



Planning for Caregiver Emergencies

Among the many stresses dementia caregivers face, a common worry is what happens to their loved one with dementia (LO) if something happens to the caregiver. Who will take care of the caregiver? Who will care for their LO?

Research has shown between 18% and 40% of dementia caregivers pass away before their LOs, and there are countless other scenarios of illness and accident that can leave them temporarily incapacitated without warning. While no one can prepare for every possibility, there are several proactive steps you can take to ease the worry and make life a little easier on yourself, your LO and others who may be involved in their care if needed.

(Because every family's circumstances are different, the following suggestions should be considered a general starting point.)

Designate a 'Point Person'

- Select someone who has the capacity and willingness to step up in an emergency and carry out your plans. Your point person doesn't necessarily have to be someone who will provide long-term direct care for your LO, rather it should be someone you trust to make decisions in your absence.
- Make sure your point person agrees to take on the responsibility and has access to the short-term information and resources they'll need to act quickly if needed.
- If you're fortunate and have multiple people in your life who can fill this role, be sure they're all on the same page and avoid the confusion of having too many people trying to call the shots.
- If your point person lives out of town or travels frequently, make sure to factor that into your plans as well. Identify at least one person who can provide immediate, short term assistance to keep your LO safe until your point person arrives. Stressful situations can exacerbate dementia symptoms, so it's best to avoid having your loved one stay home alone or go to the hospital with you.
- Under ideal circumstances, your point person will be legally recognized as your power of attorney and healthcare power of attorney and alternate POA and healthcare POA for your LO.

Inform First Responders of Your Situation

- Keep something on you at all times that indicates your LO's name and diagnosis and the name and contact info of your Point Person and one or two other emergency contacts if possible. If

your loved one is with you, this information can help first responders calm and comfort your loved one. (Some people set a photo of this info as the background photo on their phone's lock screen.)

- If your LO isn't with you and your Point Person isn't immediately available, it will be helpful for first responders to know where your LO is so they can conduct a welfare check or take other action to ensure their safety until other arrangements are made.
- [Smart911.com](https://www.smart911.com) is a free, secure website where you can enter relevant information that 911 dispatchers are able access in the event you call for help. You can add key information on yourself and anyone else in your household (pets included), including emergency contacts, relevant medical information, alarm or gate codes, vehicle descriptions and license plate numbers, etc. You can provide as much or as little information as you'd like to share, and you can update your information at any time. (You'll also get periodic reminders to check the information you've entered and make sure it's current and accurate.)

Emergency File

Several documents are helpful to have quick access to in the event of an emergency. To cover all of your bases, include information/documents for both the caregiver AND the individual with dementia.

- Copies of your driver's license or other photo identification with current address and birth date
- Notes on current medical condition(s), allergies, and/or any critically relevant medical history
- Copies of your Social Security and medical insurance cards, including supplemental insurance
- Name, contact information, and brief explanations of your relationship with the following:
 - Children/siblings / friends or other alternative caregivers
 - Note who the first point of contact should be
 - Include paid caregivers or any agency you use for in-home care
 - Include contact info for 2-3 residential facilities that offer short-term respite stays
 - Primary Care Physician
 - Pharmacist
 - Attorney
 - Other healthcare providers involved in your family's care
 - *If you have a preferred hospital, note that as well.*
- Healthcare power of attorney
- Durable power of attorney
- Living will / advanced directive
- If applicable, Do Not Resuscitate order (Note: Must be signed and dated by a physician.)
- If you have prepaid for a funeral or burial plot, contact information for appropriate companies

Because routine and consistency are so important for those with dementia, and because they can't always verbalize their needs and preferences, an informal guide to your loved one can be really helpful as well. Make life easier on those stepping in for you, and give your LO the comfort of familiarity and consistency by sharing information like:

- Recurring events or appointments with contact info for others involved in these activities (Ex. weekly lunch with friends, day programs, dog walking schedule, regular outings to parks or stores)

- Dietary considerations, restrictions and preferences (ex. meal schedule, likes and dislikes, limitations on food/drinks that impact your LO's body or behavior [spicy foods, coffee, temperature], any applicable choking precautions [small pieces, soft foods only])
- Sleep schedule and sleep aids (Ex. medications, CPAP machine, blackout curtains)
- Mobility aids and advice (Ex. needs a daily walk; must use a walker outside the home, keep their cane in arm's reach)
- Safety considerations (Ex. safety plan, alarm codes, door codes, access to tracking devices, apps, and/or video systems, exit seeking tendencies)
- Other needs (Ex. hearing aids, glasses, reading glasses, watch, wallet, keys to your home and car, access codes or passwords for you and your LO's phones, tablets or other commonly used devices, chargers, access to a calendar with upcoming appointments for your LO)
- Tips, tricks and triggers you've learned over time (e.g., sensitivities to fabrics or sounds; activities/music / TV shows that soothe or distract; hygiene routines; sundowning routine; topics they find upsetting; suggestions for keeping them hydrated)

Store your emergency file in a brightly colored and clearly marked envelope in at least one location where it's easy for first responders to find and access, such as your refrigerator, nightstand and/or the glove box of your car. Reference its location in your Smart911 profile, and make sure your point person knows where to find it and can access it using a key to your home. You can also reference this envelope in Smart911. (Consider scanning these documents and securely sharing electronic versions with your point person for maximum convenience.)

Know Your Options for Care

Chances are, your point person won't be able to assume 24/7 care for your loved one, and it will likely take time for them to reach your loved one.

- **Short-term Residential Respite** - Many residential facilities offer temporary, short-term stays, usually with a two-week or 30-day minimum for memory care. Space is subject to availability, so make time to visit several of these facilities so you'll have a few alternates in mind if your first choice isn't available in case of an emergency. Make sure the facilities can meet your loved one's care needs and learn about their admissions requirements for respite. While residential respite can be costly, it may be the best option for ensuring your loved one's needs are safely met during an emergency.
 - Admission to a residential facility isn't immediate because South Carolina requires a TB test before admission to a residential facility. Most TB tests take 48-72 hours, so consider that delay when making plans.
 - You can make the transition to temporary residential care a bit easier by sending personal comfort items that remind your LO of home, such as a favorite blanket, robe and slippers, familiar bedding, photos from their nightstand, etc. Include some suggested items in your notes to your point person. (Don't send anything of significant financial or sentimental value that you're not prepared to lose!)
- **Companion Care** - If you're using the services of a companion care provider, make sure your point person has the name and contact info for them to schedule additional coverage and/or cancel shifts as needed. Make sure they're also aware of your point person and know you've

given them authority to act on your behalf. In some cases, overnight care or 24/7 care may be available, so check with them about any special considerations. If you're not already working with a companion care provider, you may find it useful to familiarize yourself with available options.

- If you're already using a regular caregiver, ask for their help in documenting your loved one's routine, preferences, etc.

Pro Tip: Handwritten notes or brief videos can be extremely comforting to individuals with dementia when they feel uncertain or worried about disruptions to their 'normal' lives. Consider making several personalized, all-purpose messages from you to your LO, assuring them everything is okay and you'll be back as soon as possible. Other helpful messages might prompt them to eat or bathe, encourage them to help their point person (referencing them by name), remind them they're safe and loved, or suggest activities for distraction or redirection. Make sure the notes are legible, the videos are well-lit and loud enough, and the messages are positive and comforting. Keep the handwritten notes in your emergency file and email or text the videos to your point person so they can show them to your LO as needed.