HPFT

Guidelines for the Pharmacological Management of Dementia

HPFT Guideline

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Title of document	Guidelines for the Pharmacological Management of Dementia		
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1.0	22/09/2020	22/09/2023	Sally Butterworth
Staff need to know about this policy because (complete in 50 words)	Dementia guidelines are to support the effective management of service users with dementia		
Staff are encouraged to read the whole policy but I (the Author) have chosen three key messages from the document to share:	This policy details arrangements within Hertfordshire, prescribing in dementia and how to manage non-cognitive symptoms of dementia including agitation, aggression distress and psychosis.		
Summary of significant changes from previous version are:	New HPFT Guideline		

Contents Page

Part 4	Appendices	
	Appendix 1- Functional Assessment Staging (FAST) Appendix 2- Medication used in Dementia Summary table Appendix 3- Costs of medication used in Dementia Appendix 4- ABC Charts Appendix 5- Good Practice Checklist Appendix 6- Pain Assessment in Advanced Dementia (PAINAD) Scale	

PART 1 – Preliminary Issues:

1. Introduction[1]

Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing and cooking. The most common types of dementia are: Alzheimer's disease (AD), vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia. Dementia is a progressive condition, which means that the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary.

A report published by the Alzheimer's Society found that in 2013 there were approximately 815,000 people living with dementia in the UK. If current trends continue, this number is expected to increase to 1,143,000 by 2025.

The symptoms of dementia occur in three main groups:

a) Cognitive dysfunction, which results in problems with memory, language, attention, thinking, orientation, calculation and problem solving.
b) Non-cognitive and behaviour that challenges. Examples of non-cognitive symptoms include; hallucinations, delusions, anxiety, agitation and aggressive behaviour. Behaviour that challenges may include aggression, agitation, sexual disinhibition, wandering, hoarding, apathy and disruptive shouting.
c) Difficulties with activities of daily living, such as driving, shopping, eating and dressing.

2. Objectives

This guideline has been developed to act as a framework for prescribing acetylcholinesterase inhibitors (AChEIs) and memantine in dementia, based on the current National Institute for Health and Care Excellence (NICE) dementia guidelines and technology appraisal. Further guidance is also included on the pharmacological treatment options for non-cognitive symptoms in dementia.

3. Scope

All staff involved in prescribing, reviewing, supplying and administering dementia medicines across all older adult HPFT sites and services.
All above staff should be aware of these guidelines and each other's roles.
GPs within Hertfordshire will be aware of the Trust guidelines and will follow the guidance within the accompanying prescribing support document for dementia medication.

Part 2 – What needs to be done and who by

4. Assessment general principles[1]

At the GP initial assessment take a history (including cognitive, behavioural and psychological symptoms, and the impact symptoms have on their daily life):

- from the person with suspected dementia and
- if possible, from someone who knows the person well (such as a family member).

If dementia is still suspected after initial assessment:

- conduct a physical examination and
- undertake appropriate blood and urine tests to exclude reversible causes of cognitive decline and
- use cognitive testing scales.

Refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if:

- reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated **AND**
- dementia is still suspected.

The patient should be assessed by a specialist neurologist, older adult psychiatrist, learning disability psychiatrist, specialist for younger adult dementia or a geriatrician or an appropriate qualified memory service clinician for a comprehensive assessment and a formal diagnosis of dementia.

All patients should have the relevant blood tests (e.g. hepatic and renal function tests) and screening procedures undertaken (e.g. ECG), to ensure they are able to safely initiate onto an AChEI or memantine prior to referral. ECG is essential if pulse is irregular or <60 beats per minute. Ensure the patient and/or carer is provided with information on the disease, treatment initiation/discontinuation as applicable according to the diagnosis.

The Functional Assessment Staging Test (FAST) is a scale that is used to describe the stages of dementia, see appendix 1.

5. Arrangements within Hertfordshire

The clinical management of patients with dementia in Hertfordshire, including the prescribing of dementia drugs, has been the responsibility of the Specialist Mental Health Teams for Older People (SMHTOP), Hertfordshire Partnership University NHS Foundation Trust (HPFT) since 2011. The Early Memory Diagnosis and Support Service (EMDASS) is responsible for the diagnosis and initiation of medication.

There is an agreement between both Herts Valleys Clinical Commissioning Group (HVCCG), and East and North Herts Clinical Commissioning Group (ENHCCG) and HPFT for appropriate patients who are maintained on a stable dose of dementia medication to be transferred to the General Practitioner (GP) for on-going prescribing

and monitoring in primary care. See ***Prescribing Support Document: Drugs for the Management of Dementia***. One of the aims of the prescribing support document is to ensure that the transfer of care of the patient with dementia from EMDASS to the GP is safe and appropriate by providing detail of the responsibilities of the CCG, specialist, GP and patient/carer. It also outlines what information will be communicated at the handover from secondary to primary care and how primary care can access back up advice/ when to refer back to specialists. It provides information on the drugs used, doses, contraindications, cautions and common side effects as well as interactions, monitoring requirements and cost information.

The GP will assume both the responsibility of prescribing the dementia drugs and the clinical management of the patient. Patients considered complex by the HPFT Old Age Psychiatrist will be excluded from the transfer of care arrangement and if appropriate be managed by Specialist mental health services for older people rather than the EMDASS service for ongoing clinical needs.
Carers' views on the condition of the person with dementia should be sought and taken into consideration during the initial baseline assessment and for all follow up assessments, where possible.

6. Communication and Handover from Secondary to Primary care

The following information should be provided/action undertaken when requesting the transfer of prescribing of the patient with dementia to primary care:

- Clear diagnosis and care plan including information that has been discussed with patient and carer.
- Details of drug treatment and dose.
- Confirmation that the patient is stable on a maintenance dose and that there has been a benefit from treatment
- Eight weeks' prescription of on-going medication from last appointment.
- Specialist team contact details for GPs to obtain advice and support.
- Confirmation that the patient has been fully informed that prescribing will be moved from EMDASS to their GP.
- Advice on any medication or co-morbidity that may worsen cognition and should be reviewed (if applicable)
- Link to the prescribing support document to provide additional information for GPs
- The post-diagnostic support service will work in parallel with the secondary care titration clinic.
- The post-diagnostic support service will provide the following information to the GP (if consent from the patient is obtained):
    - Confirmation of the standard information handed to the patient.
    - Details of whether advanced care plan has been agreed or discussed.
    - Any patient or carer specific information (at discretion of professional)
    - Any useful telephone numbers.
    - Report at discharge.
    - Specialist team contact details for back-up advice and support.

