

**GUIDANCE DOCUMENT 7**

**Medication and Dementia  
– Palliative Assessment  
and Management**



## **Palliative Care for the Person with Dementia**

### **Guidance Document 7: Medication and Dementia – Palliative Assessment and Management**

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Guidance Documents No. 4-7 Project Lead: Dr. Alice Coffey

Guidance Documents No. 4-7 Project Researcher: Dr. Kathleen McLoughlin

Principal Investigator for Medication Management Document: Dr. Elaine Lehane

Authors: Lehane, E., McLoughlin, K., Mannix, M., O' Caoimh, R., Hickey, M., McCague, P., Coffey, A. and Gallagher, P.

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This guidance was developed after careful consideration of the evidence available at time of publication. Whilst every effort has been made by the authors to ensure the accuracy of the information and material contained in this document, errors or omissions may occur in the content.

This is a guidance document provided for information and educational purposes only. It has been designed to assist healthcare providers by providing an evidence-based framework for decision-making strategies.

This guidance document is not intended as a sole source of guidance for assessment and management of medication in dementia palliative care and healthcare professionals should also refer to professional codes of ethics and relevant national policies and laws.

This guidance is not intended to replace ethical and clinical judgment or to establish a protocol for all individuals with this condition. Guidance documents do not purport to be a legal standard of care. The guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or family. Adherence to this guidance will not ensure successful patient outcomes in every situation.

The Irish Hospice Foundation, 2016.



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## WHAT IS PALLIATIVE CARE?

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

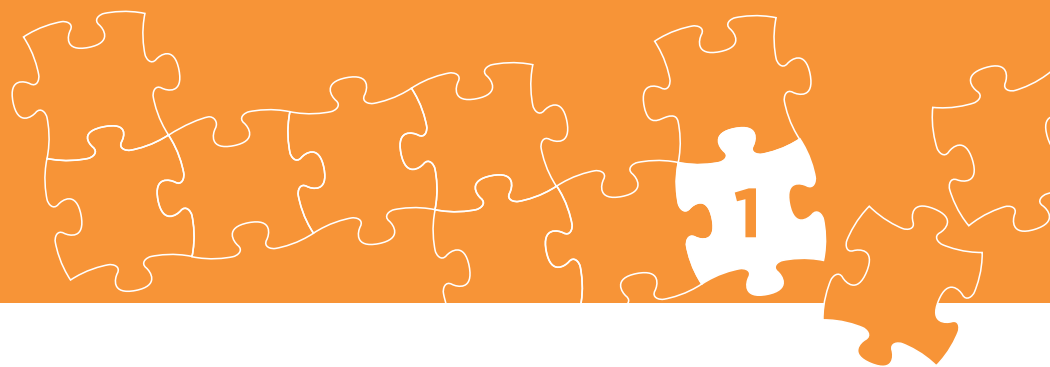
WHO (2016) Definition of Palliative Care <http://www.who.int/cancer/palliative/definition/en/>



## ABBREVIATIONS

ABC	Approach Antecedent [triggers], Behaviour description and Consequence
ABS	Anticholinergic Burden Score
AChEI's	Acetyl Cholinesterase Inhibitors
AD	Alzheimer's Disease
ADLs	Activities of Daily Living
BP	Blood Pressure
BPSD	Behavioural and Psychological Symptoms of Dementia
CAMCOG	Cambridge Cognition Examination
CAMDEX	Cambridge Mental Disorders of the Elderly Examination
ChEIs	Cholinesterase Inhibitors
COPD	Chronic Obstructive Pulmonary Disease
CDR Scale	Clinical Dementia Rating Scale
DRUGS	Drug Regimen Unassisted Grading Scale
DSDS	Dementia Scale for Down Syndrome
FAST	Functional Assessment Staging
GDS	Global Deterioration Scale for Assessment of Primary Degenerative Dementia (also known as the Reisberg Scale).
GP	General Practitioner
HSE	Health Service Executive
IHF	Irish Hospice Foundation
MedMaIDE	Medication Management Instrument for Deficiencies in the Elderly
MCI	Mild Cognitive Impairment
MMAA	Medication Management Ability Assessment
NHS	National Health Service (UK)
NICE	National Institute for Health and Care Excellence
NMBI	Nursing and Midwifery Board of Ireland
NYHA	New York Heart Association
PPPG	Policies, Procedures, Protocols, Guidelines
SMMSE	Short Mini Mental State Exam
UCC	University College Cork
UK	United Kingdom
USA	United States of America





## BACKGROUND

Dementia is an umbrella term used to describe a condition which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function including; decline in memory, reasoning, communication skills and in the ability to carry out daily activities<sup>1</sup>. The number of people living with dementia in Ireland today is estimated to be around 48,000 and this number is set to treble by 2045<sup>2</sup>. Dementia is a chronic, life limiting condition<sup>3-5</sup>.

People with dementia have a unique set of care needs which include: a progressive cognitive impairment; diminishing capacity; communication difficulties; possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis<sup>1,6</sup>. People dying with and or/from dementia require staff to have knowledge, skills, competence and confidence in both dementia and palliative care<sup>7</sup>. Palliative dementia care involves supporting the person with dementia and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs<sup>8</sup>. Providing this care and comfort presents services with a significant challenge as each person's journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia<sup>5,9</sup>. This is often compounded by staff lacking basic knowledge, awareness and skills in supporting people with dementia<sup>1,4</sup>. It is recommended that palliative care principles are introduced in the person's care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care<sup>3,8,9</sup>.

As illustrated, there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia in the literature; however, there is a notable void of practice guidelines to support healthcare staff in delivering excellence in end-of-life care for people with dementia. In order to support staff in meeting the palliative care needs of people with dementia, there was a call for the development of practice guidelines for the Irish context<sup>8,10,11,12</sup>.

As part of the Changing Minds Initiative, The Irish Hospice Foundation commissioned the development of a series of guidance documents.

1. Facilitating discussions about end-of-life care with the person with dementia
2. Advance healthcare directives and advance care planning
3. Loss and grief in dementia
4. Hydration and nutrition
5. Pain assessment and management
6. Ethical decision-making
7. Medication management

Irish Hospice Foundation (IHF) have taken the lead for the development of guidance documents 1 – 3 with assistance from relevant experts. University College Cork (UCC) successfully tendered for the development of the guidance documents 4-7.

The steering group and project team overseeing the development of this guidance document are listed in Appendix 1.



## INTRODUCTION TO THIS GUIDANCE DOCUMENT

***Optimising the management of all medication in dementia offers significant potential to improve dementia care.***

Medication management is an essential component of care for people with dementia. It encompasses evidence-based prescribing and administration, person-centered medication review, client information/ education, the capacity to communicate with multiple health providers and ensuring access to medications<sup>13,14</sup>. Optimising the management of all medication in dementia offers significant potential to improve dementia care in several ways:

- improving the quality of care for people with dementia and their carers
- improving key outcomes in dementia by reducing iatrogenic disease
- enhancing the healthcare professional/patient relationship e.g. by empowering people with dementia and their carers
- reducing inappropriate medication and the need for resource intensive interventions consequent to mismanagement
- enhancing non-medication management pathways for people with dementia<sup>15</sup>.

Cognitive impairment, in addition to concurrent co-morbid conditions, has been associated with medication management problems in people with dementia.<sup>16,17</sup> Evidence demonstrates a predominance of suboptimal or inappropriate medication management practices in populations with reduced life expectancy, including those with a diagnosis of dementia<sup>17</sup>. It is recommended that a person-centred, palliative care approach, from diagnosis until death, congruent with supporting the quality of life of people with dementia, be adopted<sup>18</sup>. Such an approach should also extend to medication management, however, clinical and ethical complexities impact upon decision-making within this care domain. Professional and non-professional caregivers, across all care settings, experience difficulty in navigating such complexities.

The aim of this document is to guide healthcare professionals in the principles of medication assessment and management in dementia palliative care.





## Scope of guidance document

This guidance document will list the principles of medication assessment and management in dementia care. Specifically, consideration is given to:

1. Medication management of cognitive symptoms and maintenance of function.
2. Medication management of non-cognitive symptoms and behaviours that challenge.
3. Optimising decision-making through application of medication management principles.
4. Medication administration practices.

*This guidance document is not intended to be a prescriptive authority and should not be used as such. Due to the extent and type of evidence currently available, limited inferences can be made in relation to medication management and therefore recommendations presented in this document should be considered in tandem with the circumstances of the individual and in consultation with the person with dementia and/or family.*

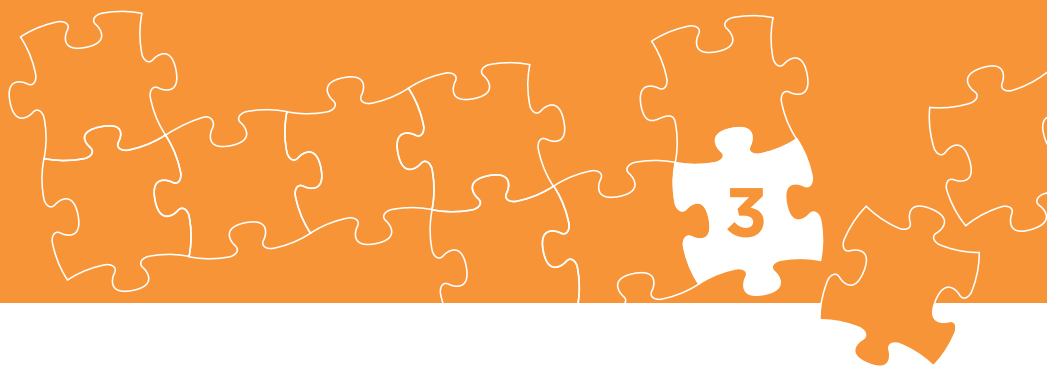
## Development of guidance document

The development of this document was overseen by a project team and steering committee (please see Appendix 1 for membership of both groups) using the process below.

1. Completion of scoping review.
2. Collation of key review themes to inform the guidance and principles of medication management.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
4. Preparation of Draft 2 for external consultation.
5. Assimilation of feedback from external consultation to final draft.
6. Final version published.

## Structure of guidance document

The guidance provided in this document focuses on four key areas, based on the agreed key themes emerging from the scoping review considered most beneficial for professional and non-professional caregivers. These areas are examined in detail in the following sections, together with the overarching principles supporting optimal medication management. Where applicable, we have sign-posted available resources and tools to guide medication assessment and management practices across care settings and stages of dementia.



## THEMES FROM THE SCOPING REVIEW

Dementia palliative care reflects the qualities of both holistic, multidisciplinary focused dementia care and palliative care. Both models adhere to a set of underlying principles focusing on quality of life, whole person care, respecting autonomy and caring for both the person and their family<sup>4</sup>. These are the core values that underpin and inform this collection of guidance documents in order to support people with dementia to live well and die with dignity. The need to support a person with dementia to plan their future care early in the trajectory of their condition has been well documented<sup>8,20,21</sup>.

A scoping study was undertaken to inform the development of this specific guidance document (See Appendix 2). The review of literature yielded a number of themes:

### Scoping review themes

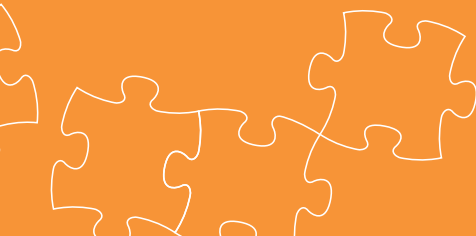
1. Medication management in dementia palliative care.
2. Medications for dementia - management of cognitive symptoms and maintenance of function.
3. Behavioural and Psychological Symptoms of Dementia (BPSD) – assessment and management of non-cognitive symptoms and behaviours that challenge.
4. Considerations for pharmacological management of co-morbid conditions.
5. Principles of prescribing and medication management in dementia care.

The key themes were presented to the Project Team. These themes were grouped into four overarching principles to guide prescribing practices and medication management and four areas of specific guidance for staff considered key to informing good practice around medication and dementia (see below).

### Four overarching principles to inform good practice

1. A person centred approach to care, from diagnosis to death.
2. Defined treatment goals to direct healthcare professionals and carers to the most appropriate medication management practices.
3. Assisted decision-making, between the person with dementia and their carers, necessitates working together to reach mutual agreement on the best course of action and preferred outcomes.
4. Regular medication review is essential for optimisation of the medication regimen as medication needs and management strategies will change as dementia progresses.





## Four areas for guidance

1. Medication management of cognitive symptoms and maintenance of function.
2. Medication management of non-cognitive symptoms and behaviours that challenge.
3. Optimising decision-making through application of medication management principles.
4. Medication administration practices.



