

# The Four Stages of Caregiving

## Stage Three: Heavy Care

You may have been providing care for years to someone whose mental or physical health is deteriorating now at a more rapid rate or, because of something unexpected such as a stroke or accident, you have been thrust suddenly into heavy, hands-on care. Your care receiver requires assistance with personal activities of daily living such as eating, toileting, transferring, walking/mobility, bathing, and dressing.

If the person for whom you are caring has Alzheimer's or another degenerative disease, you may be providing sixty hours or more of care per week, sometimes round the clock care that includes frequent waking. You may be feeling exhausted and isolated, completely caught up in caregiving tasks, with no life of your own.

Some relatives who were supportive at first may now be suggesting that you put your care receiver in a nursing home. Some friends and family members may continue to visit you and your care receiver; others may not be brave enough, stating that they want to remember the person as he or she used to be. Some may invite you to family reunions or parties but ask you not to bring your care receiver, whose presence may be seen as disruptive or unsettling. Some people who visit may call you later to tell you just how upset they were by the deterioration of your care receiver since their last visit, as if you are at fault because they were uncomfortable. Rather than support, you may feel pressure. You wonder what you should do now.

- **Your first responsibility must be to care for yourself**, doing everything you can to prevent caregiver burnout, illness, and injury. Your ability to continue caregiving and to have a healthy life after caregiving depends on caring for yourself now.
- **Your second responsibility is to protect your care receiver**, providing a safe and loving environment. At some point, you may have to **consider facility care** such as an assisted living facility or nursing home. It is good to be prepared for this possibility ahead of time.

Stage three caregiving is a very intense time. We are going to provide many strategies for preventing caregiver burnout and protecting your care receiver so that you might choose the ones that work for you.

**To access the services or programs described in this Handbook, call the Senior Helpline at 800-96-ELDER (800-963-5337) or 727-217-8111 from outside of the area.**

## Stage Three, section 1: Preventing Caregiver Burnout

Caregiver burnout is something you may not notice, but people you know may notice changes in you and express their concern. Here are some signs of caregiver burnout:

- Being on the verge of tears or crying a lot
- Feeling helpless or hopeless
- Overreacting to minor nuisances
- Feeling constantly exhausted
- Losing interest in work
- Decrease in productivity of work
- Withdrawing from social contacts
- Increasing use of alcohol or stimulants
- Nervous habits such as chain smoking
- Change in eating patterns
- Change in sleeping patterns
- Increasing use of medications for sleeplessness, anxiety, depression
- Inability to relax
- Scattered thinking
- Feeling increasingly resentful
- Being short-tempered with care receiver frequently
- Increasing thoughts of death

**If you are so frustrated that you are afraid you will hurt your care receiver if you don't find help right away, see Stage Three, section 2.** "Avoid Abuse" is near the end of that section. Resources such as the telephone number of a twenty-four hour crisis and information line and a list of things you can do to cool down immediately are provided. Resources are also provided for suicide prevention, since caregivers and care receivers are among the people at risk of suicide.

**If you are not in a crisis situation but think you may be at risk of caregiver burnout, you may find relief by using some of the ideas listed below:**

### Emotional Support

- **Support group.** Even though it seems that you have no time for your support group now, it is even more important to attend. Some people attend more than one group. Participants in your support group will understand how much the inability of some family members and friends to be with you and your care receiver now hurts, how hard it is to remain patient with some of your care receiver's behaviors, and how frustrating trying to "navigate the system" to get affordable assistance can be. If you are attending support group meetings, you are also likely to hear about caregiver workshops that might provide further support. For more information, see **Stage Two, section 3.**

- **Internet web sites that address caregiver feelings.** One web site that explains the negative emotions that caregiving can cause is Beth Israel Medical Center's site, Stop Pain, [www.stoppain.org](http://www.stoppain.org). The "For Caregivers" section of the Stop Pain web site includes "Emotional Needs". Tips for coping follow checklists of feelings and physical symptoms that indicate anxiety, depression, guilt, etc. Find a "Fact Sheet on Caregiving and Depression" on the Family Caregiver Alliance web site, [www.caregiver.org](http://www.caregiver.org).
- **Sharing your emotions can provide relief.** Write out your anger in your journal as suggested in **Stage Two**. Reading and sharing caregiver stories may help you feel less isolated and alone. If you use the internet, ALZwell Caregiver Support, [www.alzwell.com](http://www.alzwell.com), is an example of a web site that gives caregivers a chance to share their stories and feelings. Look for chat rooms for caregivers on other sites. Many web sites offer tips for preventing caregiver stress and burnout. See the **Caregiver Web Sites** section in this Handbook, or view it online at [www.agingcarefl.org/caregiver/Websites](http://www.agingcarefl.org/caregiver/Websites).
- **Counseling.** Consider counseling to deal with the natural feelings that come with caregiving, especially heavy-duty caregiving for someone whose mental and physical health is deteriorating. Among these are anger, frustration, sadness, anxiety, and guilt. Some feelings are part of the grieving process you and your care receiver are experiencing.
- **A counselor can help you see things clearly and set goals for maintaining your own life while caregiving.** It's a good idea to talk with one while in the midst of caregiving. Unfortunately, many caregivers don't take time for counseling until their caregiving days are over.
- Counselors have a variety of educational backgrounds. They include psychiatrists, who are medical doctors and who can prescribe medications if you need them but who may refer you to a different type of counselor to "talk things over," psychotherapists, psychologists, licensed mental health counselors, licensed clinical social workers, clergy, and more.
- If you are a working caregiver, counseling may be provided as part of your health insurance package even if it is an HMO. Many health insurance providers use a subcontractor to provide counseling services, so you may not see a listing in your health insurance directory. Call your health insurance provider. Employee Assistance Programs (EAP's), for those companies that offer them, may also cover counseling.
- If you are age sixty or over yourself, you may qualify for counseling under the Older Americans Act, Title III-B. Counseling may be available to the person from whom you are caring, also if needed. These services are usually available without a long wait. There is no charge for services, but donations are accepted. In Pinellas contact Suncoast Center at 727-323-2528 ext 236. In Pasco, call The Harbor at 727-841-4200.

The National Family Caregiver Support Program provides counseling for eligible caregivers of any age. This is one of the new caregiver programs described in the **More Resources and Tips** section of this Handbook. Other government funding may cover the cost of counseling for active clients. For information on “Formal Support Services” see **Stage Two, Section 5**.

## Respite Care

Respite care means taking a break from caregiving, usually because someone else is taking care of your care receiver for a few hours, days, or weeks. At this stage you must get away from caregiving at least half a day once a week (more often, if possible) and take longer breaks when needed.

