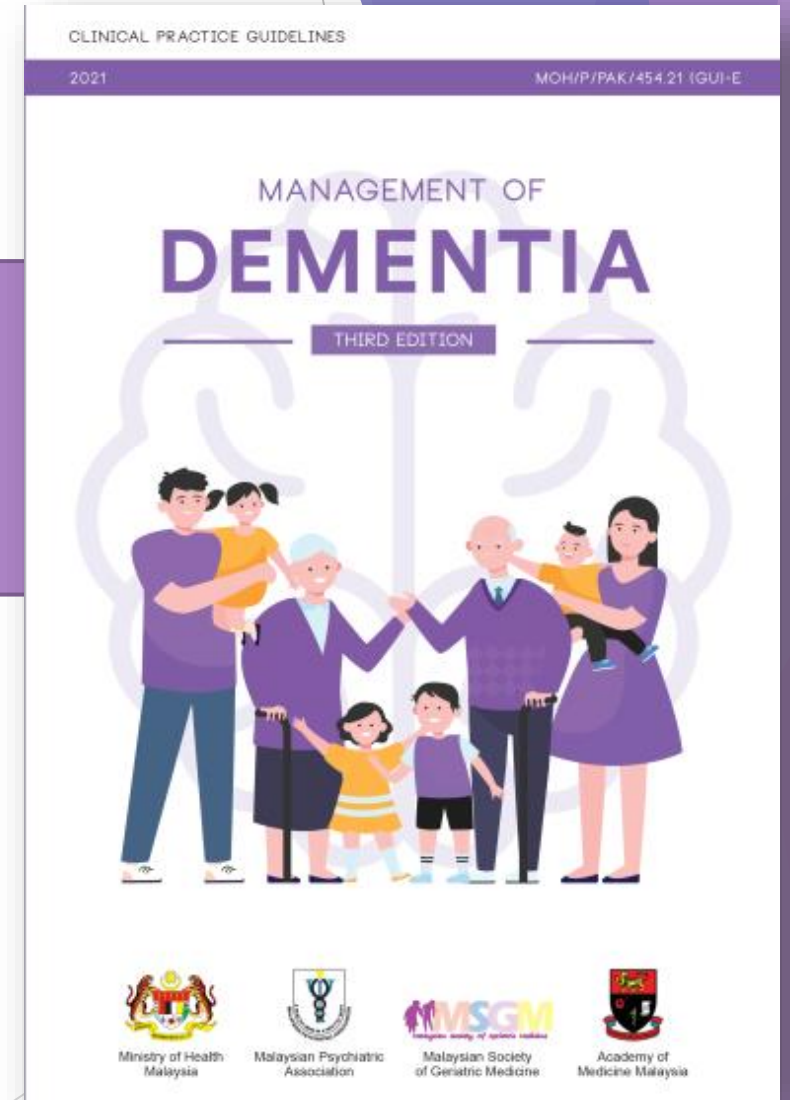


Training of Core Trainers CPG Management of Dementia (Third Edition)

Legal & Ethical Issues

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Learning Objectives

1. To learn and be familiar about legal and ethical issues regarding PWD



Introduction: Decision-making Capacity

- ▶ The key to a person's right of autonomy is adequate decision-making capacity.
- ▶ Malaysia does not have legislation governing mental capacity and therefore the Mental Capacity Act (MCA) 2005 of the UK shall be used as a reference. It is to be read together with the MCA Code of Practice 2007.
- ▶ The principle of respect for autonomy applies to patients with capacity even if the decisions chosen do not coincide with the opinions of the medical team.
- ▶ The MCA 2005 states that if the patient still has legal capacity, then it is entirely up to that individual to decide if they want their relatives and carers to be involved in determining their care and the extent to which this should be done.



