

## Caregiver Connection Guide



Dear Caregiver,

You are about to embark on a very important, challenging and rewarding role—being a caregiver. You and your loved one are beginning a journey that can be difficult and even frustrating at times. This guide was created with the purpose of answering commonly-asked questions and providing information to assist you as you care for your loved one during their rehabilitation and recovery process. We have provided checklists, information and resources to help you find additional information as needed. Please use this guide and feel free to ask members of your loved one's care team any further questions that arise.

Thank you for your dedication and selflessness.

## TAKE A DEEP BREATH! YOU CAN DO THIS!

On behalf of your loved one's care team, thank you.

## Home Safety

The importance of our homes extends beyond being a place to rest. A person's home is where one should feel the most comfortable, loved, providing a safe environment to recover and heal.

According to a recent study conducted by the National Council on Aging, more than 75% of falls take place inside or in close proximity to the home. In adults over the age of 65, falls are the leading cause of accidental injury and death. The checklists in this guide can help you create an environment that is safe and promotes healing.

Before your loved one is discharged from the hospital, take a few minutes to review these checklists as you start the process of making their environment safe for a successful return home. The checklist that follows is meant to be a starting point to help review your home for potential hazards and develop a plan to limit them. Discuss your plans with your care team—including occupational, speech and physical therapists—for additional safety recommendations. Use the following checklists periodically as a reminder to ensure continued safety in the home.



## Modifying your home

An important area you and your family may need to consider is that of home modifications. Modifications to the home are done to help improve the safety of your home and increase the ease of providing care to your loved one. The most common modifications include installing grab bars and raised toilet seats in the bathroom. Others that are more involved or technical may need a licensed contractor who has knowledge specific to regulations and requirements for home modifications (ramps, stair lifts, bath remodeling, etc.). Please talk to the Occupational and Physical Therapists on your care team for basic equipment recommendations. Other terms you may hear include ADA Compliance, Accessible or Universal Design.

### Compliance

Each term is used to describe areas that have been designed to help the most number of people “access” them, regardless of abilities.



The following list of organizations can provide additional information regarding home modifications and assistance for modifications.

### Organizations that may assist with home modification:

- [www.aarp.org](http://www.aarp.org) American Association of Retired Persons (AARP)
- [www.Homemods.org](http://www.Homemods.org) State resources for home modifications
- [www.hud.gov](http://www.hud.gov) US Department of Housing and Urban Development (HUD) – Fair Housing Act Accessibility Guidelines. Fair Housing Act Design Manual
- [www.nahb.org](http://www.nahb.org) National Association of Home Builders (NAHB) - Find Certified Aging in Place Specialists
- [www.rebuildingtogether.org](http://www.rebuildingtogether.org) Rebuilding Together – Local affiliates help provide home assessments and recommendations
- [www.va.gov](http://www.va.gov) US Department of Veterans Affairs - Home modification grants for disabled veterans.

## Home Safety Checklist Adapted from the National Council on Aging Top Tips for Preventing Falls in Your Home (2018)

### Outside/Walkway/Entry

1. Walkways are well lit and all lights are working properly.
2. All walkways are clear of clutter
3. Steps are not broken or uneven
4. Ramps have enough room to maneuver the wheelchair or walker safely

### Living Room / Common Areas

1. Remove all small area rugs, runners to prevent tripping
2. Keep stairs clutter free, install lights at both top and bottom of stairway
3. Remove furniture from hallways to keep a clear pathway
4. Raise furniture including couches to help with safe transfers
5. Install motion-activated switches to keep from having to search for the switch when entering the room

### Kitchen

1. Move items used most often within reach on lower shelf or drawer
2. Inspect all electrical appliances cords. Do not use if cords are damaged
3. Use plastic cups, plates, bowls instead of heavier glass and ceramic
4. Consider removing knobs from the stove and installing a lock on the “knife drawer” if your loved one has memory difficulties.

### Bathroom

1. Install grab bars in and near the tub/shower and toilet for safer transfers
2. Use raised toilet seats and bath/shower chairs for safety
3. Temporarily or permanently remove glass doors from tub/shower
4. Consider removing bath mats or replace with non-skid adhesive stickers on floor outside of the tub.
5. Install non slip mat/adhesive stickers to floor of tub/shower
6. Consider bathing when another person is available to assist as needed

### Bedroom

1. Keep light switches and remotes near the bed
2. Use a bed rail to assist with getting in and out of bed
3. Consider using a bed alarm or monitor to decrease potential falls
4. Keep phone nearby in case of a fall or other emergency

### Medication Management / Personal safety

1. Keep medications stored in secure location or use equipment such as pill boxes or automatic dispenser
2. Keep a list and schedule of medications and dosage in the event another person is needed to provide care for your loved one while you are away
3. Use bed or door alarms to keep loved ones safely in bed or home if they have decreased memory/ safety awareness

## Fire Safety

According to the Federal Emergency Management Administration (FEMA), there are two very important things you can do to protect your home from a fire emergency. Have smoke alarms installed and in working order, and have an escape plan that you and your family have discussed.

