

Free Caregiver's Guide

Are you worried that your aging loved one is declining in health? Have they recently been dismissed from a hospital stay, and you don't feel prepared to give them the care they deserve?



Serving East and South Jacksonville: (904) 299-6844

This guide is intended to help you balance care giving with work and family life. Home Instead wants you to have this information for free, with no obligation. Why would we do that? Because to us, it's personal. We have decades of experience and resources behind the care we provide, but many families are feeling the stress of trying to do it all themselves. We want to provide a little guidance to make sure no one feels like they have to make it up as they go. Of course, we are here to help if you need us!

Home Instead
SENIOR CARE[®]
To us, it's personal.

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Alzheimer's and Dementia

Caring for someone with dementia or Alzheimer's disease requires a great deal of time and patience. It can cause great stress to the caregiver as both illnesses lead to symptoms of serious change in memory, personality and behavior. This can be emotionally and physically demanding for a family caregiver, but understanding these conditions can help.

Recognizing Symptoms

Dementia is the loss of cognitive functioning and intellectual reasoning due to changes in the brain caused by disease. Those with dementia tend to repeat questions, become disoriented in familiar places, neglect personal hygiene or nutrition, or get confused about people or time. It can be caused by many things, some of which are reversible – such as vitamin deficiencies and poor nutrition, to reactions to medications or problems with the thyroid. However, some forms of dementia are irreversible, such as that caused by mini strokes or Alzheimer's.



Alzheimer's disease occurs when the nerve cells deteriorate in the brain due to a build up of plaques and tangles, which actually results in the death of a large number of brain cells. Doctors are not sure why this occurs, but research is underway to determine causes and cures. According to the Alzheimer's Association, 5.4 million Americans are presently living with Alzheimer's disease.



Symptoms to Watch For

- repeats questions or stories within minutes of first mention
- forgets names of recent acquaintances or younger family members
- expresses difficulty finding the “right” word when speaking
- recently becomes more (or less) assertive than known for
- mood swings, anxiety, or frustration around memory or communication

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More Symptoms to Watch For (...continued from previous page)

- signs of depression (changes in sleep, appetite, or mood)
- unusual trouble with paying bills, balancing a checkbook, etc...
- begun to have trouble preparing meals
- difficulty following a conversation or understanding an explanation
- withdrawn from once enjoyed hobbies or projects
- trouble with abstract thinking
- disoriented in new environments or doesn't remember getting there
- wanders off getting lost in public or while driving
- loses track of time, day, month, or year
- lost items turning up in unusual places such as in the freezer
- odd choices around money management, dress, or hygiene
- difficulty planning ahead for groceries, holiday plans, etc...

Many of these Alzheimer's symptoms go unnoticed for a long because they're often subtle or well concealed by the person (or a spouse), who may be understandably freaked out by these changes. Some patterns of behavior take time to make themselves obvious. If you suspect Alzheimer's, keep track of what you're noticing, ask others what they think, and make plans to see a doctor.

How to Communicate

It's important to focus on what he or she *can* do rather than which abilities have declined. Helping a loved one through such devastating changes puts a lot of stress on you as the caregiver. Your loved one may or may not always understand or appreciate your efforts, but they will always be able to feel your love.

Sadly, an ill loved one is the number one trigger for family conflict. Coping with a loved one's Alzheimer's or dementia has both emotional and logistical difficulties. Following these tips may help unite your family around your loved one when that person needs family support the most.

- *Communicate Regularly.* Don't allow weeks to turn into months and years of not communicating with family members you feel should take a vested interest in your parents' condition and care. If you've fallen out of touch with a member of your family, reach out through a phone call, email, card or letter.

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- *Empathize.* Difficult situations affect everyone differently, so try to understand other points of view before getting angry or upset. Some may be able to contribute with their time, others with finances, others emotionally, etc...

- *Ask for Help.* If you feel over-burdened by the responsibility of caregiving, inform the rest of your family (without complaining or blaming). Others may assume you're doing just fine handling everything on your own unless you tell them what challenges you're facing and specific ways they can help.



- *Make Decisions Together.* Even if you serve as the primary caregiver, involve the entire family when you need to make a major care decision. Talk through all pros, cons, financial considerations and possible alternatives before you make a decision to avoid possible hard feelings, grudges, or resentments.
- *Leave Childhood Rivalries Behind.* Stepping back and realizing how unresolved issues from long ago influence your present relationships may put a helpful new perspective on your current situation.
- *Enlist the Help of a Mediator.* Sometimes family issues become too complicated or emotionally charged to solve on your own. A third-party resource, particularly a professional such as a counselor, mediator, or even a doctor or case manager can provide an impartial voice of reason.

