

National Alzheimer's Project Act (NAPA)

The information that follows was share through the NAPA Listserv.

For more information about NAPA, visit the NAPA website at:

<https://aspe.hhs.gov/national-alzheimers-project-act>



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Caregiving in a time of Coronavirus

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 the person for whom you provide care. The Coronavirus epidemic 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 during this time.

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

Something New. Coronavirus – or Covid-19 as it is now called – is a new strain of a virus that attacks the respiratory system, but other organs as well. Because it is a new virus, there are very few people, no matter how hardy, that have a natural immunity to it. Our bodies haven't seen this before, so our immune systems haven't developed ways to fight it off. Also, there is, as yet, no vaccine, so no medical measures can yet be taken to protect us against it.

Serious. It is difficult at this time to have a very accurate picture, but Covid-19 appears to be a serious disease threat. The Centers for Disease Control and Prevention (CDC) include, in their range of possible futures for the illness, a prediction that more than half of the US population could be infected. The illness appears to have more serious outcomes than the flu, and death rate predictions are higher.

Risk Factors. Covid-19 requires the body's immune system to mount a response to fight it off, so anyone with a weakened or compromised immune system is at risk. Two factors are associated with weakened immune response: age and underlying chronic conditions. Those over 60, and especially those over 80 (even those who seem fit), are at higher risk for acquiring the illnesses. So too are individuals with chronic conditions like lung disease, diabetes, and hypertension and heart disease – as well as those who are immunocompromised (e.g., undergoing chemotherapy treatment for cancer).

Points of Entry. The illness enters the body through the nose, eyes, or mouth and then proceeds to the lungs. This is why we are advised to avoid touching our face or to be in crowded situations in which particles expelled through coughing and sneezing might be inhaled.

Alzheimer's and Covid-19. The person for whom you provide care is 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>

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.

Self-Care. It is likely that you are the person with whom your person has the most daily contact, so the best protection for the person is for you not to acquire the virus. So you should follow the general rules outlined below as well as ensuring that your person does too.

General Rules.

Handwashing and Sanitizing. If you or the person leaves the home, wash your hands – both of you – when you come back. Do it right away and do it for 20 seconds (sing Happy Birthday twice).

Manage Underlying Chronic Conditions. If the person has one or more chronic conditions, these are already taxing the immune system. So adhere to management regimens to prevent the condition from worsening and further taxing the person's system.

Monitoring. Watch yourself and your person for symptoms (fever, cough, sore throat)

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. Perhaps use smaller shops at off-hours, and avoid very crowded places
 - Think about outings that present minimal risks: going to large parks, taking walks
 - Limit going out to restaurants – or stop altogether
- Here's a really hard one: family visits.
 - Keep them small
 - Ask everyone who comes to follow the same safety rules you are (wash hands)
 - No grandkid visits

Caregiving Under These Conditions. If you follow these “general rules,” there are two things you will need to think through.

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. If following the “rules” means you are finding yourself more homebound, be sure to check to see how this is making you feel. Perhaps take some preventive steps before you begin to feel a touch of cabin fever or a sense of being isolated. Make deliberate arrangements with family, neighbors and friends to have regular contact. Phone and FaceTime calls can be helpful. If you do take walks with your person, invite another person along. 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 general rules should apply to that person as well. The person should observe the kinds of hand washing and sanitizing you are observing, be urged to follow good self-care procedures, and monitor him/herself for symptoms of Covid-19.

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 caregiving.

If you have a primary care provider (a nurse practitioner, physician, or physician’s assistant), contact the office to see if they have put procedures in place for handling routine visits and visits related to any concerns you may have should you observe possible Covid-19 symptoms. 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
- Expected delays for elective procedures
- Responding to emergency situations – should you call the office first? Go directly to an Emergency Department?

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.