



Optimum
Workforce Leadership

Dementia Diagnosis, Treatment and Management Training Pack for Care Homes



supported by



**Nottinghamshire
County Council**



Health Education England

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Introduction

This training pack has been designed to increase your knowledge on dementia and has been designed to be a self-learning tool. Based upon the knowledge that you have gained the training pack has adopted a blended approach in which to consolidate your learning. The pack enabled you to evaluate your learning through questionnaire, case studies and competency based assessment. Each assessment should be completed with the training pack facilitator/supervisor. Both you and your training facilitator/supervisor should:

- use the Competence Assessment Tool to assess yourself and devise an action plan to meet your individual development needs
- provide evidence for renewal of your registration with the Nursing and Midwifery Council revalidation
- provide evidence of achievement for your personal development plan
- use your assessment results to focus on your development needs, prepare for supervision meetings and support your career development.

While completing the tool, it is useful to use the following framework in order to gain the maximum benefit from the training pack.

Learning and Development Framework

Step 1 Review and assess

Your knowledge, skills and attitudes using the training pack compile your evidence to support your assessment.

Step 2 Identify and prioritise your learning and development needs

From your assessment results including any 360° feedback. Identify, plan and prioritise your overall learning and development needs with your facilitator/supervisor.

Step 3 Plan and action

Discuss suitable learning opportunities with your supervisor and agree relevant learning outcomes. Record these in your learning and development plan.

Step 4 Evaluate your learning and development

In relation to improvements in your knowledge, skills and attitudes. Maintain a reflective record of your learning and development in your portfolio, to support your preparation of supervision sessions or development review meetings.



Definition of dementia

Dementia is a typically progressive clinical syndrome of deteriorating mental function significant enough to interfere with activities of daily living. Impairment in mental function due to **dementia** is more severe than that expected with normal ageing.

<https://cks.nice.org.uk/dementia>

Making a diagnosis of any form of dementia

Assessing an individual's neuropsychological profile to inform diagnosis is a complex, detailed process which needs to take in various contributory factors. Age, physical health, medication, substance use, premorbid functioning, consistency in presentation, investigations, mental health, susceptibility and impact of stress, coping factors and functional ability all need to be considered.

Any performance on screening and psychometric tests can be affected by a range of factors which impact upon scoring i.e. disturbance in physical and mental health, fatigue, neuropsychological dysfunctions such as cerebrovascular disease or frontal-temporal dementia which can reduce motivation, negative beliefs. Deficits in communication, or comprehension of the testing process itself or sometimes feigning / exaggeration of the condition or confabulation as a natural defence to the cognitive decline.

Similarly it is not always easy to assess functional factors because screening measures for anxiety/depression can be invalid when someone has a cognitive impairment due to omission or positive biases (Strauss et al 2007).

Further complications occur as conditions can overlap, present similarly, overlap, anomalies or residents can have a mixed diagnosis.

A range of atypical presentations is broad and as such might include queries regarding dementia with lewy bodies, semantic dementia, fronto-temporal dementia and mixed pathologies.

Further complications can be attributed to overlapping presentations, anomalies and mixed diagnosis.



However based on the following presentations the consideration of a possible dementia is required:

- a decline in memory (difficulty in the learning of new information or the recall of previously learned information) and / or other cognitive abilities characterized by deterioration in judgment and thinking, such as planning and organizing, and general processing of information.
- preserved awareness of the environment (i.e. Absence of clouding of consciousness).
- decline in emotional control or motivation, or a change in social behaviour such as emotional lability, irritability, apathy, coarsening of social behaviour.

