

Frontier Research Clinic

The Brain and Mind Centre

The University of Sydney



A toolkit for living with dementia during COVID-19

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Introduction

The following information from Professor Olivier Piguet explains how people with dementia and other forms of cognitive impairment may be vulnerable to COVID-19, the respiratory illness caused by the new coronavirus.

At present, there is an estimated 459,000 Australians living with dementia.¹ Three in 10 people over the age of 85 and almost one in 10 people over 65 have dementia,² many of whom have underlying health conditions. In 2020, there is an estimated 1.6 million people in Australia that are involved in the care of someone living with dementia.³ Furthermore, people with dementia account for 52% of all residents in residential aged care facilities.⁴

The current research indicates that in general, older people are more at risk of infection than younger people. However, this is in the same way that older people are more at risk of contracting the flu. Importantly, a diagnosis of dementia does not increase the risk of contracting COVID-19 further. Nevertheless, it is important to be mindful of the following:

- People with dementia may have impaired communication skills. This means they may have difficulty expressing their feelings and concerns. They may also have difficulty asking questions and notifying others of symptoms. People should therefore be alert to the presence of non-verbal signs as well as symptoms if the virus.
- Those with semantic deficits may have difficulty comprehending the coronavirus situation. They may also lack an understanding of rules like social distancing.
- People with dementia may have difficulty understanding complex instructions about self-isolation and hygiene practices. Assist them where you can and break complex instructions into simple manageable tasks.
- People with dementia may have multiple health issues (e.g. reduced mobility, difficulty swallowing, reduced hearing, asthma, etc). It is important to understand if these other health issues put the person with dementia at increased risk of the virus.

Caring for someone with dementia can be challenging, even at the best of times, and we acknowledge that people with dementia and their families face particularly unique challenges during this time of isolation. We would like to provide those living with dementia, their carers, and family members some practical and helpful guidance to help manage during this difficult time.

From Prof. Olivier Piguet

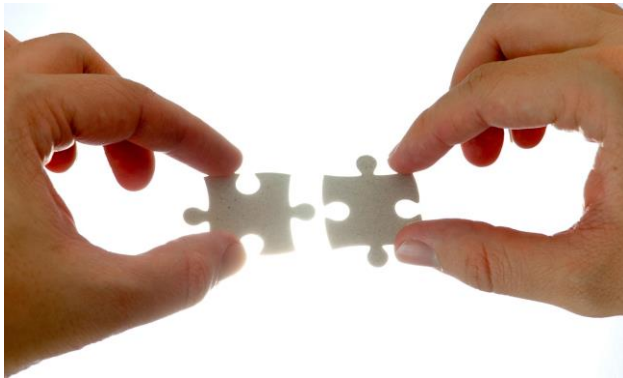
¹ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra.

² The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056.

³ Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016, Department of Health; Dementia Australia (2018) Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), Global estimates of informal care, Alzheimer's Disease International; Access Economics (2010) Caring Places: planning for aged care and dementia 2010–2050.

⁴ The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056.

General advice on dementia and COVID-19



- Firstly, it is important that you gauge what level of understanding the person with dementia has about the coronavirus situation. This way, you can fill in any gaps and correct any misconceptions. Try and use clear and simple language. For those with language difficulties, use pictures or show them a video.

- Consider how much information the person with dementia needs to know about the

coronavirus situation. If knowing about the finer details will cause undue stress, you may want to consider restricting exposure to the news and internet.

