AD is the most common cause of YOD, it accounts for only 34% of YOD c.f. 80% of LOD⁹¹.

NB: A high-index of suspicion and early referral to a neurologist is therefore recommended [**R-GDG**].

10.6.2 Clinical Assessment

A thorough clinical assessment including a clinical and collateral history should be undertaken to review the following^{27,51,93}:

- Symptoms in all cognitive domains:
 - Amnesia is usually the primary complaint from patients with insidious YOD²⁴.
- Behavioural features.
- Psychiatric history.
- Degree of functional impairment.
- Temporal profile of mode of onset and progression of symptoms.
- Past medical history.
- Social history including:
 - Educational and occupational attainment.
- Family history of neuropsychiatric illness.
- Dementia risk factors, including:
 - Head injury with loss of consciousness.
 - Alcohol/drug exposure.

A thorough examination should be undertaken which includes [**R-GDG**]:

- Vital signs, including blood pressure.
- Inspection of the skin:
 - For stigmata of a vasculitic or connective tissue disorder.
 - Achilles tendon xanthomata are found in cerebrotendinous xanthomatosis.
- Abdominal examination:
 - Subtle splenomegaly in the absence of hepatomegaly is found in adult-onset Niemann-Pick disease type C.
- Thorough neurological exam including:
 - Bedside cognitive assessment.
 - Blood pressure.
 - Fundus examination
 - Examination for pyramidal, extrapyramidal, and cerebellar signs.

NB: Systemic findings might also point to an underlying neoplasm; in particular, the breasts and testes should be examined if a paraneoplastic syndrome is a possibility [**R-GDG**].

10.6.3 Investigation

Diagnostic workup of YOD^{94,95}:

- It is advisable to start with simple tests in diagnosing toxic/metabolic encephalopathies, infectious aetiologies such as HIV or syphilis and autoimmune illnesses.
- Autoantibodies, antineuronal antibodies in limbic encephalitis should be screened for in patients with rapid-onset dementias or in patients with signs of systemic disease.
- Multiple blood films might be necessary in suspected neuroacanthocytosis.
- All patients with YOD should have:
 - Neuroimaging (preferably MRI).
 - Cerebrospinal fluid (CSF) analysis.

Neuroimaging [R-GDG]:

- Patterns of brain atrophy and signal change can help to narrow the differential diagnosis.
 - Signal change, particularly in the white matter is identified best on *T2 Weighted Imaging* (T2WI) or *Fluid Attenuated Inversion Recovery* (FLAIR) sequencing.
 - This is an important clue to underlying inflammatory disorders such as multiple sclerosis, vasculitis, limbic encephalitis, or *Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leukoencephalopathy* (CADASIL), in which there is a characteristic anterior temporal lobe white matter change.
 - In suspected Prion disease, *Diffusion Weighted Imaging* (DWI) is particularly sensitive and should be included.
 - MRI sequences using *Susceptibility Weighted Imaging* (SWI) is indicated in metabolic and genetic disorders e.g. neuroferritinopathy and pantothenate kinase-associated neurodegeneration.
 - If minimal changes on MRI are observed, FDG-PET imaging may be a useful to identify regions of hypometabolism.
 - PET imaging with ligands such as *Pittsburgh B Compound* (PiB) can show the presence of amyloid can also be used as an adjunct in AD⁹⁶.

NB: Extensive systemic imaging including CT and whole-body PET might be needed to search for primary tumours in suspected paraneoplastic syndromes [R-GDG].

CSF Examination⁹⁵:

- Recommended by both the *American Academy of Neurology* and the *European Federation of Neurological Society* guidelines for the investigation of suspected YOD.
- Can help identify inflammatory or infectious causes of symptoms.
- The presence of *14-3-3 Protein* in the CSF is supportive of a diagnosis of Creutzfeldt-Jakob disease especially with high levels of *Tau protein*.
- Decreased *amyloid β1–42* and increased *Tau protein* levels have good sensitivity and specificity for AD and are also predictive at the mild cognitive impairment stage.

Electroencephalogram (EEG) [R-GDG]:

- EEG is used to examine for subclinical seizures, periodic complexes in some prion diseases and in subacute sclerosing panencephalitis are valuable.
- Early slowing or loss of alpha rhythm is a feature of AD, but there is relative preservation of this alpha rhythm in the FTD.