Introduction: Decision-making Capacity-2

- ▶ If a PWD lacks decision-making capacity, then a surrogate decision-maker will need to make decisions for the PWD based on his/her best interest.
- ▶ The following points need to be taken into account:
 1. Decision-making capacity is determined with regard to specific tasks and decisions that need to be made. PWD can be judged to have capacity to make certain decisions, and not having capacity for other decisions at the same time.
 2. If there is any doubt regarding a PWD's decision-making capacity, a formal assessment of decision-making capacity should be carried out.
 3. The assessment should be properly documented in the patient's notes.
 4. In the event of incapacity, efforts should be taken to restore the patient's decision-making capacity or encourage the PWD's involvement in the decision-making process.
 5. The principles of Section 77 of the Mental Health Act 2001 is applicable when obtaining consent.



Advanced Directives

- ▶ End-of-life care decision-making is not easy in a multi-cultural and multi-religious society like Malaysia.
- ▶ Both the healthcare provider and recipient may come from different ethnicities and religions, and adhere to different sets of values.
- ▶ May not be confined to clinical assessments as to what would be in the best interests of the patient from a purely medical perspective, but involve due consideration of a patient's religious beliefs, customs and values, which ultimately have significant influence on a patient's response to illness, suffering and dying.
- ▶ Hence, end-of-life planning by making Advance Decisions can be immensely valuable as it can help healthcare providers in Malaysia to understand better the preferences and wishes of their patients.



Advanced Directives-2

- ▶ A PWD may decide to make advance decisions regarding treatment while they still possess the mental capacity to do so by way of an advance directive or an advance care plan (Section 10d).
- ▶ Advance directives serve to guarantee the right of mentally competent individuals to continue exercising their autonomy in the event of future incapacity.
- ▶ Although there is no law in Malaysia to govern advance directives in respect of healthcare matters, the common law right to refuse treatment is applicable.¹²⁹
- ▶ Two crucial steps need to be implemented:
 1. Patients need to have a conversation, be it between themselves and their doctor or their family members, about their wishes.
 2. These wishes need to be recorded.

129. Chan HY. Regulating advance decision-making: potential and challenges for Malaysia. Asian Bioethics Review. 2019;11:111-22.



Advanced Directives-3

- ▶ The MCA 2005 provides for the appointment of a healthcare proxy through a Lasting Power of Attorney, or for patients to make Advance Decisions to Refuse Treatment while they still have capacity.
- ▶ If the patient has none of these, the healthcare team then has a duty to consult the patient's next-of-kin, and other relatives and carers, as part of the process laid down by the said Act (s.4.6) which are as follows:
 1. determining the past and present wishes and feelings of the patient;
 2. determining the beliefs and values that would be likely to influence the patient's decision if they had capacity and;
 3. determining any other factors that the patient would be likely to consider.



Advanced Directives-4

► However, if an advanced directive is available:¹³¹

1. A doctor should comply with a patient's unequivocal written directive to refuse a particular treatment.
2. Doctors are advised to consult the next of kin or seek legal advice if there is doubt on the validity of an advance directive, and these discussions need to be documented.

131. Malaysian Medical Council. Malaysian Medical Council Guideline: Consent for Treatment of Patients by Registered Medical Practitioners. Kuala Lumpur: Malaysian Medical Council 2017.



Advanced Directives-5

- ▶ In the absence of specific legal provisions for Advance Decisions, it can be viewed that the legal and ethical positions on these decisions will rely on the ethical codes that are currently available.

The Code of Medical Ethics (CME) 2001 of the Malaysian Medical Association (MMA 2001) in Section 2.5 alludes to the use of Advance Decisions. It states that “one should always take into consideration any advance directives and the wishes of the family in this regard.”

Although ethical codes would merely provide guidance and would not be legally binding, in the event of a medicolegal suit, cases will be adjudicated in accordance with common law principles.



Fitness to Drive

- ▶ A diagnosis of dementia is not in itself a reason to stop driving.
- ▶ One in every three people with dementia still drives.
- ▶ What matters, from both a legal and a practical point of view, is whether the person is still able to drive safely.
- ▶ However, driving retirement is recommended at some point as the disease progresses.