## Levels of evidence

Where resources have been suggested, the level of evidence is cited next to the associated reference as follows:

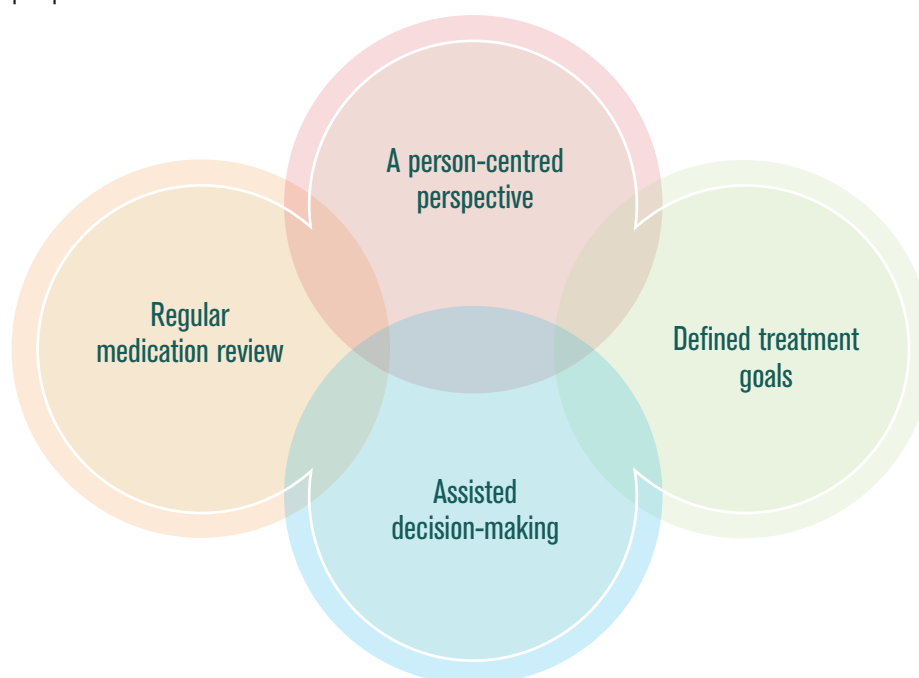
- Level 1:** Evidence obtained from systematic review of randomised trials
- Level 2:** Evidence obtained from at least one randomised trial
- Level 3:** Evidence obtained from at least one non-randomised controlled cohort/follow-up study
- Level 4:** Evidence obtained from at least one case-series, case-control or historically controlled study
- Level 5:** Evidence obtained from mechanism-based reasoning





## OVERARCHING PRINCIPLES TO INFORM GOOD PRACTICE

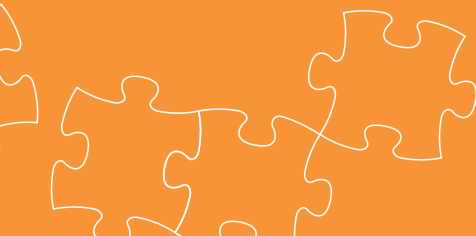
Four overarching principles or precepts on which to guide medication management in the older adult population, those with a life limiting illness and more specifically people living with dementia (Figure 1) have been proposed.<sup>22, 23, 24, 25, 26, 27</sup>



**Figure 1:** Overarching principles guiding medication management

**1. A person-centered perspective from diagnosis to death** to support the *quality of life* of people with dementia should be adopted. This approach should extend to medication management and should emphasise the following:<sup>18, 29</sup>

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them.
- the individuality of people with dementia, with their unique personality and life experiences.
- the importance of the perspective of the person with dementia.
- the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.
- the needs of carers and how they may be supported.



**2. Defined treatment goals** are of central importance and will usually direct the healthcare professional to the most appropriate pharmacotherapy and management of medications. Consideration should be given to treatment time to benefit ratios, treatment burden, functional limitations, quality of life and the priorities of the person with dementia and their caregiver<sup>25, 29</sup>. On the basis of these considerations, treatment goals can be directed appropriately towards prolonging survival (survival prolongation), preventing major morbid events (event prevention), improving or maintaining functional capacity (capacity enhancement) or relieving symptoms (symptom relief)<sup>29</sup>.

**3. Assisted decision-making** involves clinicians and people with dementia working together to clarify treatment and management goals and discuss preferred outcomes with the aim of reaching agreement on the best course of action<sup>23</sup>. It recognises an individual's right to make decisions and necessitates the provision of evidence-based information. This involves discussions regarding medication risks and benefits, side-effects, actions to take if and when side effects occur and medication discontinuation.

As dementia progresses, a person's capacity to participate in certain medication related decision-making processes can become increasingly compromised. While the person with dementia retains their right to be involved in decision-making as far as possible, assessment of capacity must be undertaken and assisted decision-making processes initiated. Decision-making should be considered in light of the relevant ethical issues and legislation. (Please refer to guidance documents 1, 2 and 6 for guiding principles relating to capacity, communication and legal/ethical issues). Specifically, in the case of medication management, with disease progression, people with dementia are at risk of medication misadventure, which must be accurately assessed to determine capacity to take and manage medications<sup>30</sup>. Assisted decision-making processes and associated rationale in relation to medication management should be documented.

**4. Regular medication review** is essential for optimisation of the medication regimen as medication needs and management strategies will change as dementia progresses<sup>30</sup>. Regular medication review (approximately 3 monthly or more frequent if necessary) facilitates the dynamic processes involved in prescribing decisions and medication management throughout the dementia illness trajectory, highlighting in a timely and proactive manner, medication problems, identifying target symptoms and monitoring effectiveness and safety of pharmacotherapy. Medication reviews allow for evaluation of pharmacological treatment effects and subsequent rationalisation of drug regimens<sup>25, 26</sup>. Such reviews should be multidisciplinary in nature and consider the use of a framework/tool to encourage a systematic to prescribing decisions<sup>27</sup>.



## GUIDANCE AND RESOURCES

The four areas that healthcare professionals, carers and people with dementia would benefit from guidance on medication management are introduced below and are outlined in further detail in the subsequent four sections of this document. These are as follows:

### **1. Medication management of cognitive symptoms and maintenance of function**

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Guidance on the treatment of dementia and mild cognitive impairment, and the conditions under which such treatment is initiated and continued is a key area of care for medication management in dementia. Directing healthcare professionals, people with dementia and their families/carers to access key resources is important in assisting decision-making in relation to management of cognitive symptoms and maintenance of function.

### **2. Medication management for behaviour and psychological symptoms of dementia (BPSD)**

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The management of behaviour and psychological symptoms of dementia (BPSD) (also known as responsive behaviour) is complex given the potential serious consequences for people with dementia and caregivers, in addition to the problematic risk-benefit profile of antipsychotic medications for such symptoms. While there are no simple solutions, there is an emerging consensus regarding the management of such symptoms and behaviours. It is important that both formal and informal carers have a clear understanding of this consensus view and the issues requiring consideration for the optimal assessment and management of BPSD.

### **3. Optimising decision-making through application of medication management principles**

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Systematic approaches to medication management through the application of principles/models are an important step in facilitating appropriate and optimal pharmacotherapy for people with dementia. Formal and informal carers should be informed of such overarching principles and directed towards useful resources to apply such principles in practice.

### **4. Medication administration practices**

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The administration of medication by caregivers and the consumption of such medications by people with dementia can become burdensome, from a clinical, ethical and quality of life perspective, particularly towards the terminal stage. Such complexities include difficulties with swallowing, lack of alternative suitable drug preparations, and covert administration practices. It is important that formal and informal carers are supported in facilitating safe and transparent practices in this area.

## 5.1 Medication management of cognitive symptoms and maintenance of function

Recent consensus statements conclude that current evidence is insufficient to support the association of any modifiable factor, pharmacologic agent, or dietary supplement with a reduction in the risk of dementia<sup>32,33</sup>. At present, there is no cure for dementia<sup>34</sup>. Current pharmacological interventions are used primarily to delay progression and improve symptoms. In most cases, dementia affects cognition, behaviour, functional activities, and caregiver burden; these are key targets for therapeutic interventions<sup>34</sup>.

In terms of the management of cognitive symptoms and maintenance of function, acetyl cholinesterase inhibitors (AChEI's) are the first-line agents for the treatment of mild to moderate Alzheimer disease<sup>34,35,36,37</sup>. While AChEI's are associated with mild improvements in cognitive function, behaviour, and activities of daily living, the clinical relevance of these effects however is unclear and the duration of improvements variable amongst people with dementia<sup>38</sup>.

Guidance on the pharmacological treatment of Alzheimer disease is available from a number of organisations<sup>18,36,38,39,40</sup>. The management of cognitive symptoms for non-Alzheimer dementias and mild cognitive impairment is also discussed in a number of these guides<sup>36,38</sup>.

### Guidance

1. Decision-making in relation to the optimal management of cognitive symptoms is based on the most up-to-date, evidence-based, clinical guidelines on pharmacotherapy for Alzheimer's disease and non-Alzheimer dementias. (Resource 1)
2. Healthcare professionals are familiar with the conditions under which such pharmacotherapy may be prescribed, adjusted and /or discontinued. (Resource 1, 3)
3. Healthcare professionals base the decision to initiate a trial of therapy and choice of medication on individualised assessment taking into consideration an evaluation of the benefits and risks associated with the individual person with dementia. (Resource 2, 3)
4. People with dementia/carers have appropriate information about the options for the initiation or discontinuation of treatment for the management of cognitive symptoms and maintenance of function. The views of the person with dementia/carer should be discussed at the start of drug treatment and at regular medication reviews. (Resources 4, 5, 6)



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## Resources for Healthcare Professionals

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### 1. Clinical Practice Guidelines

#### **a. Summary of NICE Clinical Guideline 42 (November 2006 (Amended 2011))<sup>18</sup>**

NICE Clinical Guideline 42<sup>18</sup> (review decision updates – 2007, 2011 and 2012) make both pharmacological and non-pharmacological recommendations in relation to the management of cognitive symptoms and maintenance of function in Alzheimer disease, dementia with Lewy bodies, frontotemporal dementia, vascular dementia and mixed dementia.

The current NICE guidance<sup>40</sup> on drug treatments for Alzheimer's disease recommends that people in the *mild-to-moderate stages* of the disease should be given treatment with one of three acetyl cholinesterase inhibitors (AChEIs), donepezil, galantamine or rivastigmine, including individuals with both Alzheimer's disease and intellectual disabilities.

The NICE guidance<sup>40</sup> further recommends that memantine should be prescribed for people with *severe Alzheimer's disease*, or for those with *moderate disease who cannot take the cholinesterase inhibitor drugs*.

When considering drug treatment, it is recommended that the severity of dementia should not be measured *solely* by scores on mental ability tests (e.g. the Mini Mental State Examination (MMSE)), but by a broader view of the person's condition. A decision on the initiation and maintenance of medications should be made on therapeutic and clinical grounds<sup>31</sup>. For a person with an intellectual disability, tools used to assess the severity of dementia should be sensitive to their level of competence (DSDS / CAMDEX / CAMCOG).

In relation to the Alzheimer's disease drugs, NICE makes the following recommendations:

- Treatment is started by a doctor who specialises in the care of people with dementia.
- People who are started on one of the drugs are checked regularly, usually by a specialist team unless shared care arrangements with primary care are in place.
- The check-up includes an assessment of the person's mental abilities, behaviour and ability to cope with daily life.
- The views of the carer on the person's condition are discussed at the start of drug treatment and at check-ups.
- Treatment is continued as long as it is judged to be having a worthwhile effect.

NICE guidelines do not recommend AChEIs for the treatment of cognitive decline in vascular dementia or mild cognitive impairment.

NICE guidelines recommend that a cholinesterase inhibitor is offered to a person with dementia with Lewy bodies or Parkinson's disease dementia if they have distressing symptoms (e.g. hallucinations) or challenging behaviours (e.g. agitation, aggression).

For the full clinical guideline and recent updates, please click on the following link for Dementia Intervention Pathway – Interventions for cognitive symptoms and maintenance of function. <http://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions/dementia>

#### **b. European Federation Neurological Society guidelines on the diagnosis and management of disorders associated with dementia<sup>33</sup>**

<http://www.guideline.gov/content.aspx?id=38470#Section420>



*c. European Federation Neurological Society guidelines for the diagnosis and management of Alzheimer's disease*<sup>41</sup>

## **2. National Medicines Information Centre**<sup>42</sup>

This bulletin provides guidance on the management of dementia. Specifically, indications, common adverse effects and monthly costs are summarised:

<http://www.stjames.ie/GPsHealthcareProfessionals/Newsletters/NMICBulletins/NMICBulletins2011/Dementia%202011.pdf>

## **3. GP/Primary healthcare education/information (Dementia Services, Information and Development Centre (Irish))**<sup>43</sup>

The links below are reference guides relating to GP and primary care, which offer advice on medication management, among other areas, for Alzheimer disease. Specific guidance is provided in relation to:

- When to start treatment
- Dosage regimens and pharmacology of Alzheimer drugs
- Follow up reviews
- When to stop treatment

### *a. Dementia: Diagnosis and Management in General Practice (2014)*<sup>31</sup> (Irish)

<http://www.dementia.ie/education/gp-education>

### *b. Dementia: The view from Primary Care (2013)*<sup>44</sup> (NHS)

<http://www.dementia.ie/images/uploads/site-images/dementiaprimary-care.pdf>



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## Resources for People with Dementia/Family Caregivers

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### **4. Understanding NICE Guidance – Donepezil, galantamine, rivastigmine and memantine for Alzheimer’s disease (NICE technology appraisal guidance 217)<sup>45</sup>.**

This leaflet is written for people with Alzheimer’s Disease and their families or carers who are prescribed the above named drugs.

<http://www.nice.org.uk/guidance/cg42/ifp/chapter/Treatments-for-different-types-of-dementia>

### **5. Alzheimer’s Society UK Fact Sheet 407<sup>46</sup>**

For people with Alzheimer’s or their carers on drug treatments for Alzheimer’s Disease. Specific sections relate to:

- The main drugs used
- How they work
- The effectiveness of the drugs for AD
- Side-effects
- How they are prescribed
- Effectiveness of drugs for other types of dementia
- Taking the drugs
- Questions to ask the doctor when starting the drugs
- Stopping Treatment
- Research into new treatments

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200348>

### **6. The Alzheimer’s Society of Ireland – Living with Dementia – An introduction for family members (p.15-17)<sup>47</sup>**

On pages 15 – 17 of the information booklet details are provided on drug treatments available for different types of dementia and considerations taken into account when deciding on treatment plans.