**Smoke Alarms** - Have smoke alarms on every level of your home inside and outside of all sleeping areas. Interconnect alarms so they all sound at once. Test your smoke alarms once a month.

1. Kitchen – approximately 10 feet away from stove

2. Bedroom 1

3. Bedroom 2

4. Bedroom 3

5. Bedroom 4

### Escape Plan

1. Know two ways out of every room

2. If possible live near an Exit

3. It's safest on the ground floor if you live in an apartment building

4. If you live in a multistory home, sleep on the first floor

5. Locate a safe location for all family members to meet away from the emergency

6. Contact your local fire department to inform them that a person with a physical, mental or cognitive disability lives in the home. Be sure to tell them in which room the person sleeps.

7. Review plan with family every 6 months to one year to insure that everyone is familiar with plan

(Adapted from Fire Safety for People with Disabilities, [www.usfa.fema.gov](http://www.usfa.fema.gov), 2018)

## Emergency Preparation

Now that you have checked the safety of your home, what happens in the event of a natural disaster? The below is a list of helpful ideas. For a comprehensive checklist visit the U. S. Federal Emergency Management Agency (FEMA) website: [www.ready.gov](http://www.ready.gov)

### Preparation

1. Water, one gallon per person for up to three days for drinking and sanitation

2. Food, at least three days of non-perishable food items

3. Battery powered or hand cranked radio and extra batteries

4. Flashlights with extra batteries

5. Weather proof matches, lighter

6. First Aid Kit

7. Whistle to signal for help

8. Fire extinguisher

9. Medications, list with dosage information, glasses

10. Cash in small bills and change

11. Escape plane reviewed by all family members

12. Keep a minimum of ¼ tank of gas in the event you need to evacuate the immediate area quickly

## Transportation

Many times getting your family member to a scheduled appointment or helping them complete errands can be a challenge. Discuss with your care team the possibility of performing a car transfer training with a physical therapist. This insures you and your family are safe when moving into and out of the car. There are many services available to help provide transportation to elderly or disabled persons in the community.

### Countywide Transportation

In addition to standard bus line service, The Orange Transportation Authority provides transportation to county residents who are unable to use the available bus services ([www.octa.net/Getting-Around/Bus/ACCESS-Service/Overview/](http://www.octa.net/Getting-Around/Bus/ACCESS-Service/Overview/)). There may be an application and eligibility requirement to qualify. This service may be known as Dial-a-Ride or ACCESS Services.

### City specific transportation services



Many cities provide elderly or disabled residents transportation within the city limits. Check your cities website or contact them for information regarding service areas, restrictions the application process and eligibility requirements.

### Taxi Vouchers Services

For smaller cities that do not provide their own transportation, they may have partnered with other municipalities to provide taxi service vouchers to their elderly and disabled residents. This allows the resident increased size of serviced area.

### Non-Emergency Medical Transport

Many health insurances provide vouchers, coupons for non-emergency medical transport. This allows a person to attend their scheduled medical appointments including diagnostic or doctor's appointments. Check with your loved one's specific health insurance to determine whether they provide this service. Note: there may be restrictions on the number of "trips" allowed.

## Adapted Motor Vehicles

In the event that your loved one requires special equipment (powered wheelchair), there are options for adapted motor vehicles. Examples include ramps, lifts, scooter storage rack, etc. Most major vehicle manufacturers have a division specifically for adapted vehicles (examples: [www.toyotamobility.com](http://www.toyotamobility.com), [www.gmfleet.com/overview/mobility-vehicles](http://www.gmfleet.com/overview/mobility-vehicles)) There are also dealers who specialize in adapted vehicles that can be located on the world wide web.



## Technology/ Adaptive Devices

There are currently many adaptive devices and technologies that are available to help with caring activities. Discuss with your Occupational and Physical Therapists the various options available. Whether using "low-tech" items such as sock aids and dressing devices, or higher technology such as electronic devices, Cell phone applications, or electronic personal assistants, there is a technology option available.

