

Information for Caregivers, Family and Friends of Individuals with Dementia and Alzheimer's Disease

You probably have many questions about how to continue to support and interact with your loved ones during the COVID-19 pandemic. Many things have changed in how nursing homes, personal care homes, in-care home providers and even hospitals are providing care. This document can help you with some of those questions and provide you tips on how to continue to support your loved one during this difficult time.

I AM WORRIED ABOUT MY MOTHER. SHE HAS ALZHEIMER'S AND LIVES IN A NURSING HOME. WHERE DO I START?

This is a very troublesome time especially when you have a loved one who lives in a facility. Take a deep breath and let's look at this one step at a time. Some things you can do to get organized and manage this difficult time:

- Check with the facility regarding their procedures for managing COVID-19 risk.
- Provide them with your contact information and that of another family member or friend as a backup.
- Remember visits inside the facility are NOT ALLOWED at this time. This is to protect the residents, but it can be difficult if you are unable to see your family member.
- Ask the facility how you can have contact with your family member. Options include telephone calls, video chats or even emails to check in.
- If your family member is unable to engage in calls or video chats, ask the facility how you can keep in touch with facility staff in order to get updates.
- If you don't have them already get phone numbers and email addresses for key staff like the social worker and nurses' aides so you can stay informed about your loved one. Try to identify a single point of contact if possible
- Get your local ombudsman's contact information. An ombudsman can help you advocate for your loved one. You can find your local ombudsman contact info [clicking here](#).
- If you are not comfortable managing all this information enlist someone to help you

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SHOULD I DISCUSS COVID-19 WITH MY GRANDMOTHER? SHE HAS DEMENTIA AND IS EASILY CONFUSED.

It is not advisable to discuss the COVID-19 pandemic in detail with your grandmother or any other individual who has dementia or Alzheimer's disease. They most likely will not be able to process the information. The information could make them more anxious and could lead to other problems. Just reassure them that someone will be there to take care of them.

Try to live in their reality - they may believe they are somewhere other than the facility, they may think they are back in college, go with whatever they express and ask related questions. If they think they are in college, ask them how their classes are going? Who won the big game? Who are they going to the dance with?

THE NURSING HOME WILL NOT ALLOW ME TO VISIT ANYMORE. IS THAT ALLOWED? HOW AM I SUPPOSED TO KEEP TABS ON HIS CARE?

Visits to nursing homes and other facilities are now restricted. They are only allowed if some is at the end of their life. You can continue to support your relative by:

- Calling them at a specific time everyday
- Checking in with the social worker or designated staff and getting a report from them
- Calling their doctor and getting an update
- Sending handwritten letters and cards.
- Using technology, such as video conferencing (Skype, FaceTime), Facebook, text message, or email.
- "Visiting" through a window or glass door.
- Making video greetings, including through apps such as WhatsApp and Marco Polo.
- Post a video greeting, photo or note on [Virtual Visits of Cheer and Support Facebook page](#).

I GO TO THE NURSING HOME EVERYDAY TO FEED MY HUSBAND. HE WON'T EAT UNLESS I AM THERE. I AM WORRIED ABOUT HIM LOSING WEIGHT. WHAT CAN I DO?

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Restrictions on visitors to nursing homes and other facilities are in place to prevent the spread of the COVID-19 virus. Some things you can do to stay in touch with your loved one:

- If they have a window in their room where you can view them from the outside, visit them outside the window during mealtime and call them and encourage them to eat
- Call them on a cell phone and talk to them while they are eating if you cannot access a window. Video chat if possible

I'M CONCERNED ABOUT THE INCREASING NUMBER OF POSITIVE COVID-19 CASES IN LONG TERM CARE RESIDENTIAL SETTINGS. WHAT ARE MY OPTIONS IF MY LOVED ONES FACILITY HAS AN INCIDENCE OF COVID-19?

It is important to note that there are no simple answers, and, at this time, there is no way to completely eliminate the risk of your family member being exposed to COVID-19. However, there are some questions to consider if you are faced with this situation. The answers to these questions can help you make the best decision for your family.

- Moving a person home
 - What level of care does the person need on a day-to-day basis? (For example, is the person able to bathe and dress him- or herself? Are they continent? Are they ambulatory or do they need assistance moving?)
 - Is your family able to provide the level of care needed?
 - While limiting the number of people who have contact with the individual is important, it is also important to assess the number of people needed to provide adequate care.
 - Does anyone in your family have COVID-19 currently?
 - Are there individuals in the home who work outside of the home? If so, the risk for exposure is increased.
 - Is it possible to hire home care workers? This option comes with its own level of risk.