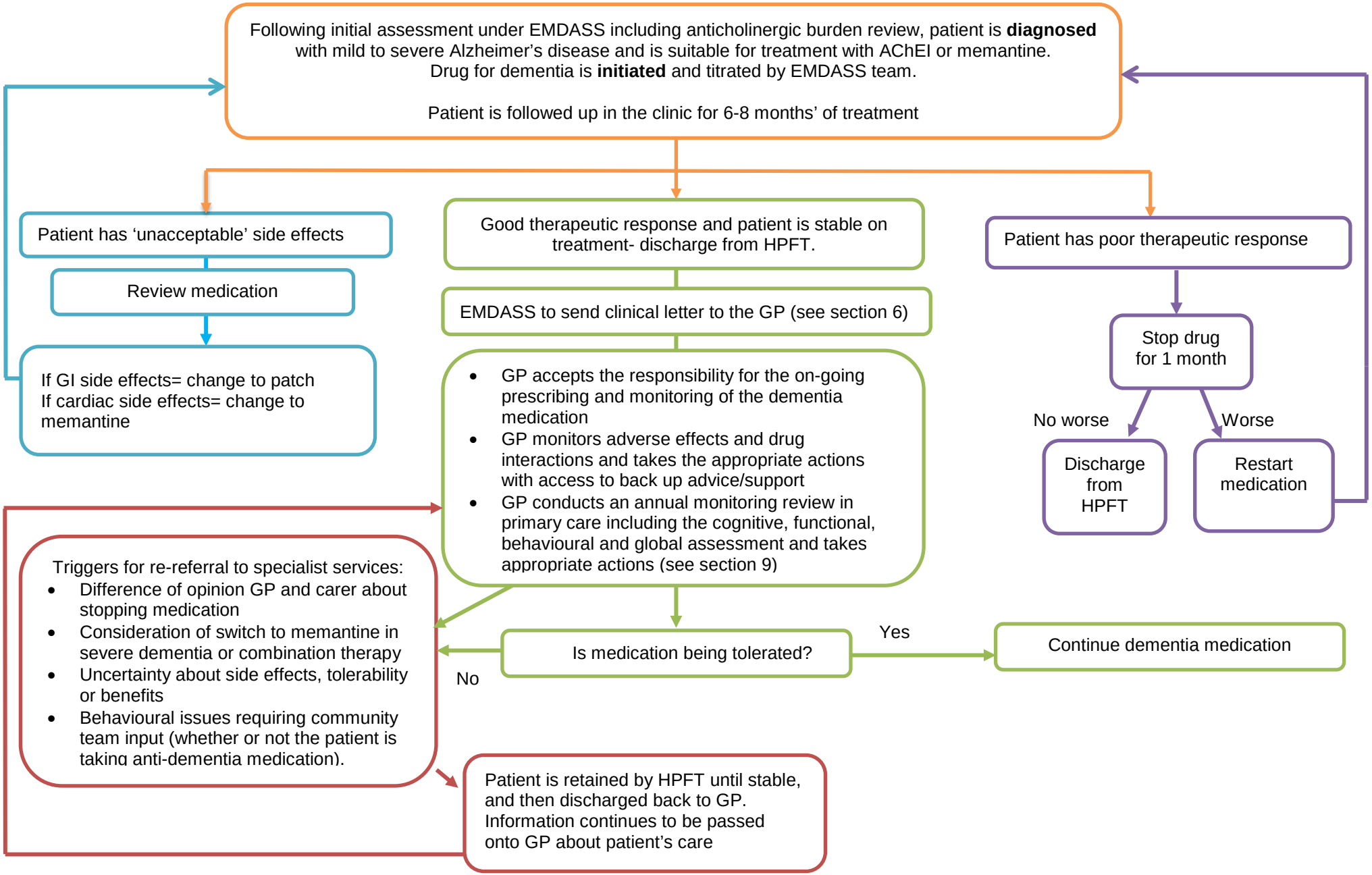
The Principles of Access to Back-Up Advice:

- GPs are expected to use the usual crisis pathway for crisis support (as with other patients).
- The EMDASS/SMHTOP team will respond to GP requests for back-up advice by telephone ***within 24 hours*** and will provide access to consultant clinics ***within 2 weeks*** (when needed). Consultants would expect to be able to answer GP queries directly by return of telephone call.
- The GP will be able to refer to the Alzheimer's Society (as usual) for signposting and support.

Triggers to re-refer to secondary care

- Difference of opinion between primary care team and carer about stopping medication
- Consideration of use of dual pharmacological therapy in patients with moderate/severe Alzheimer's disease and a global impression that cognitive enhancement would be of benefit to the service user.
- Uncertainty about side effects.
- Behavioural issues requiring community team input (whether or not the patient is taking anti-dementia medication).

Management of Dementia Drugs Process Summary



7. Prescribing in Alzheimer's Dementia[1]

a) Introduction

The NICE 2018 guidelines included some changes from the NICE guideline on dementia (CG42, published November 2006) and Hertfordshire's local interpretation is presented here. Treatment should be provided as part of a package of diagnosis, support and community care.

b) Treatment options

See NICE guidance- In particular in Hertfordshire we would clarify with these points:

- AChEIs are recommended as options for mild to moderate AD
- Memantine is recommended as an option for moderate AD and contra-indication or intolerance of AChEIs
- Memantine monotherapy is recommended as an option for severe AD if not already on AChEI (eg diagnosis in severe stage)
- Consider adding memantine to AChEI in moderate and severe AD. There is no need to add in memantine routinely, this may be done if the specialist considers that dual therapy will be beneficial over monotherapy.

- Do not stop AChEIs in people with Alzheimer's disease because of disease severity alone

- If prescribing an AChEI, treatment should normally be started with the drug with the lowest acquisition cost (taking into account required daily dose and the price per dose once transfer of care has started- see appendix 2 and 3). Branded generics should be considered if cheapest. However, an alternative AChEI could be prescribed if it is considered appropriate when taking into account adverse event profile, expectations about adherence, medical comorbidity, possibility of drug interactions and dosing profiles.