Electromyography and nerve conduction studies^{97,98}:

- Can be used to identify neuropathies or myopathy in the dementia-plus syndromes and can help to establish anterior horn cell dysfunction in patients with FTD and motor neuron disease.

Tissue biopsies:

- May be needed to establish the diagnosis in a few cases:
- Skin biopsy (including apocrine sweat glands) can be used to detect abnormal accumulations in storage diseases and in CADASIL.
- Culture of skin fibroblasts can confirm the diagnosis of Niemann-Pick disease type C.
- Muscle biopsy including histochemistry and respiratory enzyme analysis can confirm a mitochondrial disorder.
- Tonsillar biopsy can confirm the diagnosis in patients with suspected variant Creutzfeldt-Jakob Disease (vCJD) in the absence of a *pulvinar sign* on MRI.

Brain biopsy:

- May be necessary in exceptional cases of young-onset dementia if:
 - There is suspicion of a treatable process.
 - The diagnosis cannot be made by other means.
 - If potentially toxic treatment is contemplated.
- Unless a focal lesion is present, this is necessarily a “blind” procedure, generally from the non-dominant frontal lobe.
- A full thickness open biopsy including cortex, white matter, and meninges should be performed by a neurosurgical team experienced in the technique.
- Disposable instruments should be used in cases in which prion risk is thought to be clinically significant.
- A specific diagnosis can be anticipated in more than 50% of cases and a treatable process in about 10% of cases, while the procedure itself carries an about a 10% risk of significant morbidity.

Neurogenetic testing:

- May be used to predict susceptibility in family members and should always be preceded by formal genetic counselling.

10.6.4 Reversible Causes of Young-Onset Dementia

Reversible causes of YOD include^{24,91}:

- Inflammatory diseases, including:
 - Multiple sclerosis, neurosarcoidosis, and paraneoplastic and autoimmune limbic encephalitis.
- Infectious diseases, including:
 - HIV, neurosyphilis, Whipple disease, and Progressive Multifocal Leukoencephalopathy (PML).
- Toxic substances, including:
 - Alcohol, or heavy metal poisoning.
- Metabolic disorders, including:
 - Excess ammonia in hepatic encephalopathy.
 - Uraemia, hyponatremia, or hypernatraemia.
- Endocrinopathies, including:
 - Glucose dysregulation, thyroid or parathyroid dysfunction, Addison's disease, and Cushing's disease.
- Nutritional deficiencies in Vitamin B12, thiamine, and niacin.
- Wilson's disease.
- Transient epileptic amnesia presents with recurrent episodes of anterograde memory loss.

10.6.5 Treatment

Pharmacological Treatment of YOD is similar to that for LOD^{27,28,91}:

- AChE inhibitors such as donepezil, rivastigmine, and galantamine may offer symptomatic benefit in AD but do not modify the disease progression.
- Memantine, has also shown some symptomatic benefit in AD when used alone or in combination with acetylcholinesterase inhibitors⁹⁹.

10.7 Dementia in People with Learning Disabilities

People with learning disabilities (especially those with Down's syndrome) are at greater risk of developing dementia at a younger age^{100,101}.

The use of standard diagnostic tests is typically not informative for individuals with learning disabilities¹⁰¹.

Dementia generally affects people with and without learning disabilities in similar ways^{100,101}. Subtle differences in the manifestation and progress may be present:

- The initial symptoms of dementia are often less typical in patients with learning disabilities¹⁰⁰.
- Memory loss is less frequent as an early symptom in patients with Down's syndrome¹⁰⁰.
- Patients with Down's syndrome are more prone to epilepsy and seizures¹⁰⁰.
- Dementia may progress more rapidly in patients with learning disabilities^{100,101}.
- Basic skills (such as walking, swallowing) may be lost earlier¹⁰⁰.
- Be aware that individuals with learning disabilities may not be able to understand the diagnosis¹⁰⁰.
- The course of dementia in people with Down's syndrome has been well-studied and may be atypical with early development of behavioural or personality change, though memory problems are also prominent¹⁰².
- New onset of epilepsy or worsening of existing epilepsy in an older person with Down's syndrome should always raise the possibility of Alzheimer's disease¹⁰².
- Diagnostic criteria are reliable in the intellectual disability population, but dementia is more difficult to diagnose in those with severe disabilities or comorbid problems and may require sequential assessment¹⁰².
- Clinicians should also keep in mind the slightly atypical presentation of dementia in people with Down's syndrome¹⁰².
- A small number of young people with Down's syndrome seem to present with decline in their teens or early twenties, often with no clear aetiology¹⁰².
- People with intellectual disabilities without Down's syndrome who develop dementia may have the same range of pathologies as the general population¹⁰².