Long Term Care Options

“Whatever happens to me, I don’t want to end up in a nursing home!” Older adults commonly express that wish, or some variation of it, fearing the possibility of being left to the care of strangers rather than remaining amongst family. However, when loved ones develop a progressive disease like Alzheimer’s, reconciling their wishes with the reality of their needs can pose challenges for even the most devoted family caregivers.

(explore long term care options on next page...)

You want to do everything you can for your loved one, but as the disease progresses, it is likely you and your loved one will eventually need some type of outside help. Whether you're at that crossroads right now or just planning ahead, consider the following long-term care options -

Non-Medical In-Home Care

- remain in the comfort of familiar surroundings
- maximum level of independence
- help with basic tasks of daily living (meal prep, laundry, meds)
- transportation to appointments
- companionship and supervision

Medical In-Home Care

- skilled nursing assistance at home
- admin of medication, wound care, IV, injections, physical therapy, etc...
- typically shorter visits combined with non-medical caregivers
- not all agencies are licensed for both, be sure to ask up front

Adult Day Care Services

- transportation to and from facility for daytime care
- lunchtime meals and various activities
- various options may be available in your area

Assisted Living

- residential care with 24-hour supervision, meals, activities, etc...
- best for early stages of Alzheimer's to retain some independence
- each facility is unique... schedule a visit and ask lots of questions

Specialized Facilities

- specifically for residents with Alzheimer's and dementia residents
- secure exits, visual cues, additional staff members, etc...
- also offers activities, exercises, and therapies that stimulate the mind

Skilled Nursing Homes

- 24/7 care for individuals who can no longer care for themselves
- for late stages of Alzheimer's when around-the-clock care is necessary
- help with dressing, eating, bathing, restroom use mobility, etc...
- each facility is unique... schedule a visit and ask lots of questions

(other resources on next page...)

Other Resources and Training



- a resource from Home Instead
- more free caregiver resources
- experts and blogs
- free online caregiver training
- live chat webinars
- workshops

Returning Home After a Hospital Stay

It can be nerve-racking when your loved one is admitted to a hospital or healthcare facility. The last thing you'll be thinking about is what happens when the doctor discharges them to come home. Discharge is a key point in the recovery process. Planning ahead and preparing for a safe return can mean the difference between re-admission and a full recovery.

Deciding Where is Best to Recover

As caregiver, your first step is to have a meeting with the hospital staff (often a case manager or discharge planner) and let them know you would like to be involved in after care planning, including where your loved one will go upon discharge from the hospital.

Key issues to discuss with the discharge planner include -

- expected date of discharge
- type of aftercare required
- explanation of the level of skilled care or services required
- staff recommendations for discharge options
- list of resources and aftercare providers

(create a plan of care on the next page...)

Creating a Plan of Care

When a loved one is coming home from the hospital, it is important to have a good plan of care in place to help ensure a smooth transition to minimize stress for you and your loved one. There may be many additional tasks that are not covered in your loved one's hospital discharge plan. How will care be provided for those activities that are not covered in the discharge instructions?



Four Key Activities -

- 1.) Health Care Tasks (change dressings, monitor vital signs, operate or adjust medical equipment, assist with personal hygiene, arrange followup appointments)
- 2.) Medication Management (order and pick up prescriptions, understand all labels and instructions, monitor expiration dates, administer correct amounts at the right times, watch for side effects, store all medications safely, dispose of medications properly)
- 3.) Household Management (safety checks, meal preparation including possible special diets, additional shopping trips for food and supplies, greet and/or supervise visiting health and home care professionals, arrange for deliveries of medical supplies and equipment)
- 4.) Family Communications (prepare and maintain emergency medical contact lists, communicate frequently with family members, pay medical bills and other expenses, provide instructions and training to other family and friends, keep important documents - living will, insurance, power of attorney, etc...)

Selecting Medical Equipment

Your loved one's medical staff or social worker can give you a list of equipment and materials you will need. In addition, they can let you know whether a prescription is required and if insurance will generally cover the costs: cane, wheelchair, hospital bed, walker, raised toilet seat, shower chair, grab bars, colostomy care supplies, oxygen, IV equipment, respirator, etc...

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Some items such as walkers, wheelchairs and hospital beds, are reusable and considered “durable medical equipment” or DME, and anyone who has Medicare Part B can get durable medical equipment as long as the equipment is deemed medically necessary. Some of the more expensive equipment may be rented instead of purchased. In fact Medicare may *require* rental over purchase.

Safety Checklist

Each year, many seniors are injured in and around their homes - often from hazards that are easily overlooked but easy to prevent.

