

# The COVID-19 Stay-at-home Survival Guide for Those Caring for a Loved One with Dementia

Penn Memory Center, Layton Aging and Alzheimer's Center and KU Alzheimer's Disease Center

Precautionary measures are being taken to reduce the risk of exposure to COVID-19 (Coronavirus). In addition to frequent hand washing, the CDC has advised practicing “social distancing” by avoiding close contact with those that are sick and staying home as much as possible. There has meant limited to no access to care programs and services, such as adult day centers and home care, that individuals with dementia and their caregivers rely on for support. Isolation, increased stress, and changes in daily routine can generate challenges for you and your loved one with dementia. This article offers guidelines for managing daily care at home and coping with anxiety during this difficult time.

Learn about COVID-19 and how to protect yourself here:

<https://www.cdc.gov/coronavirus/2019-ncov/index.html>

## General Tips for Caregivers:

- **Stay calm.** People with dementia are very aware of non-verbal communication such as tone of voice and body language, and will often mirror it. If you are calm, your relative is more likely to be calm as well. See below for our tips on managing your own anxiety.
- **Expect some changes.** Stress, anxiety, and changes in routine can all have a negative impact on your relative's cognition. This is usually temporary, and most people will return to, or close to, their baseline once life returns to normal.
- **Look out for sudden, drastic changes, though.** As always, this could be a sign of pain, illness, or infection. If you see this, contact your relative's doctor.
- **Limit TV news.** People with dementia may not remember the content of a TV show or a movie, but they'll remember how it made them feel. Try to avoid exposure to too much panic-inducing coverage and stick with something lighter, like a cooking or travel show.
- **Simplify the message.** If your relative asks what's going on, try to make your explanation as simple as possible, focus on positives, and redirect to a favorite activity. A good place to start is: “there's an illness going around, but you're safe with me inside the house. Can you help me remember how to play that game you like?”

- **Set a daily routine.** Try to have your relative wake up, eat, and go to sleep at around the same time every day, if possible. You can also try to create a schedule to keep your relative busy and engaged throughout the day, which will improve their mood and decrease challenging behavioral symptoms. See below for an example.
- **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 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.

- **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. 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) first. They may be able to provide advice about where and if you need to be tested immediately or to wait. The clinic office or Emergency Department may not be where you can get tested

- **Research.** If you are a participant in a research study, call your research coordinator for instructions for follow up.
- **If Your Person is Living in an Assisted Living or Skilled Nursing Facility:** Most visitors, even close family, are not permitted to visit relatives in long term care facilities. Ask about a point of contact in the facility and request a regular time to be

updated on status of your family member, precautions and status of virus presence in the facility. Send cards, letters to them and have family and friends do the same.

## **Anxiety-Busting Tools for Caregivers**

- Take 10 slow, deep breaths in through your nose and out through your mouth.
- Play the 5-4-3-2-1 game to ground yourself: name 5 things you can see, 4 things you can hear, 3 things you can touch, 2 things you can smell, and 1 thing you can taste.
- Do some progressive muscle relaxation. Tense and relax one body part at a time, starting with your toes and slowly moving your way up to your head. Tense for about 5 seconds, and relax for about 30 seconds.
- Sit or lie down in a comfortable position and listen to a guided meditation, like these from Tara Brach: <https://www.tarabrach.com/guided-meditations/>
- Pamper yourself: put on some soothing music, light a candle, and take a hot shower or bath.
- Go for a walk around the block, or do an at-home yoga video, like these from Yoga With Adrienne: <https://www.youtube.com/user/yogawithadriene>
- Call a close friend or family member and catch up for a few minutes.
- Reach out to a KU ADC social worker for emotional support. You can email Michelle Niedens at [cniedens2@kumc.edu](mailto:cniedens2@kumc.edu) or Karen Clond at [kclond@kumc.edu](mailto:kclond@kumc.edu).
- Call the Alzheimer's Association's 24/7 hotline (800-272-3900) or the Alzheimer's Foundation of America's 24/7 hotline (866-232-8484).

## **Meaningful Engagement**

Meaningful engagement for your relative with dementia will be a crucial component of your caregiver toolbelt during this time of isolation because it can improve mood, improve sleep, decrease agitation, and decrease challenging behavioral symptoms. Focus on pleasant, stimulating, and meaningful activities that foster emotional connections and engage your loved one's senses and memories.