Cognitive testing should also show objective of memory problems (amnesia) and at least one of the following:

4 A's of dementia

- Aphasia (language problems expressive or receptive)
- Agnosia (process sensory information, difficulty recognising objects, people etc.)
- Apraxia (inability to carry out voluntary purposeful movements)
- Amnesia (memory loss)



As indicated amnesia refers to memory and there are three types of memory as follows:

- **Episodic memory** – refers to memory relating to events ranging from the most mundane to more significant. Episodic memory has recent memories i.e. last hour or long term occurring over an hour ago.
- **Semantic memory** – This memory interprets what words mean i.e. dog, cup etc. It is shared understanding of words based on your own cultural language. As episodic and semantic memory are not controlled in the same part of the brain a person can have problems in one area but not the other.
- **Procedural memory** – Memory that helps us to carry out actions physically / mentally such as how to use a knife, make a cup of tea.

Important note to consider prior to dementia diagnosis

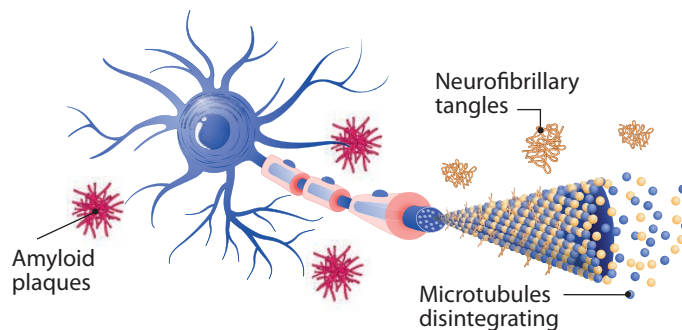
- Memory may be relatively preserved in some subtypes of dementia.
- Symptoms have been noted for at least six months minimum in order to avoid confusion with possible reversible states which may have identical behavioural syndromes.
- When the period of onset is shorter, the diagnosis can only be tentative and if there are superimposed episodes of delirium the diagnosis of dementia should be deferred.
- This is because dementia is a chronic condition and delirium is an acute condition.
- There is no 'single dementia test'.



Dementia four most common types

Alzheimer's disease (AD)

AD is one of the cortical dementias. During Alzheimer's two proteins build up abnormally in the brain. They are called amyloid and tau and form clumps called 'plaques' and 'tangles'. These plaques and tangles interfere with how brain cells work and communicate with each other. The plaques are usually first seen in the area of the brain that makes new memories. A lot of research is focused on finding ways to stop the build-up of these proteins and protect brain cells from harm. The diagram below indicates visually how these plaques and tangles appear:



AD is characterised by an insidious onset, progressive impairment of memory as well as other areas of cognitive deficits such as orientation, language, visuospatial function and praxis. Occasionally AD presents with focal features. Marked early motor impairment including abnormal gait while common in the later stages of AD is unusual in the early stages.

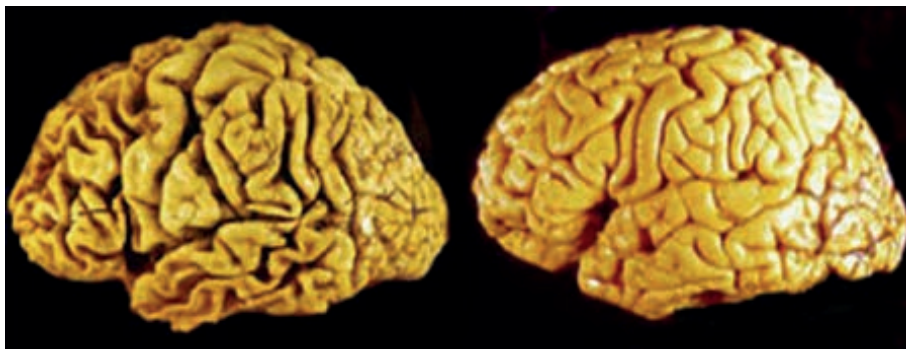
The disease trajectory with AD is long.

The course of Alzheimer's disease is not the same in every person, but symptoms seem to develop over the same general stages. In most people with Alzheimer's, symptoms first appear in their mid-60s.