- Do not offer ginseng, vitamin E supplements, or herbal formulations to treat dementia.

8. Annual Monitoring Review in Primary Care[1,2,3,4]

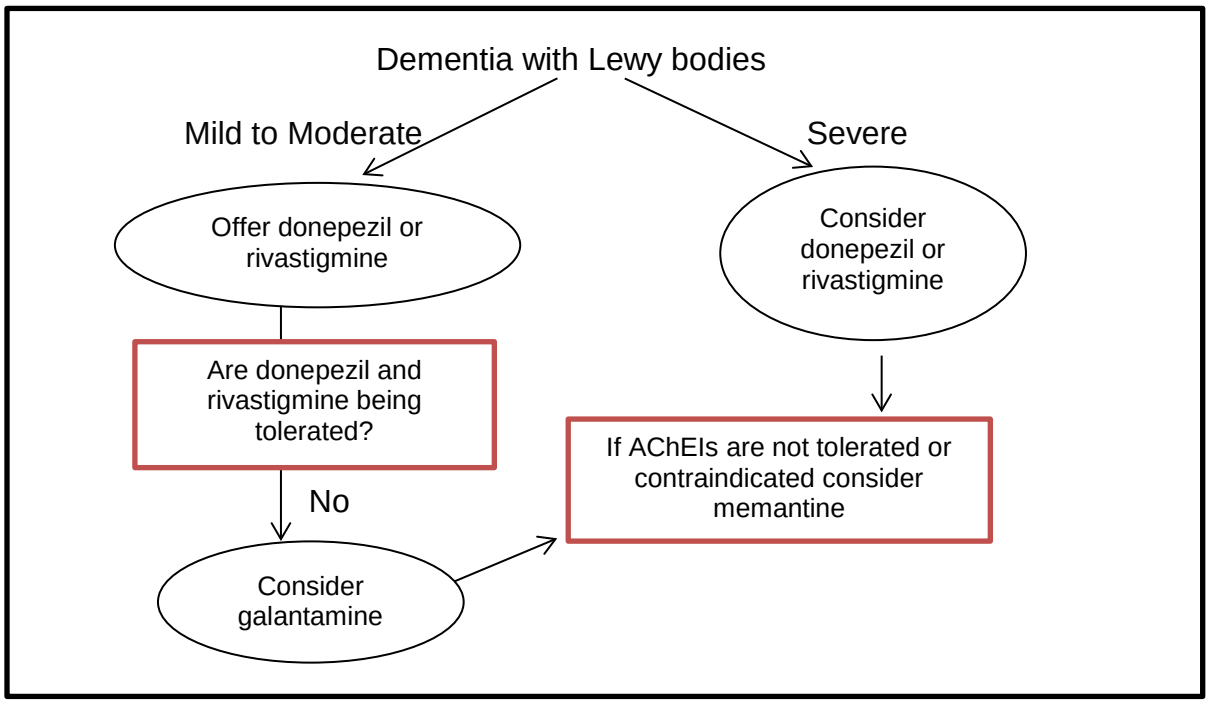
The following is a summary of the components to be included in the annual monitoring review of the patient:-

a) Compliance - is the medication being taken properly?		
b) Physical Health Monitoring		
Weight	If weight loss has started or accelerated after starting AChEI medication, this may be the cause	
Pulse	If <60 beats per minute, carry out an ECG. If PR interval > 200ms, stop drug or discuss with mental health specialist	
U+Es and LFTs	Renal or hepatic impairment may reduce an individual's tolerability to rivastigmine and/or donepezil	
Overall tolerance to medication	GI symptoms - anorexia, nausea, vomiting and diarrhoea Neurological symptoms – headaches, dizziness, drowsiness, syncope	
c) Impact on global functioning		
Functional and behavioural assessment is best made via a discussion with the patient and carer (it might be important to see the carer alone to elicit behavioural problems). Rating scales do exist for functional, behavioural and global assessment but most were designed for research purposes and none has become widely established for practical clinical use.		
Functional assessment	Impact on daily living. Is there declining function?	Review whether referral to Social Services (HCS) is required for declining function
Carer Impact	Does the carer value the effect of the medication?	It is important to take into account the impact of the medication to the carer.
Behavioural assessment	New behavioural problems? Is the patient displaying behavioural and psychological symptoms of dementia (BPSD)?	a) Acute Change Review physical health - is there a delirium superimposed on dementia? b) Chronic or Subacute Change - Consider referral back to HPFT
d) Cognitive Assessment		
• Some patients are distressed by repeated use of formal cognitive scoring tests. Therefore it is not always necessary to repeatedly use a formal scale to measure cognition as this can also be assessed via patient and carer interview. Use of formal cognitive scales is not mandatory. • It is also important to consider the global functioning of the patient by discussion with the carer/relatives. It is often the case that no management change is likely whatever the result of the test (i.e. the global functional, behavioural and global assessments are positive and the dementia is not severe). • However, in some cases a formal test can help find severe dementia and highlight that ongoing benefit of treatment is unlikely. An unexpectedly large change in a test score might prompt a conversation about other problems that need management – e.g. increased care package. • When the use of a formal cognitive scoring test is appropriate (e.g. when there has been a significant deterioration in the global functioning), consider using either of the following open access primary care validated scales –6CIT (six item cognitive impairment test) or GPCOG		
e) Is the medication still of overall benefit?		
Medication should be stopped if: **1. There is no cognitive, behavioural, functional or global benefit.** AChEIs should not be stopped because of disease severity alone in people with Alzheimer's disease. For GP management it is anticipated that if there is still an ***overall*** benefit and providing the patient is tolerating the treatment and there are no contraindications, the treatment will be maintained until such a time as it becomes inappropriate such as in extreme frailty or a severely impaired stage of dementia (eg swallowing difficulties). **2. If the patient cannot tolerate side effects** **3. Clinical co-morbidities make treatment risky or futile (e.g. terminal illness)** **4. If there are problems with patient compliance which cannot be reasonably resolved** **How to stop** It is advisable to give reducing doses – e.g. donepezil 5 mg daily for a month if the patient has been taking 10mg, before stopping. Similar gradual reduction with other drugs may be used. Evidence suggests there might not be a withdrawal reaction from AChEI medication but anecdotally these have		

been reported and therefore appears to be a reasonable precaution.