[http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Living-with-Dementia\\_web-2014.pdf?ext=.pdf](http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Living-with-Dementia_web-2014.pdf?ext=.pdf)

**See page 41 for Additional Resources**

## 5.2 Medication management of non-cognitive symptoms and behaviours that challenge

Non-cognitive symptoms include hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviours. In addition to anxiety, depression is grouped within psychological symptoms.

Behaviours that challenge, also known as responsive behaviours, can include, but are not limited to, aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and shouting<sup>18</sup>.

These symptoms and behaviours can be common problems in people with dementia, and when severe or persistent, can cause the person with dementia considerable distress and disability, as well as caregiver strain and early institutionalisation<sup>18,48</sup>.

Banerjee<sup>49</sup> and Jeste et al<sup>50</sup> in their position papers to the UK and USA government departments respectively, note that systems traditionally in place to manage these symptoms and behaviours grew by chance and delivered a largely pharmacological, anti-psychotic-based response. Jeste et al<sup>50</sup> noted that the management of non-cognitive symptoms and behaviours that challenge due to their potential serious consequences for people with dementia and their caregivers, in addition to the problematic risk-benefit profile of antipsychotic medications for such symptoms, creates a clinical conundrum for which there are no simple solutions. However, in recent years, reviews of empirical evidence and recommendations from position and white papers as well as NICE intervention pathways, consensus with respect to the management of non-cognitive symptoms and behaviours that challenge is emerging.

Such management comprises of:

- accurate and comprehensive assessment
- first line treatment with non-pharmacological interventions
- where necessary initiation and close review of pharmacological interventions.

### Guidance

1. An initial assessment on which to base management plans is essential. Documentation of the symptoms/behaviour, the specific behaviour demonstrated, the frequency and duration, what others did in response to the behaviour, and how the person reacted is required. Use of a tool(s) can aid assessment. (*Resource 1*)
2. Healthcare professionals are familiar with the conditions under which pharmacotherapy is prescribed, adjusted and/or discontinued. Careful assessment of the risks and benefits of pharmacotherapy and the type of dementia is required as no single treatment algorithm can be routinely recommended for all people with dementia. (*Resource 2 & 3*)
3. Healthcare professionals are aware of the principles of pharmacological control of violence, aggression and extreme agitation and receive appropriate training. (*Resource 3*)
4. People with dementia and their caregivers require appropriate information and guidance on the management of non-cognitive symptoms and behaviours that challenge. They have an important role in the assessment of BPSD and providing feedback on the effectiveness of any implemented interventions. (*Resources 4, 5, 6*)

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## Resources for Healthcare Professionals

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### 1. Assessment

#### a. NICE (2006; 2011; 2012) Clinical Guideline 42<sup>18</sup>

<http://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions/dementia>

#### *Initial Assessment Preceding Intervention*

If a person with dementia develops distressing non-cognitive symptoms or behaviour that challenges, offer an early assessment to identify factors that may influence the behaviour. The assessment should include:

- physical health
- depression
- possible undetected pain or discomfort
- side effects of medication
- individual biography
- psychosocial factors
- physical environmental factors
- behavioural and functional analysis in conjunction with carers and care workers.

Develop individual care plans, record in the notes and review regularly at a frequency agreed with carers and staff.

#### b. Practice Point - Clinical Practice Guidelines for Dementia in Australia 2015<sup>51</sup>

People with dementia who develop behavioural and psychological symptoms should be offered a *comprehensive assessment* at an early opportunity by a professional skilled in symptom assessment and management

- Analysis of the behaviours (e.g. antecedent [triggers], behaviour description and consequence [ABC approach]), frequency, timing and presentation
- Assessment of the person with dementia's physical and mental health
- Their level of pain or discomfort
- Whether they are experiencing side effects of medication
- The influence of religious and spiritual beliefs and cultural norms
- Physical environmental and interpersonal factors
- An assessment of carer(s) health and communication style
- The objective measurement of behavioural and psychological symptoms of dementia should be undertaken using tools with strong psychometric properties and used to monitor the type and patterns of behaviours.

#### Neuropsychiatric Inventory<sup>52</sup>

- Assesses a wide range of behaviours seen in dementia for both frequency and severity. These include delusions, agitation, depression, irritability and apathy. The scale typically takes 10 minutes for a clinician to administer to a carer. It has good psychometric properties and is widely used in drug trials, while being short enough (especially with patients without a wide range of behavioural issues) to consider for use in clinical practice.

**Cohen-Mansfield Agitation Inventory**<sup>53</sup>

- Takes 15 min for carers to rate, but requires some training. Up to 29 behaviours seen in dementia are rated for frequency – the lack of focus on severity is corrected by the breadth of behaviours covered. The behaviours covered include many of those found most disruptive, including verbal aggression, repetitiveness, screaming, hitting, grabbing and sexual advances. It is most commonly used in research settings. See Appendix 3.

**BEHAVE-AD**<sup>54</sup>

- Takes 20 min for a clinician to use, and is therefore most commonly used in interventional research studies. It covers most of the important disruptive behaviours, including aggression, overactivity, psychotic symptoms, mood disturbances, anxiety and day/night disturbances. Respondents are asked about the presence of behaviours and how troubling they are. It is reliable, sensitive to change and to stage of disease.

**Cornell Scale for Depression in Dementia (CSDD)**<sup>55</sup> to assess depressive symptomatology.



## 2. Key Specific Practice Recommendations

### a. Algorithm for Management of BPSD<sup>56</sup>

*N.B. Pain or discomfort is always a possible cause for BPSD – it must always be considered, and then either excluded or treated. Assess for delirium and other reversible conditions that may be contributing to behavioural symptoms and treat accordingly.*

- If** a person with dementia shows distressing behavioural symptoms  
**Then** → consider non-pharmacological interventions first with most evidence for music and behavioural management for depression
- If** non-pharmacological approaches have failed  
**Then** → consider psychotropic medication
- If** a person with dementia shows co-morbid depression  
**Then** → consider antidepressants (preferably SSRIs)
- If** a person with dementia shows distressing acute agitation or agitation based on anxiety  
**Then** → consider the short-term use of benzodiazepines (with caution)
- If** a person shows severe agitation/aggression and/or psychosis  
**Then** → consider antipsychotic medication
- If** antipsychotic medication is considered  
**Then** → carefully evaluate the individual risks (e.g. cardiovascular) and benefits to make a choice for typical or atypical agents
- If** an antipsychotic is started  
**Then** → initiate a low starting dose and titrate upwards in function of the resident's response and presence of adverse events
- If** an antipsychotic is started  
**Then** → treatment should be time-limited and regularly reviewed (every 3 months or according to clinical need)
- If** there is a period of behavioural stability  
**Then** → periodical attempts of antipsychotic discontinuation should be considered

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## 3. Practice Guidance on Pharmacological Interventions for non-cognitive symptoms and behaviours that challenge

### a. NICE (2006; 2011; 2012) Clinical Guideline 42<sup>18</sup>

<http://www.nice.org.uk/guidance/conditions-and-diseases/neurological-conditions/dementia>

*Guideline Summary/Pathway (Non-pharmacological / Pharmacological Intervention)*

*Note: If appropriate, non-pharmacological interventions should be implemented for less severe distress and/or agitation. This is outside the scope of this document but for further guidance in this area please access the above NICE link and consult IHF Dementia Palliative Care Guidance Document 5 for non-pharmacological management of pain.*

NICE advises that people with dementia who develop non-cognitive symptoms or behaviour that challenges should be offered a pharmacological intervention *in the first instance only if they are severely distressed or there is an immediate risk of harm to the person or others.*

Antipsychotic drugs have been associated with an increased risk of cerebrovascular adverse events and greater mortality in people with dementia and NICE advises that treatment with an antipsychotic drug may be offered only after various conditions have been met:

- risks and benefits have been fully discussed; assess cerebrovascular risk factors and discuss possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition
- changes in cognition are regularly assessed and recorded; consider alternative medication if necessary
- target symptoms have been identified, quantified and documented, and changes are regularly assessed and recorded
- comorbid conditions, such as depression, have been considered
- the drug is chosen after an individual risk–benefit analysis
- the dose is started low and titrated upwards
- treatment is time limited and regularly reviewed (every 3 months or according to clinical need).

An acetylcholinesterase inhibitor or memantine may be offered in some circumstances but the evidence to support their use for this indication is generally limited.

Other drugs that have been used (many off label) for non cognitive symptoms of dementia include antidepressants, anticonvulsants, benzodiazepines, adrenergic betablockers and hypnotics. However, evidence to support their use is lacking.

The **NICE full guideline on dementia**<sup>18</sup> concluded that there was insufficient evidence to support the use of anticonvulsant mood stabilizers, such as sodium valproate, valproate semi sodium or carbamazepine, for the treatment of depression or anxiety in people with dementia.

*Health professionals who use medication in the management of violence, aggression and extreme agitation in people with dementia should:*

- be trained in the correct use of medications for behavioural control
- be able to assess the risks associated with pharmacological control of violence, aggression and extreme agitation, particularly in people who may be dehydrated or physically ill
- understand the cardiorespiratory effects of the acute administration of benzodiazepines and antipsychotics and the need to titrate dosage to effect
- recognise the importance of positioning people who have received these medications in the recovery position and of monitoring vital signs
- be familiar with and trained in the use of resuscitation equipment
- undertake annual retraining in resuscitation techniques and understand the importance of maintaining a clear airway
- be knowledgeable about the laws for informed consent in their jurisdiction.

***b. European Federation Neurological Society guidelines on the diagnosis and management of disorders associated with dementia***<sup>33</sup>

<http://www.guideline.gov/content.aspx?id=38470#Section420>

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## Resources for People with Dementia and Caregivers

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### **4. Fact Sheet 408 - Drugs used to relieve behavioural and psychological symptoms in dementia (Alzheimers Society UK)<sup>57</sup>**

Specific sections include information on:

- When drugs should be used to treat BPSD
- Drug treatment – general information
- Antipsychotic drugs
- Issues associated with the use of antipsychotic drugs
- Antidepressants and Anti-Convulsants
- Anti-dementia drugs
- Drugs used to treat sleep disturbance

[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1099](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1099)

### **5. Fact Sheet 509 - Dementia and Management of Aggressive Behaviour (Alzheimers Society UK)<sup>58</sup>**

Specific sections include information on:

- Causes of aggressive behaviour
- Tips for carers: reacting to aggressive behaviour
- Preventing and managing aggressive behaviour – a Problem Solving Approach
- Possible solutions
- Carer's response to aggressive behaviour

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=96](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=96)

### **6. The Alzheimers Society of Ireland – Living with Dementia (p.15-17)<sup>47</sup>**

[http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Living-with-Dementia\\_web-2014.pdf?ext=.pdf](http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Living-with-Dementia_web-2014.pdf?ext=.pdf)

**See page 41 for Additional Resources**



### 5.3 Optimising decision-making through application of medication management principles.

O'Mahony and O' Connor<sup>25</sup> highlight the complexities involved in palliative pharmacotherapy including limited guidance for prescribers as to what constitutes appropriate pharmacotherapy in people at end-of-life. Barriers to rationalisation of medications include both patient/carer and healthcare professional related concerns. Barriers may include psychological discomfort when ceasing a medication the person has been taking for many years, or feeling that the situation is hopeless since medications for chronic diseases are being ceased. Healthcare professional-based barriers may include a reluctance to cease medications prescribed by other doctors, or fears that ceasing medications may affect their relationship with the person with dementia<sup>59</sup>. It is important therefore that healthcare professionals, people with dementia and carers are aware of such principles and guided to implementing them in practice.

#### Guidance

1. Healthcare professionals familiarise themselves with case studies that apply medication management principles to people with dementia throughout the disease trajectory. (Resource 1)
2. Healthcare professionals, people with dementia and carers participate in shared decision-making to optimise medication management. (Resources 5)
3. Regular review (3 monthly) of prescribed medications is undertaken involving appropriate formal and informal carers. Healthcare professionals are aware of review principles, tools and prescribing frameworks which may assist in the review process (Resources 2,3,4)



## Resources for Healthcare Professionals

### Case Studies

These case studies reflect some of the dilemmas in the literature or represent scenarios that often occur in clinical practice.



### CASE STUDY 1

#### Early diagnosis separating mild cognitive impairment from Alzheimer's dementia.

***Mrs C, a 70 year old retired pharmacist presents with a one year's history of progressive memory loss.*** Her husband corroborates her story. She takes perindopril 2.5 mg for hypertension, atorvastatin 20 mg for hypercholesterolaemia and a salbutamol inhaler as required for asthma. Prior to referral her General Practitioner started donepezil 10 mg. Her blood pressure (BP) is elevated, 160/100. Mrs C is functionally independent and drives without difficulty. Her medications are blister packed by the pharmacy. Her SMMSE score is 29/30 indicating normal cognition. Given the clinical suspicion, a Quick Mild Cognitive Impairment screen<sup>60</sup> is performed and she scores 55/100 suggesting mild cognitive impairment (MCI). Electrocardiogram and laboratory investigations including full blood count, electrolytes, glucose, haematinics, liver and thyroid function tests are unremarkable. Mrs C screens negative for depression (score < 5), using the Geriatric Depression Scale-Short form<sup>61</sup>. Her scores are unchanged at three and six month follow-up.