Scientists know that Alzheimer's progresses on a spectrum with three stages - an early, preclinical stage with no symptoms; a middle stage of mild cognitive impairment MCI and a final stage of Alzheimer's dementia. At this time, doctors cannot predict with any certainty which people with MCI will or will not develop Alzheimer's.



The first symptoms of Alzheimer's vary from person to person. Memory problems are typically one of the first signs of cognitive impairment related to Alzheimer's disease. For many, decline in non-memory aspects of cognition, such as word-finding, vision/spatial issues, and impaired reasoning or judgment, may signal the very early stages of Alzheimer's disease.



The above picture shows a picture of a brain affected by AD. Frequently AD is described in stages as follows:

Mild stage of Alzheimer's disease

As the disease progresses, people experience greater memory loss and other cognitive difficulties. Problems can include:

- wandering and getting lost
- trouble handling money and paying bills
- repeating questions
- taking longer to complete normal daily tasks
- losing things or misplacing them in odd places
- personality and behaviour changes.



Moderate Alzheimer's disease

In this stage, damage occurs in areas of the brain that control language, reasoning, sensory processing, and conscious thought. Symptoms may include:

- increased memory loss and confusion
- problems recognising family and friends
- inability to learn new things
- difficulty carrying out multistep tasks such as getting dressed
- problems coping with new situations
- hallucinations, delusions, and paranoia
- Impulsive behaviour.

Severe Alzheimer's disease

People with severe Alzheimer's cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down. Their symptoms often include:

- inability to communicate
- weight loss
- seizures
- skin infections
- difficulty swallowing
- groaning, moaning, or grunting
- increased sleeping
- lack of control of bowel and bladder.



Signs that someone with AD may be at the end stage of their life

- Weight loss > 10%
- In bed or chair > 50%
- Inability to wash, dress, eat without assistance
- Pureed diet
- Double incontinence
- Recurrent febrile episodes, infections.

People with dementia admitted to care homes are at a higher level of mortality despite being afforded the best quality of care. A useful tool to identify this is as follows.

The Advanced Dementia Prognostic Tool (ADEPT): A risk Score to Estimate Survival in Nursing Home Residents with Advanced Dementia. Susan Mitchell (2010)

- Recent nursing home admission 1.72
- Age (years) (per 5-year increment) 1.18
- Male 1.71
- Shortness of breath 1.57
- At least one pressure ulcers \geq stage 2 1.44
- Activity of Daily Living Score = 28 1.42
- Bedfast most of day 1.41
- Bowel incontinence 1.37
- Body mass index < 18.5 kg/m 1.35
- Weight loss 1.30
- Congestive heart failure 1.28
- AUROC = 0.65 (6/12) and 0.59 (12/12)
- 40% will die within 6 months



Multi infarct dementia

Multi-infarct dementia (MID) is a common cause of memory loss in the elderly. MID is caused by multiple strokes (disruption of blood flow to the brain). Disruption of blood flow leads to damaged brain tissue as the brain is deprived of oxygen.

Stroke (infarction) blocking a brain artery. Strokes that block a brain artery usually cause a range of symptoms that may include vascular dementia.

Narrowed or chronically damaged brain blood vessels. Conditions that narrow or inflict long-term damage on your brain blood vessels also can lead to vascular dementia.

The two main types are often described as follows:

1. Ischaemic stroke

A blood clot (thrombus) forms in a main artery to the brain

OR

A blood clot or fatty deposit from another part of the body is carried in the blood stream to the brain.

OR

A blockage forms in the tiny blood vessels deep within the brain

2. Haemorrhagic stroke

A blood vessel bursts causing bleeding either within or on the surface of the brain.

Risk factors include:

- high blood pressure
- heart problems
- high cholesterol
- diabetes.



MID causes a step by step decline following each event. Behavioural symptoms and focal neurological signs vary according to site of vascular pathology.

