



Caregiving During Challenging Times

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While the promise of spring means caregivers may face more days when they can be outdoors, we are still in a season of spotty weather and social isolation. This year, of course, we have an added layer of complexity with the coronavirus pandemic. By the time winter started this year, most of us had already been holed up in our houses to isolate ourselves from others for several months. The place in which we usually seek refuge can feel like a cage that holds us away from the rest of the world.

Caregivers must be constantly thinking of the person they care for and how they may have to navigate situations that arise. If you are a caregiver, you are already aware that every situation comes with its own tricky issues. For those reasons, I want to share a few tips that I have learned from my work with an Alzheimer's support group that I facilitate from my work at an adult day care facility and from interacting with seniors as a social worker. There are ways we can do more than just cope in our roles of care providers, and even to enjoy it as sacred and peaceful time spent with people we care about.

DON'T TAKE ON TOO MUCH

As we approach the spring and summer holidays, we can take lessons from other special occasions. The holidays are usually rich with tradition, perhaps baking Easter sugar cookies made from great-grandma's recipes or putting up seasonal decorations collected over years past. It can be fun and magical to get swept up in the holidays, but it can also mean a lot of extra work for you. As a caregiver, you are already busy as you keep an eye on your loved one and care for them throughout the day (and night!).

Think of activities you can do together that are

rather simple and do not require extensive preparation and cleanup. A caregiver told me that he stayed up at night for days before Thanksgiving, simply dreading the huge meal he has prepared for over 20 years for the family. The meal requires hours of prep work, wrapping it all up to transport a few hours away to the relatives' home and then finishing the cooking there. Two nights before Thanksgiving, he decided to call the relatives and say that he was not going to make the traditional meal that year. He decided to make a smaller meal with fewer sides but kept the turkey as he enjoys making it once a year. By reducing his list of things he had to get done, he was able to enjoy the holiday more and stress less. This caregiver shared that once he made that phone call, it felt like "a ton of bricks was lifted off my back" (those were his exact words!). You already take on heroic feats each day, there is no need to make things harder for yourself. Think about the parts of the holidays that you want to keep and try to keep large projects for another time.

LIMIT TRAVEL

Another suggestion that I have heard from caregivers is to limit driving and traveling time. Long drives can pose a problem, especially when it is



time to use unfamiliar restrooms. Adult diapers and other incontinence products can be used, but they are often uncomfortable for the wearer; I have heard from some caregivers that their loved one simply refuses to wear them or keep them on. Using a public restroom can be challenging, for both the caregiver and the loved one. When I worked at an adult day care program, we assisted the residents in using the bathrooms and often a participant with dementia would take off clothes that can be a challenge to get back on, or the person might forget how to use the toilet. This can make it tricky to use public restrooms, especially if family restrooms are unavailable. Since travel is already limited due to the pandemic, it should be easy to limit time on the road. The overall message is it helps to keep the to-do list short, relax with your loved ones and make new memories to cherish.

TAKE WALKS AND EXERCISE

By this stage in the coronavirus pandemic, you have certainly heard that walks are a good idea. Of course, this is not anything new to us, but the reminder to get outside (and out of that house) is a good one. Cabin fever is a real thing and during the pandemic, I think a lot of us are feeling the symptoms. Getting outside with someone who has Alzheimer's can be challenging. Remember that creativity and flexibility are two of your greatest skills as a caregiver. If your loved one can walk, go for a walk with them around the neighborhood and point out different things you see to engage her or him. For example, look for fun yard decorations, pets lounging in windows or beautiful flowers that you walk past. Talk about the shapes you see in the clouds or the different types of trees and plants around you. For safety, make sure to not walk on icy days and if you are walking on sidewalks, be careful of uneven edges that could cause someone to trip or fall. Try to avoid using the car as it will be an extra hassle for you and take away from the relaxation of the walk. If walking is not an appropriate activity for your loved one, perhaps you can use weights to exercise while they sit nearby, or practice yoga before they wake up. Consult their physician or physical therapist to see what exercises are appropriate for them or your own health care providers

for some suggestions of home exercise for you.

