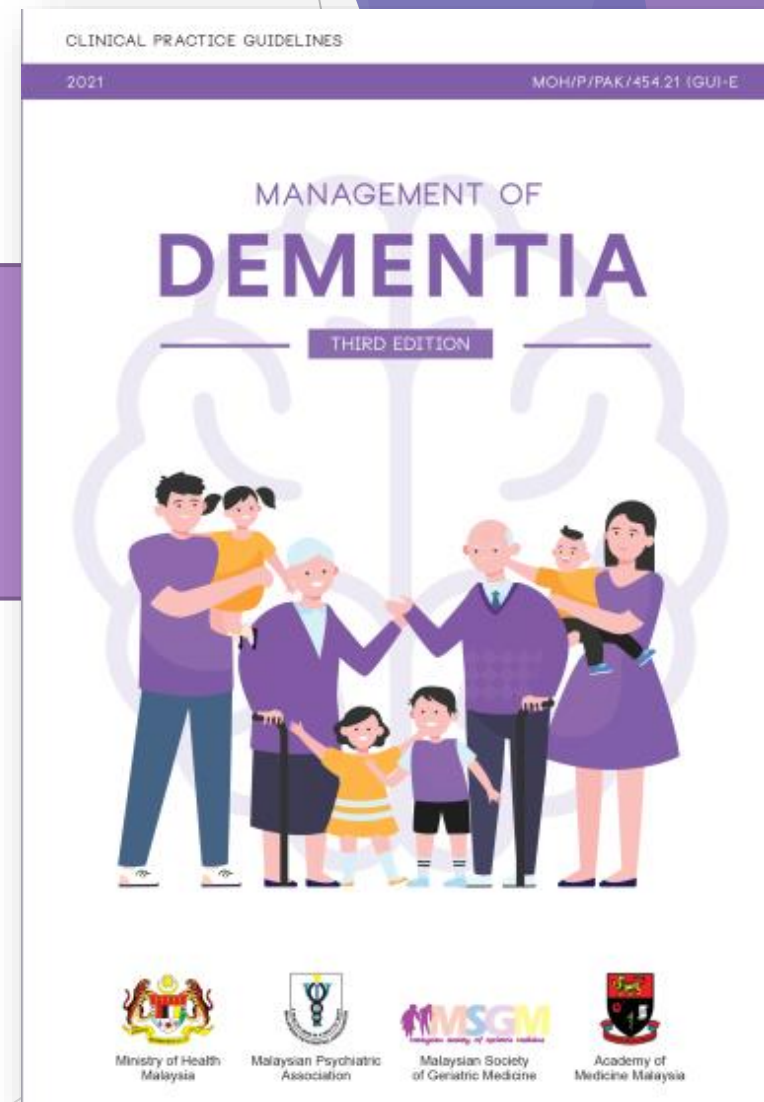


Training of Core Trainers CPG Management of Dementia (Third Edition)

CAREGIVER SUPPORT

By:
Ms. Rosita Abd Rahman
Occupational Therapist
Hospital Tuanku Ja'afar, Negeri Sembilan



Learning Objectives

1. To understand the importance of support for caregivers of PWD.
2. To be familiar with support options available for caregivers of PWD.



Caregiver Support

- ▶ Caring for PWD can be emotional and physically challenging. The role of caregiver is a central and integral part of dementia management.
- ▶ Caregivers should be involved in the management of PWD from the beginning. NICE recognizes the important role of caregivers and discusses their involvement in the management of PWD in detail.⁴²
- ▶ The assessment for caregivers – Zarit Burden Interview (ZBI) has good reliability and validity to assess burden of caregivers for PWD.⁴⁹

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.

49. Whalen KJ, Buchholz SW. The reliability, validity and feasibility of tools used to screen for caregiver burden: a systematic review. JBI library of systematic reviews. 2009;7(32):1373-430.



Zarit Burden Scale

The Zarit Burden Interview

- 0: NEVER
1: RARELY
2: SOMETIMES
3: QUITE FREQUENTLY
4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question	Score
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4
9 Do you feel strained when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Question	Score
13 Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18 Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20 Do you feel you should be doing more for your relative?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:
0 - 21 little or no burden
21 - 40 mild to moderate burden
41 - 60 moderate to severe burden
61 - 88 severe burden

Patient last name:
Patient first name:

Date of birth:/...../.....
Date:/...../.....



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Caregiver Support-2

- ▶ A few interventions to reduce the burden/ strain of caregivers have been studied and are discussed below:
 - Respite care
 - Carer training
 - Spirituality and religious support



A. Respite Care

- ▶ Respite care is any intervention designed to give rest or relief to caregivers.
- ▶ A Cochrane review showed no significant difference in caregiver burden between respite care and control. However, polarity therapy reduced caregivers perceived stress compared with respite care. (MD=5.80,95% CI1.43 to 1017)¹²⁴, level I
- ▶ An Australian guidelines on dementia recommends that PWD, their carers and family should be offered respite appropriate to their needs which include in home respite, day respite. planned activity groups and residential respite.⁵⁰

124. Maayan N, Soares-Weiser K, Lee H. Respite care for people with dementia and their carers. The Cochrane database of systematic reviews. 2014(1):CD004396.

50. Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney: Guideline Adaptation Committee; 2016



A. Respite Care-2

- ▶ Respite care can also include adding more companion time for carer. For example, sending PWD to daycare for involvement in pleasant activities, physical strengthening activities and social groups. These interventions might involve gaining additional assistance, thereby reducing time spent in direct care given to PWD at home.
- ▶ This way carer of PWD might have his/her own time for his/her own self, rejuvenating her strength, and later able to care better for PWD.



B. Carer Training

- ▶ Psychoeducation and skills training is recommended by NICE to carers of PWD which includes:⁴²
 - Education about dementia on its symptomatology natural progression
 - Development of personalized strategies and carer skills
 - Training on care of PWD, including understanding and responding to changes in behaviour.
 - Training in communication skills
 - Advise on carers' own physical , mental health and spiritual wellbeing.
 - Information on relevant services and their access.
 - Advise on planning for the future.

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.



B. Carer Training-2

Recommendation 12

- Caregivers should be actively involved and supported in the management of dementia.
 - This includes assessment of the burden of caregivers.



C. Spirituality And Religious Support

- ▶ Spiritual and religious support may be useful for caregivers to improve their coping strategy and reduce emotional distress. However, some caregivers might experience negative effect with this intervention.^{125,level II-2}
- ▶ Therefore, spiritual and religious support should be individualized according to the caregivers' preference and acceptance.

125. Giannouli V, Giannoulis K. Gazing at Medusa: Alzheimer's dementia through the lenses of spirituality and religion. Health psychology research. 2020;8(1):8833.



Our concern with caregivers of PWD....

- ▶ Stigmatisation, lack of awareness and perceived lack of credibility of health care workers are among factors that discourage caregivers from reaching out to available services and supports^{126, level III}
- ▶ Hence, collaborative efforts should be made by the government and respective stakeholder, including the MOH, Social and Welfare Department and NGOs to provide better support and services for the PWDs in Malaysia.
- ▶ Refer to **Appendix 11 on Important points for Caregiver of People with Dementia** and **Appendix 12 on Useful Resources**.

126. Nikmat Aw. Dementia in Malaysia: Issues and challenges. Asian Journal of Psychiatry. 2011;12:1-7.



Important points

- ▶ There are various community health and support services that are available in the country to assist PWD and their caregivers. Social and Welfare Department are involved in some of these services. Relevant information can be obtained from the Ministry Of Women, Family and Community Development of Malaysia and related non – governmental organisations (NGOs).



Appendix 11

APPENDIX 11

IMPORTANT POINTS FOR THE CAREGIVER OF PEOPLE WITH DEMENTIA

1. UNDERSTANDING DEMENTIA	
<ul style="list-style-type: none"> The caregivers need to understand about dementia and the importance of early detection and early diagnosis. 	
2. SUPPORT FOR CAREGIVERS/CARERS	
<ul style="list-style-type: none"> Caring for PWD may cause stress to family and caregivers. Build-up of stress may lead to emotional problems and poor health of the caregivers. One of the ways to relieve the stress is to have someone to talk to, e.g. using telephone counselling service or participating in support group events which are tailored to their needs. The support group should also involve other family members as well. Caregivers should be aware of their own physical and mental health issues e.g. increased risk of depression and over tiredness. Therefore, respite care should be offered for adequate support to help caregivers in coping with caring for PWD. 	
3. RECOGNISE FUNDAMENTAL NEEDS OF CARE FOR PWD	
a. Recognise the stress and challenges faced by PWD and suggested carer responses	
<ul style="list-style-type: none"> PWD feel stressed when they are unable to recall what has just happened. They may also be disorientated to time, place and person. Though their memory, understanding and judgement are declining, their emotion may still be intact. 	
b. Learn to engage with PWD	
i. Forgetfulness: PWD do not recall what they talked about and with whom they talked.	Helpful tips: Courteously answer the questions because PWD have difficulty to recall and may be repeatedly asking question for confirmation as a result of being anxious.
ii. Disorientated to time, place and person: PWD may repeatedly ask the day, date, where they are and who the persons around them.	Helpful tips: PWD may have problems organising and making plans and, executing tasks correctly. Confirm with them the actions that they are doing and ask what they want to do next step by step.
iii. Impaired understanding and judgement: For instance, PWD may become unable to cook, use remote control for television or operate the washing machine.	Helpful Tips: Engage in the activity together with PWD. For example, instead of allowing person with dementia to cook, let them do simple things like washing vegetables or peeling