#### Defining treatment goals

Mrs C's history suggests a diagnosis of MCI. Although no consensus yet exists for diagnosing MCI, it is a clinical diagnosis characterised by subjective and or corroborated memory loss without obvious loss of social or occupational function supported by objective evidence of cognitive impairment on independent cognitive testing<sup>62,63</sup>. The original MCI construct is based upon Alzheimers disease but MCI is a hetrogenous

## CASE STUDY 1

group of disorders and different dementia subtypes arise from different MCI syndromes. Between 5-10% of cases of MCI convert to dementia each year<sup>64</sup>. Therefore, the mainstay of management is to delay the onset of dementia. Recent systematic reviews suggests that medical management with cholinesterase inhibitors (ChEIs) has little benefit and may cause side effects<sup>65,66</sup>. There is growing evidence that targeted lifestyle change, close monitoring of cardiovascular risk and cognitive stimulation activities can prevent conversion<sup>67,68</sup>. Memory gym style interventions may provide suitable vehicles for non-pharmacological management, however more research is required<sup>69</sup>.

### **Person Centred Approach**

Mrs C is young and remains functionally independent. She remains socially active and involved in the local drama society. She admits to worry and has looked online for symptoms and treatment of dementia. The mainstay of treatment is lifestyle advice including weight reduction, increasing exercise and smoking cessation<sup>70</sup>. Mrs C has a preference for group activity.

### **Assisted decision-making**

Mrs C is concerned about the significance of her diagnosis and is worried that the condition might progress, particularly with discontinuation of medication. The diagnosis of MCI is explained and she is provided with a literature pack with additional information. Mrs C will need ongoing monitoring and is an ideal candidate for referral to a memory clinic for yearly follow-up. She agrees to a referral to the local memory gym. She is advised to buy a home blood pressure monitor.

### **Medication review**

As there is little evidence that ChEIs work, and after discussion with Mrs C, this is stopped. Mrs C's BP is elevated and there is room to increase her dose of perindopril. Hypertension, especially when executive dysfunction is evident<sup>70</sup>, increases the likelihood of progression from MCI to dementia, therefore hypertension management to within the normal target ranges is very important. There is some evidence suggesting that anti-hypertensive medications particularly centrally acting angiotension converting enzyme inhibitors can slow progression of cognitive impairment, however these studies are most often based on secondary analysis of trials or on retrospective observational studies<sup>72,73,74</sup>. She is advised regarding side effects.



## CASE STUDY 2

### **Managing behavioural and psychological symptoms of dementia-tackling caregiver strain; assessment of anticholinergic burden.**

***Mr L, a 79-year-old man, living at home with his 75-year-old wife, was diagnosed with Alzheimers' disease (AD) seven years ago.*** He has progressed to moderate stage dementia, SMMSE 18/30, and while mobile, he is incontinent of urine, constipated and dependent for most ADLs. He has a past history of hypertension, NYHA grade II heart failure, COPD, osteoporosis, depression, hypothyroidism and hypercholesterolemia. Over the last six months his wife reports that he is agitated, aggressive and has wandered twice outside the home. His symptoms have worsened acutely over two weeks. He has fallen repeatedly during this period resulting in bruising but no fractures. He is prescribed donepezil 10 mg for dementia, citalopram 40 mg for depression, alendronate 70 mg weekly for osteoporosis, amitriptyline 25 mg for insomnia, oxybutynin 5 mg for incontinence and three different anti-hypertensives (amlodipine 10 mg, bendroflumethazide 5 mg and atenolol 50 mg).

#### **Defining treatment goals**

Mr L's behavioural and psychological symptoms of dementia (BPSD) are placing considerable strain on his wife. He requires multi-disciplinary input and tailored interventions. BPSD are common. One or more of these symptoms are observed in up to 90% of people with dementia (PwD) and their prevalence increases proportional to severity<sup>75,76</sup>. BPSD include agitation, wandering, aggression, insomnia, repetitive questioning, delusions and hallucinations. Initial management involves history, examination and laboratory testing to exclude treatable causes such as infection, pain, constipation, urinary retention or electrolyte disturbances. Depression and anxiety should be screened and managed if present. Environmental strategies and non-pharmacological interventions such as sensory re-integration may be tried<sup>77</sup>. Mr L's wife should be encouraged to avail of homecare, respite services and group support.

## CASE STUDY 2

### Person Centred Approach

Mr and Mrs L never had children and live in a rural location. Mrs L previously refused services as she felt that he was “her responsibility”. They rarely socialise now and Mrs L admits she is concerned that Mr L will become agitated when out in public. She reports that she is ‘stressed all the time’ and is unable to cope. Her modified Zarit score is 22/30, indicating significant carer strain.

### Assisted decision-making

Person centred care and psychosocial interventions<sup>78</sup> are the mainstay of management of BPSD. Mrs L declines group support but is willing to go to the local Alzheimer café. Alzheimer’s Cafés provide informal group support, education, information, entertainment and counselling to people with dementia and their friends, families and caregivers, in an informal café-style environment. The Alzheimer Café model originates in the Netherlands and has spread to other countries in Europe and beyond<sup>79</sup>. Cafés are run voluntarily and are free to attend.

### Medication review

Pharmaceutical therapy has a secondary role but medication review is crucial. Mr L’s cholinergic burden is high; his anticholinergic burden score (ABS) is 7: amitriptyline (3), atenolol (1) and oxybutynin (3). An ABS of  $\geq 3$  is considered clinically relevant<sup>79</sup>. Postural blood pressure readings indicate a significant orthostatic drop and his basal readings are low. In addition his serum sodium is low (128) likely secondary to a thiazide diuretic and citalopram. These are stopped and his anti-hypertensives are reduced. A 24 hour ambulatory blood pressure monitor is arranged. He is started on a laxative for constipation. ChEIs reduce the frequency of BPSD<sup>81</sup> but given Mr L’s poor tolerance for oral medications, a topical preparation, e.g. rivastigmine should be considered instead of donepezil<sup>82</sup>. Memantine, an N-methyl-D-aspartate receptor antagonist, indicated in moderate to severe AD<sup>83,84</sup>, with or without ChEIs, slows cognitive and functional decline<sup>85,86</sup>. Memantine is not associated with a significant frequency of adverse events and when prescribed alone in moderate to severe AD, results in less agitation<sup>86</sup>, aggression<sup>87</sup> and psychotic symptoms (delusions and hallucinations)<sup>88</sup>. Memantine has also been shown to delay onset of these symptoms<sup>89</sup>. Treatment with antipsychotic medications are inappropriate for older patients with dementia, being associated with increased mortality<sup>90,91</sup> and stroke risk<sup>92</sup>.



### CASE STUDY 3

#### Medications in advanced dementia: To stop or not to stop?

***Mrs M, an 84-year-old woman, living in long-term care (LTC) for two years, was diagnosed with Alzheimers disease ten years ago.*** She is functionally dependent and scores 6/30 on an SMMSE suggesting severe dementia. Her past history includes hypertension, hypercholesterolaemia and depression. She has a history of agitation and aggression but these have settled in recent months. She takes 12 medications including aspirin 75 mg, perindopril 5 mg, atorvastatin 40 mg, escitalopram 10 mg, memantine 20 mg and donepezil 10 mg. Routine blood tests and a mid-stream urine test return normal. You are asked to review her care.

#### Defining treatment goals

Regular review (at least quarterly) of medication, including a clarification of doses and duration of treatment, is important for all people in LTC. In this case, Mrs M receives more than five medications suggesting polypharmacy and given her severe dementia one should consider deprescribing strategies. In principle, only medications with symptomatic benefit should be continued.

#### Person Centred Approach

You meet with her husband to discuss her management. Mrs M and her husband have previously discussed together that if she ever got to the point where she was unable to recognise her family or needed assistance with all the basic activities of daily living, that she would want a palliative approach to care for any life threatening illness. He tells you that in that case, she would not want to extend her life with any invasive or burdensome treatments. Her swallow has deteriorated in recent months and her medications are now crushed. She often refuses medications and her husband says her appetite is reduced and has noticed occasional vomiting.

#### Assisted decision-making

Use of medications in dementia depend on the person's characteristics, particularly response to treatment and side effects. The decision to discontinue should be made in consultation with caregivers and family<sup>93</sup>. Her husband agrees that given her previously expressed wishes and possible medication side effects, the number of medications could be reduced.

### CASE STUDY 3

Use of medications in dementia depend on the person's characteristics, particularly response to treatment and side effects. The decision to discontinue should be made in consultation with the person with dementia, caregivers and family, as appropriate. As Mrs M has severe dementia her capacity to participate in certain medication related decision-making processes may be compromised. While the person with dementia retains their right to be involved in decision-making as far as possible, assessment of capacity must be undertaken and assisted decision-making processes initiated.

(Please refer to guidance documents 1, 2 and 6 for guiding principles relating to capacity, communication and legal/ethical issues).

Her husband agrees that given her previously expressed wishes and possible medication side effects the number of medications could be reduced.

#### **Medication review**

Several of Mrs M's medications are for secondary prevention including aspirin, atorvastatin and perindopril. Use of cholinesterase inhibitors (ChEIs) and memantine, in advanced dementia is particularly controversial<sup>94</sup>. While memantine is licensed for moderate to severe AD, the rationale for ChEIs is less clear. Recent evidence suggests that people with severe disease, including residents in LTC benefit from ChEIs<sup>95-97</sup>.

The use of these medications in end-of-life care remains uncertain but many believe that these medications are ineffective and most recommend discontinuation to family members. However, 20% believe they reduce caregiver burden, stabilise cognition and maintain function. The majority feel their discontinuation would be resisted by family<sup>97</sup>. The main challenge is determining whether these medications are helping. In general, if a person remains stable there is a risk of deterioration when ChEIs are discontinued but if treatment failure occurs, discontinuation may be appropriate<sup>99</sup>.

The recommendation in this case would be to search for an alternative cause of vomiting such as constipation. If no explanation is found, medications associated with gastro-intestinal side effects, particularly those prescribed for secondary prevention such as statins and ChEIs, should be discontinued first.



## CASE STUDY 4

**Mr. M. a 72yr old gentleman is transferred to a residential care setting from an acute hospital.** He needed one-to-one care (special) while in hospital due to challenging behaviour. He was very agitated and at very high risk of absconding, often trying to climb out windows.

### Diagnosis:

1. Severe dementia (CDR 3) with behavioural and psychological symptoms
2. Small vessel ischaemic disease on brain imaging
3. History of alcohol excess
4. Multi-level cervical degenerative disc disease
5. Ischaemic heart disease
6. Hyperlipidaemia
7. Osteoarthritis with bilateral total hip replacements
8. Bilateral cataracts
9. Benign prostatic hyperplasia
10. Petite-mal seizures

### Medications on admission:

1. Aspirin 75 mg od
2. Quetiapine 50 mg bd (now on 50 mg tds)
3. Memantine 20 mg od
4. Mirtazapine 15 mg nocte (now on 30 mg nocte)
5. Pravastatin 20 mg nocte nocte(stopped)
6. Tamsulosin 400 mcg od
7. Calcichew D3 forte bd (stopped)
8. Sodium Valpoate 500 mg od (now on 400 mg bd)
9. Thiamine 300 mg od (stopped)
10. Nebivolol 7.5 mg od
11. Furosimide 40 mg od
12. Paracetamol 1gm tds

On initial assessment Mr M's **Clinical Dementia Rating Scale was Severe (CDR-3)** i.e. he is suffering from severe memory loss; not orientated to time or place; no judgement or problem solving abilities; cannot participate in community affairs outside the home; requires help with all tasks of daily living and requires help with most personal care and is often incontinent.



## CASE STUDY 4

Mr. M. regularly refuses to eat, wash, dress or sleep. He refuses to take the medication stating he does not need same or that he is being poisoned. If the nurse persists Mr. M. will get very agitated and aggressive so the nurses go away and another nurse will approach and offer the medications after 15 to 30 minutes. Mr. M may or may not take the medications at this time. His brother had to be called in at times to help with the administration of same.

The **Cohen-Mansfield Agitation Inventory** was used to assess Mr M's behaviour. Of the 29 behaviours assessed the most disruptive were:

- Pacing and aimless wandering: 5 (once or twice a day)
- Cursing or verbal aggression: 3 (once or twice a week)
- Negativism: 4 (several times a week)
- Handling things; 4 (several times a week)
- Hiding things; 5 (once or twice a day)
- Hoarding: 3 (once or twice a week)
- Verbal sexual advances: 2 (less than once a week)
- General Restlessness: 6 (several times a day)

### Medication review

The consultant reviewed Mr. M's list of medications in liaison with his family and nursing staff. He was on twelve different medications suggesting poly-pharmacy. The need and indication of each medication was examined. The Pravastatin (cholesterol lowering), Calcichew D3 Forte (bone health) and Thiamine (Vitamin B1) are stopped as these can be seen as primary prevention and not appropriate in a palliative /patient-centred approach to people with dementia. Drugs used for secondary prevention Aspirin, Furosemide, Nebivolol and Tamsulosin were continued as ongoing benefit is expected, within the Mr M's life expectancy. He has pain due to his degenerative disc disease and arthritis so it is reasonable to continue the Paracetamol.

The Quetiapine (atypical antipsychotic) was increased from 50 mg bd to 50 mg tds, to help with distressing behavioural symptoms as non-pharmacological interventions failed as per the Cohen-Mansfield Agitation Inventory and the 24 Hour Behaviour Time Chart. The Memantine was continued as it is indicated in moderate to severe dementia as it slows cognitive decline and results in less agitation, aggression and psychotic

## CASE STUDY 4

symptoms. The Mirtazipine was increased as the Mr M scored 10 on the Geriatric Depression Scale and Mirtazipine has few antimuscarinic effects and can help with sleep problems. The Sodium Valporate was increased and changed to bd in an effort to control seizures.