In specialist memory clinics and in services for adults with intellectual disabilities the use of standardised diagnostic and neuropsychological assessments for the diagnosis and monitoring of dementia, as it affects people with intellectual disabilities, is encouraged¹⁰³.

NB:

- The use of neuroimaging in dementia in people with intellectual disability should be used with caution, as imaging is likely to be abnormal in this group, making accurate interpretation of results difficult [R-GDG].
- Neuroimaging results for people with Down's syndrome may produce 'false positives' for AD from an early age if the standards derived from the general population are used [R-GDG].
- People with intellectual disability may have problems accessing neuroimaging due to challenging behaviours and the need for support [R-GDG].

11 Considerations for Inpatient Management

Admission to hospital should be avoided wherever possible **[R-GDG]**:

- Hospitalised patients with dementia more often experience falls, fractures, seizures, infections, pneumonia, delirium, and loss of function^{14,104}.
- The frequency and severity of symptoms increases with the length of stay and results in increased mortality¹⁴ **[L2, RGC]**.
- For patients with dementia, confusing environment, multiple people, multiple moves and room changes, sleep deprivation, and being in unfamiliar surroundings increases the risk of delirium^{14,104}.
- Hospital-acquired delirium worsens cognitive functions and impairs recovery from acute illness¹⁴ **[L2, RGC]**.
- A lack of personal interaction (e.g. with caregivers and/or family members) has a damaging effect on cognition **[R-GDG]**.
- Understaffed inpatient facilities and the lack the time for nursing care can increase the risk of falls, poor nutrition, dehydration, and possible drug errors^{14,15,104} **[L2, RGC]**.
- Patients with moderate or severe dementia are highly dependent and often need personal care e.g. for nutrition and fluid intake⁹⁰.
- Patients with dementia should be reviewed more frequently than usual **[R-GDG]**.
- Medical professional should encourage mobility in patients with dementia, under appropriate supervision^{14,15} **[L2, RGB]**.
- Patients should be admitted to dementia-specific wards, where possible **[R-GDG]**.

The use of restraints:

- Physical restraints should only be used in exceptional circumstances for the minimum period of time (e.g. pulling intravenous lines) and in accordance with hospital policy.
- Restraints should only be used with the consent of a senior member of the clinical team²⁹.
- At all times, wherever possible, the decision to use restraints should be discussed with the primary caregiver **[R-GDG]**.

12 Primary and Secondary Prevention of Dementia

Preventive measures should be performed as a multidomain intervention including diet, exercise, cognitive training, and monitoring vascular risk. Together, they help to improve and maintain cognitive function [R-GDG].

12.1 Dietary Modification

Eating a healthy, balanced diet and maintaining a healthy weight have been shown to delay cognitive decline^{30,31}. The risk of developing cognitive decline is reduced in people adherent to the *Mediterranean diet*, which implies^{10,30,31} [L1, RGA]:

- Inclusion of:
 - Meals consisting of fresh produce.
 - Wholegrains.
 - Olive oil.
 - Legumes.
 - Fruits.
 - Vegetables.
 - Nuts.
 - Seafood.
- Limiting:
 - Dairy products.
 - Poultry.
- Avoiding:
 - Red meat.
 - Sweets.
 - Processed foods.

The Mediterranean diet may be enhanced by combining it with the *Dietary Approach to Systolic Hypertension* (DASH) diet³¹ [L2, RGA].

Obesity puts individuals at increased risk of developing type 2 diabetes, which is itself a risk factor for cerebrovascular disease and subsequent development of dementia³³ [L2, RGA].

12.2 Physical Activity

Evidence suggests that recreational physical activity increases cognitive function later in life^{30–32}. It may improve cognition in older adults with normal cognitive function and also in individuals with different levels of cognitive impairment^{30,31} [L1, RGA].

The amount of activity seems to be more important than the type of activity³¹. However, there is evidence that neuronal structural integrity and brain mass are better supported by *aerobic exercises* [R-GDG].