One type of respite care break is when relatives, friends, or volunteers from a faith community stay with the care receiver so that the caregiver can leave the home. **Faith in Action of Upper Pinellas** is a program that uses volunteers to provide respite care to individuals in north Pinellas. For more on how to ask for help from others, see **Stage Two, sections 1 and 2**.

Formal respite care services are provided by businesses and non-profit agencies. There are several types of formal respite care: companions, homemakers, home health aides, adult day care, and overnight care for a few days or longer in a facility such as a nursing home. Sometimes you have to ask for these services by name rather than asking for respite care, but all of these provide a break for the caregiver. **Two types of respite care that have proven valuable to caregivers are described below:**

- **Adult day care.** Many people think going to an adult day care center will be the same as going into a nursing home, but adult day care programs actually help people remain independent longer. These programs are wonderful both for care receivers and their caregivers, who can get away from caregiving for a day at a time.

Adult day care programs offer close supervision, lunch, snacks, and excellent activities suited to various levels of participation: lounging in recliners, playing board games, singing, or playing indoor balloon volleyball. For tips on “Dealing With Resistance”, see **Stage Three, section 2**.

Adult Day Care is available through government-funded programs and through agencies on a private pay basis. See **Stage Two, Section 5**. Even if your care receiver is on the waiting list for state-funded programs such as Community Care for the Elderly, you may be able to get a service such as adult day care started through Older Americans Act (OAA) funding. You may also combine OAA-funding with private-pay days. The National Family Caregiver Support Program provides respite, including day care. Some assisted living facilities offer a senior day program at a reasonable rate. Cost depends on how much assistance is needed. The hours are flexible up to twelve per day, and short notice is okay after

client information is on file. Some Adult Day Care Centers will provide transportation to and from the elder's home.

- **Home Health Care.** There are several reasons to ask for home health care (personal care) as part of respite. Besides the fact that you can leave the house when the home health aide is there, you will be relieved of some personal care such as bathing, toileting, and dressing. These tasks, hard both physically and emotionally, contribute greatly to caregiver burnout. For more about this, including ideas for special garments to protect your care receiver's dignity when being bathed by others, see **Stage Three, section 2.**

Paying for a service privately gives you ability to get a service started quickly and the choice of paying for the amount of service that you need, whether it is a few hours or a day at a time. Compare rates for different types of service and consider using the least expensive choice that would meet your needs.

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**Here are several ways to take a respite care break without leaving home:**

- **Buy respite videotapes.** These occupy a care recipient, including those with Alzheimer's, with something enjoyable while the caregiver takes a break.
- **Ageless Design's Alzheimer's Store,** [www.alzstore.com](http://www.alzstore.com), sells sing-a-long to oldie's and memory tapes, beautiful scenes such as fish swimming in an aquarium, spiritual sing-a-long tapes, a videotape showing the four seasons while Handel's Water Music plays in the background, and more. These can be relaxing and allow an opportunity for singing together and reminiscing. The Alzheimer's Store has other products you might find helpful – alarms, mini-fire extinguishers to attach above the stove, and Alzheimer's activity aprons just to name a few.
- **Innovative Caregiving Resources** sells a different type of respite videotapes. Call toll-free 800-249-5600 for a catalogue or use their web site, [www.videorespite.com](http://www.videorespite.com). Sharing Christmas Cheer, A Visit with Maria, and a Kibitz with David are three of the titles. The promotional video shows Alzheimer's patients enjoying their video visitors, speaking to them and singing along. Videos to facilitate exercise, relaxation, and cooperative activities are also for sale.
- **Do something nice for yourself.** No matter how much respite care you arrange from outside sources, also take a short respite break every day by doing something just for you. Use the list of favorite leisure activities requiring little time to enjoy that you made as a beginning caregiver or make a list now if you don't have one. Pick something and do it each day. Then write what you did for yourself in your journal. For days when you can't get away from home long enough to visit a museum or walk on the beach, do something simple at home.

Use the checklist below as a daily reminder to choose at least one activity.

- Have a cup of tea or cocoa or a glass of sparkling water
  - Read your favorite section of the newspaper
  - Pet the dog or cat
  - Work in one flower bed or garden patch
  - Feed and watch birds or fish
  - Read a magazine or one chapter of a book
  - Enjoy a bubble bath or shower with music and candles
  - Watch escapism movies or television programs
  - Spend time in a private spot in the home or yard
  - Call a friend
  - Meditate for fifteen minutes.
  - Use the Internet for fun and to plan outings.
- One place to find free games and crossword puzzles online is AARP's web site, [www.aarp.org/games](http://www.aarp.org/games). Pinellas County, Florida, residents may enjoy the *St. Petersburg Times* newspaper's web site, [www.sptimes.com](http://www.sptimes.com). Find interesting things to do locally in the online Weekend section. The Marketplace section has a Restaurant Guide and Coupon Book. The *Tampa Tribune Newspaper's* web site can be found at [www.tbo.com](http://www.tbo.com). Games are one of the features of the TBO web site.

## Correct Diagnosis

If you have not already done so, make certain that your care receiver gets a correct diagnosis. For more about resources for diagnosis of memory loss, see **Stage One, section 3**. Having a diagnosis of Alzheimer's or related dementia, to the extent that it can be diagnosed during life, may increase eligibility for some government-funded programs that would provide you with services such as respite care. See **Stage Two, section 5**.

## Hands-On Caregiving Skills

**Learn as much as you can about hands-on caregiving skills.** This will increase your confidence while helping you avoid injury and exhaustion that lead to caregiver burnout. Also help your care receiver to be as independent as possible, reducing your need to assist with heavy tasks. Here are some suggestions:

- **Learn hands-on skills from physical and occupational therapists.** Physical therapists help people recover their strength and range of motion. They also can help patients improve balance, relearn walking, and learn to transfer. PT's evaluate the need for assistive devices such as canes, walkers, wheelchairs, and transfer equipment. Occupational therapists focus on activities of daily living including personal hygiene, bathing, dressing, grooming, toileting, and feeding. The occupational therapist evaluates the need for special equipment such as transfer equipment, feeding devices, and hand and skin devices to help your elder be as independent as possible. Make sure your care receiver's doctor

orders physical and occupational therapy if needed.