**Medication Administration**

As stated Mr. M often refused his medications and when first admitted the staff frequently had to request the help of his brother with administration but this was unsustainable on an ongoing basis. Crushing and covert administration of medication is always a last resort and is only considered following MDT assessment and when alternative measures have been taken and were not considered successful. In Mr M's case, more changes could be introduced. Tailoring the dose regimen to Mr M's individual routine habits helped. Ensuring a calm environment (no TV or noise), ensuring the nurse stays calm when Mr. M. refuses as he can become agitated and if the nurse continues to insist Mr M will become more agitated and aggressive. Persisting with medication administration when a person with dementia is agitated will only escalate the behaviour that some of the medications are trying to control. Returning at a later time works for Mr M and ensures that he doesn't feel rushed or afraid. Feeling a loss of control can trigger resistance and aggression. Responsive behaviours can be challenging for staff and caregivers and they are often attempts by the person with dementia to communicate their loss of control. The sight of too many pills may trigger the resistance so presenting one at a time often helps. Mr. M may refuse the medications again but the nurses report often after a nap on the armchair he is amenable to taking his medications.

**Conclusion**

A person centred approach with assisted decision-making with Mr. M, his family and carers in a homely setting where the his uniqueness and right to choice is valued, facilitates good practice. Medication review on an ongoing basis is essential as management strategies will change as staff become more aware of the triggers that escalate responsive behaviours. This may enable non-pharmacological interventions to be used and behaviour modifying drugs may be reduced or discontinued. As Mr. M's dementia progresses, a more palliative approach will facilitate a further discontinuation of medications.

## 2. Medication Review Principles

### Room for Review: A guide to medication review: the agenda for patients, practitioners and managers<sup>100</sup>

- All patients should have a chance to raise questions and highlight problems about their medicines.
- The medication review seeks to improve or optimise impact of treatment for an individual patient.
- The review is undertaken in a systematic and comprehensive way, by a competent person.
- Any changes resulting from the review are agreed with the patient.
- The review is documented in the patient's notes.
- The impact of any change is monitored.

### 3. The NO TEARS Mnemonic to Aid Medication Review in a 10 Minute Consultation<sup>101</sup>

**N** Need and Indication

**O** Open Questions

**T** Tests and Monitoring

**E** Evidence and Guidelines

**A** Adverse Effects

**R** Risk reduction or prevention

**S** Simplification and switches

#### **N**eed and indication

Does the patient know why they take each drug? Is each drug still needed? Is the diagnosis refuted? Is the dose appropriate? Was long term therapy intended? Would non-pharmacological treatments be better?

#### **O**pen questions

Allows patients to express views. Helps to reveal any problems they may have.

#### **T**est and Monitoring

Assess disease control. Any conditions under-treated?

Use appropriate reference for monitoring advice e.g. BNF

#### **E**vidence and Guidelines

Has the evidence base changed since initiating drug? Are any drugs now deemed 'less suitable'? Is dose appropriate? (Over or under-treatment, extreme old age)

Are other investigations now advised e.g. echocardiography?

#### **A**dverse Events

Any side effects? Any over the counter or complementary medicines?

Check interaction, duplications or contra-indications. Don't misinterpret an adverse reaction as a new medical condition.

#### **R**isk Reduction or Prevention

Opportunistic screening. Risk reduction e.g. Falls – are drugs optimized to reduce the risks?

#### **S**implification and Switches

Can treatment be simplified? Does patient know which treatments are important?

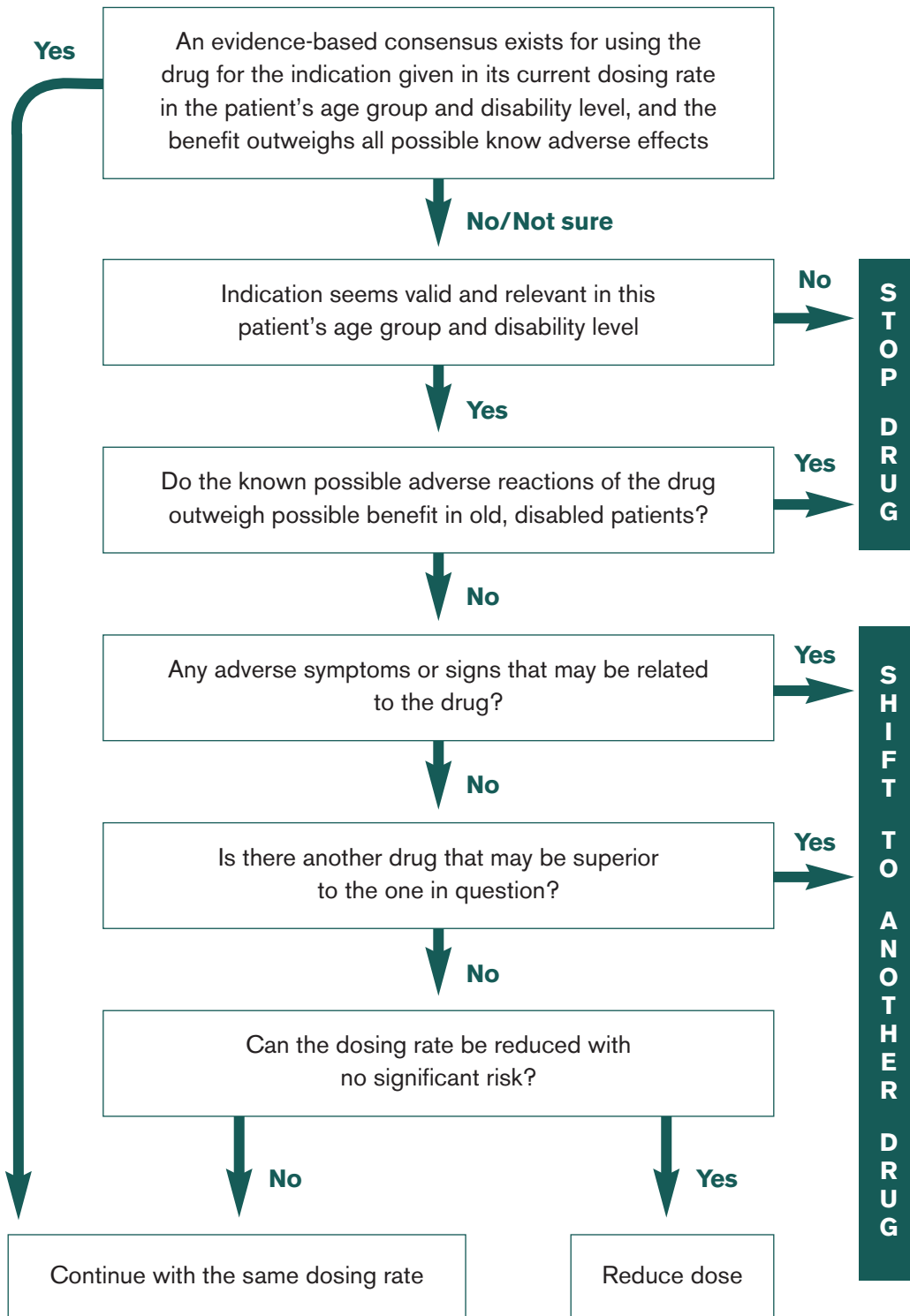
Explain any cost effective switches.

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#### 4. Decision-making tools for inappropriate prescribing in the elderly

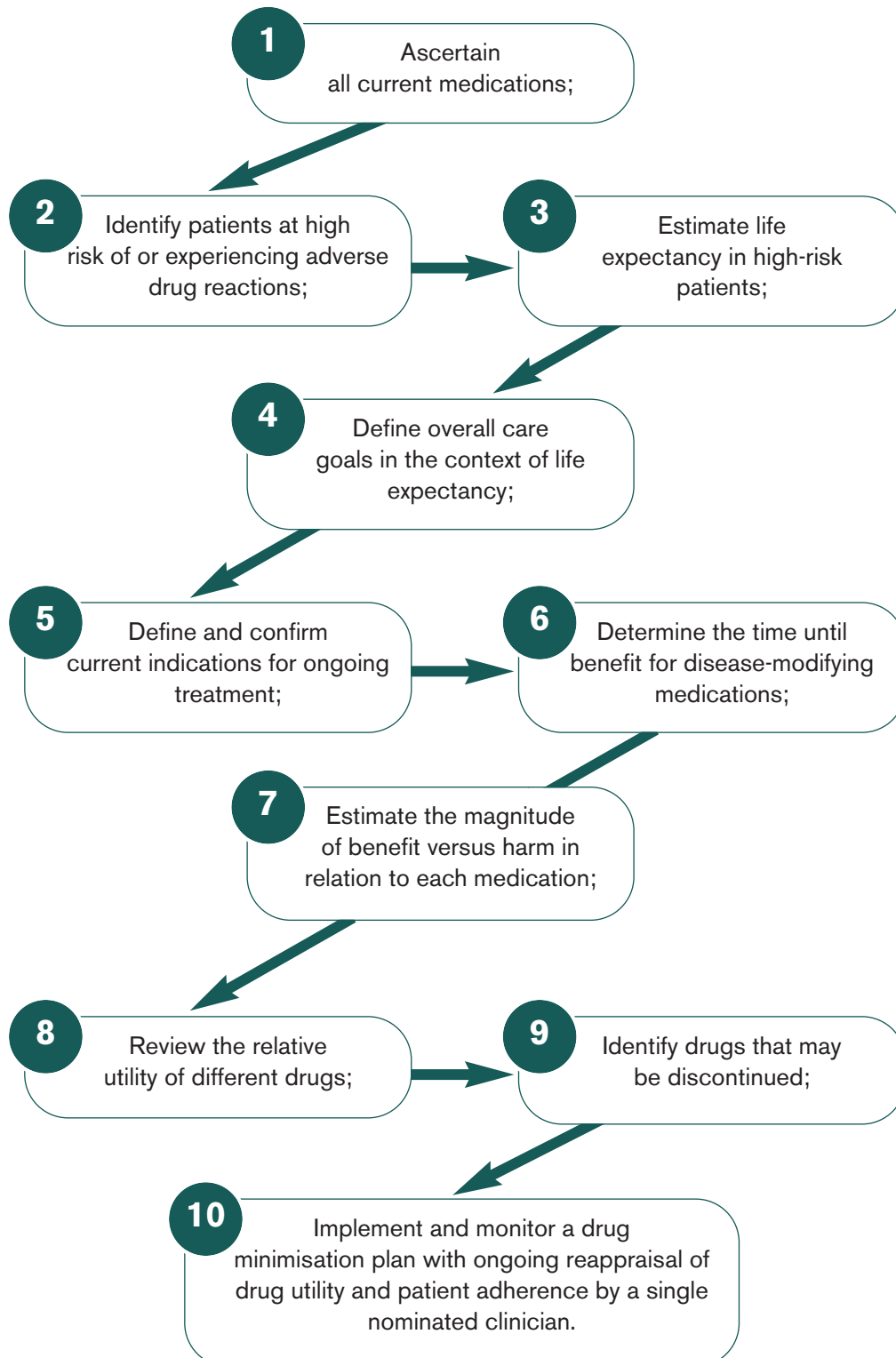
##### a) The Good Palliative – Geriatric Practice (GP-GP) Algorithm<sup>103</sup>

Discuss the following with the person with dementia/caregiver



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## b) Appropriate Medication Prescribing Framework

**10 step drug minimisation framework<sup>104</sup>**

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## Patient/Carer Resources

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### 5. Assisted decision-making<sup>105</sup>

The principles of an assisted decision-making conversation is that it should:

- support a person with dementia/carers to understand and articulate what they want to achieve from the treatment or self-management support options available (their preferred outcome or goal)
  - support a person with dementia/carers to articulate their current understanding of their condition, inform patients about their condition, about the treatment or self-management support options available and the benefits of each.
  - support people with dementia/carers to understand and articulate their own concepts of risk/harm
  - describe what is known about risks or harm associated with the treatment or self-management support options
  - ensure that people with dementia/carers and clinicians arrive at a decision based on mutual understanding of this information.
6. Please refer to IHF guidance document No. 1<sup>106</sup> on 'facilitating discussion on future and end of life care' for additional resources
7. Please refer to IHF guidance documents on assisted decision-making (No. 2) and ethical decision-making (No. 6) for guiding principles relating to capacity and legal/ethical issues<sup>107</sup>.

See page 41 for Additional Resources



## 5.4 Medication Administration

Medication administration and adherence to a regime can be particularly problematic for the person with dementia and formal and informal carers particularly with disease progression<sup>15,108</sup>.

Challenges include: Lack of ability to self-administer, swallowing difficulties, informal caregiver burden associated with medication management complexities such as ensuring safe administration, noticing and managing side-effects, supplying appropriate information<sup>109,110,111</sup>.

Instances of refusal to take medication and covert administration practices are particular areas of concern highlighted within the literature.

Supporting people with dementia, families/carers and healthcare staff in navigating the difficulties associated with medication administration has potential to improve the quality of care to people with dementia, lessen caregiver burden and clarify medication administration decision-making processes for healthcare professionals.

