

Caregiving in a time of Coronavirus

A message from your Alzheimer's Disease Research Center

We are addressing this to all the family members and friends who provide care for persons living with Alzheimer's disease and similar illnesses. The care you provide is always vital to the quality of life and well-being of that person. The Coronavirus Disease (i.e. COVID-19) pandemic places extra burdens on you in providing that care. We want to provide you with information you can use to strengthen the effectiveness of your caregiving and assist with your own peace of mind during this time.

Some Basic Facts. The information below represents what we currently know about COVID-19. We present these facts starkly because this is a serious situation. Having good information should help you to protect yourself and your person with dementia.

Something New. Coronavirus, or "COVID-19", is a virus that attacks the respiratory system and, rarely, other organs as well. Because it is a new strain, very few people in the population have immunity to the virus and are vulnerable to infection. Currently, research is underway to develop a vaccine. Research is also working to identify medication that is useful for prevention or treatment of persons infected with the virus.

Risk Factors. COVID-19 requires the body's immune system to mount a response to fight it off. According to the World Health Organization, people with weak immune systems may be at increased risk of becoming severely ill with the virus. Two factors are associated with weakened immune response: age and underlying chronic conditions. Those over 65, may be at higher risk for severe complications if they acquire the illness. Also, smokers and individuals with chronic conditions like cancer, lung disease, diabetes, and heart disease may be at increased risk of severe complications related to COVID-19.

Points of Entry. The virus is thought to be spread through respiratory droplets produced when an infected person coughs or sneezes. The virus can enter the body through the nose, eyes, or mouth and then proceed to the lungs. This is why we are advised to avoid touching our face. And why social distancing and avoiding crowded situations are recommended.

Alzheimer's and COVID-19. The person for whom you provide care may be in a high-risk situation. Most persons living with Alzheimer's are over the age of 65 (one risk factor), and most persons over 65 have at least one, and typically more than one, chronic illness (the other risk factor).

The CDC website is an excellent source of reliable information:
<https://www.cdc.gov/coronavirus/2019-ncov/index.html>

Local Health Department Numbers can be found here
https://www.cdc.gov/coronavirus/2019-ncov/downloads/Phone-Numbers_State-and-Local-Health-Departments.pdf

Guidance for Caregiving. We recognize that we are relatively early in this outbreak and that information and guidance is coming out in an ongoing way, so the guidance we are providing is guidance for now. It will certainly change, and we will provide updates as we learn of them. Follow these general rules to protect you, the person you care for, and your family.

General Rules – Please follow these rules even if you or your person has not been diagnosed with COVID-19 or neither of you is showing signs of it.

Self-Care. The best protection for you and those you care for is for you not to acquire the virus by implementing social distancing, frequent hand washing, and avoiding touching your face. Do your best to stay healthy. Take your medications as prescribed and follow your exercise and rest programs.

Handwashing and Sanitizing. If you leave the home, always wash your hands when you return as well as frequently during the course of the day. Cleanse hands with soap and water for at least 20 seconds (sing Happy Birthday twice). Use hand sanitizer with at least 60% alcohol often. Use hand lotion to prevent drying and cracking of skin.

Do not Shake Hands. Avoid direct physical contact. Wave; nod; bow; give the peace sign, instead of handshakes or fist bumps. Remain at least 6 feet away from people who are not in your household.

In Your Home. Clean surfaces in your home using a usual household disinfectant such as Lysol or Clorox. Clean doorknobs, sink handles, refrigerator and oven doors, steering wheels, and other high-use surfaces daily. Change hand and kitchen towels often. Open windows (if possible) to increase ventilation.

Manage Underlying Chronic Conditions. Chronic conditions, such as diabetes, heart disease and COPD tax the immune system. Adhere to management regimens to prevent the condition from worsening. Ask providers to call in refill orders and see if the pharmacy can deliver – or has a drive through pickup window. Do this for the medications that both you and your care-recipient take.

Monitoring. Watch yourself and your person for symptoms (fever, cough, shortness of breath). Take your temperature at least once a day.