- **Learn hands-on skills from caregiving books.** A book that describes how to do hands-on caregiving including setting up your home to accommodate a wheelchair, making the home environment safe, preventing pressure sores, caring for someone who is in bed, helping a person get out of bed and into a wheelchair using a mechanical lift or a simple gait belt, and even how caregivers can use tax strategies to save money is *The Comfort of Home*, an illustrated step-by-step guide for caregivers, by Maria Meyer with Paula Derr, RN. See the **Caregiver Books and Videos** section for more information.
- **Learn hands-on skills from caregiving videotapes.** There are also a number of videotapes that deal with subjects such as protecting your back while lifting or while helping your care receiver to transfer. The *Home Care Companion Resources for Caregivers Caregiving Series* includes *How to Help Someone Who Uses A Wheelchair Without Hurting Yourself* and *Personal Care*. These and other instructional videotapes can be ordered from the Home Care Companion web site, [www.homecarecompanion.com](http://www.homecarecompanion.com), or find them in the Pinellas County, Florida, library system.
- Another video series that heavy-duty caregivers should find helpful is *The Educated Caregiver Video Series*, Volumes 1, 2, and 3, a reasonably priced set created by Life View Resources. Call toll free 800-395-5433 or visit their web site at [www.lifeviewresources.com](http://www.lifeviewresources.com) and click on the box with the picture of their videotapes. Volume 1 is *Coping Skills* such as getting support and being realistic about how much care you can provide; Volume 2 is *Hands-on-Skills* such as bathing, dressing, safety, and bed rest; and Volume 3 is *Essential Knowledge* including medication management, diet, and prevention of infection. You can see sample clips of each video online.
- Caregiver's Marketplace, [www.caregiversmarketplace.com](http://www.caregiversmarketplace.com), offers a free membership that provides discounts on purchases of these videos and many other products available from catalogues and other web sites. You will receive a Caregivers Market membership code to be used when ordering products.
- **Learn hands-on skills from web sites.** The Suncoast Hospice's web site, [www.thehospice.org](http://www.thehospice.org), offers "Caregiving Tips" for physical care at home. Learn more about skills such as giving injections and using catheters, feeding tubes, and oxygen. Hospice programs are experts in end-of-life care, and much of this is physical care that may be provided at home. Other web sites include articles on hands-on caregiving skills. See **Caregiver Web Sites** in this Handbook or online at [www.agingcarefl.org/caregiver/Websites](http://www.agingcarefl.org/caregiver/Websites). Search for "caregiving skills" on an Internet search engine.

## Public Library Resources

Use materials from public libraries to improve your caregiving skills and to get away

mentally from caregiving. Many libraries have caregiving books and videos, and more should be available in the future. There are popular and classic movie videos and some new movie DVD's you can check out for several days as well as informational videos you can check out for a week. Anyone with a library card can check out musical CD's and popular books recorded on audiotape. People with visual problems can participate in the Pinellas Talking Book Library. See **Stage 3, section one** for more information.

Inter-library loan is a helpful feature. Materials can be sent over from other libraries within the local system or even borrowed from libraries outside the system. Your local librarian can help with this. **Many libraries offer public access catalog training sessions and basic Internet classes.** For example, volunteers at Main Library in St. Petersburg, Florida, teach free, one-hour, one-on-one classes on the use of the Internet. Interpreter services and special support can be arranged. Some of the other libraries offer group classes in their new computer labs.

If you have a computer with Internet access, you can search the electronic card catalog of the Pinellas and Pasco libraries. The Pinellas County Library Cooperative has a web site, [www.pplc.us](http://www.pplc.us). Select "cooperative Libraries" on the main menu, choose the library you want to visit, and type in your library card number (you do have to have a library card). If you need a broader search of all libraries in the system, select "Anywhere/Anytime Library". Search by a topic such as caregiver, an author, or the title of a book. Books and videos can be reserved online and sent to your neighborhood library for quick pick up. The Pasco County Library System is at <http://pascolibraries.org>. See our list of **Caregiver Books and Videos** for caregiving materials you may want to reserve.

For fun, remember that the online catalogs also list popular and classic movie videos and DVDs, and there are exercise videos such as tai chi and weightlifting for seniors.

## **Saving Time and Trouble**

- **Mobile services.** Save time and the difficulty of getting your care receiver in and out of a vehicle and into stores and offices, where he or she may become confused and frustrated, by using mobile services that come to your home. In Pinellas County, Florida, there are mobile pet groomers, a mobile veterinarian, hair dressers who make house calls, personal trainers who work with disabled people in their homes, and at least one mobile medical van that brings doctors, nurses, and technicians to your home for medical treatment and lab tests such as a blood test with results in two minutes. The mobile medical van's services are covered by Medicare but not by HMO's.
- **Membership medical services.** This is an innovative medical practice concept that has been implemented in Pinellas County. Patients of these physicians pay a membership fee. Membership benefits include easy access to physicians by phone and in person and the availability of home visits. The Pinellas County caregiver who told us about this service said it had eased her stress level. She joined after a former doctor refused to see them because, with the hassles of

getting him ready and in and out of the car, they were fifteen minutes late. The membership medical practice provides some services under Medicare.

- **More efficient grocery shopping.** This may seem like a strange suggestion for preventing caregiver burnout, but grocery shopping adds to caregiver stress. You may have to rush through the store while your care receiver is alone for an hour or someone is staying with him or her for a short period. Also, you may worry about how to get groceries when you can't leave your care receiver.

**Here are ideas for making grocery shopping less of a hassle:**

Ask your store whether they can give you a **printed floor plan** or list showing the aisles where various types of items can be found. If your store's customer service desk can't give you this, suggest the need to the store manager. If you can't get something like this from the store, consider making your own. This may help you and persons who shop for you.

Ask for other **special help** your store may provide. This can be personal shopping assistance for blind or disabled persons, ride-on grocery carts for persons who have trouble walking, and someone to lift a fifty pound bag of dog food into your cart or help you reach a can on a high shelf. Chances are you will have plenty to load because of stocking up in case you can't get away for a big shopping trip the next week. Ask for help in loading the car.

If you go shopping with your care receiver or you are disabled yourself, see "Florida's Disabled Parking Program" in the *More Tips and Resources* section. To improve your chances of finding a good parking space, find out when the store is least crowded and shop then.

**Carry a cell or mobile phone** into the store after giving the number to your care receiver or substitute caregiver. That way you can check on things at home. Knowing that you can be reached in an emergency may give you peace of mind, and your care receiver may worry less. If you are concerned about courtesy to other shoppers, buy one of the new earphone/microphone combinations.

**Use assistive devices.** Some shoppers bring a grabber tool to reach items on top shelves – this type of tool extends your reach and will hold up to five pounds. Find these in drug stores or order from television commercials, catalogs, or caregiver web sites. See the *Caregiver Web Sites* section.