Top 10 safety issues -

- 1.) loose area rugs or other tripping hazards
- 2.) no “life alert” or other pendant emergency alert system
- 3.) spoiled food in the refrigerator
- 4.) lack of safety bar in bathtub or shower
- 5.) shower within tub (no walk-in shower)
- 6.) lots of clutter or furniture making mobility difficult
- 7.) steep steps
- 8.) low supply of food
- 9.) poor lighting
- 10.) no telephone near the bed



Nutritional Risks and Warning Signs

Family caregivers know how difficult it can be to ensure their loved one's are eating properly. Seniors often face multiple challenges that stand in the way of good nutrition and health.

Illnesses and diseases can dampen taste buds. Seniors on multiple medications or recovering from an illness may lose interest in eating. The conditions of aging sometimes make shopping and preparing food difficult.

Warning Signs and Suggestions

1.) Loneliness: Who wants to eat alone? Not only are seniors at more risk of poor nutrition, loneliness can lead to depression, which could make problems worse. More than three-fourths (76 percent) of seniors who live alone eat alone most of the time.

Suggestion: Try to make sure your loved one has companionship at home or in a common meals with others as often as possible.

2.) Multiple Meds: Nearly three-fourths (71 percent) of seniors take three or more different medications a day.

Suggestion: Talk to your loved one's health care team about how medications might be impacting their appetite, and discuss with them what to do about it.

3.) Lack of Healthy Staples: For a number of reasons, important staples for a good diet are not always found in a senior's kitchen. Nearly half (46 percent) of seniors who live alone consume few fruits and vegetables or dairy products.

Suggestion: In season, why not find an affordable local farmer's market? Talk with your loved one about their favorite recipes – or yours – that incorporate healthy products.

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4.) Illness: Many seniors are struggling with health conditions. Some don't feel like eating as a result. 31 percent say that an illness has forced them to change the food they eat.

Suggestion: Discovering favorite recipes from the recipe box and making mealtime a social event may help.

5.) Physical Problems: 25 percent of seniors who live alone encounter issues getting to a grocery store, causing more stress on shopping or cooking for themselves.

Suggestion: Try to tap into neighbors and compassionate friends. If you know of seniors who live alone, cook extra at mealtimes and take it to them. Other local agencies may also be available to help.

6.) The Smelly Fridge: Check out expiration dates of food in the refrigerator when you're visiting your loved one. Have you noticed an increase in spoiled food? Remember to check the freezer for outdated frozen items or foods that have not been packaged appropriately.

Suggestion: Help your loved one by packaging their food in small portions and labeling the containers by date with big letters.

7.) Suspicious Grocery Lists: If you go to the store for your loved one, and the list is mostly sweets, they may need assistance with their diet.

Suggestion: Help them put together a grocery list, reminding them of all the wonderful foods they used to cook for you. Make it a happy time of memories. Why not buy the ingredients and make that recipe together?

8.) Important Details: Check out things like skin tone – it should be healthy looking and well-hydrated – as well as any weight fluctuations. A loss or gain of 10 pounds in six months could be a sign of trouble.

Suggestion: A visit to the doctor can help ensure your loved one is healthy.

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9.) Empty Cupboard: An emergency could trap a loved one home for days. Do they have enough food and supplies to get by, even if they have to prepare things alone?

Suggestion: Prepare by stocking back-up food, water, and high-nutrition products such as Ensure® in case a trip to the store isn't possible.

10.) Support: Isolation is one of the biggest threats to your loved one.

Suggestion: Encourage your loved one to invite friends to dinner. If you can't be there, develop a schedule of friends and neighbors who can stop by for lunch or dinner.

Managing Medications and Appointments

When your loved one returns home from the hospital, they are likely to come home with several new medications. Making sure that these new medications are taken correctly and don't create any adverse effects with existing medications is vital to ensuring your loved one's recovery.

Medication mismanagement is one of the leading problems that can send your loved one back to the hospital.



It's also imperative that you help make sure your loved one gets to each and every followup appointment. These are critical for any necessary prescription updates, blood tests, incision and wound care, or follow-up X-rays and CT scans that ensures everything is on track.

Keep a large desk or wall calendar handy, and write in follow-up visits using a bright colored ink such as red or green. It's also good to keep the appointment calendar by the phone so new appointments are easily added as they are scheduled.

Finding Balance

The Sandwich Generation

As our society ages and lives longer, the need for caregivers continues to climb. Most often this role falls onto the shoulders of women, specifically daughters in the prime of their career, juggling increased family and career responsibilities.

This generation of women is being pulled in three directions: parenting, caregiving, and working. 26% of working women are caring for children and parents. If you don't fall into that category, maybe you're financially supporting an adult child just like more than 50 percent of caregivers surveyed. Perhaps you're regularly caring for a grandchild. In any circumstance, you're stretched thin.

6 Tips for Caregiver Self Care

1.) Recognize the Signs of Stress: Are you snapping at friends, family members, or co-workers? Forgetting tasks that are normally like second nature? It could be stress. Put a plan of action into place to improve what you can control, and try to forget the rest.