9. Pharmacological management of non-Alzheimer's dementia[1,5,6]

a) Dementia with Lewy bodies



b) Vascular dementia

- Only consider AChEIs or memantine for people with vascular dementia if they have suspected comorbid Alzheimer's disease, Parkinson's disease dementia or dementia with Lewy bodies.
- Care and prescribing will be held with HPFT for 6 months before discharging back to GP where treatment is effective and tolerated, under the conditions laid out in the prescribing support document.

c) Frontotemporal dementia

- Do not offer AChEIs or memantine to people with frontotemporal dementia.

d) Parkinson's disease

- Offer an AChEI for people with mild or moderate Parkinson's disease dementia. Rivastigmine is first choice due to licence and evidence.
- Consider an AChEI for people with severe Parkinson's disease dementia. Rivastigmine is first choice due to licence and evidence.
- Consider memantine for people with Parkinson's disease dementia, only if AChEIs are not tolerated or are contraindicated.
- In addition to the common side effects in Alzheimer’s Disease, be aware that the AChEIs can worsen the motor symptoms of Parkinson’s Disease

10. Other prescribing issues

a) Medicines that may cause cognitive impairment[7,8]

Anticholinergic drugs reduce the efficacy of AChEIs and also cause sedation, cognitive impairment, delirium and falls. These effects may be more severe in older patients with dementia.

Consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives:

- when assessing whether to refer a person with suspected dementia for diagnosis
- during medication reviews with people living with dementia.

Commonly used medications that have a high anticholinergic burden include:

- Tricyclic antidepressants
- Medications for urinary incontinence
- Antihistamines
- Procyclidine

There are several validated tools for assessing anticholinergic burden. One suggested tool is http://www.medichec.com/ which uses the Anticholinergic Effect on Cognition (AEC) scale.

- This aims to help clinicians to identify which drugs have an anticholinergic effect on cognition and defines the extent of this effect.
- The AEC scale takes into account the anticholinergic effect of a drug, the extent of this effect, whether it is able to penetrate the brain or not and whether there are in fact reports of cognitive impairment with the drug to support the score given.
- Medications are categorised according to their anticholinergic score as follows:

  3- Review and withdraw or switch
  2- Review and withdraw or switch
  1- Caution required
  0- Safe to use

- Consider reviewing all individual drugs with an AEC score of 2 or above to see whether they can either be withdrawn or switched to a drug with a lower AEC score (preferably 0).
- The individual AEC scores of drugs are added together for each patient so as to calculate the total AEC score.
- Consider carrying out a medication review for all patients with a total AEC score of 3 or above to see whether the total AEC score can be reduced to the minimum possible.

- Note that drug dosage is not taken into account when using this scale.

- This scale scores drugs according to anticholinergic safety only. **Some medicines may give an AEC score of 0 but may still worsen cognitive impairment through other pharmacological action.**

b) Managing non-cognitive symptoms - Agitation, aggression, distress and psychosis[1,6,7,9]

i. What are non-cognitive symptoms?

Non-cognitive symptoms of dementia include depression, hallucinations, anxiety, delusions, marked agitation and associated aggressive behaviour. The behavioural disturbances or challenging behaviour includes; aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and disruptive vocal activity such as shouting and sun downing (ie. behaviour worsens after 5pm). Symptoms such as wandering, social withdrawal, shouting, pacing do not usually respond to antipsychotic or AChEIs.

Non-cognitive symptoms and behaviours that pose a challenge can be the most difficult aspects of dementia to manage, both for caregivers and clinicians.

Patients should initially be assessed identifying biopsychosocial factors that may influence non-cognitive symptoms and behaviour including; physical health (such as underlying infection), depression, pain or discomfort (e.g. from constipation), side effects of medication, psychosocial and physical environmental factors (e.g. maintaining a suitable level of activity and interaction). The patient should be treated accordingly.

It is important to recognise what starts the behaviour off (Antecedent, A), the manifestations (Behaviour, B) and the consequence of the behaviour (C). This is collectively known as ABC, or behavioural charts (See appendix 4). The recognition of these and knowledge of the patients'; life history, relationships, pastimes and interests as well as likes and dislikes can help reduce the need for pharmacological intervention. Nursing staff and family members should be encouraged to use a behaviour diary/record, as a useful assessment of possible causes of challenging behaviour and treatment response. An example of such a record may be found in appendix 4.

Behavioural charts should be used to record symptoms. The Multi-disciplinary Team (MDT) should document what risks we are taking, why we are taking them, and when to review, especially when pharmacological approaches are used.

There are a range of potential treatments for the non-cognitive symptoms of dementia which can be divided into two groups: pharmacological and non-pharmacological interventions.

