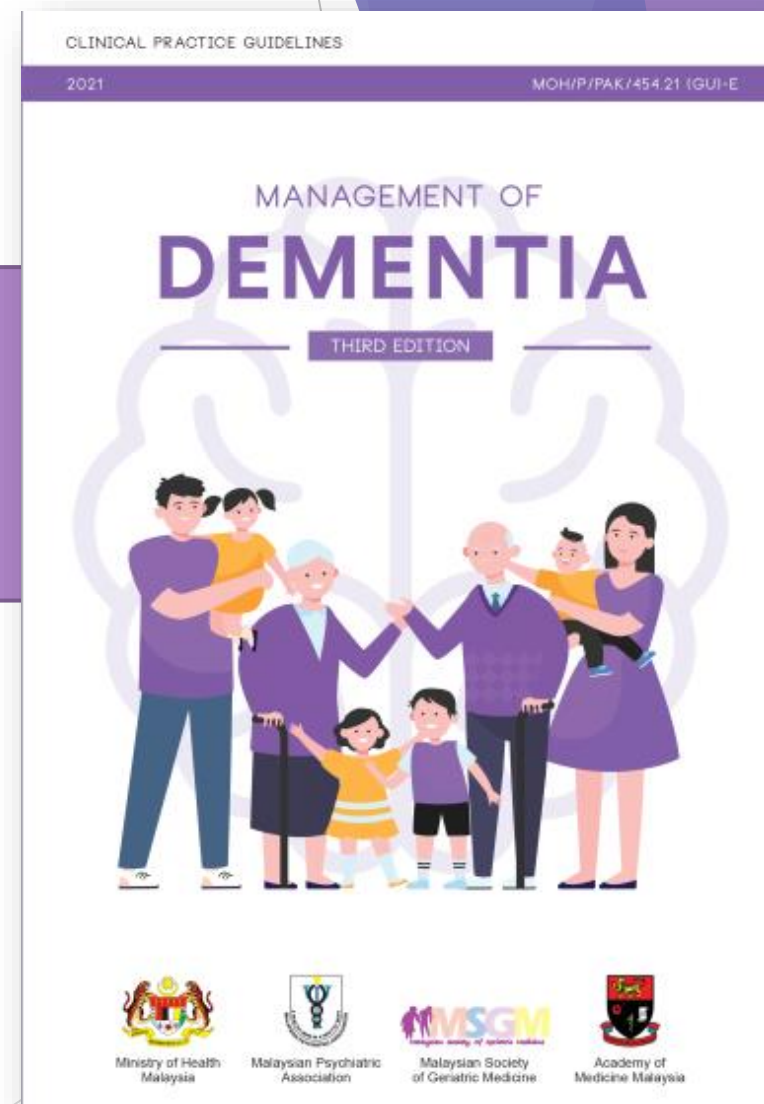


Training of Core Trainers CPG Management of Dementia (Third Edition)