## Caring for the Caregiver

You have made a very selfless decision to care for your loved one. This section is focused on **your** well-being to insure that you have the health, energy and physical ability to continue providing care for your loved one. It is as important to care for yourself as it is for your loved one. According to the U.S. Department of Health and Human Services, "Caregiving is hard, and caregivers of chronically ill people often feel stress. They are on call 24 hours a day, 7 days a week". Many times caregivers are so involved in providing assistance for their loved one that they have difficulty with maintaining their own healthy stress, nutrition, activity for their own well-being. Remember, invincible superheroes are make-believe. Every living, breathing "real" person requires assistance at times. You may feel that you can handle everything, but at some point everyone feels tired, exhausted and even "burned out".

There are a number of steps you can take to help limit "caregiver burn-out". Remember, you do not have to go at this alone. There are many

resources available from the national to local level to help. The following tips are adapted from UC Irvine Health's Caring for the Caregiver education information (2018)

### Caregivers need to care for themselves

Millions of Americans help care for older adult family members or friends, but caregivers often don't identify themselves with this role. Whether you call yourself a caregiver or simply a good daughter or son, caring for an aging or disabled loved one has its rewards and trials.

### Preparing for care

Have an honest talk about future care giving plans with your loved ones. It's best to do this while they are still able to handle aspects of their daily lives. If you are an adult child caring for a parent and have siblings, ask the sibling who is most comfortable with the parent to talk to them about it. If you're caring for a spouse, start the conversation by sharing what you'd like for yourself (such as, an assisted living apartment). Don't assume that the method of care you want is also what your loved one wants.



## Finding a Geriatric Care Manager

Care managers help families work out plans to meet an older loved one's care giving needs. You can find one through the National Association of Professional Geriatric Care Managers. Or, you can call local agencies for referrals. Look in the phone book under "older adults" or "senior citizens." Be very careful to check references and credentials before hiring anyone to care for your family member. Use the National Center on Caregiving Family Care Locator or the Administration on Aging to find help in your state.

### Sharing responsibilities

Caregivers need to share duties with others. Set a schedule and say, for example, "On Sunday, you can take Mom to church; on Monday, you can drive her to the store," and so forth. By sharing the duties, it may allow for the primary caregiver to



care for their own needs (appointments, exercise, home management).

### Keeping a balance in your life

A burned-out caregiver isn't much help to anyone. Here are suggestions to help maintain life-balance:

- **Sleep:** This is one area that many busy individuals neglect. Add the responsibility of caring for a loved one, and it is easy to see how people report being exhausted. Exhaustion is a common complaint among caregivers due to having to provide care for 24 hours a day.
- **Exercise:** Exercise helps ease stress. It also gives you a break from care giving duties, and keeps depression at bay. Replace with: Exercise doesn't necessarily mean just going to the gym. Activities such as walking, yoga, stretching and deep breathing can help with decreasing stress.

## Caregiver support Groups

Many times you may feel alone or unsupported. There are many support groups available in the community to help lessen that feeling of isolation. They can also be a great resource to find answers to questions that arise from others in similar situations. Many diagnoses have national associations with local chapters. The most well-known include the American Heart, American Stroke, Brain Injury, Alzheimer's, ALS and National Spinal Cord Injury Associations.

## Respite care

As mentioned before, "Caregiver Burn-out" is a very serious challenge when caring for your loved one. It can affect one's physical, emotional and mental health, put strain on relationships, and even affect the quality of care being provided. Sometimes you may feel like you just need to take a break. It is okay for you to feel this way. Respite care can help provide relief. Respite care can range from a few hours to several weeks of care being provided in a variety of settings such as home, adult day health care, skilled nursing, and short term institutional facilities. Respite care allows temporary relief for the primary caregiver providing a chance to "recharge" and/or care for themselves.

## Caregiver Resources

- [www.acl.gov](http://www.acl.gov) Administration for Community Living – Resources to connect people with disabilities, caregivers, families and professionals to federal, national and local programs and information.
- [www.caregiver.org](http://www.caregiver.org) Family Caregiver Alliance.
- [www.caregiveraction.org](http://www.caregiveraction.org) Caregiver Actions Network – Provides tips, help and community for caregivers.
- [www.eldercare.acl.gov](http://www.eldercare.acl.gov) Eldercare Locator – State By State locator for respite care providers.
- [www.healthfinder.gov](http://www.healthfinder.gov) Government website with information and tools to help you and those you care about stay healthy
- [www.hhs.gov/programs](http://www.hhs.gov/programs) US Department of Health and Human Services (HHS) Resources for caregivers
- [www.medlineplus.gov](http://www.medlineplus.gov) Caregiver information provided by National Institute of Health, US National Library of medicine

## Thank you

We hope you have found the information provided in this guide to be helpful. Please revisit this guide book periodically and use the resources as needed. Feel free to reach out to any member of your loved one's care team with any questions.

Good luck and thank you!