# Appendix 1. Types of Dementia

ТҮРЕ	INCIDENCE	CAUSE	SPECIFIC SYMPTOMS
ALZHEIMERS DISEASE (AD)	Most common 50% cases	Brain progressively damaged by formation of amyloid plaques and neurofibrillary tangles Loss of Acetylcholine cells in the brain	Ach levels decline by 40-90% in moderate to severe AD There is a significant deficit of Ach when the first symptoms of AD occur. Gradual decline.
VASCULAR DEMENTIA	Second most common 20% of cases	Hypertension is the cause in 50% of cases THIS DEMENTIA IS PREVENTABLE	periods of rapid decline (in comparison to AD)
MIXED DEMENTIA		Alzheimers and vascular dementia	May mutually induce each other [Expert reviewer's comment: Increasingly we diagnose mixed dementia, where there is a gradual decline but in the context of vascular risk factors and disease]
LEWY BODY DEMENTIA		Extranuclear inclusions (Lewy bodies) Can only be confirmed on post mortem examination	Must have reduction in functioning plus two out of three of: - recurrent visual hallucinations, - fluctuating cognition - spontaneous motor features of Parkinsonism Often display falls, syncope and transient loss of consciousness 50% develop severe extrapyramidal symptoms with antipsychotics and increased risk of neuroleptic malignant syndrome (NMS)
FRONTO- TEMPORAL DEMENTIA	More common in under 65's		Personality changes such as being uncharacteristically tactless or rude, apathetic, lacking volition, early reduction in self-care, losing inhibitions resulting in being sexually inappropriate. Aggression. Language difficulties. All of these can be overlooked, as memory usually preserved.
SUB-CORTICAL DEMENTIA		Associated with Parkinson's disease, Huntington's chorea and AIDS	Affects attention, motivation and emotionality and there is slowing of thought processes.  Language and memory functions are less affected in the initial stages

#### APPENDIX 2



The 4A Test: screening

(label)
Time:

instrument for cognitive impairment and delirium	Date: Time	Time:	
	Tester:		
		CIRCLE	
during assessment) or agitated/hyperact	edly drowsy (eg. difficult to rouse and/or obviously sleepy ive. Observe the patient. If asleep, attempt to wake with the patient to state their name and address to assist rating.		
	Normal (fully alert, but not agitated, throughout assessment)	0	
	Mild sleepiness for <10 seconds after waking, then normal	0	
	Clearly abnormal	4	
[2] AMT4 Age, date of birth, place (name of the ho	spital or building), current year.		
	No mistakes	0	
	1 mistake	1	
	2 or more mistakes/untestable	2	
•	ths of the year in backwards order, starting at December." ot of "what is the month before December?" is permitted.		
Months of the year backwards	Achieves 7 months or more correctly	0	
	Starts but scores < 7 months / refuses to start	1	
	Untestable (cannot start because unwell, drowsy, inattentive)	2	
	TUATING COURSE  tion in: alertness, cognition, other mental function or the last 2 weeks and still evident in last 24hrs		
, 5 ,		0	
	No Yes	4	
	165	**	

4 or above: possible delirium +/- cognitive impairment

1-3: possible cognitive impairment

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

<b>4AT SCORE</b>	
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#### **GUIDANCE NOTES**

Information and download: www.the4AT.com

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

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

#### **Appendix 3 GPCOG and 6CIT**

#### **GPCOG**

Firstly, ask the patient to remember the following name and address: *John Brown, 42 West Street, Kensingston* 

**Time orientation:** What is the date (score 1 if exact, score 0 if any errors)

**Clock drawing:** Use a blank page and get the patient to draw a clock including all the hours shown by numbers. (Score 1 if correct spacing, score 0 if not the case)

*Hands of the clock:* Please mark in the hands to show the time as ten minutes past 11 o'clock (Score 1 if correct, score 0 if not the case)

**Tell me something that happened in the news recently:** (Score 1 if specific answer given, score 0 if not the case. "War" or "a lot of rain" do not score, as answers like that are too vague. However if the patient was able to give details when prompted, then a score could be awarded).

