## Questions and answers about caregiving during COVID-19



- 1. How can caregivers help loved ones with dementia living in a long-term care community feel less isolated if they can't visit them? Communication with a person with dementia living in a care community during this time of social distancing will depend on the stage of the disease. For those who are in the earlier stage, using Facetime, an Echo Dot, or Skype can work, with the assistance of the staff as needed. Sending short notes and greeting cards with photos by mail can help the individual feel connected. If possible, you might arrange to stand outside a window and talk on the phone with your loved one so they can see you and hear your voice at the same time. Communication should be positive, centering around the key message that the individual is loved and cared for.
- 2. How should caregivers respond if their loved one expresses anxiety or questions why they can't have visitors or why they have to stay in their room during this time of social distancing? There are a lot of unknowns with this current situation. It's best to acknowledge feelings ("I know this is difficult", "This is a strange time for all of us") and provide reassurance ("Everything is going to be okay", "We are all thinking of you") and then introduce a topic for discussion ("I was thinking about that quilt you made me for my wedding. Was that the first quilt you made?"). Talk to the staff if anxiety persists.
- 3. What questions should caregivers with individuals with dementia who live in long term care be asking the staff during this time when they can't make visits? Even if your loved one lives in a care community, you are still an important part of their care team. Attempt to work with the staff to address concerns and meet the needs of your loved one by calling or emailing the social worker or director of nursing at the care community. Ask whether your loved one needs any toiletries and supplies not provided by the care community. Ask if they have observed any changes in behavior or sleep habits that might be a sign of depression or anxiety. Provide information about things that could help bring comfort and reassurance such as looking at family photos or listening to books on tape. Work with the staff to identify ways to communicate with and support your loved one.
- **4. How can I support the staff of the care community in caring for my loved one?** This is a challenging time for care community staff. They may be working extra hours or may be concerned about their own family. Support services such as volunteers and those who normally come into the care community to provide entertainment or activities are also not able to visit at this time. Be sure to show appreciation by sending an encouraging email, card or even flowers to let them know they are appreciated. One staff member at a local care community reported that donations of masks, gloves and cleaning supplies (disinfectants) are needed by nursing homes. This person also asked for prayers and for people to stay home as much as possible.
- 5. How can caregivers adhere to social distancing if the person with dementia doesn't understand or doesn't believe that this is an issue (for example, they want to go to the store or go visit friends and family?) A person with dementia may not be able to understand the widespread impact on socialization for many reasons, including dementia's impact on memory, thinking, and logical reasoning. If mom or dad asks to go to the grocery store, state that you are having food delivered or that you will take care of it, then move the conversation along. Carefully explaining the situation may not work and instead cause irritation. Redirection may be a key strategy to use during repetitive questioning. Follow the guidance and instructions from the Centers for Disease Control and Prevention (CDC) to wash your hands frequently, and apply moisturizers to avoid drying out the skin. Avoid touching your eyes, nose, and mouth. Take medications appropriately, adopt social distancing practices to the extent possible, don't share items, and regularly disinfect frequently touched surfaces, even in your own home.
- **6.** How can caregivers encourage other family members and friends to stay involved in their loved one's care if they can't come over to visit? Supporting the primary caregiver virtually is a great way to help relieve the caregiver and provide respite. For example, they can reach out through Facetime, video chat, or by calling the person with dementia to reminisce. The idea is to spark a memory or simply share a story of a memorable moment without asking "do you remember?" Additionally, a caregiver that is feeling socially isolated on top of being told to remain at home, might benefit from virtual social time including chatting virtually, watching a movie, playing a virtual game, or eating dinner together virtually.
- 7. How can caregivers support individuals with dementia who live alone at this time? How can you help them with safety issues? Many people with Alzheimer's can live successfully on their own in the early stages of the disease. However, safety precautions that have been implemented may need to be increased by the family. Consider the essential needs for day-to-day living: how is the person with dementia getting their food? Is he or she still driving? Who is able to check in on the person with dementia during the week? Is he or she able to stay in touch with their social circle? If you assess that the person with dementia is isolated, not able to get their meals, or is experiencing increased confusion from the stress of social distancing, it's time to consider alternatives. For example, you may ask the person with dementia to move in with you temporarily. If that is not a possibility, think about who can help purchase groceries, drop off meals, or do a daily check-in. This may be a time to reach out to the neighbor, close church friend, and your family to pitch in and work together. It may be helpful to keep a weekly calendar of who is able to help, with what task, and when they are doing it. Please take into account that increased stress from the news on COVID-19, prepping, and social distancing may cause increased confusion and reduce the person with dementia's ability to live alone. Their safety is top priority!
- services be used safely at this time? These types of community-based services are currently functioning on a case by case situation. It's important to think ahead and make plans in case an adult day care or other service is canceled or changed. If you are thinking of bringing in a new service, such as in-home care, make sure to ask what safety precautions they have implemented to protect the safety of their clients. You can also do your part and disinfect frequently touched areas and encourage handwashing to reduce the risk of possible transmission. Our 24/7 Helpline (1-800-272-3900) is available to provide you with names and contact information of resources in your area.