### Guidance

1. People with dementia should be supported to maintain independence in taking medications for as long as it is safe to do so. (*Resources 1, 2, 6*)
2. A medication management risk assessment should be performed to determine the extent to which a person can either self-administer or requires support in medication-taking. (*Resource 1*)
3. Family/carers require guidance on practical strategies to assist medication administration and adherence to a drug regimen. (*Resources 2, 6*)
4. Healthcare professionals should be aware of the practical, ethical and legal considerations with respect to changing the form of a prescribed medication (crushing) or covert medication administration. (*Resources 3, 4, 5*)



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## Resources for Healthcare Professionals

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### 1. Medication management assessment

Individualised performance-based medication management assessment is recommended and should be combined with a careful drug history, proxy information and continual medication monitoring<sup>112</sup>.

A number of tools are available to help healthcare providers to identify barriers for managing medications and to more adequately address an individual patient's deficits. The most promising instruments, but still warranting further investigation are<sup>113</sup>:

- DRUGS (Drug Regimen Unassisted Grading Scale)
- MedMalDE (Medication Management Instrument for Deficiencies in the Elderly)
- MMAA (Medication Management Ability Assessment)

(See Additional Resources Page 41 for description of tools)

### 2. Interventions to aid administration/adherence<sup>112</sup>

- Minimising number of drugs
- Tailoring the dose regimen to the person's routine habits
- Coordinating drug dosing
- Providing drug reminders and organisers (assuming the person is able to use the device appropriately)
- Different medication formulations e.g. liquid instead of tablet

### 3. Covert administration of medication

Covert administration of medicine refers to when a medicine is administered in a disguised form to a person without their knowledge or consent<sup>114</sup>. Nurses and midwives must not engage in the practice of covert administration of medicines and new guidance is pending publication from the NMBI in 2016. There are specific provisions in the Mental Health Act 2001<sup>115</sup> in relation to continued administration of medicines in the treatment of mental disorder for a period longer than three months for adults and children. Nurses and midwives should use existing legal and best practice frameworks for individual patient situations. These frameworks include Assisted Decision-Making Capacity Bill (2013)<sup>116</sup>, the HSE National Consent Policy<sup>117</sup>, Quality Framework for Mental Health Services in Ireland – (National Mental Health Services Standards)<sup>118</sup> relevant organisational policy, associated capacity assessment tools and the NMBI Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives<sup>119</sup>.

HIQA<sup>114</sup> advises the following:

- Any medicine that is being given covertly must be checked to ensure it is safe when administered in this fashion and that the chemical nature of the medicine is not changed.
- A full written assessment of the resident is performed prior to the administration of medicines covertly.
- The assessment identifies the medicines being administered, the indications for these medicines, alternative measures that have been taken and the rationale for the use of covert administration.
- All decisions to administer medicines covertly must be made following a multidisciplinary agreement that this practice is in the person's best interests.



- This agreement must be documented and reviewed in line with the relevant legislation or more often if circumstances change.
- If a medicine is to be administered covertly, this should be stated on the prescription sheet.
- Where medicines are covertly administered it is important to observe for and document side effects.
- Appropriate action should be taken to reduce and eliminate side effects.

#### 4. NICE Guidance - Managing medicines in care homes<sup>120</sup>

<https://www.nice.org.uk/guidance/sc1>

*(Please note that NICE guidance applies to the NHS in the UK)*

##### **1.15 Care home staff giving medicines to residents without their knowledge (covert administration)**

###### 1.15.1

*Health and social care practitioners should not administer medicines to a resident without their knowledge (covert administration) if the resident has capacity to make decisions about their treatment and care.*

###### 1.15.2

*Health and social care practitioners should ensure that covert administration only takes place in the context of **existing legal and good practice frameworks** to protect both the resident who is receiving the medicine(s) and the care home staff involved in administering the medicines.*

###### 1.15.3

*Health and social care practitioners should ensure that the process for covert administration of medicines to adult residents in care homes includes:*

- *assessing mental capacity*
- *holding a best interest meeting involving care home staff, the health professional prescribing the medicine(s), pharmacist and family member or advocate to agree whether administering medicines without the resident knowing (covertly) is in the resident's best interests*
- *recording the reasons for presuming mental incapacity and the proposed management plan*
- *planning how medicines will be administered without the resident knowing*
- *regularly reviewing whether covert administration is still needed.*

###### 1.15.4

*Commissioners and providers of care home services should consider establishing a wider policy on the covert administration of medicines across several health and social care organisations.*

## **5. Case scenarios for health and social care staff managing medicines in care homes. Implementing the NICE guideline on managing medicines in care homes<sup>120</sup>**

<http://www.nice.org.uk/guidance/sc1/resources/managing-medicines-in-care-homes6>

Provides three relevant case scenarios related to the mangaing of medicines in care homes – (*please note NICE guidance applies to care in the UK - the practitioner must adhere to local policies/ best practice frameworks in place*)

Case scenario 1: A new resident is admitted to the care home

Case scenario 2: A resident refuses their medicines

Case scenario 3: A resident requires medicine in their best interest

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### **Resources for patients and families**

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## **6. Dementia Ireland - A Practical Guide to Daily Living for Family Caregivers<sup>121</sup>**

Please see p.15 -17 of this guide for information on taking medications at home

<http://dementia.ie/images/uploads/site-images/practicalguidefamilycaregivers.pdf>

**See page 41 for 'Additional Resources'**



## ADDITIONAL RESOURCES

### 6.1 Understanding the Progression of Dementia

When considering the assessment and management of medication for a person with dementia, it is important to understand the progression of the condition and consider its effect on relevant factors such as the person's memory, ability to comply with a medication regime and their ability to swallow.

Whilst many classification systems exist to grade the severity of the dementia (e.g. Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS)<sup>122</sup> (also known as the Reisberg Scale) and the FAST – Functional Assessment Staging<sup>123</sup>, the Clinical Dementia Rating (CDR) Scale<sup>124,125</sup> is considered to be the most widely used staging system in dementia research. Here, the person with suspected dementia is evaluated by a health professional in six areas: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care and one of five possible stages (0-3) of dementia is assigned (see below).

<b>CDR-0</b>	<b>No dementia</b>
<b>CDR-0.5</b>	<b>Mild</b> Memory problems are slight but consistent; some difficulties with time and problem solving; daily life slightly impaired
<b>CDR-1</b>	<b>Mild</b> Memory loss moderate, especially for recent events, and interferes with daily activities. Moderate difficulty with solving problems; cannot function independently at community affairs; difficulty with daily activities and hobbies, especially complex ones
<b>CDR-2</b>	<b>Moderate</b> More profound memory loss, only retaining highly learned material; disoriented with respect to time and place; lacking good judgment and difficulty handling problems; little or no independent function at home; can only do simple chores and has few interests.
<b>CDR-3</b>	<b>Severe</b> Severe memory loss; not oriented with respect to time or place; no judgment or problem solving abilities; cannot participate in community affairs outside the home; requires help with all tasks of daily living and requires help with most personal care. Often incontinent.

**The Clinical Dementia Rating Scale**<sup>124,125</sup>

## Progression of Dementia

Three important influences on the life-span of dementia are the type of dementia, the stage of dementia, and whether the course of deterioration is rapid or slow<sup>126,127</sup>.

## Life expectancy of the person with dementia

Although dementia is a progressive, life limiting and incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their relatives/friends.

Although, specific life expectancy cannot be provided, there are some indicators below that healthcare staff can provide on the probable life expectancy of the person:

- 4.5 years is the average survival time for a person living with dementia<sup>127</sup>. However, some people can live for 20 years post diagnosis.
- Half of the people with late stage dementia will die within 1.3 years<sup>126</sup>.

## 6.2 Medication Management of Cognitive Symptoms and Maintenance of Function

### *a. Box 3 Recommendations for pharmacological treatment and discontinuation of ChEI's*

Recommendations of the 4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4)<sup>38</sup>

<http://www.cfp.ca/content/60/5/433.full.pdf>

### *b. BMJ Management of dementia in primary care (HCP) – Accredited professional development module*

Learning outcomes relate to:

- Timely diagnosis of dementia
- Treatment of underlying medical conditions, pain and vascular risk factors
- Specific drug treatments for AD and dementia associated with Parkinson's
- Management of behavioral and psychological symptoms

<http://learning.bmj.com/learning/module-intro/.html?moduleId=10032231>

## 6.3 Medication Management of Non-Cognitive Symptoms and Behaviours That Challenge

**a. Development Group of the Clinical Practice Guideline. Clinical practice guideline on the comprehensive care of people with Alzheimer's disease and other dementias. Barcelona (Spain)<sup>128</sup>**

A comprehensive Spanish Guideline, using a Q&A format, making recommendations on the care of patients with Alzheimer's disease and other dementias, such as, for example, vascular dementia, Parkinson's disease dementia, dementia with Lewy bodies and frontotemporal lobar degeneration.

[http://www.guiasalud.es/GPC/GPC\\_484\\_Alzheimer\\_AIQS\\_comp\\_eng.pdf](http://www.guiasalud.es/GPC/GPC_484_Alzheimer_AIQS_comp_eng.pdf)

**b. Care Planning Guide in a Residential Setting with Assessment Tools and Side-effect profile of medications used to treat behavioural symptoms in dementia.**

- Appendix 1: Behaviour frequency & severity daily tracking form and guidelines for completion
- Appendix 2: Resident behaviour observation record
- Appendix 3: A guide to optimal use of television/radios/ music listening equipment
- Appendix 4: Cohen-Mansfield Agitation Inventory (CMAI)
- Appendix 5: Side effects of medications used to treat behavioural symptoms in dementia
- Appendix 6: Behaviour assessment form
- Appendix 7: A step-wise approach to assessing and managing behaviours in dementia

[http://sunnybrook.ca/uploads/ABLE\\_CarePlanningGuide.pdf](http://sunnybrook.ca/uploads/ABLE_CarePlanningGuide.pdf)

## 6.4 Optimising Decision-Making Through Application of Medication Management Principles

**This table refers to medication management for a person with late stage dementia and approaching the end of life.** Holmes et al. Classification with ATC (Anatomical Therapeutic Chemical classification system)<sup>129</sup>

<b>Always appropriate</b>	Antiemetics (A04A) Laxatives A06 Antidiarrheals (A07) Lidoderm (N01BB05) Narcotics (N02A) Non-narcotic analgesics (N02B)	Antiepileptics (N03) Anxiolytics (N05B) Inhaled bronchodilators (R03A) Expectorants (R05) Lubricating eye drops Pressure ulcer products.
<b>Sometimes appropriate</b>	Histamine-2-receptor blockers (A02BA) Proton pump inhibitors (A02BC) Insulin (A10A) Oral hypoglycemics (A10B) Electrolytes (A12) Nitroglycerin (C01DA) Diuretics (C03) Beta-blockers (C07) Calcium channel blockers (C08) Angiotensin-converting enzyme (C09) Angiotensin receptor blockers (C09) Antifungal creams (D01) Corticosteroids (H02) Thyroid hormones (H03A) Antithyroid medications (H03B) Antibacterials (J01)	Antivirals (J05) Capsaicin (N01BX04) Antidepressants (N06A) Allopurinol (M04AA01) Colchicine (M04AC01) Antipsychotics (N05A) Tricyclic antidepressants (N06AA) Antiparasitic agents (P0) Decongestants (R01) Inhaled corticosteroids (R03BA) Mucolytics (R05) Antihistamines (R06) Antiinflammatory eye drops (S01B) Antiglaucoma drops (S01E) Nutritional supplements (V06).
<b>Rarely appropriate</b>	Appetite stimulants (A15) Antispasmodics (A03A; A03B) Warfarin (B01AA03) Heparin and low molecular weight heparin (B01AB) Digoxin (C01AA) Antiarrhythmics (C01B) Clonidine (C02AC01)	Hydralazine (C02DB02) Antiandrogens (G03H) Alpha blockers (G04CA01; G04CA03) Bladder relaxants (G04BD) Tamsulosin (G04CA02) Mineral corticoids (H02AA) Biphosphonates (M05BA).
<b>Never appropriate</b>	Antiplatelets, excluding Aspirin (B01AC excl B01AC06) Lipid lowering medications (C10) Sex hormones (G03H) Cytotoxic chemotherapy (L01) Hormone antagonists (L02B)	Antiestrogens (L02BA; L02BB) Immunomodulators (L03) Nemantine (N06DX01) Acetylcholinesterase inhibitors (N07AA) Leucotriene receptor antagonists (R03DC)
<b>No consensus</b>	Meclizine (A04AB04) Vitamins (A11) Mineral supplements (A12) Aspirin (B01AC06) Iron (B03A) Red blood cell stimulating factors (B03XA)	Bladder stimulants (G04BD) Finasteride (G04CB01) Calcitonin (H05BA) Muscle relaxants (M03) Sedatives and hypnotics (N05C) Central nervous system stimulants (N06B; N06D)

*Reproduced with permission from publisher*

## 6.5 Medication Administration

### 1. Medication Assessment Tools

Name of tool and author	Purpose	Description	Scoring	Completion time
DRUGS {Edelberg, et al 1999}	To assess patients' ability to take their own medications independently. Designed to be used in clinic settings as part of a 'brown bag' medication review.	Person performs the following four tasks with each of their medications: 1) identify the medication, 2) open the container, 3) select the correct dose, and 4) report the appropriate timing of doses using a grid marked with specific times of the day as a role-play of their typical day.	Out of 100. Each drug is scored out of 4, with 1 for each correct response/action. This is then converted to a percentage score. The composite score is the overall average score.	5-15 minutes
MedMalDE (Orwig, et al 2006)	To identify deficiencies in older adults' ability to self-medicate at home.	Designed to be used in patients' homes. 20 items covering three areas: 1) Medication knowledge (name all medications, indications and dose regimens); 2) Medication-taking ability (access doses from packaging, fill glass of water, sip water); 3) Access to ongoing supply of medication (awareness of refills/repeats, able to arrange supply).	Out of 13 (only 13 of the 20 items are scored). A yes (or able) response scores 0, and a no (unable) response scores 1. Therefore the higher the score the less capable the patient is.	30+
MMAA (Patterson, et al 2002)	To assess ability of older mental health patients to independently manage medications.	Four plastic pill bottles with dried beans are labelled with directions. The interviewer describes the medication regimen to the person, then 45-60 minutes later the person is asked to walk through their day, saying when they would wake up, eat meals, and take each medication. They are required to dispense the pills for each dose and hand them to the interviewer.	Four scores reported: A) Total MMAA score (out of 25): One point deducted for each deviation from prescribed regimen (i.e. too many, too few pills, or incorrect timing in relation to food). B) Total number of pills correct (out of 21) C) Number over: Total number of pills exceeding prescribed number D) Number under: Total number of pills fewer than prescribed number Note: Since publication the scoring system has been revised and total MMA score is now out of 33.	15 mins

(Adapted from Elliott, R. A., & Marriott, J. L. (2009). Standardised assessment of patients' capacity to manage medications: a systematic review of published instruments. *BMC geriatrics*, 9(1), 27.)

