



# THE REFERENCE HANDBOOK OF DEMENTIA CARE RESPONDING TO COVID-19

Taiwan Alzheimer's Disease Association

20 March 2020

## The coronavirus disease (COVID-19) pandemic

As the outbreak and global spread of coronavirus disease (COVID-19), World Health Organization (WHO) and Taiwan Centers for Disease Control (TCDC) have provided related information and guidance on the disease. During the epidemic period, people are prone to be upset and anxious, bring about huge negative impact upon the quality of life in the people with dementia and their caregivers.

The Inter-Agency Standing Committee (IASC) of the United Nations (UN) has proposed and emphasised the importance of providing 'mental health and psychosocial support' (MHPSS) to protect and improve people's mental health and psychosocial well-being in the midst of an emergency crisis. All countries should follow the core principles in every aspect implementing social security services, community and family supports, and personal services. The principles include doing no harm, promoting human rights and equality, using participatory approaches, building on existing resources and capacities, adopting multi-layered interventions, and working with integrated support systems. In addition, TCDC provided the guidelines for healthcare, long-term care, and social welfare systems to ensure the most vulnerable groups of seniors and people with disabilities can acquire adequate preventive services and psychosocial supports.

However, due to cognitive impairment, people with dementia have difficulties in understanding the preventive measures. They may not be able to remember or follow the relevant regulations and become the breach in the front of the war against infections. Family members, caregivers, and professionals also face more challenges and pressure when taking care of people with dementia. During an infectious disease outbreak with limited resources, the needs of people with dementia and their family caregivers are prone to be neglected and obscured, who instead require special attention. Therefore, Taiwan Alzheimer's Disease Association (TADA) reviews currently available literature and collates the experiences from healthcare professionals, people with dementia, and their family members and issues this reference handbook. With the handbook, TADA intended to help professionals know more about the needs of people with dementia and their family caregivers, and supply better prevention and care services.

# What challenges will people experience when taking care of people with dementia during the pandemic?

## 1. People with dementia

- ✓ People with dementia may not be able to understand the information of the pandemic and the announcement about preventive measures.
- ✓ It may be hard for people with dementia to remember or follow the instructions of infection prevention, such as locking down at home, wearing face masks, or washing hands frequently.
- ✓ People with dementia have difficulties in recalling or describing the history of travel, contact, and cluster correctly.
- ✓ It is more difficult for people with dementia to express their discomforts or symptoms exactly, such as fever, dyspnoea, malaise, headache, or muscle pain, etc. Instead, they are more likely to manifest problematic behaviours than talk about their true feelings clearly.
- ✓ People with dementia may have reduced capability in emotional adjustment, and may become excessively anxious or even present catastrophic reaction due to the intensified stress around them or misunderstanding of the information.
- ✓ People with dementia may violate the infection control regulations simply because they forget they are in quarantine.
- ✓ People with dementia may become even more anxious and panic when they are isolated because of the unfamiliar environment or discomforts. The existent behavioural and psychological symptoms may be worsened, and even an acute confusional state will happen.
- ✓ The decreased activities and stimulation during the epidemic may result in disturbed circadian rhythms and possibly deteriorate dementia syndromes.
- ✓ People with dementia who live alone are more vulnerable because they may have difficulties complying with the pandemic measures and obtaining prevention resources, such as face masks, sanitizers and other protective equipment.

## 2. Family members and caregivers

- ✓ In addition to their worries about the pandemic, family members and caregivers may have to face the deteriorated psychiatric symptoms of people with dementia and lose patience toward them. Furthermore, caregivers' anxiety may trigger or worsen the aggression of people with dementia.
- ✓ Family members may have different opinions on the decision whether people with dementia can

attend to the community activities. There will be a dilemma between the increased risk of infection when going out and the deteriorating function related with reduced activities and stimulation when people with dementia are restricted at home.

- ✓ There may be increased conflicts between people with dementia and their family caregivers because of the needs of people with dementia to go out, especially when the community services and activities are reduced.
- ✓ Family members of people with dementia may be occupied by the caring tasks and not be able to prepare or deal with the measures for infection prevention.
- ✓ Foreign caregivers may not fully understand prevention measures due to language barriers.

### **3. Professional caregivers**

- ✓ Professional caregivers at the long-term care facilities may have increased workloads and pressure because of the special preventive measures in addition to the ordinary care.
- ✓ As people with dementia may not be so cooperative and more time has to be spent in care, professional caregivers may lose their patience in taking care of the people with dementia.
- ✓ Professionals will be concerned with the exacerbated functional deterioration caused by the decrease of activities and stimulation.
- ✓ The caring difficulties may vary across individual persons with dementia at different stages of dementia because of their different understanding and cooperation with the preventive measures.