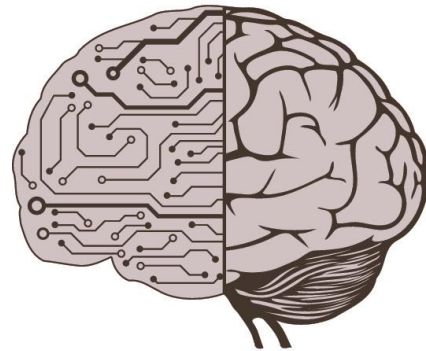
- It is also a good idea to check-in with the person with dementia and ask how they are feeling about the situation. This way you can address any anxiety, worry, or distress. This is particularly important for those who have difficulty communicating.
- Be aware that the person with dementia may need help adapting to the changes in their day-to-day activities. Remind them that these changes will only be in place for a short time, and assist them with establishing a new routine.
- For those with dementia, consistency and routine have never been more important. Come up with a new routine together, and even include basic activities like washing your hands after a walk. Remember, routine adds predictability in unpredictable times.
- Make a list of informal and formal supports. Your informal supports could be neighbours, family, and friends. Formal supports are the phone numbers of your GP, local neurologist, and even local hospital.
- With the general increase in online activity, be aware that scamming is also increasing. People with dementia can be vulnerable to this.
- If physical aggression and wandering are issues, inform the local police you are living with a person with dementia and you may need to call them.
- If boredom is an issue, create an “activity menu” listing various home-based activities as well as activities that can be done in the backyard. Consider doing some of these activities together.
- Remember, just because we are distancing ourselves physically doesn’t mean we have to distance ourselves socially. Schedule one “social activity” per day. For example, a 10 minute video call with grandchildren.
- Numerous studies have shown the positive effects of exercise on physical and mental health. Research has also shown that regular exercise can be of benefit to those with dementia. Incorporate exercise into the daily routine, and try and make it a positive experience so that it doesn’t feel like a chore.
- Make a plan for if you need to take the person with dementia to the GP or hospital. Prepare a “go-bag” with important medical documents, medications, gloves, mask, a change of clothes, etc.

The importance of routine

Routine is important for people living with dementia as it reduces the utilisation of cognitive skills such as organisation, planning, decision making, prioritising, etc. Exercising some of these skills can be difficult for those with dementia. Further, a consistent routine serves as a memory aid due to its repetitive nature. A consistent routine can also be of use to those individuals with apathy as they don't have to rely on their own initiation to complete tasks, or prompts from their carer. Ticking completed tasks off the routine can also incite feelings of productivity and achievement.

Key points for utilising a daily routine:

- Keep the routine as consistent as possible. Begin each day at the same time (i.e. wake time), and end at the same time (i.e. bed time). If possible, perform exercise and eat meals at roughly the same time each day. This way, you can train your “body clock” and appetite to be consistent as well.
- Overlap some of the routines of those in the household so that it doesn't feel too isolating. For example, perform exercise together, or have afternoon tea together.
- Consider having a portion of the day that is “free time” where the person with dementia can choose to do whatever they want, depending on how they are feeling on the day. This way, the routine doesn't seem so rigid.
- Consider writing the routine down and putting it in visible areas of the house (e.g. on the fridge, on the bathroom mirror, on the dining table, as the background of your mobile phone, etc).
- Ask the person with dementia what they like and don't like in their routine. If the person with dementia feels the routine is becoming too repetitive, it can be changed.
- Minimise distractions when the person with dementia is engaging in each task/activity.
- Add one social activity per day (e.g. writing a postcard to a family member)
- Adapt activities that may have required going out (e.g. regular coffee meeting could be adapted to a Zoom or Whatsapp call coffee).
- Make sure the routine has a variety of activities. To prevent boredom, monotony, etc.
- Consider beginning an achievable project during this time of isolation (e.g. a collage, a puzzle, a sewing project, etc). The person with dementia can work on this each day and feel like they are achieving something with their time.