	onions and, at the same time ensuring their safety.
iv. Delusion: A false belief that is beyond challenge. For instance, PWD may have delusion of theft, that is the false belief that their valuable thing, e.g. money or purse, has been stolen by someone despite being reassured that this does not occur.	Helpful tips: Caregiver should show interest in looking for the item together with the PWD. Once search is done, distract the activity by saying for e.g. 'We have tried searching for the item, but can't find it, let's have a cup of tea and look again later'.
v. Wandering: PWD may also try to leave the house to go somewhere but loses his or her way before reaching the destination.	Helpful tips: Person with dementia may have their own reason to go out. The carer can try to engage by asking "where are you going" and "why are you going?" Carer may then help them to achieve their purpose. It is also useful to put a name tag with their name, address and contact details on their clothes so that others can assist them in finding their way home.
vi. Anger: PWD may suddenly get upset and become verbally or physically agitated. They can be sensitive to certain conversations and may become angry and restless as they are unable to express their feelings and difficulties.	Helpful tips: Carers will need to be more accommodating and avoid triggers or situations that hurt their feelings.
c. Understand important daily life activities of PWD	
i. Eating: PWD often forget they have eaten and may also not recognise edible/food items from nonedible items.	Helpful tips: Explain regarding timing of meals by mentioning actual time. Avoid having nonedible items within reach for those who cannot tell the difference.
ii. Bathing: PWD may not be co-operative to take bath; they may refuse	Helpful tips: When a PWD who usually takes bath refuses to do so, it may be

to undress, wash themselves or dress after their bath.

due to being unwell. Hence, caregiver need to ask about their physical condition.

During the bathing process:

- talk to them gently and be careful not to hurt their pride.

During the dressing process:

- replace their clothes fasteners or buttons with Velcro tape
- put signs on their clothes to distinguish the front and back
- prepare their clothes in the correct order of putting on

iii. Excretion:

PWD may urinate in inappropriate places, repeatedly go to the bathroom or do not understand the need to urinate or defecate.

Helpful tips:

Caregiver may put a large sign on the bathroom door, keep the doorways bright and switch on the lights in the bathroom at night. Another tip is to bring the PWD to the toilet at frequent interval.

Source:

- Division for Dementia and Community Care Promotion. Living together with people with dementia; Key points for the care of people with dementia at home. Kumamoto Prefecture; Department of Health and Social Services; 2013.
- National Institute for Health and Care Excellence (NICE). Dementia: assessment, management and support for people living with dementia and their carers. London: NICE; 2018.



Appendix 12

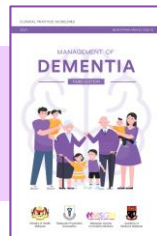
APPENDIX 12

USEFUL RESOURCES

State	Organisation Information
National	Alzheimer's Disease Foundation Malaysia Tel: +603-79562008 / +603-79583008 (Mon - Fri: 9am to 5pm) Email: office.adfm@gmail.com Website: https://adfm.org.my ADFM National Caregivers Support Network: admalaysia.ning.com
Penang	Penang Dementia Association Tel: +6016-6745429 Facebook: Penang Dementia Association
Perak	Dementia Society Perak Ipoh AD Support Group Tel: +605-2411691 / +6019-5712738 Email: tdsperak@gmail.com Facebook: The Dementia Society Perak
Selangor, Wilayah Persekutuan Kuala Lumpur & Putrajaya	Alzheimer's Disease Foundation Malaysia National Helpline: +603-79315850 (Mon - Fri: 9am to 5pm) Putrajaya Email: office.adfm@gmail.com Facebook: Alzheimer's Disease Foundation Malaysia-ADFM ADFM National Caregivers Support Network: admalaysia.ning.com
Selangor	Alzheimer's Disease Foundation Malaysia Atria ADFM Community Corner Tel: +6017-8867703 (Mon - Sun & PH: 11am to 7pm) Email: office.adfm@gmail.com Facebook: Alzheimer's Disease Foundation Malaysia-ADFM ADFM National Caregivers Support Network: admalaysia.ning.com
Negeri Sembilan	Kumpulan Sokongan Dementia Negeri Sembilan (KUSDeNS) Email: wecaredementia9@gmail.com Tel: +606-7684804
Johor	Johor Bahru Alzheimer's Disease Support Association (JOBADA) Tel: +607-2222016 (JOBADA office) / +6012-7091277 Email: jobadajohor@gmail.com Facebook: Jobada Johor
Sabah	Sabah Alzheimer' Disease Association (Sabah AZ) Tel: +6088-231030 / +6088-270730 Email: kjchau88@hotmail.com Facebook: Sabah Alzheimer's Disease Support Association
Sarawak	Trinity ElderCare Centre (TEC) Tel/Fax: +6082-255758 Email: tmceldercare@gmail.com Facebook: Trinity ElderCare Centre



Thank You



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