12.3 Stress Reduction

Stress is tightly bound to the development and progression of dementia^{31,105}. Controlling stress levels is a good way of dementia prevention [L2, RGA]. Possible interventions include:

- Regular meditation, as part of stress reduction methodology, may improve cognitive function of healthy individuals^{31,105} [L2, RGA].
- Long-term meditation may delay age-related decline of several cognitive functions³¹ [L2, RGA].
- Spirituality, recreational activities and levity may also be beneficial.
- Untreated depression increases the risk of negative cognitive outcomes later in life³¹.

12.4 Treatment of Vascular Risk Factors

The control of cardiovascular risk factors, such as obesity, diabetes, dyslipidaemia and hypertension, are important targets for dementia prevention^{31,33,34} [L1, RGA]. Antihypertensive treatments decrease the risk of VaD³¹ [L1, RGA]. This prevention strategy is more effective in individuals with a high risk for vascular disease³¹ [L2, RGA].

12.5 Hearing

Mid-life peripheral hearing impairment can increase the risk of dementia and should therefore be actively evaluated and managed¹⁷. Encourage people with dementia to have hearing tests, every 2 years² [RGA].

12.6 Mental and Social Activity

Maintaining mental and social activity at high levels can reduce the risk of age-related cognitive decline³⁴ [L2, RGA].

12.7 Other Lifestyle Habits

Stopping smoking and reducing alcohol consumption, are effective ways of decreasing the risk of vascular dementia^{10,31} [L2, RGA].

13 Supporting Caregivers

Caregivers of people with dementia are at an increased risk of^{2,4,35}.

- Depression and anxiety.
- High levels of stress, resulting from:
 - Financial stress.
 - Loss of social supporting network and social isolation.
 - Breakdown in relationships.
 - Loss of self-esteem.
 - Sleep deprivation.
- Long-term medical conditions.
- Burnout Syndrome.

Caregivers' needs should be routinely evaluated using the *Zarit Burden Interview* (see *Section 8.5*)^{5,7,8} [**L1, RGA**]. Offer caregivers of people living with dementia emotional and informational support as well as resources to handle stress³⁵ [**L2, RGA**].

Offer caregivers a psychoeducation and skills training intervention that includes²:

- Education about dementia, its symptoms, and progression.
- Training to help them to:
 - Provide care, including how to understand and respond to changes in behaviour.
 - Improve interactions with the person with dementia.
- Advice on planning enjoyable and meaningful activities to do with the person they care for.
- Advice on planning for the future.
- Advice on how to look after their own physical, mental, and emotional health.
- Information about relevant services (including support services and psychological therapies for caregivers).

Consider respite care for the patient, if necessary^{36,37} [**L2, GRA**].

14 Key Considerations for Patient Preferences

Patient preferences refer to patient perspectives, beliefs, expectations, and goals for health and life, and to the steps employed by individuals in assessing the potential benefits, harms, costs, and limitations of the management options in relation to one another. Patients may have preferences when it comes to defining their problems, identifying the range of management options and selecting or ranking the outcomes used to compare these options.

It is important for healthcare professionals to develop an understanding of the patient as an individual and the unique way in which each person experiences a condition and its impact on their life.

The following recommendations are therefore made for physicians and other healthcare professionals regarding general principles of patient care in Qatar:

- **Respect Patients:** Treat patients with respect, kindness, dignity, courtesy and honesty. Ensure that the environment is conducive to discussion and that the patient's privacy is respected, particularly when discussing sensitive, personal issues. Ask the patient how they wish to be addressed and ensure that their choice is respected and used.
- **Maintain Confidentiality:** Respect the patient's right to confidentiality and avoid disclosing or sharing patients' information without their informed consent. In this context, students and anyone not directly involved in the delivery of care should first be introduced to the patient before starting consultations or meetings, and let the patient decide if they want them to stay.
- **Clarify Third-Party Involvement:** Clarify with the patient at the first point of contact whether and how they like their partner, family members or carers to be involved in key decisions about their care or management and review this regularly. If the patient agrees, share information with their partner, family members or carers.
- **Obtain Informed Consent:** Obtain and document informed consent from patients, in accordance with MOPH policy and guidance.
- **Encourage Shared Decision Making:** Ensure that patients are involved in decision making about their own care, or their dependent's care, and that factors that could impact the patient's participation in their own consultation and care including physical or learning disabilities, sight, speech or hearing impairments and problems with understanding, reading or speaking English are addressed.
- **Disclose Medical Errors:** Disclose errors when they occur and show empathy to patients.
- **Ensure Effective Communication:** Explore ways to improve communication including using pictures, symbols or involving an interpreter or family members. Avoid using medical jargon. Use words the patient will understand and confirm understanding by asking questions.
- **Ensure Continuity of Care:** Provide clear and timely sharing of patient information between healthcare professionals especially at the point of any transitions in care.