Common **early signs** of widespread small vessel disease are as follows:

- impaired planning and judgement
- uncontrolled laughing or crying
- declining ability to pay attention
- impaired function of social situations
- difficulty finding the right words.

Some of these strokes may occur without noticeable clinical symptoms. Doctors refer to these as 'silent strokes'. An individual having a silent stroke may not even know it is happening, but over time, as more areas of the brain are damaged and more small blood vessels are blocked, the symptoms of MID begin to appear. MID can be diagnosed by an MRI or CT of the brain, along with a neurological examination.

Signs and symptoms are as follows:

- confusion or problems with short-term memory
- impact on thinking skills varies widely
- trouble speaking
- wandering, or getting lost in familiar places
- walking with rapid, shuffling steps
- losing bladder or bowel control
- headache
- depression
- hallucinations, delusions
- problems with balance
- numbness, paralysis on side of face
- laughing or crying inappropriately



- having difficulty following instructions
- having problems counting money and making monetary transactions.

MID, which typically begins between the ages of 60 and 75, affects men more often than women. Because the symptoms of MID are so similar to Alzheimer's disease, it can be difficult for a doctor to make a firm diagnosis. Since the diseases often occur together, making a single diagnosis of one or the other is even more problematic. Older people can also suffer with both AD and MID and this is known as mixed dementia.

Lewy Body Dementia

Lewy bodies are:

- spherical protein deposits found in nerve cells in sub-cortex, limbic system and cortex
- interrupt action of important chemical messengers, including acetylcholine (cognitive impairment) and dopamine (physical symptoms)
- shares characteristics with DAT and Parkinson's disease
- grey matter changes – two patterns (Rektorova et al., 2014)
- reductions in hippocampus and temporal lobes
- reductions in front-parietal regions and increased in the midbrain/cerebellum.

Symptoms of LBD are as follows:

- hallucinations (mainly visual) and delusions
- fluctuations in cognitive impairment (particularly attention and alertness)
- falls, syncope (fainting)
- irregular blood pressure
- disturbed sleep at night



- hypersensitivity to neuroleptic (antipsychotic) drugs
- patients show signs of confusion when transitioning between sleep and waking realities
- a lack of alertness and awareness of their surroundings.
- problems with vision, sound, taste and smell as disease progresses
- depression, delusions and aggression.

Frontal Temporal Dementias

There are three types of FTD these being Behavioural Variant Frontal Dementia. Semantic dementia and Progressive non fluent dementia. For the purpose of this resource the most common form of these three types of FTD will be addressed.

Behavioural Variant dementia (BvFD)

BvFD is responsible for two thirds of frontal temporal dementia. This is the most common type of FTD. Two thirds of people with FTD are diagnosed with this type. During the early stages, changes are seen in the person's personality and behaviour.

A person with behavioural variant FTD may:

- lose their inhibitions – behave in socially inappropriate ways and act in an impulsive or rash manner. This could include making tactless or inappropriate comments about someone's appearance
- lose interest in people and things (apathy) – lose motivation, but (unlike someone with depression) they are not sad
- lose sympathy or empathy – become less responsive to the needs of others and show less social interest or personal warmth. They may also show reduced humour or laugh at other people's misfortunes. This can make the person appear selfish and unfeeling
- show repetitive, compulsive or ritualised behaviours – this can include repeated use of phrases or gestures, hoarding and obsessions with timekeeping. It may also include new interests, such as music or spirituality
- crave sweet, fatty foods or carbohydrates and forget table etiquette. They may also no longer know when to stop eating, drinking alcohol or smoking.



It is common for a person with behavioural variant FTD to struggle with planning, organising and making decisions. These difficulties may first appear at work or with managing finances.

In contrast to those with Alzheimer's disease, people in the early stages of behavioural variant FTD tend not to have problems with day-to-day memory or with visuospatial skills (judging relationships and distances between objects). Someone with FTD may go walking without obvious purpose but, unlike a person with Alzheimer's, will often find their way home without getting lost.