Palliative and End-of-life Care

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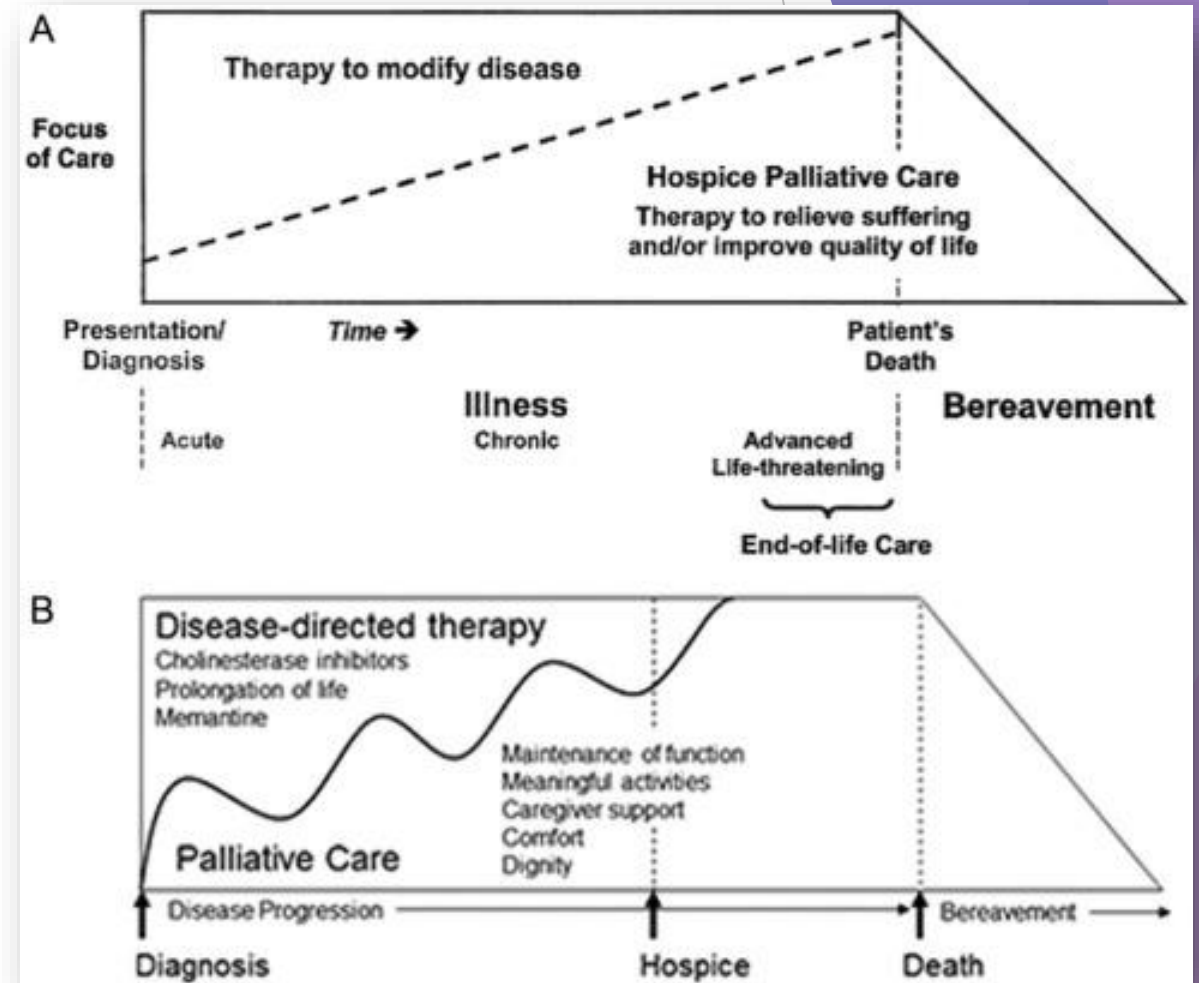
Learning Objectives

1. To understand about the importance of Advance Care Planning (ACP)
2. To be familiar with the conduct of ACP discussion with PWD and family members
3. To learn about evidence-based recommendations on end-of-life care management:
 - Artificial feeding
 - Pain management
 - Physical restraints



Palliative and End-of-life Care

- ▶ Palliative care should be initiated at the time of diagnosis throughout different stages of illness.
- ▶ As the disease progressed and the PWD become more dependent, the palliative care components should be more emphasised in their management to achieve the best quality of life.



Advance Care Planning (ACP)

- ▶ ACP is a process of discussing and recording PWD's wishes, values and preferences of future care together with their family members and HCP which will take effect once the PWD lose their capacity to make decision.
- ▶ Every PWD has the right to plan ahead for their future when they still have the capability to make decision. Hence, ACP should be discussed with PWD and their family members as early as possible after the diagnosis is established.
- ▶ PWD and their family members are allowed to review and change any advance statements they have made as the disease progresses.⁴²
- ▶ ACP significantly reduced inappropriate hospital admissions and healthcare costs.¹⁴³

42. National Institute for Health and Care Excellence (NICE). Dementia: assessment, management and support for people living with dementia and their carers. London: NICE; 2018.

