

What if Something Happens to Me?

by Donna Schempp, LCSW

Susan took care of her husband, Eric, with Alzheimer's. She tripped at home and broke her right arm. She called her daughter, who took care of Eric that night. But her daughter had to go to work the next day. And with her broken arm, Susan couldn't do basic caregiving tasks for Eric, like dressing, showering, or cooking.

Norma has been meticulous about Covid, is fully vaccinated, and wears a mask whenever she is not at home. She cares for her husband Charles, who has suffered several strokes, is incontinent, and needs assistance with transferring. Lately, she has been worried about what they would do if she got sick or was in some other way incapacitated. They have no children and no family in the area. Neighbors and friends are helpful, but they can't take care of Charles in case of an emergency.

What if ...?

As a caregiver, it is understandable if your imagination occasionally lingers on unexpected developments that could turn your work and routines upside down. And when the what-ifs apply to you, they can produce even more anxiety. Wondering what will happen to your caregiving duties if you get Covid, if you have a fall, if you're in a car accident – all of those are normal concerns to cross your mind. If you're not careful, you could easily fall into a worry loop – an endless cascade of increasingly stressful questions asking, "what would happen if ...?"

Managing your concerns

What should you do when you feel your mind start to spin with worry or anxiety? Try this three-step response:

Step 1: Pause. Be aware of when you feel yourself growing anxious.

Step 2: Breathe slowly. Or try a grounding exercise – name the objects in the room you're in or count backward from 100 by sevens. The point of the activity is to lead you to a reasonable and functional level of calm so you can move to the next step.

Step 3: Plan.

The truth is that many scenarios could compromise your ability to care for your friend or family member. That's part of life. The important thing is to move from feelings of anxiety to a place where you can take action – do something to help improve the situation. Proactively considering possible scenarios means you can thoughtfully and effectively create backup and emergency plans.

First things first; Identify your backup caregiver

Your most important question is who your backup would be if you could not take care of your friend or family member.

Whether your needs might be short- or long-term, start with who may be available and open to helping: An adult child, an extended family member, a neighbor, a good friend? Think about your network and who would be the most likely person to come through to help you if you needed it. Talk with them about what you might need and their willingness to step in and lend a hand. Sometimes, this might be professional caregiving help hired from an agency or service.

Planning for all what-if scenarios begins with finding the right person to back you up. You may find several people, or a mix of friends, family, and professional caregivers: a more realistic approach than relying on a single individual.

Create a resource to support your backup

Next, you'll want to create an emergency how-to guide for anyone filling in for you. Even when the risk of needing a backup is low, it's always a good idea to have all relevant care information in one place and easily accessible. An easily identifiable brightly colored binder is a good choice.

Your binder should include the following:

- **A list of key contacts**
 - Physician and clinician contact information
 - Family member contact information
 - Emergency Medical Service contact information (including 911)
- **Existing or chronic health conditions**, for example:
 - Diabetes, COPD, Parkinson's disease, multiple sclerosis, loss of limb/limb use, depression, anxiety, or PTSD
- **Medication information**
 - Medication names. If prescribed, include Rx number and prescribing physicians
 - Dosage
 - Dosage instructions
 - Frequency
 - Timing
 - Special instructions (e.g., take with food)
 - Drug interactions or contraindications
 - Side effects to watch for, when to contact a doctor
 - Prescribing pharmacy name, address, and phone number
- **Itinerary of an average day's routine** (morning to night, hour by hour), including:
 - Sleep schedule: times/windows for waking, naps, and bedtime
 - Bathroom activities, personal care, grooming, and dressing
 - Meal and snack times (with notes on food allergies, supplements, or foods they particularly like or dislike)
- **Standing appointments, outings, or activities** on particular days of the week and times of day, for example:
 - Favorite TV shows,
 - Scheduled activities or programs at the local VA or senior center
 - Regular visits from family or friends
- **A list of your friend or family member's favorite things or activities** – the things you consistently reach for to engage, soothe or distract them. This might include:
 - Music or musical era they love (note how to find/play it in the home)
 - Jigsaw puzzles, card games, trivia, sudoku
 - Favorite podcasts or videos
 - Favorite writing (note where to find a magnifying tool, if needed)
 - Hobbies or pastimes where they have expertise or passion – e.g., sketching, painting, photography. Even if they no longer partake in the activity, these may be fertile topics of conversation.
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A critical to-do list

Preparation is everything. Steps you take now – from online, phone, and in-person research to booking contingency arrangements – will help everyone should the need arise in the future for substitute/temporary caregiving help.

- **Contact local home care agencies** and see their process for hiring in-home care. Find out if they have attendants available on an emergency basis or if you must be registered with them in advance. If possible, do a test run – try using their services a few times (perhaps as respite care during time off for you).
- **If your friend or family member qualifies for Medicaid, apply now.** This can provide a payment source should they need placement in a long-term care facility.
- **Contact your Area Agency on Aging** (<http://eldercare.acl.gov>) to see what resources they have for emergency care. Tell them you are a caregiver and are preparing for the unexpected. Ask if they recommend reaching out to Adult Protective Services when the primary caregiver is not available, to let them know that your friend or loved one is alone and needs help. APS may be able to look in on them and see if there are resources that can help with their care.
- **Let trusted people know there is a vulnerable person in the home.** Reach out to a neighbor, landlord, or local fire department, and introduce yourself as your friend or family member's caregiver. Ask them to look in during an emergency or natural disaster.
- **It's important you provide someone trustworthy with a spare key** so they may check in during such a scenario. In addition to giving a spare key to your back-up person, you may want to have another one hidden outside, where a neighbor or others know where it is.
- **Consider hiring a geriatric care manager** who will work with you on an ongoing basis to ensure everything is in place. You can find care managers through the National Association for Aging Life Care Managers (www.aginglifecare.org).