Recall: of the address given earlier. Each item scores one point, maximum score being 5

John (1) Brown (1) 42 (1) West (or West St) (1) Kensington (1)

**Total maximum would be 9.** If scores 9, no impairment and no further tests needed. If 5 - 8, more info needed from carer (see below). If 0 - 4, cognitive impairment is diagnosed.

#### **GPCOG Carer Interview**

Complete this if GPCOG score is intermediate, i.e. score 5 - 8. Ask the carer/informant to compare the patient to when he/she was well, say five to ten years ago.

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"yes" (Score = 0) or "no", "don't know" or N/A (Score = 1)
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- Does he/she have more trouble remembering things that have happened recently, than he/she used to?
- Does he/she have more trouble recalling conversations a few days later?
- Does he/she have more difficulty find the right words to say, or use the wrong words more often?
- Is he/she less able to manage money and financial affair (bills, budgeting)?
- Is he/she less able to manage medication independently?
- Does he/she need more assistance with transport (either private or public? (NB if there is a physical reason for this, e.g. osteoarthritis, then score as "No")

A high number of "yes" answers indicates that the carer has noticed signs of cognitive impairment. If the score is 0 - 3, consider cognitive impairment diagnosed.

#### The 6CIT Dementia Test

How the test works						
Question	Score range	Weighting				
What Year is it	0-1	x4				
What month is it  Give the memory phrase e.g. (John/Smith/42/West Street/Bedford)	0-1	х3				
About what time is it	0-1	<b>x3</b>				
Count back from 20-1	0-2	<b>x2</b>				
Say months in reverse	0-2	<b>x2</b>				
Repeat the memory phrase	0-5	<b>x2</b>				
Total score for 6CIT	0-28					

0-7 = normal - referral not necessary at present 8-9 = mild cognitive impairment - probably refer 10-28 = significant cognitive impairment - refer

Score zero for a correct score and 1 for incorrect.

For the address: Say "John / Brown / 42 / West Street / Bedford" (or devise a similar address relevant to your country with 5 main elements.

Make sure that the patient is able to repeat the address correctly before moving on and warn them to try and memorise it as you are going to ask them to repeat it again in a few minutes. No score is made at this stage.

The address is broken into 5 segments and is scored for each error they make in remembering it up to a score of 5. I.e. All correct = zero, one bit wrong = 1, 2 parts wrong = 2, 3 parts wrong = 3, 4 parts wrong = 4 and all wrong = 5

Finally to complete the scoring multiply the score for each question by the weight in the neighbouring column and then add up all the weighted scores which should give you a score of between 0 – 28.

#### Appendix 4. - An ACP for a patient with Dementia

# Good practice for people with dementia:

- Encourage early discussion about future care
- Help the person and their carers to develop an Advanced Care Plan
- Promote the appointment of a Welfare Power of Attorney
- Always assess capacity and, where possible, include the patient in the decision-making process
- Make appropriate use of Part V of the Adults with Incapacity Act (2000)
- Adhere to the principles of the Act when considering content of a careplan
- Involve all relevant parties in development of the plan
- Include preferences for palliative and end of life care
- Take account of any advanced directive
- Document and share the plan.

# Where a patient lacks capacity, Part V of the Adults with Incapacity Act must be used, and the appropriate certificate completed.

A certificate can be issued for a three-year period, although at least annual review is encouraged.

The treatment plan attached to the completed certificate should cover all necessary interventions, including medical, nursing and dental treatments and must be discussed and agreed with any appointed proxy. It may include a plan for managing their long term conditions, what to do in the event of a deterioration, and should include discussion about palliative and end of life care.

It should not authorise an intervention that would normally require signed consent from the patient.

Any appointed Attorney or Guardian must be included in the process as well as members of the multidisciplinary team.

Decisions, including those relating to withdrawal of treatments and resuscitation, should be clearly recorded and communicated to all relevant members of the care team.