**Save time and prevent injury by using a cart** to bring in the groceries. At discount stores you can buy lightweight, inexpensive carts that unfold to look like plastic cubes or baskets with wheels and handles. A moment unfolding the cart can save several extra trips to the car. These carts are handy also when visiting fruit stands that do not have shopping carts with wheels.

**Keep a grocery list** in a magnetic holder on the refrigerator or in another handy

spot in the kitchen to add items as you run out of them. If you write down the specific products that you and your care receiver prefer (brand name or store brand, sugar-free or regular, low-fat or fat-free, gallon or half gallon, etc.), it makes it easier to have a relative, neighbor, or friend shop for you.

If you need a hard-to-find or new item, **call the store** and ask whether they have it and what aisle it's on. Write the aisle number on your grocery list. Also use the telephone to place deli, meat, or bakery orders for quicker pick up in the store. Consider convenience items such as salad bars, shrimp steamed by the grocery store while you shop, pies and cakes from the bakery, and holiday dinners you can order. Although more expensive than homemade, these items may be worth it for the time saved.

When you can't get away or are too exhausted to shop, review your list of people who offered help and **ask a neighbor, friend, relative, or volunteer from a faith community to shop for you**. If you feel guilty, remember that you stocked up when you went to the store yourself, which means that the list you give your volunteer shopper will be shorter. For more on how to ask for help, see **Stage Two, sections 1 and 2**.

If you can afford it, you may want to use **businesses that run errands such as shopping for a fee**. Look up "Errands" in the *Senior Resource Directory* Subject Index or call the Senior Helpline. Besides errand services, there are homemaker services and transportation providers that also do grocery shopping. For a list of transportation providers, see "Transportation Options for Seniors" at [www.agingcarefl.org/aging/transportation](http://www.agingcarefl.org/aging/transportation) or call the Senior Helpline for a copy.

Most grocery stores do not deliver, but some small specialty markets do provide that service. Compare prices to see if the convenience is worth it, at least for weeks when you can't get away to shop. Private-pay home delivered meals, described below under Protecting Your Health – Healthy Food, is another option.

## Protecting Your Health

- **Preventive medical care.** Visit your doctor regularly. Having mammograms, prostate tests, colon cancer tests, and a pneumonia shot are important. Medicare and private insurance may cover costs. Make sure you put these tests for yourself on your calendar.

If you and your doctor agree that you need to take medications because of stress, also consider adding some of the other types of support described here:

- **Exercise.** Attend exercise, yoga or Tai Chi classes at local community or fitness centers, exercise at home to a yoga or Tai Chi video tape, swim, dance, garden, lift small weights, walk around the block or on a treadmill, or use an in-home fitness company. Pinellas County has at least one company that provides a personal trainer with expertise in helping older persons. Care managers

sometimes suggest purchasing this service when Medicare stops covering physical therapy.

For online exercise videos, visit the National Library of Medicine's Medlineplus, [www.nlm.nih.gov/medlineplus/exerciseforseniors.html](http://www.nlm.nih.gov/medlineplus/exerciseforseniors.html). An inexpensive exercise video can be found on the web site of The National Institute on Aging, [www.nih.gov/nia](http://www.nih.gov/nia).

- **Pet Therapy.** Spend time with a pet. Let your dog or cat provide you with comfort and laughs, enjoy a neighborhood walk with your dog, or watch the fish in the aquarium or goldfish pond. Just holding a furry pet is good for your health, and watching fish is relaxing.
- **Meditate.** Even a few moments spent in quiet thought can reduce stress.
- **Healthy food.** Eating right is hard to do when you are so busy. Recommendations include the following:
  - **Eat three well-balanced meals** a day, with breads and cereals, milk and cheese, fruits and vegetables, and lean meat, poultry, fish, and eggs. Canned or bottled nutritional drinks may be helpful when you have to skip a meal.
  - **Choose healthy snacks** such as fruit, vegetables, yogurt, cereals, crackers, and low-fat cheese and popcorn. For ice cream cravings, there are many low fat and low calorie choices.
  - **Limit high sugar and most high fat foods to small servings, but do not eliminate all fat from your diet.** Olive oil, flax seed oil, and the oil in nuts and fish such as salmon are considered healthy fats that should be eaten. Also, chocolate in moderation offers some health benefits, and it's a very comforting food enjoyed by people from childhood to one hundred years and older.
- **Don't self medicate with alcohol.**
- **Avoid food and medication interactions** by being informed. Ask your doctor and pharmacist about interactions. A web site that offers dietary precautions for each medication listed is the National Library of Medicine's MedlinePlus, [www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus). See the **Caregiver Web Sites** section for others.
- For **nutrition tips** and names of dieticians by area, visit the American Dietetic Association web site, [www.eatright.org](http://www.eatright.org) or call the ADA Consumer Nutrition Hot Line at 800-366-1655. This organization provides nutrition tips and names of dieticians in the area where you live.

If you need to learn how to cook for someone on a **special diet**, your doctor may be able to refer you to a dietician, often within the same medical facility. At the Veterans Administration Hospital in St. Petersburg, Florida, for example, diabetic

patients attend a Diabetes Clinic diet planning session. The Joslin Center for Diabetes at Morton Plant Hospital in Clearwater, Florida, offers diabetes management classes that may be covered by Medicare or other insurance. You may also want to visit the American Diabetes' Association web site, [www.diabetes.org](http://www.diabetes.org) or call them toll-free at 1-800-DIABETES (1-800-342-2383). They will mail you materials related to planning meals for diabetic patients.

If cooking for yourself and your care receiver is becoming increasingly more difficult, consider **home-delivered meals services**. Your care receiver may qualify for government-funded home-delivered meals. Some spouses may also qualify. Meals can also be purchased from both for-profit companies and from government-funded home-delivered meals. Some companies offer delivery of as few as ten frozen meals at a time to your door with choice of menus and special diets at a cost of around \$5.00 per complete meal or \$50.00 per delivery. Food preferences are very individual. You may have to try different companies and different menus to find products that suit your tastes.

If you are the primary caregiver and your out-of-town relatives want to know what they can do, ask for a care package of home-delivered meals. See "Gifts for Caregivers" in the *More Resources and Tips* section.

## Better Sleep

**Lack of sleep is a frequent problem for stage three caregivers. Here are some strategies for improving sleep.**

- **Exercise daily** but not too close to bedtime unless that is your only opportunity.
- Listen to **relaxation tapes** or do **relaxation exercises** while listening to relaxing **music** just before bedtime.
- **Avoid caffeine in the evenings.**
- **Change your sleep cycle to coordinate with your care receiver's sleep pattern.** In other words, if he or she sleeps during the day but wakes you up a lot at night, try to nap during the day yourself.
- **Get some outside help at night.** Hire a home health agency or recruit a friend or relative to stay over and care for your care receiver while you sleep.
- If confusion and fear of going to the bathroom alone are causing your care receiver to demand your assistance every time, **adapt the environment.** Items that may make the care receiver more comfortable include: grab bars, a raised toilet seat, a bell that the care receiver can ring if he or she has problems in the bathroom, night lights, a sign or picture on the bathroom door, and a tape path on the floor from bedroom to bathroom.