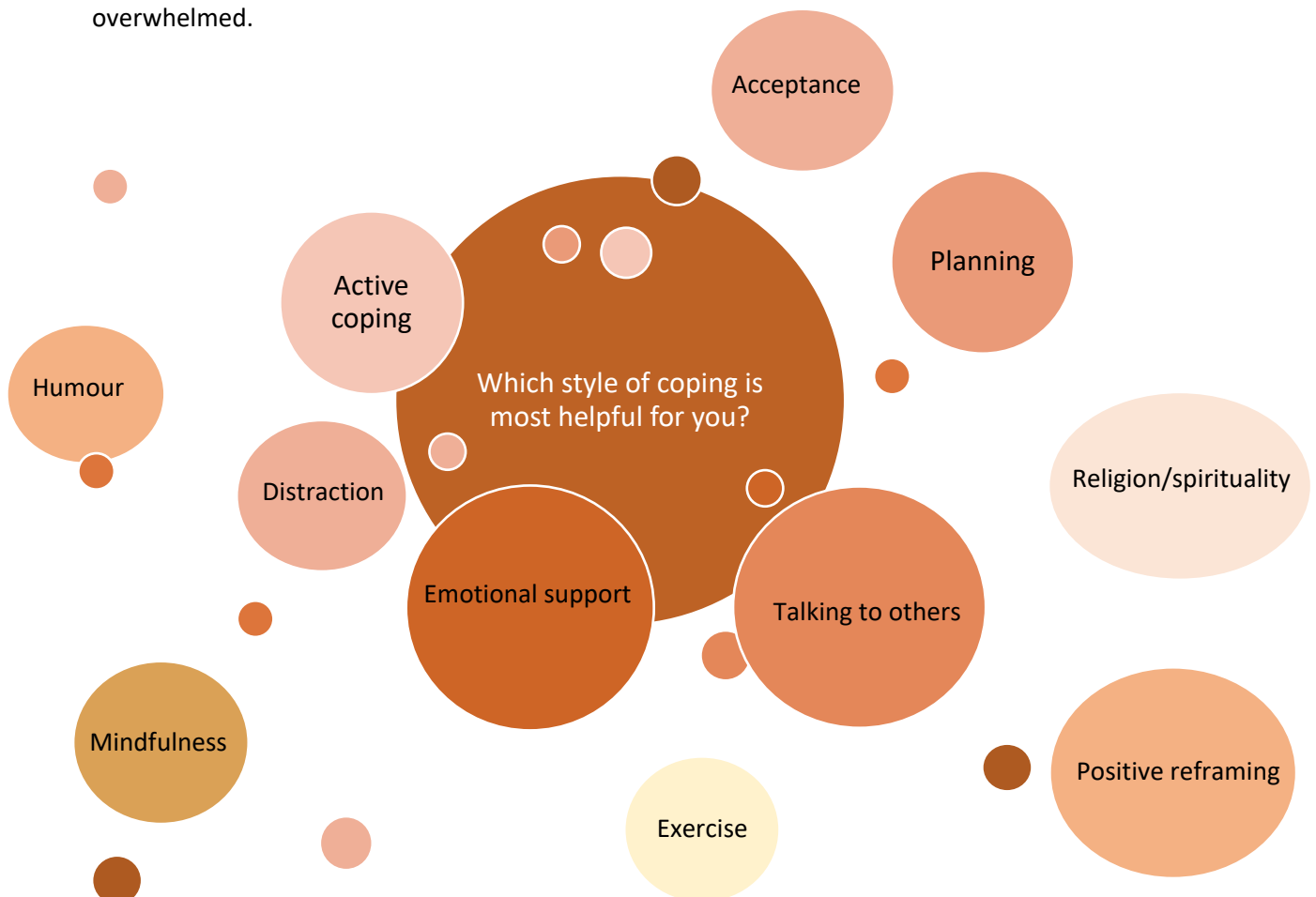
Managing challenging behaviours

Behaviour/Symptom	Challenge	Strategy
Apathy	Difficulty maintaining hygiene practices Keeping socially and physically active	Schedule it into daily routine Provide reward when the routine is followed Wash/sanitise hands together (make use of mimicry) Ask friends/family to call more often
Disinhibited/impulsive behaviour	Person with dementia walks up to strangers Ignores social distancing rules Touches everything	Reinforce appropriate behaviour Remind of consequences (they'll get sick, in trouble etc) Go to the shops or other public places at the least busiest time Wear gloves and mask (Carer to wear this too to model behaviour) Hold their hand to avoid them using that hand to touch things Carry a 'I have dementia' card to show to shop assistants and members of the public discreetly
Financial vulnerability	Increased risk of scamming due to more online activity	Restrict time spent on the internet Put parental filters on Register phone number on www.donotcall.gov.au
Memory	Forgets to maintain hygiene practices	Set alarms to wash hands Put picture reminders up Incorporate into routine
Communication difficulty	Difficulty comprehending situation Difficulty communicating virus symptoms Increased social isolation Difficulty answering questions if stopped by police	Use picture cards to communicate Show them a video Take their temperature daily Observe non-verbal signs of confusion and/or infection Carry a card or note that indicates the person has dementia and a contact number for the carer
Confusion	Online methods of communication (Zoom, Facetime, etc) can be new and confronting	Stick to what is familiar to the person (i.e. phone calls) Use other methods of communication – text messages, pictures, letters, etc.
Wandering	Increased risk of infection from exposure to others Fined by police for going out unnecessarily	Use tracking apps Notify neighbours you are living with someone who has dementia. They can help keep an eye out for wandering Cover the door (e.g. with a bed sheet)