# Anticipatory care planning may include:

- managing physical symptoms and changes in behaviour;
- managing complications such as pneumonia, febrile episodes and swallowing and eating problems;
- avoiding admission to hospital; and/or facilitating early discharge if admitted to hospital;

The following template may be useful for checking at all areas have been discussed while preparing an ACP for a patient with dementia:

Is patient on the dementia register?	YES	NO
Diagnosis: Alzheimer's, vascular, mixed, Lewy Body, frontotemporal, or "other"		
Stage: early, mid, late, palliative		
Chronic physical illness? e.g. cardiac, respiratory, or neurological disease		
Physical disease Care Plan?	YES	NO
Preferred place of treatment: home, care home, hospital		
DNACPR in place?	YES	NO
Capacity assessed?	YES	NO
AWI part V cert in place?	YES	NO
Power of Attorney?	YES	NO
Advance care plan made by patient?	YES	NO
Risk assessment: e.g. risk of falls, pain level, recurrent sepsis, medication compliance, hydration/nutrition, continence, behaviour/mood change		
Carer: Cohabiting, near relative, professional, institution		

# Appendix 5. Cognitive enhancers 1,19

Prescribing is initiated in secondary care and usually handed on to primary care after 6 months, so some knowledge of these drugs is now essential.

Acetylcholinesterase inhibitors - donepezil, rivastigmine, galantamine.

All three of these drugs are licensed for use in mild to moderate Alzheimer's disease, and are approved by NICE and endorsed by the Scottish Medicines Consortium for use in NHS Scotland for cognitive decline in Alzheimer's Disease.

They are not a cure for dementia but studies show that between 40-70% of people benefit from treatment in terms of memory, and they also can experience improvement in motivation, anxiety levels and confidence. Symptoms improve in most cases for 6-12 months, although some benefit for much longer. Benefits of treatment are rapidly lost when the drug is discontinued and may not be fully regained when reinstated.

The three drugs produce their pharmacological effect in a slightly different way, thus if one drug does not have a clinical effect or causes intolerable side effects it is worth trying another.

Monitoring of patients should be done regularly by a scoring tool, and global, functional and behavioural assessment, to ensure there continues to be a worthwhile effect. A carer's view on the patient's condition and response to treatment should also be taken into account.

[Expert reviewer's comment: Practise has changed in recent years. Once the patient is assessed as responding to the medication, in most health board areas psychogeriatric services discharge care to GPs for monitoring of blood tests and general health. Patients usually remain on treatment long term, as there is evidence that many decline if the medication is discontinued.]

Recent research has suggested that these drugs are also beneficial in reducing behavioural and psychological symptoms of dementia (BPSD) but the evidence is not robust. NICE recommends considering them for BPSD in people with:

- dementia with Lewy Bodies if this is causing significant distress
- mild, moderate and severe Alzheimer's Disease if a non-pharmacological approach and/or antipsychotic drugs are inappropriate or ineffective
- note: they should not be used for BPSD in patients with purely vascular dementia.

#### Side-effects and cautions include:

- diarrhoea, nausea, vomiting (+/- dizziness) are common and are usually mild and transient. Taking the medication with food, reducing the dose or speed of titration and short-term prescription of an antiemetic may help. If rivastigmine is not tolerated orally due to gastrointestinal side-effects it may be worth trying patches.
- caution: co-prescribing these drugs with SSRI's, NSAID's, aspirin, warfarin and oral steroids can lead to increased risk of gastrointestinal bleeding
- other side-effects include bradycardia (thus caution with digoxin, B blockers, amiodarone and verapamil), insomnia, weight loss and muscle cramps.

### **Memantine - a** glutamate receptor antagonist.

This is licenced for treatment of moderate to severe Alzheimer's Disease. NICE only recommends its use if the patient is intolerant of (or has a contraindication to) acetylcholinesterase inhibitors. It is generally well tolerated, the main side effects being sedation and constipation. Rarely, patients have paradoxical agitation and psychotic symptoms. Combined therapy may be indicated in later stages of illness, for BPSD symptom control.