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- **Maintaining the person in the facility: Ask the facility about their quarantine procedures.**
 - What is your level of confidence that CDC guidelines are being followed?
 - How many people in the facility have been impacted by COVID-19? Are those affected staff, residents or both?
 - Is your family member able to follow social distancing procedures (with or without help)?
 - In some cases, the person may not be able to walk or move about on their own. This could help maintain social distancing.
 - Does the facility have and use personal protective equipment?
 - How many staff members interact with your family members on a regular basis? Is the facility able to limit the number of staff who work with your family member?
 - Is the facility adequately staffed to provide the level of care your family member requires?
- **Moving to another facility:** Moving a family member to another facility may be an option. However, there is no way to know whether the new facility will remain free of COVID-19 cases.
 - Is the facility accepting new residents?
 - Some facilities are not accepting new residents, depending on location.
 - Have there been COVID-19 cases in the new facility?

I AM THE PRIMARY CAREGIVER AND I'M FEELING STRESSED AND OVERWHELMED. WHAT SHOULD I DO?

As a caregiver, you likely have many responsibilities and with the increased worry and stress associated with COVID-19, it is easy to feel overwhelmed. It is important to take care of your own well-being and to connect with others that understand.

- **Know what community resources are available.**

Adult day programs, in-home assistance, visiting nurses and meal delivery If you experience signs of stress on a regular basis, consult your doctor. Ignoring symptoms can cause your physical and mental health to decline. Use our online [Community Resource Finder](#) or contact [your local Alzheimer's Association® chapter](#) for assistance in finding Alzheimer's care resources in your community.
- **Get help and find support.**

Be able to connect with other is so important during this time. You may benefit from

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local support groups offered by the Alzheimer's Association as they are good sources for finding comfort and reassurance. If stress becomes overwhelming, seek professional help.

- **Use relaxation techniques.**

There are several simple relaxation techniques that can help relieve stress. Try more than one to find which works best for you. Techniques include:

- Visualization (mentally picturing a place or situation that is peaceful and calm)
- Meditation (which can be as simple as dedicating 15 minutes a day to letting go of all stressful thoughts)
- Breathing exercises (slowing your breathing and focusing on taking deep breaths)
- Progressive muscle relaxation (tightening and then relaxing each muscle group, starting at one end of your body and working your way to the other end)

Learn more about [relaxation techniques](#) on the Mayo Clinic website.

- **Get moving.**

Physical activity — in any form — can help reduce stress and improve overall well-being. Even 10 minutes of exercise a day can help. Take a walk. Do an activity you love, such as gardening or dancing.

- **Find time for yourself.**

Consider taking advantage of respite care so you can spend time doing something you enjoy. Respite care provides caregivers with a temporary rest from caregiving, while the person with Alzheimer's disease continues to receive care in a safe environment.

- **Become an educated caregiver.**

As the disease progresses, new caregiving skills may be necessary. The Alzheimer's Association offers [programs](#) to help you better understand and cope with the behaviors and personality changes that often accompany Alzheimer's. You may also find it helpful to talk to other care partners and caregivers about how they are coping with the challenges of the disease and uncertainty about the future.

- **Take care of yourself.**

Visit your doctor regularly. Try to eat well, exercise and get plenty of rest. Making sure that you are healthy can help you be a better caregiver.

- **Make legal and financial plans.**

Putting legal and financial plans in place after an Alzheimer's diagnosis is important

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so that the person with the disease can participate. Having future plans in place can provide comfort to the entire family. Many documents can be prepared without the help of an attorney. However, if you are unsure about how to complete legal documents or make financial plans, you may want to seek assistance from an attorney specializing in elder law, a financial advisor who is familiar with elder or long-term care planning, or both.

ARE THERE RESOURCES AVAILABLE TO HELP ME?

Ombudsman Program

[Your Local Ombudsman](#) The first person you can call is your local ombudsman. Local ombudsmen are available in every county in Pennsylvania. They advocate for residents of long-term care facilities.

Alzheimer's Association

24/7 Alzheimer's Association Helpline 1.800.272.3900

This helpline provides free support and guidance to individuals and families impacted by Alzheimer's and other dementias across the country.

[Alzheimer's Association Long Distance Caregiving](#)

[Alzheimer's' Association Tips for Dementia Caregiver Tips During Coronavirus](#)

[Emergency Preparedness Tips for Individuals with Dementia](#)

These tips are primarily for providers of long-term care, but they can provide you with valuable insight into what the long-term care facility should be doing to provide adequate care.

[Other Alzheimer's Association Resources](#)

[Caregiver Guidance on Aphasia](#)

[10 Methods to Calm Agitation and Aggression in Older Adults with Alzheimer's](#)

[6 Easy Caregiving Tips When Dealing with Dementia](#)

[Mayo Clinic Tips for Caregivers](#)

[National Institutes of Health Alzheimer's Caregiving](#)