Exercise is an excellent stress reliever. When you are a caregiver, your health is twice as important as you are caring for not only yourself but also someone else. Exercise will help you have the energy to keep going, to maintain your health, and the time you spend exercising can be a special time for either yourself or for you and the person you care for.

HONOR WHAT IS GOING ON, BE HONEST AND OPEN

It is unfortunate but true that there is a stigma surrounding Alzheimer's and dementia. It may not be something you want to share with anyone. Remember that there is nothing for you to feel embarrassed or ashamed about! That old saying "the squeaky wheel gets the grease" is very true; if you do not share your situation or your struggles with family or close friends, they will not be able to help you out. Be honest if you need a break. Family members can help in different ways. Family members nearby can help out with respite options and family members far away can provide an ear to listen and a friendly face for a video call. Use the resources and connections that you already have to help you. Caregiving is hard and it is perfectly normal to need help once in a while.

Have honest conversations with your family about what is going on with the person you care for. This will make it easier for them to understand how you are feeling and it may bring you closer. Family members may offer to Zoom each week or send fun mail (receiving mail can make

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the loved one feel special and remembered). For a man with early onset Alzheimer's who loves old American cars, members of his family sent him vintage postcards featuring different cars from the '50s, and they sent books with lots of pictures and illustrations of the cars.

If your social network is lacking, there are national resources available to you and there are



virtual support groups just for caregivers. Both the Alzheimer's Association and AARP offer support groups specifically for caregivers. These are currently online due to the pandemic, but you can find a support group near you on their websites. There are also many books on Alzheimer's disease and other types of dementia, such as the well-known book *The 36-Hour Day* by Nancy L. Mace and Peter V. Rabins, which some consider to be the best resource book on dementia for caregivers available. I have even seen books that help explain Alzheimer's to young children who may be confused or scared by the new things grandpa has been doing or saying. The take-home message here is: you are not alone. Connect with the community around you and familiarize yourself with available resources. Do not make things harder for yourself by reinventing the wheel or trying to do it all on your own.

TAKE CARE OF YOURSELF, BODY AND MIND

As a caregiver, you are so focused on the well-being of someone else that it is very easy to simply forget that you have needs as well. A caregiver shared with me that she had an internal battle with herself over the amount of time her husband was sleeping. Normally an early riser, the woman's husband (in the mid-stage of Alzheimer's disease) started sleeping until past noon. At first the woman would wake him up early to get started with the day. She felt badly letting him sleep all day and worried he was sleeping too much. The woman decided, after speaking with her husband's doctor, that she would let the man sleep in until 11 a.m. She made this decision after gathering the appropriate facts to make sure it was all right to let him sleep that much, and it was. Now, she wakes early and spends the morning with herself. She says that she is incredibly grateful for that time in the morning, which allows her to videochat with her support group or others without having to worry about what her husband is doing. This time also offers her some time to take care of herself; carving out time just for you is so important. It offers you a mini-respite each day

and that will allow you to stay fresh, energized and less stressed about your many duties and responsibilities.

Consider your own situation and think of what you need. Is there a time that is just yours during the day? If you can, make a special time for yourself. You can use the time to do things you already enjoy or to find new hobbies. Journaling is a won-

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derful hobby that can be customized to an individual's preferences; a visual person may draw their memories and a more analytical person may enjoy writing out their feelings that day. Journaling is a good activity for caregivers because it helps connect a person to their feelings and emotions. Journaling allows us to set aside time just for us to reflect and process what has happened. If you are not into journaling, even a simple daily reflection would work, perhaps while you drink your morning coffee.

It is important to take time to care for yourself. If you have a few minutes alone, you will be able to check-in with yourself. Ask yourself what you need right then: sometimes just a snack or to breathe deeply for a few peaceful minutes helps us feel better. It is crucial to be in tune with your own needs, just as you are with the loved one you care for.

Remember above all that you are doing this job of caregiving out of love. It is one of the kindest acts a person can do for another, caring for someone when they cannot care for themselves. Caregivers are strong, and I hope these suggestions combined with what you are already doing makes this time a little easier on you and your loved one.

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