

Living with dementia during **COVID-19** **lockdown**

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THE UNIVERSITY OF
SYDNEY
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Brain and Mind
Centre

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COVID-19 and dementia

We have been working with researchers around the world to understand the key challenges faced by people living with dementia and their carers during the COVID-19 pandemic.



This toolkit provides practical tips and information for carers about how to support a person living with dementia and look after yourselves during the COVID-19 lockdown.

Health care support



Remember it's important to maintain medical care during the COVID-19 lockdown. Call your GP or specialist before visiting to discuss your circumstances and remote or telehealth options.

They can also assist with any questions or concerns you or your loved one may have about the COVID-19 situation, vaccinations and how best to protect yourselves.

Understanding COVID-19

Why is it important?

Our 2020 study found that **limited understanding of the COVID-19 situation** was associated with worsened psychological and behavioural symptoms in people living with dementia.

When talking about COVID-19, it may be helpful to break down information and news items into manageable chunks, which you can repeat as necessary.

What is COVID-19?

Coronavirus (COVID-19) is a disease that can affect your lungs and breathing.

If you get sick, you might have:

- A cough
- Fever
- Difficulty breathing
- Loss of sense of taste or smell



How can you protect yourself?

- Wash your hands
- Wear a mask when you go outside
- Cover your coughs and sneezes
- Keep at least 2 metres away from other people when you leave home
- Get vaccinated

Staying at home

To stop the spread of COVID-19, you may be asked to stay at home and only go out when you must. During this time, you may not be allowed to have visitors.

Communication Tips

Before you communicate:

- ✓ Make sure the environment is quiet and calm.
- ✓ Turn off any distractions such as the TV or radio.

How to communicate:

- ✓ Sit or stand where the person can see and hear you as clearly as possible
- ✓ Use short, simple sentences
- ✓ Allow time between sentences for the person to process the information and respond
- ✓ Use prompts (for example, pointing to a photo or object you are talking about)
- ✓ Phrase questions in a way that allows for a simple answer (for example, "yes" or "no" questions)

Managing Psychological & Behavioural Symptoms

Depression

Lifestyle changes

Where possible, try to increase exercise, time spent outdoors, social engagement, improve sleeping habits and maintain a healthy diet.

Set goals together

Try to promote a sense of purpose and meaning by setting shared goals. For example, you can try doing a puzzle together, cooking a meal together, or exercising together.

Get professional help

Seek advice from a medical or mental health professional. Contact their GP, specialist or psychologist for evaluation and treatment.

Signs of depression:

- Expressing feelings of sadness or hopelessness
- Loss of interest in activities and hobbies
- Social withdrawal
- Loss of appetite
- Fatigue

Managing Psychological & Behavioural Symptoms

Apathy

Apathy is a lack of motivation or interest in everyday activities and social interactions.

Be the 'starter'

Help them to initiate tasks or conversation.

Break down tasks into simple steps

Try to break down tasks into smaller steps. For example, if they are making lunch; have all the components out and ready for them.

Staying socially engaged

Use shared activities to help them stay engaged. Focus on familiar topics of interest such as their hobbies, strengths and life roles. Try scheduling times for family and friends to call.

Try an activity schedule

Make a list of different activities they can do. Try to schedule these into a routine.

Lockdown Activities:

- Cooking
- Gardening
- Reading, puzzles and games
- Arts and crafts
- Watching TV or listening to the radio
- Outdoor walks

Managing Psychological & Behavioural Symptoms

Delusions

- Delusions are beliefs that are not real or true. ●
- Confusion or memory loss can contribute to these false ●
- beliefs. ●

Try not to take it personally

Remember delusions are caused by the disease. They are trying to make sense of their world with declining cognitive function. They are not doing this on purpose.

Avoid trying to rationalise

Try not to argue or rationalise with them; this will often make the situation worse. Allow them to express their feelings and offer reassurance.

Distract them

Offer a distraction or redirect them to another activity. Put on something they enjoy such as calming music, TV or radio.

Identify patterns in behaviour

Try to identify what triggers their delusions; do they occur at particular times of the day or with particular people? Identifying the causes can help you make changes to their environment.