143. Robinson L, Dickinson C, Rousseau N, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age and ageing. 2012;41(2):263-9.



The discussion of ACP should include:

- ▶ benefits of planning ahead
- ▶ PWD's proxy or substitute decision-maker when the PWD lacks capacity to make decisions
- ▶ advance statement about their wishes, values, preferences and beliefs regarding their future care
- ▶ advance decisions to refuse certain treatments e.g. intubation, cardiopulmonary resuscitation, enteral feeding, etc.
- ▶ their preferences for place of care and place of death



Recommendations for HCP during ACP discussion.

- ▶ Start ACP as early as possible when the PWD and family members are ready.
- ▶ ACP conversations are not one-off occurrence, and it should be revised from time to time especially when changes of clinical condition occur.
- ▶ Try to understand the PWD from their perspectives before initiation of discussion on ACP - explore their life stories, important values, norms, beliefs and preferences.
- ▶ Use the language which is familiar to the PWD.
- ▶ Adjust conversation style and content to the PWD's level and rhythm.
- ▶ Obtain the PWD's permit to invite family members to join the conversation.
- ▶ Evaluate their disease awareness and inform them about the expected disease trajectory and possible end-of-life decisions.
- ▶ Explore the PWD's current experiences, their fears and concerns for the future and end-of-life.
- ▶ Lead the conversation but do not force it or dominate the discussion.
- ▶ Keep connected with the PWD to ensure their maximum participation, respond to their emotions, attend to non-verbal communication and observe their behaviour.



Artificial feeding and hydration

- ▶ Dysphagia is a common problem in advance dementia
 - The rate of dysphagia in PWD residing in long-term care facilities has been estimated to be up to 53%, and the rate of silent aspiration has been reported to be 68%
- ▶ Dysphagia diagnostic assessment which can be used to determine the type of deficits in oropharyngeal dysphagia
 - clinical swallowing examination
 - video fluoroscopy swallowing study
 - flexible endoscopic examination of swallowing



Artificial feeding and hydration-2

► Tube feeding

- There was limited evidence to show that enteral tube feeding may prolong the survival rate and reduce aspiration pneumonia in advanced dementia based on a systematic review. On the other hand, PEG tube was associated with increased risk of pressure ulcer development or aggravation.¹³⁸

138. Ribeiro Salomon AL, Carvalho Garbi Novaes MR. Outcomes of enteral nutrition for patients with advanced dementia: a systematic review. The journal of nutrition, health & aging. 2015;19(2):169-77.



Artificial feeding and hydration-3

► Other measures

- there was limited evidence on the benefits of postural change, diet and liquid modification, and medication in management of this condition¹³⁶
- In another systematic review, there was moderate quality of evidence on the use of high-calorie supplements to improve weight gain in person with advance dementia and not on function and survival¹³⁷

- There was insufficient evidence to recommend enteral feeding in patients with severe dementia.

136. Alagiakrishnan K, Bhanji RA, Kurian M. Evaluation and management of oropharyngeal dysphagia in different types of dementia: a systematic review. Archives of gerontology and geriatrics. 2013;56(1):1-9.

137. Hanson LC, Ersek M, Gilliam R, et al. Oral feeding options for people with dementia: a systematic review. Journal of the American Geriatrics Society. 2011;59(3):463-72.



Aspiration Pneumonia

- ▶ Tips to prevent aspiration pneumonia in advance dementia
 - Position
 - Swallowing assessment to determine the type of food consistency to feed
 - Oral hygiene
 - Feed slowly, allow time to swallow
 - Spoon feeding is preferred



Pain Management

- ▶ Pain is another prevalent and distressing issue for person with advance dementia. However, the affected person is not able to express themselves accurately on the pain they experience and very often it is manifested as behavioural problems.
- ▶ An RCT examining on the impact of a stepwise protocol for treating pain on PWD in nursing home showed that pain medication significantly improved pain control in the intervention group.¹³⁹
- ▶ However, a systematic review showed that evidence on pain management for advance dementia was limited and heterogenous. Despite increased use of analgesia, pain was still prevalent in PWD.¹⁴⁰

139. Sandvik RK, Selbaek G, Seifert R, et al. Impact of a stepwise protocol for treating pain on pain intensity in nursing home patients with dementia: a cluster randomized trial. *European journal of pain* (London, England). 2014;18(10):1490-500.