2.) Guard Yourself From Depression: Depression could sneak up on you and impact multiple areas of your life. If you're feeling overwhelmed and depressed, contact your HR (Human Resources) department or Employee Assistance Program (EAP) to find what benefits might be available to you. Many insurance policies cover counseling.

3.) Take a Vacation: A vacation to the Bahamas may not be in the budget, the work schedule, or the family caregiving plans, but find a way for a mini-vacation (or at least a break now and then). Splurge by stopping at your favorite coffee shop on the way to work, rent a movie, or take walks at a nearby park. Anytime time to decompress will help.

4.) Keep Learning to Communicate Better: Effective communication can help you get what you need to stay healthy. If you need help, don't be afraid to ask for it. It's important to be proactive with your challenges and needs.

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5.) Sleep, Diet, and Exercise: If there were a magic potion for family caregivers, this could be it. Eating healthy, walking as much as you can (at least 30 minutes a day is recommended), and getting seven to eight hours of sleep may seem like an impossible goal, but it could make the difference between maintaining health and a downward spiral.

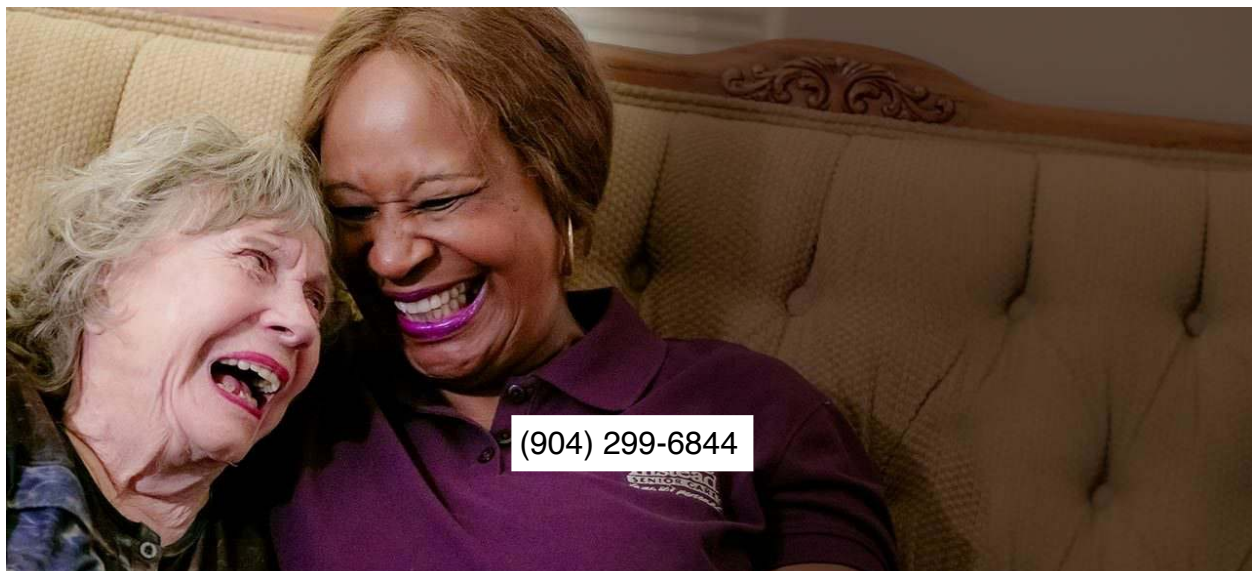
6.) Don't Go it Alone: Your Employee Assistance Program (EAP) could be a great source of information on whether your company offers counseling, resources, referral services, support groups, and other help. In addition, more companies have wellness programs. Find out if yours does. If not, try to connect with a group in your community or church. Even scheduling coffee once a week with a friend could bolster your attitude and help you remember you're not alone.

When to Ask for Help

When you start to feel overwhelmed, it's important to recognize that you have the power to control your life situation; don't let it control you.

You can do this in a variety of ways -

- Make a "Working Family Caregiver Support List" and share with your employer. If flexible scheduling would make it easier for you to balance caregiving and parenting, be sure to speak up.
- Hire personal and home care aides, like those employed by your local Home Instead Senior Care office, to provide companionship, meal preparation, light housekeeping, run errands and help with shopping. Home care aides are often seniors themselves, who can relate to the interests and lifestyles of your loved one.



We're Here to Help

Hi, I'm David Gardenhire, franchise owner of Home Instead Senior Care. My family personally knows what it means to need help for a loved one at home. My team would like to join your family in providing quality in home care for your loved one. To us, it's personal...



Sources

All information from this guide has been provided using information from CaregiverStress (a resource of Home Instead Senior Care). Used with permission. Visit CaregiverStress.com for more information, or contact our office if you have any questions.