- **Make sure your friend or family member knows when and how to call 911** (if they have dementia, this does not apply). Or pre-program a speed-dial button for emergency response and be sure they know how to use it if needed.
- **Get a Medical Alert ID bracelet for yourself** so that emergency response professionals will know when tending to you that there is an impaired person at home and can check on them. You can get a bracelet that says, “I am a caregiver” and allows you to put contact information on the back. (Available through the Alzheimer’s Association, www.alz.org, the ID Band, www.theidbandco.com, or Medic Alert, www.medicalert.org/bracelets).
- **Have legal papers in order and easy to find** – your own as well as those of your friend or family member. You may want to note the location of these important documents in your emergency binder, adding a note on the refrigerator for EMS personnel that access to legal paperwork is explained in the binder.

Special to-dos for agency help and assisted living facilities

- **Before there is a need, research home care agencies in your area and register with them.** That way, when/if you need someone to come into the house to help, you can call and start the service without completing the intake process before services begin.

Conversely, you might **network with friends for private caregivers** you can call on. Often private caregivers will put up a notice at the local senior center, and you can interview and check them out ahead of time. See links to FCA resources to help with the process of hiring help.

- **The same is true for assisted living facilities.** If you break a hip or need a knee replacement, you might be unable to provide care for several weeks. In this scenario, a good choice may be a respite room in a nearby retirement community or Board and Care. Doing your research ahead of time and knowing what is available and what is required takes the burden off you to figure out your options while dealing with many other decisions.

It’s important to note that **most live-in facilities require an up-to-date TB test** for someone to move in. You can talk with your friend or family member’s physician to ensure this is done every six months to assure there is current proof of the test and results on file.

Explore community resources

If you can’t provide all the care for your friend or family member, it helps to know what resources are available within your community.

- **Meals on Wheels** will provide meals for you and your friend or family member, and in the event of an emergency, they will often put you at the top of the list. This can help as sometimes there can be a waiting list. Meals on Wheels charges customers using a sliding fee scale.
- **Paratransit** can help transport you and your friend or family member to doctors’ appointments and necessary errands. Your local Area Agency on Aging (<http://eldercare.acl.gov> or in some areas, they can be accessed by calling 211) has an information and referral service that you can call to find out what resources are available in your community and how to access them.

Set up regular check-ins

When someone is isolated, elderly, or unwell/recovering, it’s always a good idea to arrange regular check-ins to confirm they are safe.

- **Some organizations make daily phone calls** to isolated people to ensure they are OK. Contact your local Area Agency on Aging for resources in your community.
- Other people plan with **neighbors/friends/family members** to do a regular check-in. It might be a phone call or a signal, such as opening the blinds, which will cue someone that you are all right.

Emergency Response Systems

There are several emergency response systems available throughout the country. You can find out which systems are available in your area through the Area Agency on Aging or the local senior center.

These systems allow you to push a button you wear as a necklace or bracelet to call for help. Some systems also have fall detection, where they automatically trigger a phone call if the wearer falls and isn't able to push the button themselves.

These are valuable for the person you care for, but you should also consider whether you need one for yourself. As a caregiver, if you fell or were in another type of distress, such a device would allow you to call for help as well as request support for your friend or family member.

Complete long-term planning

In preparing for the unexpected, it's essential to consider all types of needs and care – including health, legal, and financial.

- Have you completed the **necessary forms** for someone to care for your friend or family member if you become incapacitated?
- Have you completed the **legal paperwork** for your own care?
- Who can sign on to your **checking account**? Who can sign on to the account of your friend or family member?
- If you or the person you care for becomes incapacitated, who has **power of attorney** for finances or health? This fact sheet, “**Legal Planning for Incapacity**” (<https://www.caregiver.org/resource/legal-planning-incapacity/>), should help.

In case of emergency (ICE)

If you have a cell phone, you probably have put ICE (In Case of Emergency) into your contact list. But another place to have this information is in your wallet, with your driver's license. It should say: "I am a caregiver to someone incapacitated. If something happens to me, please look in on them and contact _____, who will know how to help them."

Additional Resources

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

Email: info@caregiver.org

FCA CareNav: www.fca.cacrc.org

Caregiver Services by State: <https://www.caregiver.org/connecting-caregivers/services-by-state/>

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's, and other debilitating brain disorders that strike adults.

Other Organizations and Links

National Eldercare Locator

<https://www.eldercare.acl.gov>

Caregiver Action Network

<https://www.caregiveraction.org/>

American Association of Retired Persons (AARP)

<https://www.aarp.org>

Area Agency on Aging

<http://eldercare.acl.gov>

This information was authored by Donna Schempp, LCSW and edited for readability by Trish Doherty (<http://trishdoherty.net>). It was reviewed and approved by Family Caregiver Alliance. ©2022 Family Caregiver Alliance. All rights reserved

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