Recent research shows that FTD can also affect the sensitivity of people with dementia to physical or environmental stimulation such as temperature, sounds and even pain.

It is unusual for a person with behavioural variant FTD to be aware of the extent of their problems. Even early on, people generally lack control over their behaviour or insight into what is happening to them. Their symptoms are more often noticed by the people close to them or by the general public sometimes leading to the local authorities or police being called.

How does dementia affect the brain itself and why is this important?

Parietal lobe

Making sense of my surroundings and my relationship to it.

Occipital lobe

Making sense of vision.

Cerebellum

Reflex movement function.

Frontal lobe

Reasoning, social behaviour, stopping and starting.

Temporal lobe

Memory, speech and understanding.

Brain stem

Co-ordination and automatic body functions.



Understanding how the brain works when a resident has dementia will help you support your residents and understand their behaviours.

Frontal lobe

The frontal lobe (FL) as all parts of the brain has two parts and is located behind the forehead. The frontal lobe is the largest lobe in the brain and is prone to injury. The FL is involved on the following:

Planning, organising, problem solving, memory, impulse control, decision making, selective attention, controls our behaviour and emotions.

Deficits to this part of the brain causes problems with emotional control. Impulsivity, social behavioural control and sexual disinhibition.

Parietal lobe

The parietal lobe (PL) lies behind the Frontal lobe. The main role of the parietal lobe is to integrate sensory information from various parts of the body. The PL controls the primary sensory cortex which controls sensation. The PL is responsible for the following:

Touch, pain, hot and cold. Tells up which way is up! Stops us bumping into things when we walk. Helps us locate and recognise parts of the body.

Occipital lobe

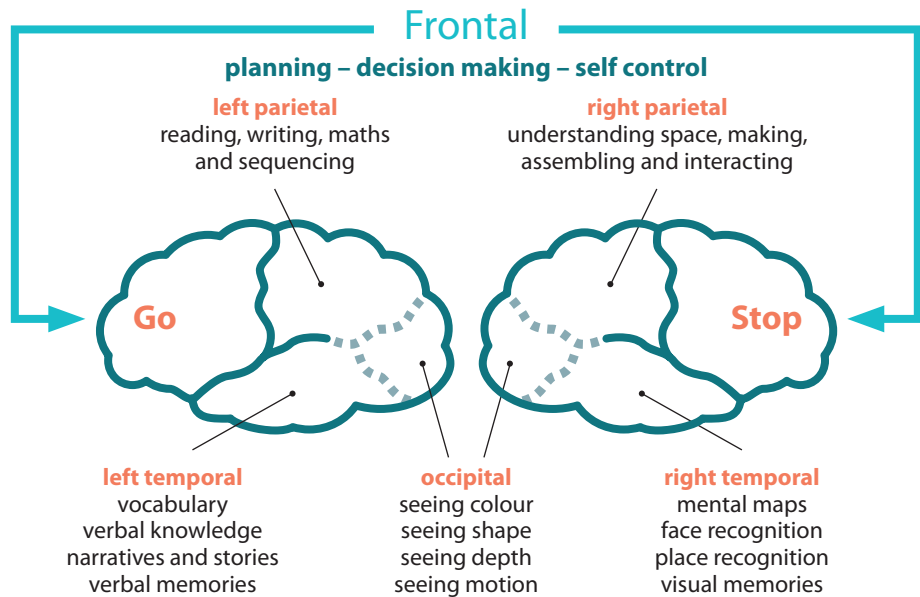
The occipital lobe (OL) is located at the back of the head. The OL receives and processes visual information. The OL contains areas that help in perceiving shapes and colours.

Problems in this area of the brain causes distortion in the visual field and difficulties with the perception of size and colour.

Temporal lobe

The temporal Lobe (TL) sits at the side of the brain under the parietal lobe behind the frontal lobe level with the ears. The TL is responsible for recognising and process sound. Understanding and processing speech and various aspects of memory. Deficits to this part of the brain causes problems with hearing and language. Recognition of familiar faces. Processing sensory information.