- The tape path idea came from a book called *The Complete Guide to Alzheimer's Proofing Your Home* by Mark L. Warner, available for purchase on the Ageless Design web site, [www.agelessdesign.com](http://www.agelessdesign.com) and in the library system in Pinellas County. This book lists ways to deal with difficult behaviors by adapting the home. Product suggestions for each problem and information about who makes them are included.
- Find other strategies to help reduce nighttime wandering in "How To Deal With Wandering" in the **More Tips and Resources** section.
- Find out from the doctor whether anything can be done to **reduce the physical need for frequent bathroom breaks**. Changing medications, treating physical conditions such as diabetes, and changing the time that liquids are consumed may reduce the number of times that your care receiver wakes you for help.
- If your care receiver seems to be waking you because of a habit that could be changed, you may want to **try mild behavior modification**. Provide little rewards for letting you sleep more hours at a time or for using the bathroom alone. If you feel your care receiver does not have the capacity to learn new habits at this stage of illness, try the other strategies listed above.

## Massage

Therapeutic massage, which is massage by a licensed massage therapist as a form of therapy, has been shown to have **physical and emotional benefits**. These include lowering blood pressure, promoting healing, relieving pain, reducing stress, and aiding relaxation. Massage does not have to be whole body, but can focus on the face or even the feet. Massage may be available under your insurance coverage. Even if you were never one to splurge on yourself, now is the time to treat yourself to services such as massages. You may also want to suggest a gift certificate

## Spiritual Support

**Maintain your spiritual life.** See **Stage Two, Section 2** for suggestions of support from faith communities. The And Thou Shalt Honor web site, [www.thoushalthonor.org](http://www.thoushalthonor.org), was started in connection with the PBS (Public Broadcasting Service) special designed to raise awareness concerning caregiving, with broadcast date of October 9, 2002. This web site has a section on spiritual caregiving.

## Music

Music is good for you and for the person for whom you are caring. Music is called the universal language, connecting us with our inner feelings and with other humans in a way that words alone cannot. Music can be relaxing for you, and it can make working with your care receiver easier. Music is helpful for pain management. Stroke survivors who have lost some of their ability to articulate or use words (aphasia) may get their lost

words back by singing. Persons with Alzheimer's disease may play instruments and create songs. Even people with late stage Alzheimer's disease may still respond to music. A person who fights having a shower may follow you to the bathroom if singing, making your life easier. Since music that is invigorating to one person can cause agitation in another, try wireless headphones or personal audiotape, CD or MP3 players with headphones if you and your care receiver like different types of music.

**Reminiscing with music may trigger long-term memory.** This can be enjoyable for the care receiver and the caregiver. As mentioned in the respite care section above, reminiscence/respite video tapes are available at the Alzheimer's Store, [www.alzstore.com](http://www.alzstore.com), and from Innovative Caregiving Resources, [www.videorespite.com](http://www.videorespite.com), or call toll-free 800-249-5600 for a catalogue.

### **Strategies That Protect Both Your Care Receiver and You**

Other strategies that can help prevent caregiver burnout and injury are discussed more fully in **Stage Three, section 2**. Although this section is titled "Protecting Your Care Receiver", many of the strategies also protect the caregiver.

**To access the services or programs described in this Handbook, call the Senior Helpline at 727-217-8111 in Pinellas or 800-861-8111 in other areas of Florida.**

## Stage Three, section 2: Protecting Your Care Receiver

Your job is to provide a healthy, safe, and loving environment for your care receiver, not to provide all the care yourself. This section of the *Caregiver Handbook* includes suggestions to improve the quality of life for your care receiver and for you as well.

### Help With Personal Care

Get help with personal care. **Be realistic about how much you can handle.** Hands-on personal care such as toileting and bathing is difficult not only physically, but also emotionally. Having home health aides provide part of this care can make a huge difference. Find out whether your care receiver's insurance will cover home health or personal care, what type of service would be provided, what the eligibility requirements are, and how often and how long service would be available. For information about how to get help with personal care, see *Stage Two, section 5*.

**To preserve your care receiver's dignity and privacy while being showered or bathed,** consider products such as Honor Guard, invented by a Brooksville, Florida woman who was a caregiver for her mother. Find these on the Personal Care Wear web site, [www.personalcarewear.com](http://www.personalcarewear.com). These undergarments provide visual coverage while allowing access to all parts of the body for washing without embarrassment. A disposable version is also available. Not having to remove all clothing may overcome objections by your care receiver to taking a shower, and it may add to your comfort level whether using outside help or bathing your care receiver yourself to know that you are preserving as much dignity as possible.

### Home Modifications

Consider minor home modifications to increase safety and improve accessibility. Visit the **Home Modifications** section of a Canadian web site called How To Care, [www.howtocare.com](http://www.howtocare.com). This web site discusses activities of daily living (ADL) risk factors and how they can be addressed through minor changes in the home environment. The site also lists home adaptations to help with various Alzheimer's behaviors.

*The Complete Guide to Alzheimer's Proofing Your Home* by Mark L. Warner lists products and manufacturers that may be of use to caregivers of persons with other disabilities as well. Home adaptations to provide solutions to activities of daily living problems as well as behavior problems are described. Some changes are inexpensive. For more information, see the **Caregiver Books and Videos** section.

### Help For Vision Loss

Seek help for vision loss, a problem that affects many older adults. One of the main causes of blindness in older persons is macular degeneration, which destroys central vision needed to do tasks such as driving and reading. See "What Is Low Vision?" in

the **More Resources and Tips** section. Visit the National Eye Institute web site, [www.nei.nih.gov](http://www.nei.nih.gov) and Lighthouse International's web site, [www.lighthouse.org](http://www.lighthouse.org).

If your care receiver has physical impairments that make it impossible to read, he or she might enjoy the **WUSF Radio Reading Service**, offered throughout Pinellas and surrounding counties of Florida. Your care receiver's home would be provided with a special receiver at no cost. Volunteers read the *St. Petersburg Times*, *Tampa Tribune*, *USA Today*, and other interesting material. Call 813-974-4193 for more information. Public radio stations in other parts of the country may have similar programs.