  9. How will COVID-19 impact individuals living with dementia? There is no current Alzheimer's or

8. What outside care options are available at this time, such as home health, or adult day care. Can these

that it does not increase the risk for flu. However, people with dementia are typically older and may have health conditions that do increase their risk for COVID-19. According to information provided by the CDC, people with dementia are often underdiagnosed and undertreated, so look for flu or pneumonia-like symptoms, take the person's temperature and contact their doctor for assessment and treatment as soon as possible. To reduce the risk of exposure, please follow the CDC guidelines, including: avoid contact with people who are sick, clean and disinfect frequently touched objects, help the person with dementia wash their hands with soap and water for 20 seconds, and stay home.

People living with dementia may become more confused, frustrated or even display an increase in dementia-related behaviors during a crisis. Individuals are often less able to adapt to changes in their environment,

dementia-specific data on COVID-19. Dementia likely does not increase the risk for COVID-19 since we know

and may react to others' stress. It is recommended to try to minimize any changes in routine, environment and daily structure for individuals with dementia. If you observe a sudden increase in confusion, contact the doctor.

10. What can caregivers who are now working from home and trying to manage the care of a person with dementia do to manage stress? Working from home while also caring for someone with dementia can be

challenging. Maintaining a daily routine will help both you and your care recipient. In order to give yourself time to

do your work, consider setting a timer or a clock alarm and placing it in the room with the person with dementia. Let him or her know that you will be back to check in when the alarm goes off. You can also attempt to create a quiet work environment by asking your care recipient to help you sort through "files" or "books" while you work. You can also set-up a schedule of friends/family who will call your care recipient to engage them in conversation so you can focus on work. This is a challenging time and you may not be at your most productive, but know that you are doing your best.

Everyone needs a break or "respite". In times when the caregiver and care recipient are forced to stay home together all or almost all of the time, finding a way to get respite is more important now than ever. In order to get some time to yourself, consider creating a "Respite Zone" in your home, a space to go to for some time off.

According to Maria Meyer and Paula Derr, authors of The Comfort of Home: A Complete Guide for Caregivers, respite zones could be your bedroom, a spare room, or an office. It should be a private, comfortable place for you to take a break while the care recipient rests or is taken care of by someone else. It is important for the people you live with to understand that this space is yours. If you don't have a physical place you can go for this private time, you can create a "psychic respite zone" where you close your eyes and practice mindfulness or another form of meditation. The key is to set aside time to relax, meditate, listen to music, read, do something fun or complete an activity such as sewing, or surfing the internet. You may need to get creative. For instance, in order to discourage interruptions, you may need to pretend you're on the phone while you're taking a break in your respite zone. It isn't selfish to set aside time and space for yourself. It is important to take this time to refresh and relax so that you are in the best state of mind to support your care recipient.

11. What can caregivers do to plan for the possibility that they or the person with dementia develops COVID-19? It is important to provide a calm, positive environment for the person with dementia. Some advance planning can help reduce your own stress. Check with your pharmacist or doctor about getting prescriptions filled

- for a greater number of days to reduce trips to the pharmacy. Consider who would take care of the person with dementia if you become sick, and create a list of information that person would need in order to take over their care such as insurance information and a list of their doctors and medications. Advance planning is important to ensure an individual's wishes regarding treatment and care options are fulfilled. Make sure that the individuals' advance directives, Provider Orders for Life-Sustaining Treatment (POLST), and other documents are all up to date with current documented wishes, and that physician orders are consistent with these wishes. Make sure that these wishes are followed if a transfer of care becomes necessary.

  12. How can caregivers keep the person with dementia engaged in meaningful activities when they can't leave home? A dementia diagnosis does not mean that the person with dementia loses the desire to participate in
- leave home? A dementia diagnosis does not mean that the person with dementia loses the desire to participate in meaningful activities, even as the disease progresses. Try to provide the opportunity for structured activities throughout the day. An individual who was the homemaker may still wish to help manage the household and the breadwinner may experience loss and depression from having to retire. It's important to encourage a person with dementia to remain active socially and cognitively. It is also important to ensure that persons with dementia get regular exercise. Think about what activities they enjoyed in the past and how that activity can be modified into an activity that only requires 1 or 2 steps. For example, a person with dementia may not be able to do all of the laundry, but asking them to fold a load of laundry that just came out of the dryer may be simple enough. To fulfill a sense of purpose, let the person with dementia know how meaningful or helpful the task would be to you, their children, or even grandchildren. Activities are a good way to stimulate the brain and body and can help reduce behaviors like agitation or wandering. You can also enjoy some family time by completing a word search or jigsaw puzzles together! Walking is a purposeful activity that promotes mobility and strength building.

Unsafe wandering occurs when a person living with dementia gets lost, intrudes into inappropriate places or leaves a safe environment. The risk for unsafe wandering may increase when the person becomes upset, agitated or faces stressful situations. Possible interventions include: Provide persons with dementia the opportunity to walk about in a safe and secure area within the home, as well as outdoors.