### **General Useful Tips:**

- Focus on process rather than results. If your relative spends an hour sorting items and they're more jumbled than they were to begin with, that's ok! It's most important that they are engaged.
- Break activities into small, manageable chunks. For example, if your relative used to throw elaborate dinner parties, try giving them small, discrete tasks one at a time (ie:

“please mash these potatoes,” or “let’s go through this cookbook together and choose a menu”).

- Focus on roles. Humans want to feel useful! If your relative worked as a nurse but had to retire, think about what they might have gotten out of their work. They probably enjoy helping and nurturing people during a difficult time, so you might try giving them a “case” and asking for advice. Or, introduce any activity by saying, “I need your help with this. Can you show me how to do it?”
- Choose activities that can be done in short bursts. People with memory loss often have shorter attention spans and difficulty concentrating.
- Choose physical activities over sedentary ones, when possible.
- Have a few activities available so if your relative tires of one you can move on to another quickly.
- Have materials set up in advance and keep the surrounding environment as distraction-free as possible.
- Change your approach:
  - a) Instead of asking “Would you like to \_\_\_\_?” Try, “Now it’s time to \_\_\_\_” or “I would love for you to join me.”
  - b) Instead of asking at all, sit down next to your relative and quietly start doing the activity yourself.
- If your relative refuses an activity, don’t force them to participate. You can always try again in a few days, weeks, or months.
- Be confident and positive in your approach. If you’re skeptical that your relative won’t like an activity, they may pick up on your non-verbal cues and feel skeptical as well.

## **Engagement Ideas:**

### **ARTS & CRAFTS**

Cut pictures from old magazines or catalogs and create a collage to display or send to a family member

Decorate/write cards or postcards together to send to friends and family

Paint

- Try using nontraditional materials

Print coloring pages

- <https://www.justcolor.net>
- <https://dailycaring.com/free-coloring-pages-for-seniors-our-top-5-picks/>

## **ENTERTAINMENT**

### ***LISTEN***

Create music playlists on phone applications such as “Spotify” or listen to premade ones

- [https://www.youtube.com/playlist?list=PL3JT1T\\_sADDE7p3TCHLZFKU5wS0BnQLpL](https://www.youtube.com/playlist?list=PL3JT1T_sADDE7p3TCHLZFKU5wS0BnQLpL)

Listen to podcasts or informative TEDTalks

- <https://tunein.com/podcasts/>
- <https://storycorps.org/podcast/>
- <https://www.ted.com/talks>

Rent and listen to audiobooks online

- <https://bookriot.com/2016/09/15/11-websites-find-free-audiobooks-online/>
- <https://www.audible.com>
- <https://www.audiobooks.com>

Sermons/religious services

- For those whom faith/spirituality is important and reassuring, many faith communities provide sermons online. Talk with your faith community and they can direct you.

### ***LIVE CAMS***

Berry College eagle cam

- <https://www.berry.edu/eaglecam/>

Georgia Aquarium

- <https://www.georgiaaquarium.org/webcam/beluga-whale-webcam/>
  - African penguin, underwater puffin, beluga whale, ocean voyager, piranha, jellyfish, California sea lion, Indo-Pacific Barrier Reef

Kansas City Zoo

- <https://www.kansascityzoo.org/animal-cams/>
  - King penguin, Gentoo penguin, polar bear, Masai Giraffe

Monterey Bay Aquarium

- <https://www.montereybayaquarium.org/animals/live-cams>
  - Aviary, coral reef, jellyfish, kelp forest, Monterey Bay, moon jelly, open sea, penguin, sea otter, shark

Puppies

- <https://explore.org/livecams/currently-live/service-puppy-cam>

St. Andrews golf course, Scotland

- <https://www.standrews.com/Play/Links-webcam>

Train rides

- [https://www.youtube.com/channel/UCP8wWzfUcral\\_E6iNMdIdKg](https://www.youtube.com/channel/UCP8wWzfUcral_E6iNMdIdKg)

Use explore.org to explore hundreds of live cams from around the world documenting a variety of animal species