The Pinellas Public Library Cooperative offers the Pinellas Talking Book Library to support reading for individuals with vision problems. Call them at 727-441-8408 for more information. You can also visit the web site at [www.pplc.us](http://www.pplc.us). According to their web site the Pinellas Talking Book Library is "...part of a nationwide network of cooperating libraries serving people who have difficulty using or reading regular print. Books and magazines in audio formats and Braille, plus compatible playback equipment from the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress, are loaned free of charge. All materials are sent to clients and returned to the library via postage-free mail. The PTBL collection has thousands of recreational reading titles to choose from in fiction and non-fiction, pre-school to adult."

## **Help For Swallowing, Taste, Smell, and Eating Problems**

Learn strategies for dealing with swallowing, taste, smell, and eating problems. Speech therapists evaluate and assist with swallowing problems. Visit the How to Care web site, [www.howtocare.com](http://www.howtocare.com), and select "Eating/Nutrition/Diets" for a discussion of medical conditions and medications that affect taste and smell, conditions that affect nutrition, signs of chewing and swallowing problems (a condition called Dysphagia), and suggestions for improving nutritional intake.

A book that discusses swallowing problems that sometimes accompany strokes is *Managing Stroke, A Guide to Living Well After Stroke*, edited by Paul R. Rao, Ph.D., Mark N. Ozer, M.D., and John E. Toerge, D.O. Another is *Living With Stroke: A Guide for Families* by Richard C. Senellick, MD, Peter W. Rossi, MD, and Karla Dougherty. This second book is published by Heath South Press and used by Heath South in working with families of stroke survivors. See **Caregiver Books and Videos**.

People who have difficulty swallowing may have a feeding tube inserted by their health care provider. Instructions for using the feeding tube and tips for caring for the tube site can be found in the **Practical Caregiving Tips** section of The Suncoast Hospice web site, [www.thehospice.org](http://www.thehospice.org). There are eating tips for people who have Chronic Obstructive Pulmonary Disease (COPD), also.

## Guarding Against Dehydration

Recognize and prevent dehydration. Older people may not realize they are dehydrated because the ability to detect thirst diminishes with age. If a person gets less than six cups of liquid daily (drinking eight cups is recommended) or excretes too much urine, dehydration can occur. Being sick and taking certain medications can contribute to dehydration. Having problems swallowing or drinking from a glass can contribute, also.

### **Symptoms of dehydration include the following:**

- Thirst (but a dehydrated elderly person may not feel thirsty)
- Headache
- Dry skin, dry mouth and tongue, cracked lips
- Fatigue
- Sunken eyes
- Vomiting, diarrhea
- Dark, strong smelling urine
- Weight loss
- Fast heart beat
- Fast breathing
- Low blood pressure
- Confusion, dizziness
- Increased body temperature
- Disorientation

In severe cases, there may be swollen tongue, delirium, kidney failure, and death.

### **To help prevent dehydration in your care receiver, offer plain or filtered water plus beverages and foods that are high in water content:**

- cracked or shaved ice
- popsicles or juice bars
- gelatin
- sherbet or ice cream
- soup or broth
- fruit or vegetable juices
- lemonade or flavored water

**Coffee and soft drinks with caffeine contribute to dehydration.** Avoid them if possible and do not count in the total glasses of water and liquid for the day. Caffeine-free teas including most herb teas sold at grocery stores can be used, but do not use unusual herb teas that may act like drugs. If your care receiver chooses to self treat with herbs, make certain that the pharmacist and doctor know in order to rule out harmful interactions between any herbs, prescriptions, and over-the-counter drugs.

## Preserving Communication

**Preserve communication even if it has to take new forms.** Communication with your care receiver continues to be important even if he or she has trouble hearing or speaking or no longer recognizes you. Here are several suggestions:

- Communication problems experienced by stroke survivors may improve through speech therapy. Make sure the doctor orders this service if needed.
- For a description of types of **assistive devices** for hearing loss and a list of drugs that can cause hearing loss, visit the Hard of Hearing Advocates web site, [www.hohadvocates.org](http://www.hohadvocates.org).
- The Home Care Companion Communication Series includes three **videos for better communication** with hearing-impaired persons, persons with aphasia (trouble speaking and understanding experienced by some stroke survivors), and Alzheimer's patients. Buy these videos online at [www.homecarecompanion.com](http://www.homecarecompanion.com) or find them in the Pinellas County, Florida, library system.

## Assistive Devices

Assistive devices can improve your care receiver's quality of life and independence, and some can protect your back when helping your care receiver transfer from bed to chair to standing position. Assistive devices range from simple eating utensils with wrapped handholds to fancy computer software, electric scooters, and much more.

An occupational therapist can provide advice. A nurse, pharmacist, or doctor may be helpful, also. Find out whether Medicare or other insurance covers an item and whether a doctor's prescription is needed. Low-tech and inexpensive items such as one-handed kitchen tools for stroke survivors could make your life easier.

Call ABLEDATA toll-free at 800-227-0216 for information about assistive devices and what companies manufacture them. ABLEDATA, [www.abledata.com](http://www.abledata.com), is funded by the U.S. Department of Education.

Caregiver's Marketplace, [www.caregiversmarketplace.com](http://www.caregiversmarketplace.com), offers rebates and discounts on products sold by other companies that have catalogs and web sites. Join for free and receive a code number to use when ordering everything from caregiving videos to adult undergarments from various suppliers.

Another web site with assistive device information is Network of Care, [www.networkofcare.org](http://www.networkofcare.org). This site, by the California Department of Aging, provides information specific to each California county. A resource library and assistive device section provide help for caregivers anywhere.

Listed below are several more web sites with assistive device information. See the *Caregiver Web Sites* section for more information about these sites:

- Dynamic Living: [www.dynamic-living.com](http://www.dynamic-living.com) (note hyphen)
- Alzheimer's Store: [www.alzstore.com](http://www.alzstore.com)
- National Stroke Association: [www.stroke.org](http://www.stroke.org)
- Florida Alliance for Assistive Services and Technology (FAAST): [www.faast.org](http://www.faast.org).

Remember that any kind of tool that helps make a job easier for you or your care receiver is an assistive device worth considering for safety and convenience. An example is an electric shaver, which many people find less likely to nick than a non-electric razor. If the electric shaver in your household is several decades old, you may want to invest in one of the recent designs for sensitive skin.

## Help For Incontinence

If incontinence of bladder or bowel is a problem, report to your care receiver's doctor for diagnosis and get ideas for dealing with these from doctor, nurse, or pharmacist.