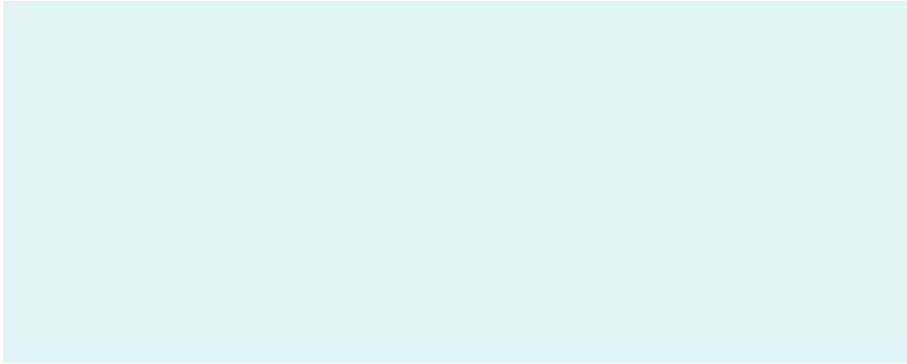


The above diagram again identifies some of the specific roles of various parts of the brain.

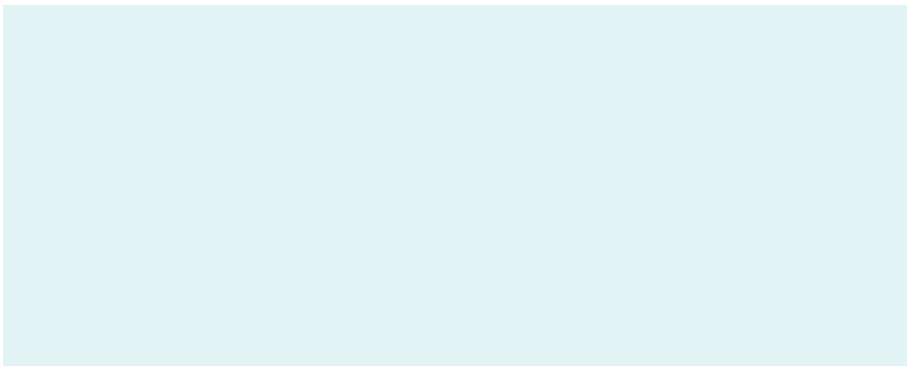
Based upon the above consider what can be done to support a resident who may have problems in the following areas. Consider how may this impact upon their activities of daily living and how can you support them?



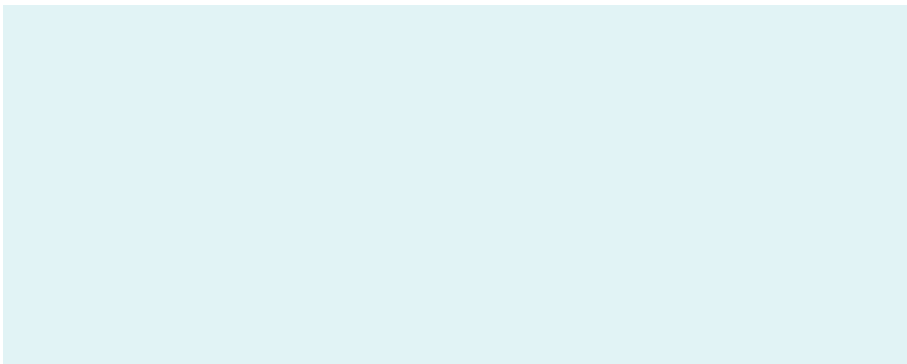
Occipital lobe



Frontal lobe



Left temporal lobe



Cerebellum

The cerebellum sits at the back of the brain and controls balance, movement and coordination.

The cerebellum allows us to stand upright, keep our balance and move around.