- <https://explore.org/livecams>

### **VIRTUAL TOURS**

Farm

- <https://www.farmfood360.ca>

Museums

- <https://www.travelandleisure.com/attractions/museums-galleries/museums-with-virtual-tours>

National Parks

- <https://www.travelandleisure.com/trip-ideas/national-parks/virtual-national-parks-tours>

### **WATCH**

Hallmark's "Countdown to Christmas"

- Starting Friday, March 20<sup>th</sup> at 12 p.m. ET/PT, Hallmark will air 27 original holiday films from recent years

Recreate the movie theater experience by dimming the lights and providing popcorn and favorite movie candy or snacks

Rent a musical or Broadway show

- <https://www.playbill.com/article/15-broadway-plays-and-musicals-you-can-watch-on-stage-from-home>

Stream shows from The Metropolitan Opera

- <https://www.metopera.org>

Use "Flixable" to search the Netflix library by movie genre and release date to help you find old favorites

- <https://flixable.com>

### **OTHER**

Call/FaceTime friends or family members

## EXERCISE

### Chair & other exercises

- <https://www.healthline.com/health/fitness-exercise/chair-yoga-for-seniors#5>
- <https://www.youtube.com/playlist?list=PLmk21KJuZUM4HTTrJ7hrJ8yxhToKkJT8a8>

### Dancing

- <https://www.youtube.com/playlist?list=PLdppGAsLpfnel-pFzJPF1UJnEt5CS2fZE>

### Gardening/yard work

- Water plants, weed, rake, etc.

### Go on walks around the neighborhood

### Housework/chores

- Vacuum, fold laundry, wipe surfaces, set the table, sweep, dust, etc.
- Cooking related tasks such as stirring, peeling, shucking, mashing, or mixing

### Yoga

- <https://www.youtube.com/user/yogawithadriene>

## GAMES

### Download phone applications such as “MindMate” or “Lumosity”

### Online brain games

- <https://stayingsharp.aarp.org/about/brain-health/games-play/?migration=rdrct>
- <https://www.brainhq.com/?v4=true&fr=y>

### Other games

- Board games, puzzles (can participate even if a person has trouble putting pieces together—match colors, flat edges, etc.), dominos, matching games, card games (don't worry about the rules)

### Word games

- Word searches, crosswords

## RELAXATION

### Aromatherapy

- Candles, scented lotions, essential oils

### Guided meditation

- <https://www.tarabrach.com/guided-meditations/>

Hand massage

- <https://www.youtube.com/watch?v=JzqDCQAav-0>

Keep a “gratitude journal” together and write down what makes you grateful each day

Make homemade body scrub

- <https://www.perrysplate.com/2014/06/homemade-body-scrub-brown-sugar.html>

Relaxation videos

- <https://www.youtube.com/channel/UCq72Hd6UZAqPBAUZplnmPMQ>

## **REMINISCE**

Bake a family recipe or treat

Create a scrapbook of memories

Fill out life story templates together

- <https://www.dementiauk.org/wp-content/uploads/2017/03/Lifestory-.compressed.pdf>
- <https://www.dementia.org.au/sites/default/files/20110303-NSW-LifeHistoryBook.pdf>

Look through photo albums or family videos

Use reminiscing prompts/topics or have “I remember when...” conversations

- <https://www.goldencarers.com/school-days-reminiscing-cards/3831/>
- <https://www.goldencarers.com/13-reminiscing-themes-for-seniors/4293/>

## **Additional Articles and Resources**

Alzheimer’s Disease:

- <https://alz.org/help-support/caregiving/daily-care/activities>
- <https://www.alzheimers.net/checklist-and-daily-care-plan-for-dementia/>

Frontotemporal Degeneration:

- [https://www.theaftd.org/wp-content/uploads/2018/03/PinFTDcare\\_Newsletter\\_summer2016.pdf](https://www.theaftd.org/wp-content/uploads/2018/03/PinFTDcare_Newsletter_summer2016.pdf)
- <https://www.theaftd.org/living-with-ftd/managing-ftd/>

Lewy Body Dementia:

- <https://www.lbda.org/encouraging-independence>

COVID-19: Coping with Stress and Anxiety

- <https://www.cdc.gov/coronavirus/2019-ncov/prepare/managing-stress-anxiety.html>