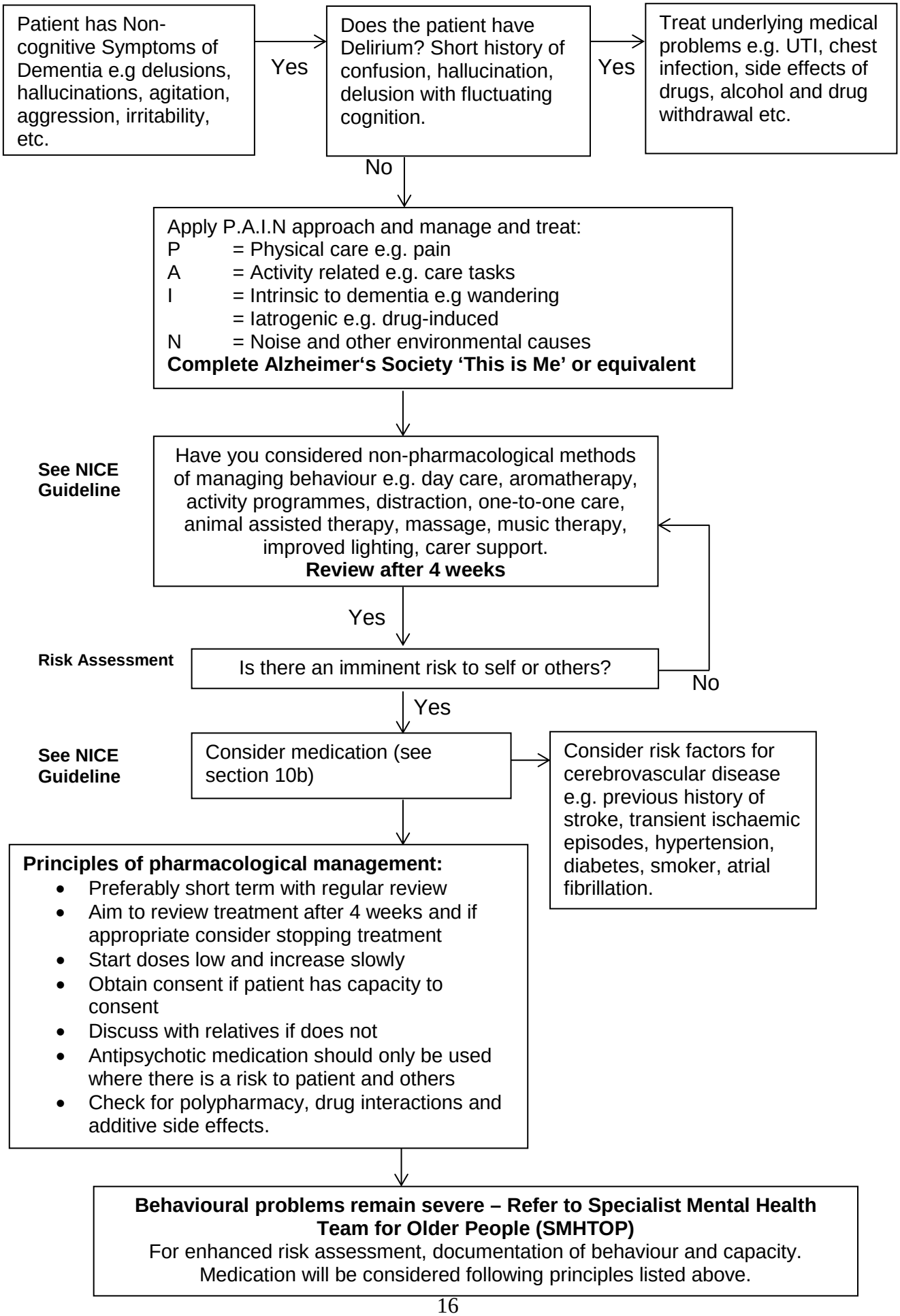
- Pharmacological interventions are targeted to the problematic behaviour of the person with dementia and include the use of antidepressants, antipsychotics, mood stabilisers and drugs to modify sleep patterns.
- In contrast, non-pharmacological interventions take a wider view and may include approaches aimed at: resetting sleep patterns using bright light therapy or by increasing the activity levels of the person with dementia; calming and distracting an agitated person; and altering the carer's behaviour to better cope with and manage the person with dementia.

Due to the often fluctuating course of non-cognitive symptoms of dementia, consider watchful waiting and monitoring first before pharmacological treatments.

Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to:

- explore possible reasons for their distress and
- check for and address clinical or environmental causes. This may include:
    - Physical ill health such as infection, delirium, pain (see section 10e),
    - Depression/ anxiety (see section 10c)

ii. Care Pathway for Managing Non-cognitive symptoms of dementia.



iii. Non-pharmacological approaches

Behavioural strategies and non-pharmacological interventions should be used first-line for those presenting with behavioural and psychological symptoms of dementia such as aggression.

As initial and ongoing management, offer psychosocial and environmental interventions to reduce distress in people living with dementia. For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest.

iv. Pharmacological treatments

Many classes of drugs have been used to treat the non-cognitive symptoms of dementia, and much use has been off-label. The potential benefits of using these drugs, such as reduced levels of depression and neuropsychiatric symptoms, must be weighed against the potential risk of side effects and serious adverse events. In particular, a number of these drugs may cause confusion or worsen cognition, especially drugs that have anticholinergic properties, for example antipsychotics.

See Care Pathway for Managing Non-cognitive symptoms of dementia flow chart and Appendix 5- Good Practice Checklist for the Pharmacological Management of non-cognitive symptoms of dementia. Note that in older age group psychotropic medication should be started low and increased slower than in adults.

Pharmacological treatments for the non-cognitive symptoms of dementia should be initiated by a specialist.

1. Anticonvulsants

Valproate

Do not offer valproate to manage agitation or aggression in people living with dementia, unless it is indicated for another condition.

Carbamazepine

Carbamazepine may be considered in the treatment of challenging behaviours, such as agitation, aggression and manic-like symptoms. This is “off-label” use.

2. Dementia drugs

Evidence is inconsistent and effect is moderate at best.

3. Antidepressants

NICE advises that antidepressants should not be routinely used to manage mild to moderate depression in people living with mild to moderate dementia. However, trazodone at a starting dose of 50mg nocte is sometimes used for non-cognitive symptoms of dementia. Evidence is limited and it is thought to reduce irritability and agitation by means of its sedative effects.

4. Other drugs

Benzodiazepines are widely used but their use is poorly supported. They may cause paradoxical agitation and disinhibition in some patients and possibly cause an increased risk of falls. Lorazepam is licensed for short-term use in managing agitation and anxiety. It may be used short-term when a calming or sedative effect is

appropriate. The usual dose prescribed in older adults is 0.5mg-2mg daily in divided doses.

Promethazine is frequently used for non-cognitive symptoms of dementia for its sedative effects. It has strong anticholinergic effects and can potentially cause significant cognitive impairment. It should be used short term only and evidence is minimal. Starting dose 25mg daily.

Analgesics – see section 10e.

5. Antipsychotics

Only offer antipsychotics for people living with dementia who are either:

- at risk of harming themselves or others or
- experiencing agitation, hallucinations or delusions that are causing them severe distress.

The patient's medical history must be taken into account, assessing the cerebrovascular risk factors and potential impact on cognition. Before starting antipsychotics, discuss the benefits and harms with the person and their family members or carers (as appropriate). Consider using a decision aid to support this discussion, such as the NICE decision aid:

https://www.nice.org.uk/guidance/ng97/resources/antipsychotic-medicines-for-treating-agitation-aggression-and-distress-in-people-living-with-dementia-patient-decision-aid-pdf-4852697005

When using antipsychotics:

- use the lowest effective dose and use them for the shortest possible time.
- reassess the person at least every 6 weeks, to check whether they still need medication.