FACT SHEET 7A 7B 7C 7D

# Medication and Dementia – Palliative Assessment and Management



## Why is this important?



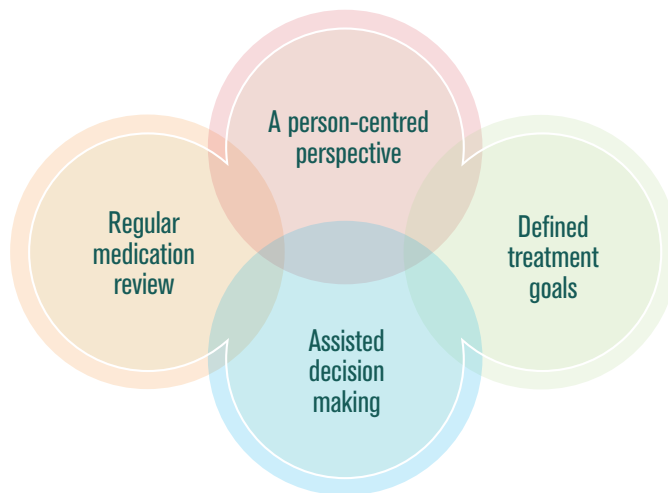
### Optimising the management of all medication in dementia can:

- improve quality of care
- reduce inappropriate medication
- enhance non-medication management pathways
- enhance the healthcare professional/patient relationship through empowerment

### Medication management includes:

- evidence based prescribing and administration
- person centered medication review
- information/education
- the capacity to communicate with multiple health providers
- ensuring access to medications

## Principles of Medication Management



**Dementia affects cognition, behaviour, functional activities, and caregiver burden; these are key targets for therapeutic interventions**



*This factsheet has been developed based on Irish Hospice Foundation Dementia Palliative Care Guidance Document No 7. Medication Management. Developed by Lehane et al. (2016). Available from [www.hospicefoundation.ie](http://www.hospicefoundation.ie)*





FACT SHEET 7A **7B** 7C 7D**Medication management of non-cognitive symptoms and behaviours that challenge**

**Non-cognitive symptoms include hallucinations, delusions, anxiety, marked agitation and associated aggressive behaviours. In addition to anxiety, depression is grouped within psychological symptoms.**

**Behaviours that challenge, also known as responsive behaviours, can include, but are not limited to: aggression, agitation, wandering, hoarding, sexual disinhibition, apathy and shouting.**

Management comprises of:

- accurate and comprehensive assessment
- first line treatment with non-pharmacological interventions
- where necessary initiation and close review of pharmacological interventions.

Remember – People with dementia and their caregivers require appropriate information and guidance on the management of non-cognitive symptoms and behaviours that challenge. They have an important role in the assessment of Behavioural and Psychological Symptoms of Dementia (BPSD) and providing feedback on the effectiveness of any implemented interventions.

**Medication Administration**

Medication administration complexities include an individual's lack of cognitive capacity to self-administer, swallowing difficulties and caregiver burden associated with ensuring safe administration and noticing and managing side-effects.

Supporting people with dementia, families/carers and healthcare staff in navigating the difficulties associated with medication administration has potential to improve the quality of care, lessen caregiver burden and clarify medication administration decision-making processes for healthcare professionals.

- 1 People with dementia should be supported to maintain independence in taking medications for as long as it is safe to do so.
- 2 A medication management risk assessment should be performed to determine the extent to which a person can either self-administer or requires support in taking medication.
- 3 Family/carers require guidance on practical strategies to assist medication administration and adherence to a drug regimen.
- 4 Healthcare professionals should be aware of the practical, ethical and legal considerations with respect to changing the form of a prescribed medication (crushing) or covert medication administration.



*This factsheet has been developed based on Irish Hospice Foundation Dementia Palliative Care Guidance Document No 7. Medication Management. Developed by Lehane et al. (2016). Available from [www.hospicefoundation.ie](http://www.hospicefoundation.ie)*



FACT SHEET 7A 7B **7C** 7D

# Medication and Dementia – Palliative Assessment and Management



## Medications in advanced dementia: To stop or not to stop? A Clinical Case Study

### Mrs M, an 84-year-old woman, living in long-term care (LTC) for two years, was diagnosed with Alzheimers disease ten years ago

She is functionally dependent and scores 6/30 on an SMMSE suggesting severe dementia. Her past history includes hypertension, hypercholesterolaemia and depression. She has a history of agitation and aggression but these have settled in recent months. She takes 12 medications including aspirin 75mg, perindopril 5mg, atorvastatin 40mg, escitalopram 10mg, memantine 20mg and donepezil 10mg. Routine blood tests and a mid-stream urine test return normal. You are asked to review her care.

#### Defining treatment goals

Regular review (three monthly) of medication, including a clarification of doses and duration of treatment, is important for all people in LTC. In this case, Mrs M receives more than five medications suggesting polypharmacy and given her severe dementia one should consider deprescribing strategies. In principle, only medications with symptomatic benefit should be continued.

#### Person-centred approach

You meet with her husband to discuss her management. Mrs M and her husband have previously discussed together that if she ever got to the point where she was unable to recognise her family or needed assistance with all the basic activities of daily living, that she would want a palliative approach to care for any life threatening illness. He tells you that in that case she would not want to extend her life with any invasive or burdensome treatments. Her swallow has deteriorated in recent months and her medications are now crushed. She often refuses medications and her husband says her appetite is reduced and has noticed occasional vomiting.

#### Assisted decision-making

Use of medications in dementia depend on the person's characteristics, particularly response to treatment and side effects. The decision to discontinue should be made in consultation the person with dementia. Discussions may also take place with the person's caregivers and family. As Mrs M has severe dementia her capacity to participate in certain medication related decision making processes may be compromised. While the person with dementia retains their right to be involved in decision making as far as possible,

assessment of capacity must be undertaken and assisted decision-making processes initiated. (Please refer to guidance documents 1, 2 and 6 for guiding principles relating to capacity, communication and legal/ethical issues). Her husband agrees that given her previously expressed wishes and possible medication side effects the number of medications could be reduced.

#### Medication review

Several of Mrs Ms' medications are for secondary prevention including aspirin, atorvastatin and perindopril. Use of cholinesterase inhibitors (ChEIs) and memantine, in advanced dementia is particularly controversial. While memantine is licensed for moderate to severe AD, the rationale for ChEIs is less clear. Recent evidence suggests that people with severe dementia, including residents in LTC benefit from ChEIs. The use of these medications in end-of-life care remains uncertain. Many believe that these medications are ineffective and most recommend discontinuation. 20% believe they reduce caregiver burden, stabilise cognition and maintain function. The majority feel their discontinuation would be resisted by family. The main challenge is determining whether these medications are helping. In general, if a person remains stable there is a risk of deterioration when ChEIs are discontinued but if treatment failure occurs, discontinuation may be appropriate. The recommendation in this case would be to search for an alternative cause of vomiting such as constipation. If no explanation is found, medications associated with gastro-intestinal side effects, particularly those prescribed for secondary prevention such as statins and ChEIs, should be discontinued first.



*This factsheet has been developed based on Irish Hospice Foundation Dementia Palliative Care Guidance Document No 7. Medication Management. Developed by Lehane et al. (2016). Available from [www.hospicefoundation.ie](http://www.hospicefoundation.ie)*



FACT SHEET 7A 7B 7C **7D****The NO TEARS\* Mnemonic to Aid Medication Review in a 10 Minute Consultation**

- N** Need and indication  
**O** Open questions  
**T** Tests and monitoring  
**E** Evidence and guidelines  
**A** Adverse effects  
**R** Risk reduction or prevention  
**S** Simplification and switches

**Need and indication**

Does the person know why they take each drug? Is each drug still needed? Is the diagnosis refuted? Is the dose appropriate? Was long term therapy intended? Would non-pharmacological treatments be better?

**Open questions**

Allows the person to express views.  
 Helps to reveal any problems they may have.

**Test and monitoring**

Assess disease control.  
 Any conditions under-treated?  
 Use appropriate reference for monitoring advice e.g. BNF

**Evidence and Guidelines**

Has the evidence base changed since initiating drug?  
 Are any drugs now deemed 'less suitable'?  
 Is dose appropriate? (Over or under-treatment, extreme old age)  
 Are other investigations now advised e.g. echocardiography?

**Adverse Events**

Any side effects?  
 Any over the counter or complementary medicines?  
 Check interaction, duplications or contra-indications.  
 Don't misinterpret an adverse reaction as a new medical condition.

**Risk Reduction or Prevention**

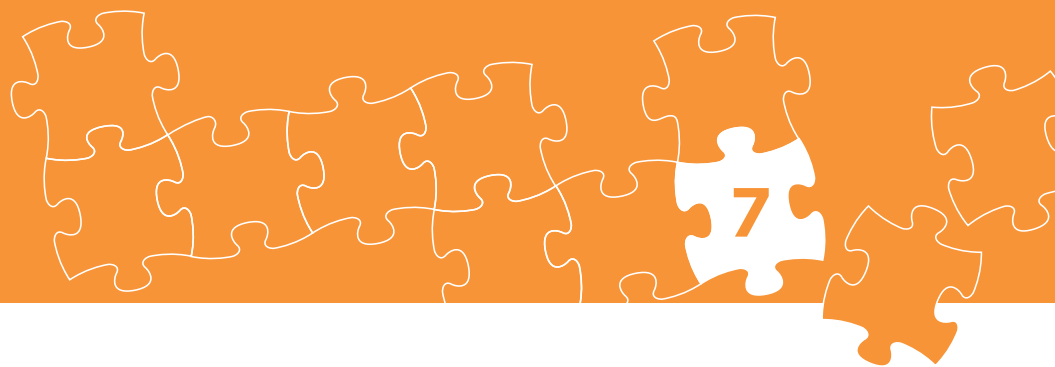
Opportunistic screening.  
 Risk reduction e.g. Falls – are drugs optimised to reduce the risks?

**Simplification and Switches**

Can treatment be simplified?  
 Does person know which treatments are important?  
 Explain any cost effective switches.

\* Lewis, T. (2004). Using the NO TEARS tool for medication review. *BMJ* 2004, Vol 329, 433-434.\*





## CONCLUSION

Medication management is a significant component of dementia palliative care and can be a substantial challenge for healthcare professionals, people with dementia and carers. Suboptimal and inappropriate medication use is repeatedly highlighted as an issue requiring dedicated attention to facilitate the enhancement of a person's quality of life, particularly in the advanced stages. The challenges of a person-centered palliative approach to medication management decision-making are complex in nature, and are influenced by a number of factors which include, but are not limited to; estimating life expectancy with a view to determining goals of treatment, decision-making with regard to withdrawing / discontinuing medications, administration difficulties and the limited and often contradictory research evidence provided by clinical drugs trials and explicit drug prescribing criteria specifically for people with dementia.

The pharmacological management of cognitive and non-cognitive symptoms in dementia, with a particular emphasis on management of behaviours that challenge are predominant themes within the literature and key areas for decision-making in practice. Specific guidelines are available with respect to management of cognitive symptoms and maintenance of function. There is an emerging consensus regarding the management of non-cognitive symptoms and behaviours that challenge.

Medication administration, a core element of medication management, can present certain difficulties throughout the disease trajectory, which requires careful deliberation in terms of the most appropriate solutions.

The literature suggests that such deliberation or decision-making around medication management is predicated on core principles, including; (1) adopting a person-centered approach; (2) defining treatment goals; (3) assisted decision-making; and (4) regular medication review. The implementation of such principles to actual practice has the potential to promote the quality of life for the person with dementia/carer and provide much needed guidance for healthcare professionals.

This document therefore seeks to provide healthcare professionals, with specific guidance and resources for good practice in relation to medication management.