15 Performance Measures

A list of performance measures is given in the table below. Healthcare organisations are encouraged to monitor service performance using the indicator definitions below.

Number	Numerator	Denominator
D01	Number of caregivers with a record of interview by a healthcare professional.	All patients with a recorded diagnosis of dementia.
D02	Number of patients with a record of functional ability to complete ADLs.	All patients with a recorded diagnosis of dementia.
D03	Number of patients in whom a test of cognition is recorded.	All patients with a recorded diagnosis of dementia or suspected dementia.
D04	Number of patients who have routine blood tests including TSH, folate and B12.	All patients with a recorded diagnosis of dementia or suspected dementia.
D05	Number of patients who have a referral for neuroimaging.	All patients with a recorded diagnosis of dementia or suspected dementia.
D06	Number of patients who have a 12-lead ECG recorded prior to initiation of anti-dementia medication.	All patients with a recorded diagnosis of AD.
D07	Number of patients who were prescribed anti-dementia medication.	All patients with a recorded diagnosis of AD.
D08	Number of patients who were prescribed antipsychotics.	All patients with a recorded diagnosis of dementia.
D09	Number of patients who have a recorded visual acuity test in the last two years.	All patients with a recorded diagnosis of dementia.
D10	Number of patients who have a recorded hearing test in the last two years.	All patients with a recorded diagnosis of dementia.
D11	Number of caregivers who are provided with a care and support plan.	All people who are recorded to be caregivers of people with a diagnosis of dementia.
D12	Number of caregivers who were offered psychoeducation and skills training courses.	All people who are recorded to be caregivers of people with a diagnosis of dementia.
D13	Number of caregivers who have been formally assessed for Carer Burden.	All people who are recorded to be caregivers of people with a diagnosis of dementia.

Table 15.1: Performance measures.

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Appendix: Detailed Description of the Literature Search

A systematic search for existing literature on dementia was performed in the period March 10th - November 5th, 2019.

The search for clinical practice guidelines on dementia diagnosis and/or management was performed in the *PubMed* database and websites of relevant organisations and societies including the *Alzheimer Society*, *American Psychiatric Association*, *American Speech-Language-Hearing Association*, and the *Alzheimer Association*. The present guideline is primarily based on UK NICE, and Canadian guidelines and is supplemented with other relevant studies.