Stop treatment with antipsychotics:

- if the person is not getting a clear ongoing benefit from taking them and
- after discussion with the person taking them and their family members or carers (as appropriate).

Ensure that people living with dementia can continue to access psychosocial and environmental interventions for distress while they are taking antipsychotics and after they have stopped taking them.

A recent study shows that no significant differences were found across measures of effectiveness and safety among aripiprazole, olanzapine, quetiapine, and risperidone[10]. Therefore an individualised approach to treatment should be taken.

Doses

- Risperidone initially 250 micrograms twice daily, then increased in steps of 250 micrograms twice a day on alternate days, adjusted according to response; usual dose 500 micrograms twice daily (max. per dose 1 mg twice daily).
- Promazine starting dose 25mg daily. Maximum 25–50 mg 4 times a day. Licensed for agitation and restlessness in elderly.
- Quetiapine starting dose 12.5mg daily - do not prescribe more than 100mg daily without specialist input.

Risks of using antipsychotics
Antipsychotic use in dementia patients is associated with a significantly increased risk of stroke and death. Both atypical and typical antipsychotics appear to carry an increased risk for mortality and stroke in patients with dementia.

Be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions.

Antipsychotics – licensed in dementia patients
The only antipsychotics with a UK marketing authorisation for use in dementia are risperidone and haloperidol. The marketing authorisation for risperidone only covers short-term treatment (up to 6 weeks) of persistent aggression in people with moderate to severe Alzheimer's disease unresponsive to non-pharmacological approaches and when there is a risk of harm to self or others. The marketing authorisation for haloperidol only covers treatment of persistent aggression and psychotic symptoms in people with moderate to severe Alzheimer's dementia and vascular dementia when non-pharmacological treatments have failed and when there is a risk of harm to self or others. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. All other antipsychotics used in dementia are unlicensed.

c) Depression and anxiety

For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider psychological treatments.

Do not routinely offer antidepressants to manage mild to moderate depression in people living with mild to moderate dementia, unless they are indicated for a pre-existing severe mental health problem.

d) Sleep problems

Do not offer melatonin to manage insomnia in people living with Alzheimer's disease.

For people living with dementia who have sleep problems, consider a personalised multicomponent sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.

e) Pain[4,7,11,12,13]

Pain is one of the most common symptoms that people with dementia experience. However, often it is poorly recognised and undertreated in dementia. The main reason for this is that, as dementia progresses, the person's ability to communicate their needs becomes more difficult.

Consider using a structured observational pain assessment tool, such as the Pain Assessment in Advanced Dementia (PAINAD) Scale (See Appendix 6):

- alongside self-reported pain and standard clinical assessment for people living with moderate to severe dementia
- alongside standard clinical assessment for people living with dementia who are unable to self-report pain.

Repeat pain assessments for people living with dementia:

- who seem to be in pain
- who show signs of behavioural changes that may be caused by pain
- after any pain management intervention.

For people living with dementia who are in pain, consider using a stepwise treatment protocol that balances pain management and potential adverse events.

Consider non-pharmacological treatments including massage, heat pads, gentle exercises to relieve stiff joints, air mattresses and air cushions.

Pharmacological interventions

When prescribing a pharmacological treatment, the following principles should be followed:

- start low and go slow
- analgesics should be titrated to response rather than dose
- people with dementia have increased sensitivity to side-effects of drugs
- the least invasive route of administration should be chosen; transdermal or topical medications may be of value; in patients with swallowing difficulties a patch or liquid formulation is preferred
- understanding the precipitants of pain often allows analgesia for acute pain to be used pre-emptively, for example 15–20 minutes before painful dressing changes

- try to match the duration of action of the drug/formulation to the duration of the pain, i.e. long-acting drugs, to prevent the re-emergence of chronic pain, short-acting drugs for brief pain
- most people with dementia can be treated at STEP 1 of the WHO pain ladder and very few will need a weak (STEP 2) or strong (STEP 3) opioid. See https://www.who.int/cancer/palliative/painladder/en/

Non-opioid treatments

- Paracetamol - A therapeutic trial of paracetamol should be considered first-line in everyone with acute or chronic pain unless contraindicated. It is available in a variety of formulations.
- Antidepressants
- Antiepileptics (anticonvulsants)
- NSAIDs
- Other classes

Opioid treatments

The following principles should be followed:

- Treatment will need to be individualised according to the type of pain experienced
- Start at the lowest recommended dose. If it is necessary to step up treatment, the recommendations in the WHO pain ladder should be followed.
- The oral route is best. Patches should be used with caution.
- Proactively manage common side-effects especially constipation and/or emesis
- Review treatment regularly, especially in people with advanced dementia

f) Falls[14,15]

For guidance on managing the risk of falling for people living with dementia see the NICE guideline on falls in older people, and HPFT Service User Falls Prevention and Management Policy and Procedure (2018). When using these guidelines:

- take account of the additional support people living with dementia may need to participate effectively
- be aware that multifactorial falls interventions may not be suitable for a person living with severe dementia.

g) Incontinence[16]

For guidance on pharmacological treatment of overactive bladder, see the NICE technology appraisal on mirabegron for treating symptoms of overactive bladder and local formulary guidance. Bear in mind that many of the medications for incontinence are anticholinergics, and may worsen dementia.

h) Covert medication[17]

- Covert medication administration is when staff or carers administer medicine without the patient's knowledge or informed consent; for example, disguising it in food or drink without the patient knowing. Sometimes this becomes necessary in people with dementia.
- A patient must be assessed as lacking capacity to consent and the medication to be administered covertly must be considered essential.

- Once a patient has been assessed as lacking capacity to make a decision about medication, a best interest decision will be taken as part of a multidisciplinary meeting, including the patient's carers.
- For more information please refer to HPFT Covert Administration of Medicines Policy (2018)

i) Palliative care and end of life care[18]

From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.

For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process. Involve the person and their family members or carers as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.

For inpatients discuss DNA, CPR and Ceiling of Care forms with all patients who have capacity and carers if the patient does not have capacity. See HPFT Mental Health Services for Older People - Inpatient Organic Assessment and Treatment Operational Policy 2019[20].