140. Husebo BS, Achterberg W, Flo E. Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review. *CNS drugs*. 2016;30(6):481-97.

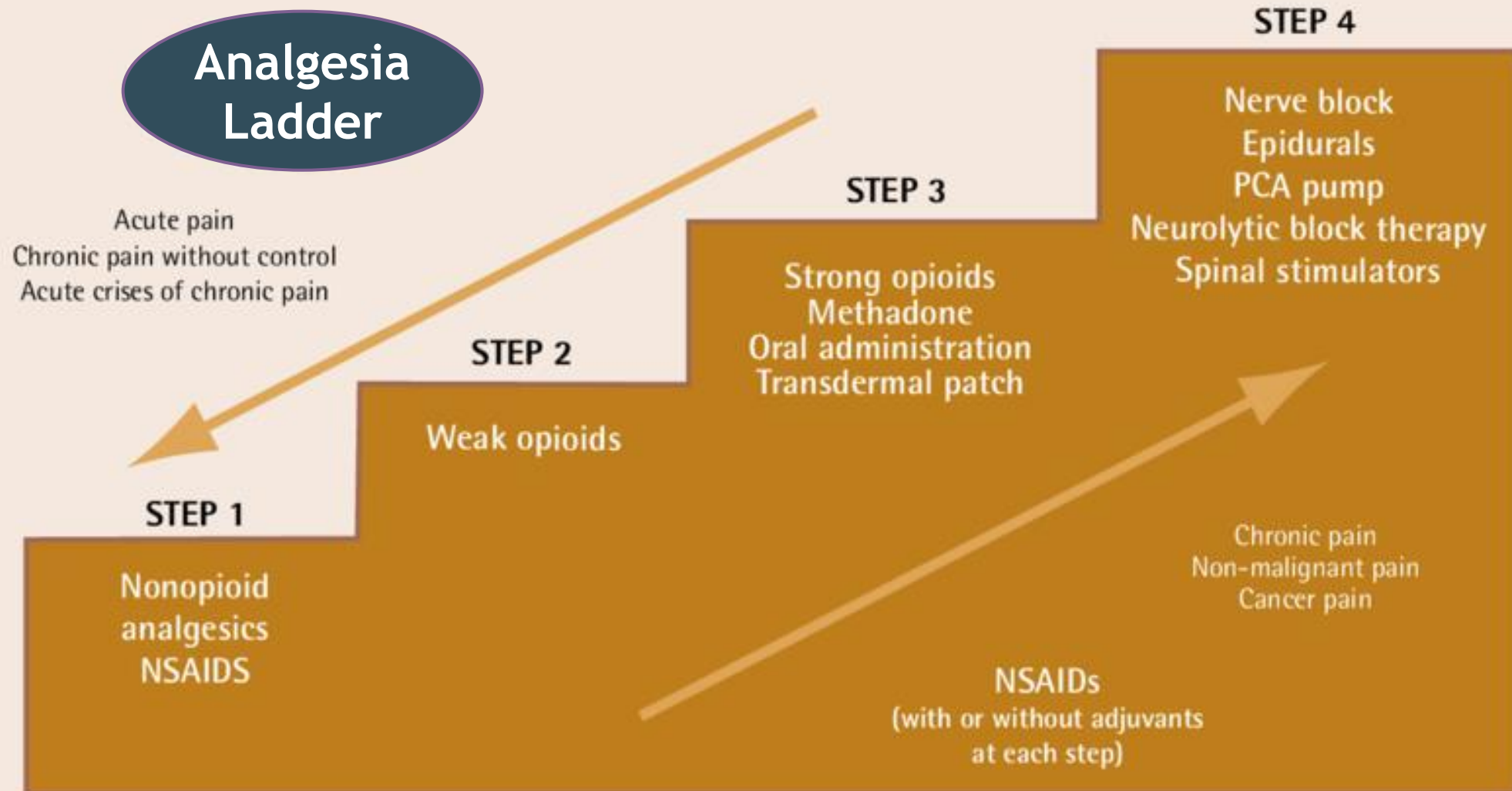


PAINAD SCALE

(Pain Assessment In Advance Dementia)