Managing Psychological & Behavioural Symptoms

Anxiety

Identify triggers

Try to identify what is making them feel anxious and minimise causes of stress where possible.

Practice grounding techniques

Get them to do something physical. For example, holding something hot or cold, or counting using their hands. Regular exercise such as going for walks may also be helpful in reducing anxiety.

Maintain a daily routine

Try to establish a lockdown routine and sense of familiarity. Have regular meal, shower and activity times.

Limit news

Limit exposure to the endless news cycle. Try selecting other channels to watch or suggesting other activities.

Managing Psychological & Behavioural Symptoms

Irritability

Identify cause

Try to identify why they may be irritated or disturbed.

Distract them

Offer a distraction or redirect them to another activity. Put on something they enjoy such as calming music, TV or radio.

Stay calm

Maintain a calm tone of voice, posture and facial expression.

Use touch

Use physical touch to reassure them, such as holding their hand or rubbing their shoulder.

Causes:

Physical

- Pain, illness or discomfort
- Tiredness or lack of sleep
- Hunger or thirst
- Side effects of medications

Environmental

- Under or overstimulation
- Time of day

Social

- Poor communication
- Reacting to your stress

Managing Psychological & Behavioural Symptoms

Aggression/ Agitation

Give them time

Give them plenty of time to express how they are feeling and options to do so. For example, use pictures, objects or gestures.

Modify the activity

Try to match tasks and activities to the person's strengths and abilities. Modify or simplify the activity if they are finding it difficult.

Maintain a daily routine

Try to establish a lockdown routine and sense of familiarity. Have regular meal, shower and activity times.

Remove yourself from the situation

If possible, remove yourself from the situation by going into a different room or to the backyard.

If you think that you or others may be in immediate danger, call 000.

Managing Psychological & Behavioural Symptoms

Disinhibition

Pick the least busy times

If you need to visit a public place (e.g. shops), try to go at the least busy time.

Distract them

Use a gentle touch or gesture to redirect them in the moment. Keep them engaged in an activity to avoid impulsive behaviour (e.g. snacks, videos or photos on your smartphone).

Hold their hand

Hold their hand to avoid them using that hand to touch things.

Carry a companion card

Have a companion card with you when going out to show shop assistants and members of the public discreetly if needed.

Staying Connected



Stay in touch

It's important to stay connected with family and friends at this time. Stay in touch via phone, email, post or have a video call (e.g. on FaceTime, Skype, Zoom or WhatsApp).



Schedule it

Arrange a regular time to catch up with family or friends to give you a routine and something to look forward to.

Get outside

If possible, go for a walk or have a picnic with your loved one, or other family members and friends if it is safe to do so (i.e. socially distanced, wearing masks).



Coping During Lockdown

Self care is vitally important

Taking care of yourself will allow you to provide better care for your loved one

Mindfulness

Take a moment to focus on the present. Pay attention to your senses - notice the things you can see, touch, hear, smell and taste.



Breathing exercises

Place both feet flat on the ground, hip-width apart (either sitting or standing).

Breathe in gently through your nose for a count of 5.

Let it flow out through your mouth, counting from 1-5.

Keep doing this for 3-5 minutes.



Ask for help

If you can, ask a family member or friend for help. Make a list of specific tasks you would like to get help with (e.g. grocery shopping, household chores, or spending time with your loved one so you can take a break).

Coping During Lockdown

- People are likely to be experiencing increased anxiety or stress during this period of lockdown and isolation. This can be a particularly challenging time for carers.
- **Remember to be kind to yourself.**

Keeping positive

Think about the challenges you have already overcome and focus on the strength you found then. Make a list of the aspects of your life that you're grateful for. Think about the things and people you love and value, and future things you can look forward to.

Limit news

Try to limit exposure to the endless news cycle. Instead, tune into one well-sourced daily update.

Seek professional help

If you're struggling or feeling very low, contact your GP or psychologist or contact:

Older Persons COVID-19 Support Line:
1800 171 866 (8:30am - 6:00pm weekdays)

BeyondBlue Coronavirus Mental Wellbeing Support Service:

1800 512 348 (24 hours/7 days)
<http://coronavirus.beyondblue.org.au/>

Lifeline:
131 114 (24 hours/7 days)