Part 3 – Document Control & Standards Information

11. Version Control

Version	Date of Issue	Author	Status	Comment
1	September	Sally Butterworth		

12. Supporting References

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Linked documents

HPFT-Prescribing Support Document: Drugs for the management of Dementia (donepezil, galantamine, rivastigmine, memantine) July 2020.

Part 4 Appendices

Appendix 1- Functional Assessment Staging (FAST)[21]: Check highest consecutive level of disability

(clinical severity below in bold has been added to the original Reisberg FAST scale to correspond to current clinical concepts)

Stage	Clinical severity	Signs and symptoms (*Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver)
1	**Normal**	No difficulty, either subjectively or objectively.
2	**Subjective Cognitive Impairment (SCI)**	Complains of forgetting location of objects. Subjective work difficulties.
3	**MCI**	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
4	**Mild Dementia**	Decreased ability to perform complex tasks, e.g. planning dinner for guests, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.*
5	**Moderate Dementia**	Requires assistance in choosing proper clothing to wear for the day, season, or occasion, e.g. patient may wear the same clothing repeatedly, unless supervised.*
6	**Moderately Severe Dementia**	**a.** Improperly putting on clothes without assistance or cuing (e.g. may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks.* b. Unable to bathe (shower) properly (e.g., difficulty adjusting bath-water (shower) temperature) occasionally or more frequently over the past weeks.* c. Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.* d. Urinary incontinence (occasionally or more frequently over the past weeks).* e. Fecal incontinence (occasionally or more frequently over the past weeks).*
7	**Severe Dementia**	a. Ability to speak limited to approximately a half a dozen intelligible different words or fewer, in the course of an average day or in the course of an intensive interview. b. Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over). c. Ambulatory ability lost (cannot walk without personal assistance). d. Cannot sit up without assistance (e.g., the individual will fall over if there are no lateral rests [arms] on the chair). e. Loss of ability to smile. f. Loss of ability to hold up head independently.

FAST scoring instructions:
The **FAST Stage** is the highest consecutive level of disability. For clinical purposes, in addition to staging the level of disability, additional, non-ordinal (nonconsecutive) deficits should be noted, since these additional deficits are of clear clinical relevance.

Reference: M.D. Reisberg, B. Functional Assessment Staging (FAST). Psychopharmacology Bulletin, 1988; 24:653-659 (with Permission).

Appendix 2- Medication used in Dementia Summary table[4,6]

	Donepezil	Galantamine	Rivastigmine	Memantine
Dosage and formulation	5mg once daily in the evening, just before bed, increased if necessary after 1 month to 10mg once daily. Orodispersible tablet available (significantly more expensive)	<u>Standard release tablet and liquid</u> Start at 4mg twice daily preferably with meals. Increase to maximum tolerated up to 12mg twice daily. Minimum of 4 weeks between dose increases. <u>Modified release tablet</u> 8mg once daily increasing to maximum tolerated up to 24mg once daily. Minimum of 4 weeks between doses.	<u>Capsule and liquid</u> Starting dose 1.5mg twice daily with meals. Increase dose to maximum tolerated up to 6mg twice daily. Minimum of 2 weeks between dose increases. If treatment is interrupted for more than three days, it should be re-initiated at 1.5 mg twice daily to reduce the possibility of adverse reactions (e.g. vomiting). <u>Patch *(only if capsule/liquid cannot be administered)*</u> 4.6mg/24hours increasing to 9.5mg/24hours after a minimum of 4 weeks. After a further 6 months, may be increased to 13.3mg/24 hours if clinically appropriate	<u>Tablet/orodispersible tablet and oral solution</u> 5mg once daily, increased in steps of 5mg at weekly intervals, until reaching the recommended maintenance dose of 20mg once daily. Orodispersible tablets are preferred to the solution.
Cautions – to be used with caution in the following	• Sino-atrial or AV node block, or sick sinus syndrome • Severe asthma • Concomitant beta-blocker therapy • Urinary symptoms (avoid use of galantamine) • People at increased risk of peptic ulcers (those with history of ulcer disease or on concomitant NSAIDs) • Chronic obstructive pulmonary disease or active pulmonary infections • Epilepsy • CVD *May exacerbate/induce extrapyramidal symptoms*			• History of convulsions • Patients with recent MI, uncontrolled hypertension or uncompensated congestive heart failure were excluded from the clinical trials and there is limited data for the use in these patients. These patients should be closely supervised. • Patients who have had drastic diet changes e.g. carnivore to vegetarian or a massive ingestion of alkalising gastric buffers since this causes alkalisation of urine which

<table>
<tr><td></td><td colspan="3"></td><td>reduces elimination of memantine.</td></tr>
<tr><td></td><td>Donepezil</td><td>Galantamine</td><td>Rivastigmine</td><td>Memantine</td></tr>
<tr><td rowspan="2">Absolute Contraindications</td><td>Known sensitivity to piperidine derivatives.</td><td>• Severe hepatic/renal impairment or those who have both significant renal and hepatic dysfunction.
• Urinary retention or history of prostatic condition.</td><td rowspan="2">• Known hypersensitivity to carbamate derivatives
• Severe liver impairment
• Previous history of application site reactions suggestive of allergic contact dermatitis with rivastigmine patch</td><td rowspan="2">Patients with rare hereditary problems of fructose intolerance should not take oral solution (contains sorbitol).</td></tr>
<tr><td colspan="2">Patients with rare hereditary problems of galactose intolerance, the Lapp lactase deficiency or glucose-galactose malabsorption</td></tr>
<tr><td>Adverse effects</td><td colspan="3">There are two practically important groups of adverse effects:
1. GI – common S/Es include abdominal pain, nausea, vomiting, diarrhoea, anorexia, weight loss
2. Cardiac
• heart block (sino-atrial block, AV block) – this is rare but potentially serious and easily missed
• bradycardia – if this occurs, carry out an ECG. If symptoms of collapse or dizzy spells and PR interval >200ms, then stop AChEI</td><td>Appears to be well tolerated in practice but it is important to note that it might be easy to miss distressing side effects when it is used exclusively in a population with severe dementia.</td></tr>
<tr><td rowspan="2">Clinically important drug interactions</td><td colspan="3">• May interact (antagonism of effects) with medicines that have anticholinergic activity e.g. oxybutynin, antipsychotics and tricyclics.
• Potential for synergistic activity with medicines such as succinylcholine (suxamethonium) and other neuromuscular blocking agents, cholinergic agonists or beta-blocking agents that have effects on cardiac conduction.
• Potential for additive effects with other drugs that share the same side effects (e.g. beta blockers and bradycardia, SSRIs and anorexia)</td><td rowspan="2"></td></tr>
<tr><td colspan="2">• Metabolised via CYP3A4 and CYP2D6 pathways in the liver. Inhibitors of these pathways (e.g. erythromycin, clarithromycin, ketoconazole, fluvoxamine, fluoxetine, paroxetine) may increase drug levels and patients may experience increased side effects. A dose reduction may be required.
• Enzyme inducers (e.g. rifampicin, phenytoin, carbamazepine and alcohol) may reduce levels so care should be taken with concurrent prescribing.</td><td></td></tr>
</table>