Deficits to the cerebellum causes problems with movement. Muscle tone and gait.

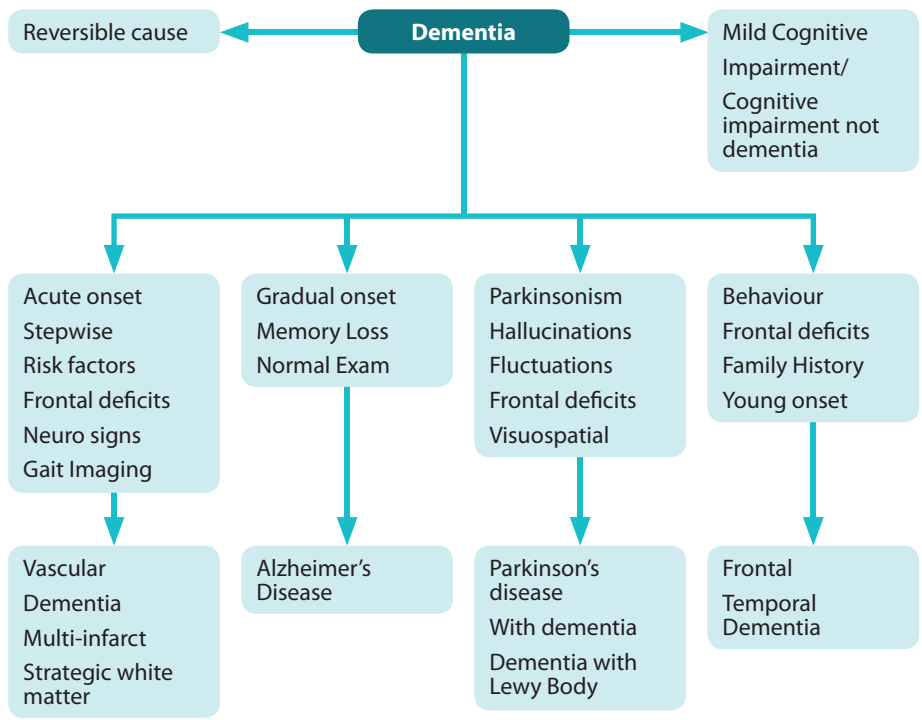
Brain stem

The brain stem is located the base of brain and is composed of the mid brain, pons and medulla. The brain stem regulates basic involuntary functions necessary for survival such as breathing, heart rate, blood pressure and swallowing. It also plays a role in alertness and sensation.

Deficits in this area of the brain cause problems with heart rate, breathing and swallowing.



Differential diagnostic consideration for common dementias



Assessment tools

Common assessment tools to support diagnosis

Cognitive assessments aim to make an assessment of recall, reasoning, abstract thinking, verbal and visual-spatial skills. The most common assessment tools (by no means exhaustive) are as follows:

Mini Mental State Assessment MMSE (Folstein) – Tests is graded in relation to declining cognition etc. and is out of a score of 30.

- 20 – 26 = Mild cognitive impairment
- 10 – 20 = Moderate impairment
- 10 or less Severe cognitive impairment.

Montgomery (MOCA) Score less than 26/30 indicating cognitive impairment. More complex than MMSE.

ACE III more detailed test score out of 100. Score of less than 82 indicating impairment. Recognised as good diagnostic test and is useful when identifying problems in specific domains.

- Attention mark out of 18
- Memory marked out of 26
- Fluency marked out of 14
- Language marked out of 26
- Visuospatial marked out of 16

*** Important to note in ACE III testing the older person is asked to draw a clock and then put the clock handset a particular time. If this is done successfully this can almost certainly exclude a dementia diagnosis.

*** Also note language and fluency are two separate points

Upon testing people may score well in one domain and not so well in others, but usually there is a general deterioration in all domains.



Drugs used in dementia

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

All AChEI's are licensed for mild to moderate dementia but can continue to be prescribed if they are effective in severe dementia.