## APPENDIX 1

### STEERING AND PROJECT GROUP MEMBERSHIP

**Guidance Documents Project Lead:** Dr. Alice Coffey

**Guidance Documents Project Researcher:** Dr. Kathleen McLoughlin

**Principal Investigator for Medication Management Document:** Dr. Elaine Lehane

#### Authors:

- Elaine Lehane, Lecturer in Nursing, Catherine McAuley School of Nursing & Midwifery, University College Cork.
- Kathleen McLoughlin, Research Project Associate, UCC.
- Rónán O’Caoimh, Research Fellow, Centre for Gerontology and Rehabilitation, University College Cork, St Finbarr’s Hospital.
- Mary Hickey, Mary F. Hickey, Clinical Nurse Manager 2, Nurse Prescriber, Assessment & Treatment Centre, St. Finbarr’s Hospital, Cork.
- Mary Mannix, Clinical Nurse Specialist Dementia Care, Mercy University Hospital, Cork.
- Paul McCague, Lecturer in Pharmacy Practice, Queens University Belfast.
- Paul Gallagher, Consultant Physician in Geriatric Medicine, Cork University Hospital & St. Finbarr’s Hospital, Senior Lecturer, School of Medicine, UCC.

Draft documents were reviewed by the following international and national subject experts:

**National Reviewer:** Dr Marie O’Connor, Consultant Geriatrician, Connolly Hospital, Dublin.

**International Reviewer:** Professor Patrick Kehoe, Gestetner Professor of Translational Dementia Research, University of Bristol, UK.

#### Steering Committee

The outputs from the Project Group were overseen by a Steering Committee convened by The Irish Hospice Foundation comprising of:

1. Prof. Geraldine McCarthy, Emeritus Professor, University College Cork and Chair South/South West Hospitals Group.
2. Dr. Ailis Quinlan, former member of National Clinical Effectiveness Committee (NCEC).
3. Ms. Marie Lynch, Head of Healthcare Programmes, Irish Hospice Foundation.
4. Prof. Cillian Twomey, Geriatrician (Retired).
5. Ms. Kay O’Sullivan, Lay Representative, Marymount Hospice, Volunteer Support.
6. Ms. Mary Mannix, Clinical Nurse Specialist Dementia Care, Mercy University Hospital, Cork.
7. Prof. Philip Larkin, Director of the Palliative Care Research Programme, School of Nursing and Midwifery, University Collge Dublin.
8. Dr. Bernadette Brady, Consultant in Palliative Medicine, Marymount Hospital & Hospice, Cork.



## APPENDIX 2

### METHODOLOGY

The process for developing this guidance document is outlined as follows:

1. The IHF project advisory group issued a tender for the development of a suite of four guidance documents. A team led by Dr Alice Coffey successfully won the tender to develop these documents and a project team led by Dr Elaine Lehane, UCC, successfully tendered to develop this guidance document regarding the assessment and management of medication (See Appendix 1 for membership of the team). A Steering Committee was established by the IHF to oversee the development of this guidance document (See Appendix 1 for membership of the group). Drafts of the guidance document were reviewed by international/national subject experts (See Appendix 1 for details).
2. A literature review was conducted using scoping review methodology.<sup>130,131</sup>

#### DATABASES SEARCHED

EBSCO Database  
Medline  
CINAHL Plus with Full Text  
Academic Search Complete  
Psychology and Behavioural Sciences Collection  
SocINDEX  
PsycINFO  
PsycARTICLES  
EMBASE  
The Cochrane Library

## SEARCH STRATEGY

The following key word strategy was agreed by the project team and used in EBSCO, adapted variations were developed for the other databases:

S1: palliative OR dying OR “end of life” OR “end-of-life” OR hospice OR terminal\* OR “end-stage” OR “end stage” OR chronic\* OR “advanced illness” OR “advanced life limiting illness” OR “advanced life-limiting illness” OR “advanced life limited illness” OR “advanced life-limited illness” OR “late stage”

S2: Dementia OR Alzheimer\* OR demented

S3: Guideline\* OR guidance OR algorithm\* OR “decision aid” OR pathway\* OR policy OR policies OR protocol\* OR standard\* OR checklist\* OR Decision N3 (aid OR aids OR support OR tool OR tools OR system OR systems OR making) OR Standard N3 (care OR clinical OR treatment) OR care N3 (model OR framework OR flowchart)

S4: TI (Medicat\* OR prescri\*) OR AB (Medicat\* OR prescri\*)

S5: S1 AND S2 AND S3 AND S4

References from relevant papers were scanned to identify additional papers as necessary.

## INCLUSION CRITERIA

English language

Peer reviewed publication

Focus on adult populations (patients /family caregivers) with dementia

Studies published between 2005-2015

## EXCLUSION CRITERIA

Written in a language other than English

Conference abstracts, thought pieces, reflective articles, dissertations, book chapters and book reviews.

Focus on populations under 18 years of age

Studies with a purely biochemical focus

Animal/lab based studies

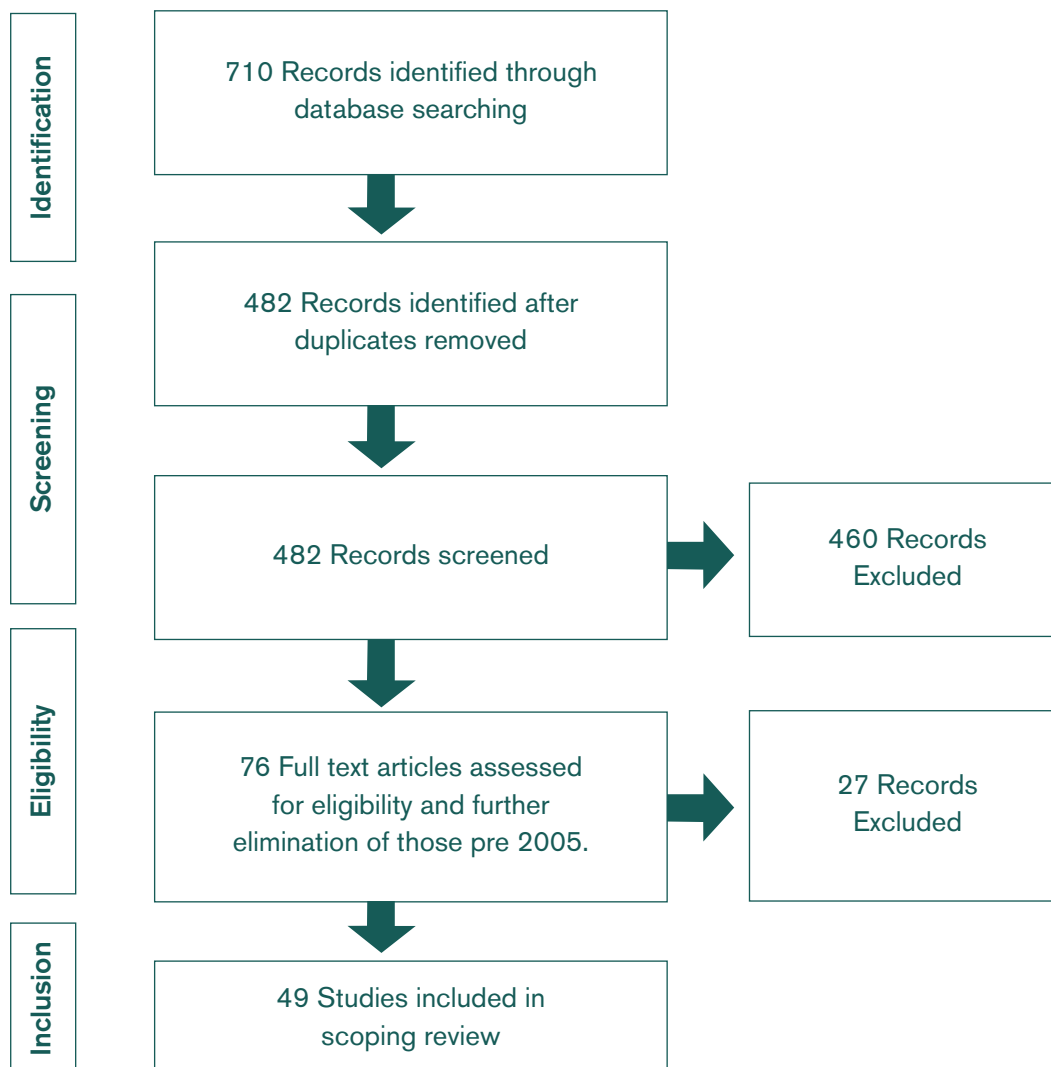
Papers generic to older people

Mixed populations e.g. Parkinson's and Dementia

Records retrieved were divided into three groups “Yes”, “Maybe” and “Reject”. A second and third screening of the “Yes” and “Maybe” folders was conducted to produce a final list for full-text review. Only papers satisfying the criteria above were included for data extraction. Where there was a disagreement regarding inclusion of a record, a third reviewer was consulted.



## OUTCOME OF LITERATURE SEARCH



### LITERATURE WAS REVIEWED TO CONSIDER:

- The volume and level of evidence available.
- Theoretical models or principles proposed.
- Instruments and procedures to assess manage and review patients with regard to assessment and management of pain in dementia palliative care.
- Evidence specific to a variety of care settings.
- Recommendations for practice.
- Gaps in current knowledge, relevant research in progress and key emerging issues.

Based on the review of full text papers, data was extracted onto a table, organised under the following headings, to aid thematic analysis:

- (1) Title of Paper
- (2) Authors
- (3) Year of Publication
- (4) County of Origin
- (5) Level of Evidence
- (6) Aim
- (7) Setting (Primary Care / Residential Care Setting / Hospital / Hospice/Other (specify))
- (8) Population – Patients - to include age profile; comorbidities; classification of stage of dementia (against the CDR scale) / Family caregivers / Healthcare Providers
- (9) Focus on: Assessment / Treatment / Review / Other
- (10) Reference to other pre-existing guidance
- (11) Key findings / arguments
- (12) Key recommendations for practice

### **CLEARING HOUSES AND PROFESSIONAL BODIES**

Searches of the following major clearing houses to identify pre-existing guidance documents, relevant to the domains above were also conducted:

Australian Government NHMRC  
 NHS Quality Improvement Scotland  
 Department of Health Australian Government  
 WHO  
 US: Institute of Medicine  
 Institute for Healthcare Improvement  
 United States National Guideline Clearinghouse  
 The Guidelines International Network  
 New Zealand Guidelines Group, NLH  
 National Library of Guidelines (UK) Includes NICE  
 Scottish Intercollegiate Guidelines Network  
 Health Technology Assessment  
 NICE

Where specific guidance documents were sourced, these were critically assessed using the AGREE tool.

**3.** Collation of key themes to inform the guidance and principles of medication management and assessment by the Project Team.

### LITERATURE REVIEW THEMES

1. Challenges of medication management in dementia palliative care
2. Medications for Alzheimer's Disease - management of cognitive symptoms and maintenance of function
3. Behavioural and Psychological Symptoms of Dementia – assessment and management of non-cognitive symptoms & behaviours that challenge
4. Considerations for pharmacological management of co-morbid conditions
5. Principles of prescribing & medication management in dementia care.

4. Hand search of international and national policy and best practice guidelines - ongoing throughout the process in order to inform and populate the resources.

### Limitations

Evidence on effectiveness and cost effectiveness was not explored due to time and resource constraints. It is challenging to include representatives from all relevant professional associations and people with dementia in the initial phases of development. It is hoped that the targeted external consultation will include as many groups as possible in order to get feedback from all relevant stakeholders in this area.



## APPENDIX 3

### USEFUL TOOLS

**CMAI – Permission granted to reproduce – PLEASE CONSULT THE MANUAL BEFORE USE.**

#### ***THE COHEN-MANSFIELD AGITATION INVENTORY - Long Form***

Please read each of the 29 agitated behaviours, and circle how often (from 1-7) each was manifested by the resident during the last 2 weeks:

	Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
1. Pace, aimless wandering	1	2	3	4	5	6	7
2. Inappropriate dress or disrobing	1	2	3	4	5	6	7
3. Spitting (include at meals)	1	2	3	4	5	6	7
4. Cursing or verbal aggression	1	2	3	4	5	6	7
5. Constant unwarranted request for attention or help	1	2	3	4	5	6	7
6. Repetitive sentences or questions	1	2	3	4	5	6	7
7. Hitting (including self)	1	2	3	4	5	6	7
8. Kicking	1	2	3	4	5	6	7
9. Grabbing onto people	1	2	3	4	5	6	7
10. Pushing	1	2	3	4	5	6	7
11. Throwing things	1	2	3	4	5	6	7
12. Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
13. Screaming	1	2	3	4	5	6	7

	Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
14. Biting	1	2	3	4	5	6	7
15. Scratching	1	2	3	4	5	6	7
16. Trying to get to a different place (e.g., out of the room, building)	1	2	3	4	5	6	7
17. Intentional falling	1	2	3	4	5	6	7
18. Complaining	1	2	3	4	5	6	7
19. Negativism	1	2	3	4	5	6	7
20. Eating/drinking inappropriate substances	1	2	3	4	5	6	7
21. Hurt self or other (cigarette, hot water, etc.)	1	2	3	4	5	6	7
22. Handling things inappropriately	1	2	3	4	5	6	7
23. Hiding things	1	2	3	4	5	6	7
24. Hoarding things	1	2	3	4	5	6	7
25. Tearing things or destroying property	1	2	3	4	5	6	7
26. Performing repetitious mannerisms	1	2	3	4	5	6	7
27. Making verbal sexual advances	1	2	3	4	5	6	7
28. Making physical sexual advances	1	2	3	4	5	6	7
29. General restlessness	1	2	3	4	5	6	7

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**The Irish Hospice Foundation**

Morrison Chambers  
32 Nassau Street, Dublin 2, Ireland

Telephone: + 353 (0) 1 679 3188

Fax: +353 (0) 1 673 0040

Email: [info@hospicefoundation.ie](mailto:info@hospicefoundation.ie)

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