**Many causes of incontinence respond to treatment, and sometimes simple changes can be effective:**

- change diet and time of fluid intake
- stop laxatives
- change medication
- provide visual cues as reminders for visiting the bathroom (pictures of a toilet on the bathroom door, a bright tape path from bedroom to bath)
- make the bathroom more secure with grab bars and raised toilet seat
- use adult undergarments

**ABLEDATA**, 800-227-0216 or [www.abledata.com](http://www.abledata.com), and many of the other web sites that have information about assistive devices, also include incontinence products such as adult undergarments. **See *Caregiver Web Sites*** in this Handbook. For discounts, visit Caregivers Marketplace at [www.caregiversmarketplace.com](http://www.caregiversmarketplace.com).

Clients of the Medicaid Waiver programs or the National Family Caregiver Support Program who cannot afford incontinence products may get help with these supplies. For more about government-funded programs, see **Stage Two, section 5**.

## Managing Medications

Unless insurance or a program such as Medicaid Waiver provides a nurse to manage medications or your care receiver can afford to pay for a nurse, this responsibility will probably fall on you as caregiver. **Nurse's aides are not allowed to manage medications.**

**The Home Care Companion Series video**, *How to Manage Medications*, is very thorough. There are demonstrations of proper use of inhalers, eye drops, and medication dispensers with alarms. Order from [www.homecarecompanion.com](http://www.homecarecompanion.com) or find in the library system in Pinellas County, Florida.

How to Manage Medications offers excellent suggestions for **preventing dangerous medication mistakes**:

- **Double-check the container** to make certain that it is the patient's correct prescription, not a prescription for someone else in the household or for another drug the patient takes, and that you are following the directions for administering.
- **Keep a record** of what is taken in your Caregiving Notebook. See *Stage One, section 5*.
- **Tell doctor and pharmacist about herbs and over-the-counter medications** that are also being taken or considered.
- **Read the pharmacy's patient information sheet**, which lists common side effects, and **report side effects** to doctor and pharmacist.
- **Also report adverse reactions**, problems the patient developed after taking the medication even though not listed as a side effect.
- **Make sure all of the medication is taken** (don't stop antibiotics at the first sign of improvement).
- **Throw out expired medication.**
- **Have the pharmacist or doctor review all medications** to make certain that all are still needed. Sometimes a doctor changes a medication, but the patient may think it was an addition and take both.
- **Report problems such as incontinence or frequent urination** during the night to your health care provider. Perhaps a change in medications or the time of day they are administered could improve the situation.

*The Caregiver's Support Kit*, available free to caregivers by calling the National Caregivers Foundation at 800-930-1357, **recommends memorizing the six medication "rights."** **Make sure that:**

- The RIGHT PERSON
- Receives the RIGHT MEDICATION
- In the RIGHT DOSE
- At the RIGHT TIME
- Via the RIGHT METHOD/ROUTE
- Followed by the RIGHT CHARTING METHODS

## Overcoming Resistance To Outside Help

Some care receivers are very resistant to allowing outside help and to trying a respite care solution such as adult day care. In order to get support services needed by care receiver and caregiver alike, it helps to know some **strategies for fostering cooperation**.

For advice on how to handle your care receiver's resistance to accepting help from anyone but you, visit the American Geriatrics Society Foundation web site, [www.healthinaging.org](http://www.healthinaging.org). Select "Public Education Resources", followed by "Eldercare at Home", then "Caregiving" on the Table of Contents page. Whether discussing hearing problems or behaviors associated with dementia, this web site explains the problem, tells you what you can do yourself and when you should seek professional help. It also provides sample conversations to use with service agencies and doctors, and gives suggestions for overcoming obstacles. There is even an article on what to do when you can't get information from doctors.

Here are three suggestions from the American Geriatrics Society Foundation's online caregiving guide, *Eldercare at Home*, regarding **how to overcome resistance**:

- **Involve the older person** in developing and carrying out care plans.
- **Explain your needs openly**. Sometimes you need to ask the older person to do things to make your life easier just as a favor to you.
- If the older person disagrees or won't cooperate with the plan, suggest a **trial run or a time limit** – this puts off the final decision until he or she has had a chance to try the plan.

At the February 11, 2003 Fearless Caregiver Forum held in Tampa, Florida (one of many forums hosted throughout the U. S. by *Today's Caregiver Magazine* ([www.caregiver.com](http://www.caregiver.com)), ideas for overcoming resistance were shared:

- **Enlist the help of an independent third party who is a professional** such as doctor, lawyer, or care manager in convincing your care receiver to accept services. Many people resist or ignore requests from spouse or child while listening to a person seen as an authority.
- Try statements such as, "**Mom, do it for me**" or, "**I would feel so much better if I knew that you had \_\_\_\_\_** (an emergency alert response button to call for help after a fall, home-delivered meals, someone to help you take a shower safely, etc.).
- Leave **brochures or newsletters** that tell about services lying around where the care receiver may see them and get interested.

- **Show how a service will make it possible to remain independent longer.** For example, attending an adult day care program may be feared as much as going into a nursing home. The reality is that it is more like going to a club that provides fun-filled daytime activities with the added benefit of being able to remain in the home longer. A visit to see what's going on there may help.
- If a **“triggering event”** such as a minor fall takes place, use that as the time and reason to add services that may prevent a major catastrophe. For a description of funding sources for services, see *Stage Two, section 5*.
- **If all else fails and the care receiver is endangering himself or herself**, you may have to make a decision that he or she opposes. If it seems necessary for you to take control of an incapacitated person in a way that goes beyond what you have in place now, **you may need to apply for Guardianship.** Guardianship is a last resort that can often be prevented by planning for incapacity. For more on this topic, see “Legal Considerations When Facing Incapacity” in the Alzheimer’s (purple edged pages) of the *Senior Resource Directory* and online at [www.agingcarefl.org/caregiver/alzheimers/legal](http://www.agingcarefl.org/caregiver/alzheimers/legal). Another helpful article is “What Is An Elder Law Attorney?” found in the *Senior Resource Directory* and online at [www.agingcarefl.org/aging/legal](http://www.agingcarefl.org/aging/legal).

## **Support Groups and Counseling For Your Care Receiver**

A support group could provide your care receiver with companionship and support from people with similar experiences. There are groups for persons affected by various illnesses and conditions such as Stroke, Parkinson’s, or Hepatitis. For more about the value of support groups and how to find support groups, see **Stage Two, section 3**.