## The caring strategies during the epidemic period

- 1. Follow the guidelines on epidemic prevention of the Taiwan Centers for Disease Control** ([https://www.cdc.gov.tw/En/Category/ListContent/bg0g\\_VU\\_Ysrgkes\\_KRUDgQ?uaid=0nAzwpXdBNIAPovJhwrGoQ](https://www.cdc.gov.tw/En/Category/ListContent/bg0g_VU_Ysrgkes_KRUDgQ?uaid=0nAzwpXdBNIAPovJhwrGoQ))
- 2. Provide person-centred care in response to the needs of people with dementia, family members, and caregivers.**
  - ✓ Under the official guidelines, professionals should provide person-centred care based on the condition of people with dementia, family members, and caregivers.
  - ✓ Look after the needs of people with dementia, family members, and caregivers, and provide necessary support and resources.
  - ✓ Keep as minimum changes as possible in the life of people with dementia. Watch their nutrition and monitor sleep condition. Help them stay healthy.
  - ✓ Attention should be paid on the physical health and emotional adjustment of family members and caregivers.
- 3. Obtain the information on the history of travel, contact, and cluster of people with dementia, their family members, and caregivers, and promote the epidemic preventive measures**
  - ✓ Everyone who enters the service units (such as support centres for people with dementia and their families) should use appropriate sanitizer, take body temperature and record. Besides, their history of travel, contact, and cluster should mandatorily be enquired and recorded.
  - ✓ If a person has a fever or respiratory symptoms, he/she should stay at home and avoid going out. Remember to take and record body temperature, and supplement nutrition and water regularly. If the fever lasts longer than 24 hours or more serious symptoms such as heavy sputum production, severe vomiting, or difficulty in breathing, please do seek medical advices. When seeking medical help, please provide the history of travel, occupation, contact, and cluster. If he/she has fever or serious symptoms, please do disclose the information in advance and cooperate with the instructions of medical facilities to receive treatments appropriately.
  - ✓ If people are informed to be quarantined at home, they should not go out, go abroad, take public transportation, or go to public places. If people are informed to conduct the self-health management measures, they should avoid going out. If they have to go out, they must wear facial masks all the time, wash hands frequently, and implement courtesy of respiratory hygiene

and cough.

- ✓ Professional caregivers should provide educational health information about infection prevention to family members in various ways such as contact logs or social media. They should also help the family members to be informed with the most updated accurate information or provide the access to the official information sources.
- ✓ Professional caregivers can download Covid-19 leaflets and posters from the official website (<https://www.cdc.gov.tw/En>) and post them in places where readily seen. For example, posting the posters of standard hand-washing procedures above the sink to remind the staff, people with dementia, family members, and visitors to follow.
- ✓ Professional caregiver can distribute the leaflets with brief and understandable health information to help people with dementia and their family to be informed with proper preventive information. It is also necessary to offer leaflets in the various languages for those foreign caregivers in need.
- ✓ Based on the availability, professional caregivers should take the initiative to provide the resources for infection prevention, such as face masks and sanitizers.

#### **4. Take the initiative to care for people with dementia and remind them repeatedly**

- ✓ The professional caregivers should take action to observe and monitor for suspected infection symptoms and deal with them according to epidemic prevention measures.
- ✓ Make sure people with dementia and their family receive the latest information of COVID-19.
- ✓ The epidemic prevention information for people with dementia should be presented in a simple and clear manner, being explained in the way they can understand, and better be demonstrated in practice, such as proper hand-washing and mask-wearing.
- ✓ Remind people with dementia to wash their hands regularly and protect the skin from cracking.
- ✓ Ensure people with dementia wash their hands before eating, after going to the toilet, coughing, and blowing noses.
- ✓ It is difficult for people with dementia to cooperate with prevention measures, such as “Do not touch your eyes, mouth, and nose.” Therefore, it is recommended to actively remind people with dementia to wash hands, assist people with dementia to use hand sanitizer, and increase the frequency of environmental disinfection.
- ✓ If people with dementia violate anti-epidemic measures, professional caregivers should advise, explain the reasons, divert attention, and avoid accusing them directly.
- ✓ If the primary caregiver is separated for quarantine, it is advisable to actively assist people with

dementia in screening and discussing follow-up care arrangements.

- ✓ If the primary caregiver is quarantined at home, it is recommended that they are separated from people with dementia to reduce the chance of infection of people with dementia.
- ✓ Make sure the daily and medical needs of people with dementia can be satisfied, such as the continuous treatment and care of chronic diseases.
- ✓ Convening care meetings and discussing strategies for dementia.
- ✓ For people with dementia living in institutions or hospitals, professional caregivers should ensure the implementation of preventive measures and avoid cross-infection. Besides, professional caregivers should assist family members in using video calls or visiting people with dementia in a public courtyard of the institution.