For more information please see BNF and Summary of Product Characteristics

Appendix 3- Costs of medication used in Dementia (Source: Drug Tariff June 2020)[19]

All costs below are quoted for maximum doses. Treatment is often at maximum dose although practice varies. In the case of oral rivastigmine, the maximum is often not reached.

Drug	Formulation	Dose	28 days cost	Annual Cost
Donepezil	Tablets	10mg od	£1.36	£18
	Orodispersible tablets	10mg od	£10.43	£136
Rivastigmine	capsules	6mg bd 2x3mg bd	£33 £12.96	£430 £168.48
	Oral solution 2mg/ml (120ml bottle)	6mg bd (6ml)	£193.44 (120ml = £96.72)	£2524
	Patches	13.3/24	£77.97	£1016
		9.5/24	£19.97	£260
		4.6/24	£77.97	£1016
Galantamine	Standard release tablets	8mg bd	£63.29	£825
		12mg bd	£77.27	£1007
	Modified release capsules (prescribed generically)	16mg od	£64.90	£846
		24mg od	£79.80	£1040
	Oral solution 4mg/ml (100ml bottle)	8mg bd (4ml)	£240 (100ml = £120)	£1800
		12mg bd (6ml)	£240	£2640
Memantine	Tablets	20mg od	£10.48	£136
	Orodispersible tablets	2od	£49.98	£652
	Oral solution 10mg/ml	20mg od	£61.77 (50ml=£55.15)	£741

Appendix 4- ABC Charts

ABC stands for Antecedence, Behaviour and Consequence, and is an important way of reviewing how well a person with behavioural problems is responding to different situations. Completed ABC charts and / or diaries should be reviewed along with the person-centred care plan at regular intervals, including at medication review, to help decide what plan of actions to continue with.

Antecedence
Record the situation in which the problem behaviour occurred, for example

- time of day, activities that were happening or about to happen.
- Was anything different to usual?
- Any other clues to set the scene.

Behaviour Record the actual behaviour.

- What happened? How long did it last for? How severe was it?
- Did anyone present do anything to try and manage it? If so, what?

Consequence How did the behaviour settle? How did the person respond to attempts to manage the behaviour?

- Important to include things that didn't work. What worked well?
- Were there any significant consequences, eg family member now refusing to visit, care staff injured, patient fell or hurt themselves?
- Did anything else happen after the episode of behaviour?

Date and time	**Antecedent** *(What triggered or came before the behaviour?)*	**Describe the behaviour** *(include location and other aspects of the environment (eg, lighting, noise)*	**Consequence** *What did you do, or what happened to the behaviour? How severe was it?*	**Final outcome** *What did the observed person do after the incident was over?*

Appendix 5- Good Practice Checklist.
Pharmacological Management of non-cognitive symptoms of dementia
Consider, where appropriate, and document the following:
At Initiation

- ✓ Define target symptom(s), including history, severity and frequency
- ✓ Exclude possible underlying cause(s), e.g. pain, infection, drug-induced
- ✓ Consider aggravating or alleviating factors
- ✓ Consider non-pharmacological approaches, if appropriate
- ✓ Document reason(s) for pharmacological management, e.g. severe distress
- ✓ Consider cardiovascular risk factors, when initiating antipsychotics
- ✓ Ensure baseline physical health monitoring, including relevant blood tests
- ✓ Discuss with service user/carers, i.e. risks versus benefits, & if “off-label” use
- ✓ Document details of treatment, i.e. medicine name, dose and frequency
- ✓ Confirm next review, ideally within two weeks

At Review

- ✓ Assess changes in target symptom(s), including severity and frequency
- ✓ Assess for any side-effects, including any necessary management
- ✓ Ensure physical health monitoring completed, including observations & blood tests
- ✓ Consider medication cessation or reduction, if appropriate and rationale

Appendix 6- Pain Assessment in Advanced Dementia (PAINAD) Scale[13]

Instructions: Observe the patient for five minutes before scoring his or her behaviours. Score the behaviours according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional laboured breathing. Short period of hyperventilation	Noisy laboured breathing. Long periods of hyperventilation. Cheyne-Stokes respirations	
Negative vocalization	None	Occasional moan or groan. Low level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial Expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing	
Body language	Relaxed	Fidgeting. Tense. Distressed pacing.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
			Total score**	

Scoring: The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain;
4-6=moderate pain;
7-10=severe pain.
These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source: Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc*. 2003;4(1):9-15.

PAINAD Item definitions

Breathing
1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional laboured breathing is characterized by episodic bursts of harsh, difficult or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy laboured breathing is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, or wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative vocalization
1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails or laments.
Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails or laments much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial expression
1. Smiling is characterized by upturned corners of the mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body language
1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. Tense is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched (exclude any contractures).
3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also is observed.
5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (exclude any contractures).
6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).
8. Pulling or pushing away is characterized by restiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.
9. striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability
1. No need to console is characterized by a sense of wellbeing. The person appears content.
2. Distracted or reassured by voice or touch is characterized by a disruption in the behaviour when the person is spoken to or touched. The behaviour stops during the period of interaction with no indication that the person is at all distressed.
3. Unable to console, distract or reassure is characterized by the inability to sooth the person or stop behaviour with words or actions. No amount of comforting, verbal or physical will alleviate the behaviour.