Drug	Indication	Dosage	Main C/I or S/E
Memantine	<p>Alzheimer's disease, moderate to severe.</p> <p>Preferred drug if they are cardiac conduction problems or bradycardia.</p> <p>Can be trialed in conjunction with a AChEI in later stages of Alzheimer's disease.</p>	Dispensed starter pack initially 5mg once daily to 20mg once daily within one month.	<p>Check renal function prior to prescribing.</p> <p>Constipation.</p> <p>Hypotension.</p> <p>Dizziness.</p> <p>Metabolised by enzyme 2D6 so it competes for metabolism with other psychiatric drugs.</p>

Memantine is an NMDA antagonist, licensed for moderate or severe dementia and may be helpful with behavioural symptoms associated with dementia.

Anticholinergics and other drugs to be used in caution with dementia

Drugs for bladder instability	Avoid if possible. If not Solifenacin is preferred to Tolerodine or Oxybutynin.
Antiemetic's	Domperidone and Ondanetron preferred to Cyclizine, Metoclopramide, Prochlorperazine (and other phenothiazines).
Antihistamines	Avoid if possible if required use Loratadine and Fexofenadine preferable to Chlorpheniramine, Promethazine, Hydroxyzine.
Tricyclics generally	Includes very commonly used Amitriptyline.
Analgesics	Avoid Tramadol and Pethidine.
Sedation	All sedation to use with caution – long acting benzodiazepines and anti – psychotics especially.



Behavioural symptoms

Behavioural symptoms associated with dementia (BPSD)

Up to 90% of residents with dementia will display behavioural symptoms associated with dementia during the disease trajectory and overall symptoms are said to last for approximately three months. However many residents may present with symptoms for longer.

Frequently BPSD is seen as challenging to care workers but importantly such behaviours need to be seen as an unmet need which the resident is having difficulty in expressing. It is important to eliminate any reversible causes of such behaviours such as pain. Urinary infections are often a cause for deteriorating behaviours as is Delirium (see learning resource on Delirium).

Hallucinations are common especially visual in Parkinson's Dementia and Lewy Body Dementia. Hallucinations often worsen late afternoon (phenomenon called sun downing) Residents are not always frightened by what they experience but may experience some surprisingly real things. Many residents will see children, dogs. At night time if a resident is frightened consider how hallucinogenic props are managed i.e. wardrobe. Curtains in the wind, modify lighting to reduce shadows etc. The Newcastle Challenging behaviour team have done much work in Managing Complex behaviours displayed by residents in care homes and as such Ian James (Clinical Psychologist) has developed a book *The Newcastle Model. Managing challenging Behaviour in Dementia* and is a valuable resource for any care home.

The use of antipsychotic medication should only be used as a last resort in residents with BPSD and the following points may be useful:

- Drugs in dementia should never be first line intervention in managing BPSD.
- Anti - depressants and anti - Alzheimer drugs may be useful.
- Quetiapine in low dose is the safest anti - psychotic.
- If anti - psychotics are used they should only be used for very short periods and reviewed.
- Anti - psychotic medication are potentially fatal in LBD and PD.



Question

Answer

1 What score on the ACER III would lead you to suspect a resident has a dementia diagnosis?

2 Name two types of cortical and subcortical dementias?

3 Describe the role of the left parietal lobe.

4 Name four symptoms associated with Parkinsonism and dementia.

5 Identify three functions of the brain stem.



Question	Answer
6 Name three types of frontotemporal dementias.	
7 What are the four “A’s” when making a diagnosis of dementia and what area of cognitive deficits do they cause?	
8 Name four of the side effects associated with Donepezil.	
9 Describe the difference between an ischaemic stroke and haemorrhagic stroke and identify four of the associated risk factors with multi – infarct dementia.	
10 Identify symptoms associated with early small vessel disease.	



Notes



Thank you to the Alzheimer's Society for their help and support to develop this publication.