## **5. Assist family members, caregivers, and people with dementia to remain calm**

- ✓ It is a normal response that family members, caregivers, and people with dementia may experience excessive worry, anxiety, and fear of the epidemic. Professionals should listen, empathize, and give appropriate support.
- ✓ Remind family members, caregivers, and people with dementia to avoid watching epidemic information guides for too long to avoid excessive anxiety. It is recommended to refer only to official epidemic information disclosed by government to avoid unnecessary panic resulting from rumors.
- ✓ When people with dementia lose their temper, please be more tolerant, understand and take care of potential needs. Professional caregivers should try to explore potential physical discomfort, and then to soothe the temper by providing a quiet environment, listening to favourite music, and diverting their attention with familiar items.
- ✓ Encourage people with dementia to use social media to communicate and interact with family and friends.
- ✓ Encourage family caregivers to share thoughts and discuss difficulties during the epidemic period, so that they can relieve stress.
- ✓ When people with dementia are diagnosed and have to be isolated, their familiar caregiver or relatives can contact them by phone or video call to reduce anxiety. The primary caregiver needs to provide people with dementia with personal emergency kits which include their regular medicines, soothing snacks, and familiar items, information addressing living habits, communication skills, favourite activities and supplies, and personal entertainment equipment containing favourite music and songs for smooth care. If necessary, ask the primary caregiver to

assist in isolation and care.

- ✓ If family members, caregivers, and people with dementia have excessive and persistent anxiety, depression, or sleep problem, it is advised to seek the primary care physicians or geriatric psychiatrist for assistance.

## **6. Help people with dementia and their family to arrange home activities, environments, and life**

- ✓ People with dementia, their families, and caregivers need a balanced diet, regular rest, and sufficient sleep. At the same time, pay more attention to maintaining home environmental hygiene and air circulation to maintain optimal health.
- ✓ Increase the amount of indoor activities that the people with dementia usually enjoy, such as board games, paintings, karaoke, nostalgic old movies, etc., depending on each individuals' liking, to reduce their anxiety due to lesser outdoor activities.
- ✓ Activities can be arranged in response to the epidemic, such as making masks together, which can increase the incentive for people with dementia to wear them.
- ✓ Assist people with dementia to establish a routine that increases daytime activities such as environment cleaning, gardening, exercising, or watching aerobics TVs, to help improve sleep quality at night.
- ✓ When people with dementia are isolated, the indoor space can be fine-tuned to form a loop, allowing people with dementia to move freely indoors. The family members can place familiar items around spaces to reduce the anxiety caused by unfamiliar environments.
- ✓ When services are suspended due to an epidemic, the case managers should make phone calls to people with dementia, family members and caregivers, and may use video calls to instruct home rehabilitation activities and preventive measures, providing resources, and make adjustment in responding to the epidemic.

## **7. Enhance self-care and well-being**

- ✓ Dementia care professionals should look after their own physical and mental health. It is encouraged to share and express feelings with family, friends, or colleagues when feeling uneasy or experiencing anxious emotions.
- ✓ It is suggested for the care professionals to take exercise, yoga, meditation, gardening, and singing to relieve their pressure and achieve physical and mental well-being.
- ✓ If a professional is experiencing excessive anxiety, depression, or insomnia, please ask

psychiatrists for help immediately.

- ✓ Professionals should express difficulties to supervisors and ask for help in time if they are overloaded.
- ✓ The care professionals can refer to the guideline for care methods in responding to various severities and behavioural and psychological symptoms of dementia at the TADA website (<http://www.tada2002.org.tw/Download/BookVideo/1?page=2>) .

## 8. Cross-functional cooperation

- ✓ If someone who has suspected signs of dementia (<http://www.tada2002.org.tw/About/IsntDementia#bn5>) and fails to cooperate with the quarantine measures, the infection prevention units can refer to this handbook and should collaborate with the local Integrated Dementia Care Centre which will provide support and help.
- ✓ If infection prevention units experience problems in caring for the people with dementia required for quarantine, it is recommended to inform the dementia care team, psychiatrists, and neurologists, or initiate the emergency mental health services especially when crisis occurs.
- ✓ Particularly, people with dementia living alone in the community requires special support to implement preventive measures through the collaboration of social workers, chiefs of village, community volunteers, religious groups, charities, police officers, and neighbors.
- ✓ When many people with dementia and older people must quarantine at home, television media are required to assist in showing nostalgic series of movies, TV series, variety shows, old songs, and rhythmic programs to appease the elderly trapped at home and reduce the pressure of family caregiving.
- ✓ For dementia-related questions, please contact **the National Dementia Helpline at 0800-474-580.**

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