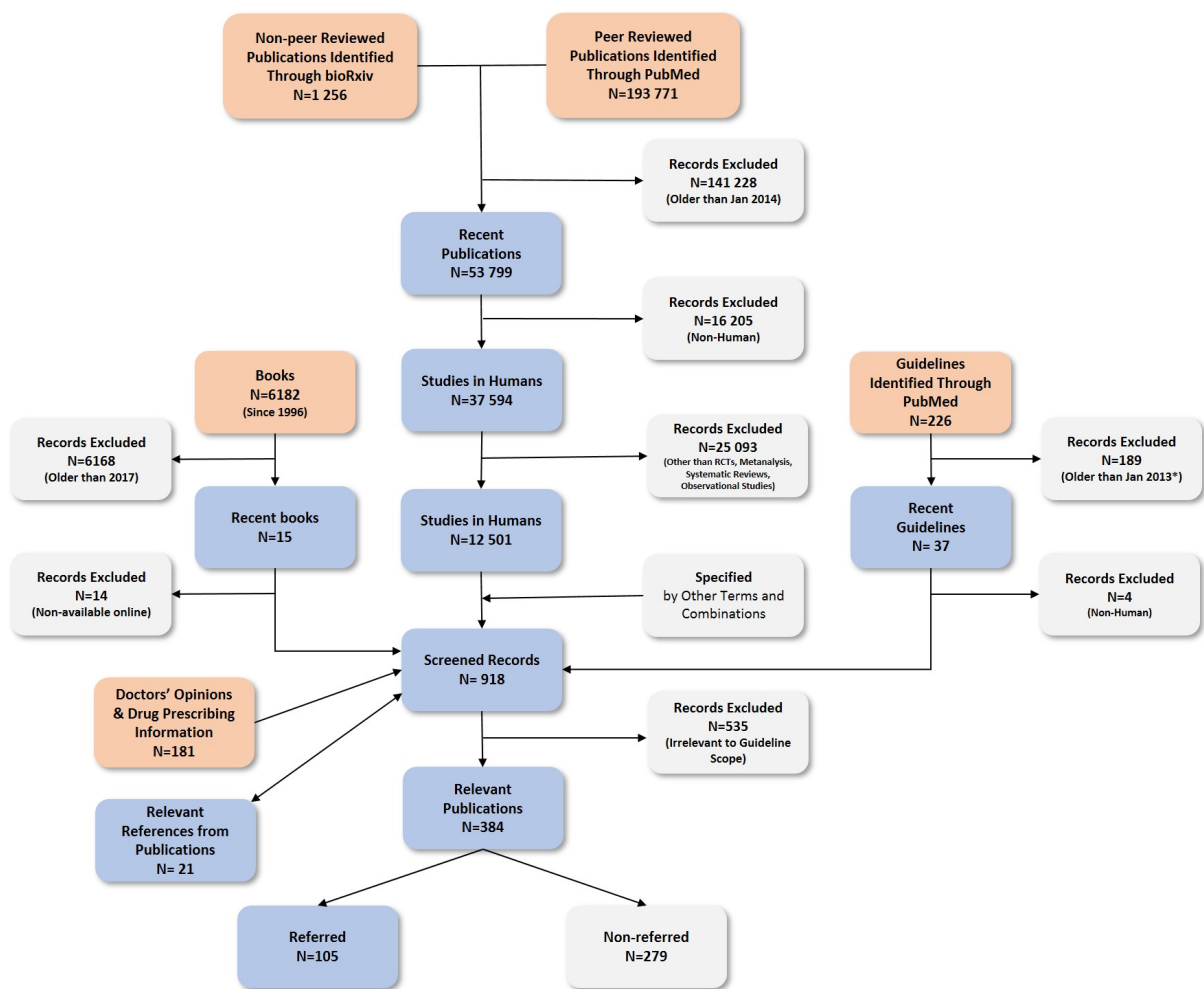
Peer-reviewed scientific publications were found in PubMed and via *Google Scholar* Internet search engine. Non-peer reviewed studies were identified in *bioRxiv*. Books were checked on *Amazon* and via *Google* and *Google Scholar* search engines. Personal opinions of healthcare professionals, information published on medical websites, and drug prescribing information sheets were found via Google search engine.

The included publications were identified using the term “dementia” and specified with the following terms in combinations:

guideline, disease, cognitive, cognitive decline, cognitive impairment, early/young onset, syndromes, epidemiology, aetiology, risk factors, presentation symptoms, DSM-V criteria, investigation, cognitive tests, basic laboratory tests, structural imaging, neuropsychological testing, management, treatment, prevention, frontotemporal dementia, dementia with Lewy bodies, Parkinson dementia, vascular dementia, Alzheimer’s, subtypes, delirium, depression, stress, learning disability, antipsychotics, caregivers, carers, homecare, inpatient management, alternative therapy, diet, music therapy, animal-assisted therapy, ginkgo biloba, vitamin E, vitamin B₁₂, omega-3, reminiscent, aromatherapy, multisensory therapy.

The date limit for the search for guidelines was set up as January 2013 based on a recent systemic review of dementia practice guidelines published in 2015 ⁵.

Figure A.1 on the next page demonstrates graphically the results of the search and application of exclusion criteria.



Key:

- Type of Publication
- Process
- Notes

Fig A.1: Literature search results and application of exclusion criteria.

Acknowledgements

The following individuals are recognised for their contribution to the successful development of the National Clinical Guideline.

MOPH National Clinical Guidelines Team:


- **Ms Huda Amer Al-Katheeri**, *Director of Strategic Planning & Performance Dept, MOPH.*
- **Dr Rasmeh Ali Salameh Al Huneiti**, *Guideline & Standardisation Specialist, MOPH.*
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