		Register with Safely Home or register person with local police
Aggression	Verbal and/or physical aggression Aggression precipitated by anxiety and/or confusion	Hide objects around the house that could be hazardous Avoid trying to reason or arguing Maintain a calm tone of voice Maintain a neutral non-threatening posture and facial expression Distract the person with something else Offer them physical comfort – touch their hand or give them a hug Remove yourself from the situation (go to another room or the backyard) Notify local police you are living with a person with dementia Utilise the DBMAS (link on Page 7)
Non-compliance	Won't listen to the carer Refuses to wear protective items (gloves and mask) Refuses to wash hands	“Blame” the new rules on the prime minister or the police so it doesn't seem like the carers idea Offer rewards Utilise mimicry – carer to wear protective clothing and wash hands at the same time.
Agitation	Restlessness, pacing, combativeness, etc	Talk to the person with dementia calmly Give them plenty of time to express how they are feeling Give them different options for expressing their emotion – verbally, gestures, pointing to words, faces, etc Maintain a calm and quiet environment Encourage them to move to a calm area (e.g. the backyard) Put on calming music or a calming video Provide physical comfort such as holding their hand, putting your arm around their shoulder, etc

Advice for carers

- We acknowledge that for caregivers, this is a particularly challenging time. You may feel increasingly strained, experience change to your own routine, be unable to access respite, have to adapt to online services, and manage your loved one in a nursing home.
- Acknowledge that you may have to seek additional support for yourself during this time. Share your experience or ask advice from another caregiver, ask your friends and family to call more often, access counselling, or join an online support group.
- Check-in with yourself daily, and do a daily rating out of 10 of your mood, anxiety, and stress.
- Maintaining boundaries and self-care is particularly important during this time. Try to find moments in the day where you can safeguard yourself. Even a couple of minutes to yourself is worth taking.
- Remember that the additional strain you are going through is temporary and there will be a day where life will go back to normal and you will be able to access your previous supports.
- Evaluate whether this time offers you any opportunities. Consider making plans of action, and visualise these to see if they could work.
- Lastly, remember caregivers cope with dementia and its challenges in all different ways. There is no right or wrong way of coping. Take time to reflect on your style of coping and utilise it when you feel overwhelmed.



Where to find more information

Information on COVID-19 in Australia:

Australian Government Department of Health COVID-19

Information: <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert>

If you need urgent assistance:

Dementia Australia Helpline: 1800 100 500 <https://www.dementia.org.au/helpline>

Dementia Behaviour Management Advisory Service Hotline: 1800 699 799
(<https://www.dementia.org.au/services/programs/dbmas>)

Frontier Research Clinic:

Website: <https://frontierftd.org/>

Facebook: <https://www.facebook.com/frontierbrainandmind/>

Twitter: https://twitter.com/Frontier_Usyd

Youtube: <https://www.youtube.com/channel/UCnajg0O0PQshq1mB4TZDWSg>

Useful links about COVID-19 and Dementia:

Dementia Australia: <https://www.dementia.org.au/media-releases/2020/dementia-help-sheets-to-navigate-coronavirus-covid-19>

The Association for Frontotemporal Degeneration: <https://www.theaftd.org/>

Rare Dementia Living with dementia and COVID-19: an emergency kit: <https://www.raredementiasupport.org/coronavirus-covid-19-information/>

UK Alzheimer's Society: <https://www.alzheimers.org.uk/coronavirus>

National Aphasia Association: <https://www.aphasia.org/>

Australian Government Support:

National Disability Insurance Scheme (NDIS): <https://www.ndis.gov.au/coronavirus>

My Aged Care: <https://www.myagedcare.gov.au/covid-19-information-support>

Other:

Hammond Care: <https://www.hammond.com.au>

Tactus Therapy: <https://tactustherapy.com/>

AcToDementia: <https://www.actodementia.com/homepage>

Australian Government Do Not Call Register: <https://www.donotcall.gov.au/>