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

Analgesia Ladder



NSAID—nonsteroidal anti-inflammatory drug, PCA—patient-controlled analgesia.





MINISTRY OF HEALTH MALAYSIA

GUIDELINES FOR PAIN MANAGEMENT IN THE ELDERLY



1st Edition

EXECUTIVE SUMMARY OF PAIN MANAGEMENT

- A. Paracetamol is considered the first-line treatment for both acute and persistent pain in older adults due to its efficacy and good safety profile. There are few absolute contraindications and relative cautions to prescribing paracetamol and the maximum total daily dose should not exceed 4 grams.
- B. Non-selective non-steroidal anti-inflammatory drugs, (NSAIDs) may be cautiously used if other safer treatments have not provided adequate pain relief. The lowest dose should be used and for the shortest duration. A proton pump inhibitor (PPI) should be co-prescribed together with the NSAID or cyclooxygenase-2 (COX-2) selective inhibitor. Older adults taking NSAIDs should be monitored for gastrointestinal, renal and cardiovascular adverse effects; drug–drug and drug–disease interactions.
- C. Opioid therapy may be considered for patients with moderate or severe pain, e.g. if the pain is causing functional impairment or is reducing their quality of life. Adverse effects such as nausea and vomiting should be anticipated and suitable prophylaxis considered. Laxatives such as the combination of a stool softener and a stimulant laxative, should be prescribed throughout treatment with opioid.
- D. Tricyclic antidepressants and anti-epileptic drugs have demonstrated efficacy in several types of neuropathic pain. However, their use in an older population is limited by adverse effects.
- E. Intra-articular corticosteroid injections are effective in relieving knee osteoarthritic pain in the short term, with little risk of complications and/or joint damage. Intra-articular hyaluronic acid is effective, free of systemic adverse effects and should be considered in patients who are intolerant to systemic therapy. Intra-articular hyaluronic acid appears to have a slower onset of action than intra-articular steroids, but the effects tend to last longer.
- F. The current evidence for the use of epidural steroid injections in the management of sciatica is conflicting and, until further larger studies become available, no firm recommendations can be made. There is, however, a limited body of evidence to support the use of epidural injections in spinal stenosis.

Physical Restraints

- ▶ Restraints are used to protect people with severe dementia from harming themselves. These can be physical, chemical or psychological restraints.
- ▶ A multinational cohort study on PWD in nursing homes showed that physical restraint was associated with a higher risk of both functional (RR=2.30, 95% CI 1.52 to 3.49) and cognitive decline (RR=1.93, 95% CI 1.44 to 2.58) compared with AP alone. These risks were even higher among residents receiving both AP and physical restraints with RR of 2.49 (95% CI 1.89 to 3.27) and 2.31 (95% CI 1.54 to 3.48) respectively.¹⁴¹
- ▶ Hence, physical restraints should be avoided in PWD

141. Foebel AD, Onder G, Finne-Soveri H, et al. Physical Restraint and Antipsychotic Medication Use Among Nursing Home Residents With Dementia. Journal of the American Medical Directors Association. 2016;17(2):184.e9-14.



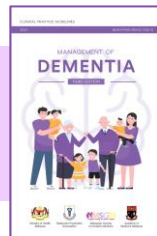
Take Home Messages

Recommendation 14

- Physical restraints should be avoided in dementia.
- Advance care planning should be considered in the management of dementia once the diagnosis is established.



Thank You



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CPG Management of Dementia
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