In order to drive safely, a person must use a range of mental abilities including:

- ▶ **Attention and concentration** – to focus on, and switch between, multiple different driving tasks while ‘reading’ the road.
- ▶ **Visuospatial skills** – to keep to an appropriate speed and distance, and the right road position.
- ▶ **Problem-solving skills** – to respond to incidents, diversions or obstacles in the road.
- ▶ **Judgement and decision-making** –to interpret and anticipate what other road users are doing
- ▶ **Reaction and processing skills** –to act quickly to avoid an accident.
- ▶ Other factors important in determining driving safety are vision, mobility, head-turning and day-time somnolence.
- ▶ In mild dementia, some patients may retain the skills needed for driving. Patients with moderate-severe dementia are unlikely to be fit to drive.



Fitness to Drive: Assessment

- ▶ For patients who decide to stop driving or who are forced to stop, clinicians must discuss practical alternatives, the impact on psychosocial benefits and the loss of autonomy with patients and their caregivers.¹³²
- ▶ Assessment of fitness to drive involves composite cognitive test batteries in combination with other types of assessments e.g. driving simulator test¹³² or on-road test.¹³³
- ▶ Locally, an assessment of fitness to drive can be done by referring the patient to an occupational therapist with the prescribed form (Borang Pemeriksaan Kesihatan Permohonan Lesen Memandu Orang Kurang Upaya) as provided in the Medical Examination Standards for Disabled Driver's Licensing.¹³⁴

132. Allan CL, Behrman S, Baruch N, et al. Driving and dementia: a clinical update for mental health professionals. Evidence Based Mental Health. 2016;19(4):110.

133. Martin AJ, Marottoli R, O'Neill D. Driving assessment for maintaining mobility and safety in drivers with dementia. The Cochrane database of systematic reviews. 2013;2013(8):Cd006222.

134. Ministry of Health Malaysia. Medical Examination Standards For Disabled Driver's Licensing. Putrajaya: Ministry of Health Malaysia; 2011.





Medical Examination Standards

For Disabled Driver's Licensing



Occupational Health Unit
Disease Control Division
Ministry of Health Malaysia



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Assessment Process

- ▶ Physical and cognitive testing.
- ▶ Composite cognitive testing +/- driving simulator test.
- ▶ No on-road testing.

1. Cognitive Assessment

- ▶ Screening : MMSE or MoCA
- ▶ Specific cognitive tests:
 - Rivermead Perceptual Assessment Battery
 - Chessington O.T. Neurological Assessment Battery
 - Lowenstein Occupational Therapy Cognitive Assessment



Assessment Process-2

2. Occupational Therapy Pre-Driver Assessment form
Results of assessment and recommendations.
3. Driving simulator assessment if necessary.
4. Fit to drive/ Unfit to drive/ Need for further rehabilitation.
5. Referral for Cognitive Stimulation Therapy
6. Assessment process may take multiple sessions depending on the patients ability to complete the assessment tasks.



Legal Requirements: Reporting

- ▶ Section 30(3) & 30(4) RTA 1987
- ▶ It is the responsibility of a PWD to report his/her disability to the authorities for licensing purposes.¹³⁵
- ▶ However, medical practitioners may voluntarily report new cases of disability to the Road Transport Department.¹³⁴
- ▶ It is good medical practice to seek the PWD's consent for such reporting.
- ▶ However, if the PWD does not consent to the disclosure, medical practitioners may still permissibly breach the confidentiality of the PWD utilizing reasons for disclosure in the patient's medical interests and/or disclosure in the public interest if they judge that doing so will provide important benefits to the patient or prevent serious harm to third parties.¹³¹

135. Laws of Malaysia Act 333 Road Transport Act 1987. (Available at: <http://www.agc.gov.my/agcportal/uploads/files/Publications/LOM/EN/Act%20333%20-%20Road%20Transport%20Act%201987.pdf>)



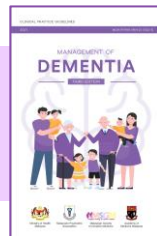
Take Home Messages

Recommendation 13

- If there is any doubt regarding people with dementia (PWD)'s decision-making capacity, a formal assessment of decision-making capacity should be carried out.
- A doctor should comply with a patient's unequivocal written directive to refuse a particular treatment if that decision was made while the patient had mental capacity.
- PWD (particularly moderate to severe) should be assessed for their driving ability if they still wish to drive.



Thank You



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