Social Distancing. Remove yourself and your person from close contact with groups of people. This is admittedly very difficult, so here are some thoughts:

- If you are working outside the home, see if it is possible to work at a distance through telecommuting means (phone and videocall contact, etc.)
- Examine patterns of social interactions.
 - If you regularly attend worship services, see if your place of worship offers streamed services, or consider using the regular time of attendance as a time of home worship.
 - If you take your person shopping or to malls, reconsider. If you must, perhaps use smaller shops at off-hours, and avoid very crowded places. Call friends, family, or neighbors to see if they are going to the store and can pick up items you might need
 - Think about outings that present minimal risks: going to large parks, taking walks

- Order take out from restaurants and see if they can deliver curbside
- Here's a really hard one: family visits should be avoided until the Stay Home, Stay Safe order is lifted. If anyone does come for visits
 - Keep them small – one or two people at a time
 - Ask everyone who feels unwell, has come into contact with people with the virus, or has any symptoms to stay away. Ask all others to follow the same safety rules you are (frequently washing hands, disinfecting surfaces, and maintaining social distancing).
 - Avoid visits from small children who may not adhere to these safety rules as necessary
- Do not Shake Hands. Avoid direct physical contact. Wave; nod; bow; give the peace sign, instead of handshakes or fist bumps. Remain at least 6 feet away from people who are not in your household.

More Home Engagement Opportunities. If you have relied on outings – like those listed above – as a way to keep your person pleasantly occupied during the day, then removing them from the schedule means you have to fill in those times with other engaging tasks and activities. So, plan for that. Consider the kinds of at-home activities that seem to please and engage your person. Are there ways to repeat such activities over the course of a day? Are there similar kinds of activities you might try (if the person enjoys helping with cooking, might s/he enjoy helping with the laundry)? Try new things out and add those to your toolbox that you see to be working well.

Pay Attention to Your Own Isolation. be sure to check to see how this is making you feel. Take some preventive steps before you begin to feel a sense of being isolated. Make arrangements with family, neighbors and friends to have regular virtual contact. Phone and FaceTime calls can be helpful. If a friend or family member can come in to be with your person for brief periods of time, seek and accept that help, and take yourself for an outing – observing all the rules when you return (and also the advice about having help come in).

Help from Outside the Home. If you have someone coming into the home to help care for your person, then the rules should apply to them as well. The person should adhere to hand washing rules, be urged to follow good self-care procedures, and monitor him/herself for symptoms of COVID-19. If a home health care worker comes to your home and also visits other

homes, ask to review the procedures she or he has in place to prevent the spread of COVID-19 to their clients.

Medical Care. You are very likely in a position where you have to manage your person's routine and chronic health care as well as to respond to changes in condition or react in an emergency situation. It's important to recognize that, with COVID-19, you need to have a plan for how to handle some medical situations that might arise in the course of If additional funds are received from funders, we may allocate boxes to regions based on funder preference.

Primary care providers (nurse practitioners, physicians, physician assistants) can bill for telehealth with Medicare and Medicaid patients. So, call the office and see if they have put procedures in place for handling – through a phone call or a video call – routine visits and visits related to any concerns you may have. If they don't, ask for advice about

- Handling routine and chronic care situations that you'd usually manage by bringing the person to the office.
- Dealing with possible COVID-19 symptoms
- Responding to emergency situations – should you call the office first? Go directly to an Emergency Department?

If you feel you have an emergency, but are not sure, and cannot get through to your primary care provider, call your local Emergency Department. Most have a nurse or physician on duty who can offer advice about the need to come in immediately or wait at home.

If you think you or your person might be showing signs of COVID-19 and think you should be tested, it's important to **call** your primary care provider (or the Emergency Department or your Health Department) first. They may be able to provide advice about whether you need to be tested immediately or if it is appropriate to wait. If you do need to be tested immediately, they may also be able to direct you to the appropriate testing location. In many areas of the country, the clinic office or Emergency Department may not be where you can get tested, and testing sites may need a provider's referral before they will test you.

If you and/or your person are participating in a research study, call your research coordinator for current information. Some studies have been put

on hold; others may have moved to enable contact at a distance (e.g., by phone).

If Your Person is Living in an Assisted Living or Skilled Nursing Facility:

It is increasingly likely that visitors, even close family, will not be permitted to visit relatives in such facilities.

See if the facility can help you to make contact at a distance. Can they help put a phone call through? If the facility has WiFi and if you have an extra phone or tablet computer (iPad), will they help the person to use it when you call so the person can see your face.

The staff will continue to provide care and comfort, but you will not be able to have in-person time with the person that may be important to you. If you are alone and feeling this as yet another loss, take action. Try to go out for a walk, call family and friends, listen to your favorite music, look at scrapbooks or read a good book. If you belong to a church or synagogue, call and ask to be put on a prayer list. Many religious staff are working from home and can respond to your messages. Have family and friends mail cards and letters to them.