Just as your care receiver’s illness has caused you to have to deal with many painful emotions, it has caused many feelings for the care receiver. Former U. S. First Lady Rosalyn Carter, in her book, *Helping Yourself Help Others*, **lists eight fears people coping with chronic illness may face:**

- **Fear of loss of control**, including loss of plans that had been made for the future and inability to know from day to day what to expect.
- **Fear of changed self-image**, including feeling less attractive, defective, unlovable, and unable to earn a living.
- **Fear of dependency**, or changing from the head of the household or an independent person to someone dependent on the caregiver even for normally private functions such as toileting. Sometimes the person with the illness reacts by resisting assistance; sometimes, by becoming overly dependent or what some caregivers would call, “spoiled.”

- **Fear of stigma**, or not feeling that you can share much with friends without having them pull back due to the nature of the illness. Aids, Alzheimer's, Schizophrenia, Parkinson's – many diseases are misunderstood by people, who may withdraw from their friend, especially in later stages of the disease.
- **Fear of abandonment**, or fear that your family will tire of the drudgery of constant care. The disease threatens a person's sense of security, intimacy with a marriage partner may be reduced, and a person may feel that he or she is a burden.
- **Fear of expressing anger**. Anger is a natural response when a person realizes he has done everything possible but cannot be cured of his disease or condition. Anger is also part of the grieving process. Feeling that it would not be acceptable to express anger or that expressing anger might lead to losing control, a person with a severe illness or injury may become depressed instead.
- **Fear of isolation** or losing friends and social opportunities. The person with the illness has to turn down and cannot return invitations, is invited less, and withdraws even further.
- **Fear of death** and sometimes an even **greater fear of how one will live with the illness until death**.

In addition to attending a support group, **your care receiver may need counseling** to deal with losses and fears. For more information on access to counseling, see **Stage Three, Section 1**.

### **Enjoyable Time Spent Together**

**Spend time with your care receiver in mutually enjoyable activities.** The *Caregivers Support Kit*, which the National Caregivers Foundation provides free to caregivers who call 800-930-1357, recommends two books with ideas for how to spend enjoyable time together.

- *Making the Moment Count: Leisure Activities for Caregiving Relationships*, by Joanne Ardolf Decker, 1997, Johns Hopkins University Press, \$14.95
- *Failure-free Activities for the Alzheimer's Patient*, Carmel Sheridan, 1995, Dell Books, \$8.95.

Remember that a few moments spent together looking through an old photograph album, petting the dog or cat, listening to music, or watching your goldfish swim can be enjoyable for both of you.

## Relief From Pain

Untreated pain not only causes unnecessary suffering but can also contribute to depression, immobility, dementia, sleeplessness, substance abuse, and inability to enjoy simple pleasures. Pain management will contribute to your care receiver's well being and to yours. A combination of medications, therapies, and lifestyle changes such as yoga, massage, meditation, exercise, and counseling may control pain and help your care receiver (and you) remain as active as possible.

**Seniors under-report the amount of pain they feel, and doctors often under-treat them for pain.** Report evidence of pain to your care receiver's doctor and demand that your request for pain management taken seriously. The American Pain Foundation ([www.painfoundation.org](http://www.painfoundation.org)) offers a *Pain Action Guide* and a *Pain Care Bill of Rights*.

Here are some **symptoms that may tell you someone is in pain even if he or she cannot describe the pain verbally:**

- Limping
- Groaning
- Wincing
- Holding or protecting part of the body
- Refusing to get up or get out
- Not wanting to see other people or engage in enjoyable activities

**Intensity of pain** is sometimes measured on a scale of 1 to 10 if the person is verbal or can point to a number on a written scale. Medical professionals also use a picture board showing smiles, tears, frowns, and more to describe how someone feels. Look for the *Happy Face Pain Assessment* on the Pain.com web site, [www.pain.com](http://www.pain.com). Select "Consumer Information", then "Pain Support", followed by "Pain Assessment Tools". This web site describes many types of pain such as cancer pain, arthritis pain, and breakthrough pain (pain which occurs in spite of pain management strategies) and has a listing of pain management professionals and an "Ask The Doctor" feature.

**Discuss pain medication needs with the care receiver's health care provider.** Additional information can be found many places on the Internet. Visit the National Library of Medicine's web site, [www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus). This web site also includes disease and healthy lifestyle information, and more sites with information like this are included in the *Caregiver Web Sites* section. You may also want to run a general search for "medications" or "drug interactions" on an Internet search engine.

*Caregiving—A Step-By-Step Resource for Caring for the Person With Cancer at Home* discusses pain. This American Cancer Society publication is available in the public library system. It includes a list of observations you should write down before calling the doctor or nurse about a severe pain emergency, which means a time when your care receiver is in terrible pain (perhaps an 8 on a scale of 10) not relieved by medication, hot water bottles, etc., and more pain medication is not due for hours.

Also included in this cancer caregiving book is an emergency pain chart and a list of symptoms that indicate that you need to get immediate help from the doctor or nurse because your care receiver is allergic to a pain medication, the medication is too strong, or there is a drug interaction.

**Danger signs for drug interactions that should be reported include the following:**

- Hallucinations
- Ringing or buzzing in ears
- Confusion or being “out of it”
- Trouble waking up even when others try to wake the person
- Severe trembling, uncontrolled muscle movements or convulsions
- Unable to hold in urine or stool when this was not a problem in past
- Unable to urinate despite feeling the need to urinate
- Nausea or vomiting with no relief
- Hives, itching, skin rash, or swelling of the face
- Feeling anxious or “fidgety”
- Slow breathing (less than eight breaths per minute) or very shallow breathing (short breaths that don’t take in much air)

It is recommended that **before calling** about problems with medications, you make a note of **what medicine was taken** during the past few days, **how much** was taken, and **how often** it was taken. You will have this information if you are regularly recording it in your Caregiving Notebook.

## **Hospitalization and Rehabilitation**

At this stage, your care receiver may be having frequent hospitalizations sometimes followed by short rehabilitative stays in a nursing home if he or she can meet the specific Medicare requirements. Please notify community service providers such as adult day care, homemaker, home health aides, and home-delivered meals when your care recipient is going to be out of the home. Ask how long services can be placed on hold before a reassessment is needed before services can be re-started.

As the caregiver you will need to monitor the process of transferring your care receiver from the hospital to a nursing home and you may have to serve as an outspoken advocate during this transition process. One caregiver reported that a clerical error almost had his wife admitted as a private pay patient rather than as a Medicare admission.

Learn more about what Medicare covers. You can call 800-MEDICARE (800-633-4227) to request the publication “Medicare and You” for the current year. Medicare also offers information about “Medigap” policies by geographical area. You can also visit the Medicare web site, [www.medicare.gov](http://www.medicare.gov).

More Medicare information is available through the Florida Department of Insurance. They publish a booklet that provides information on **Medicare supplement insurance**. Another booklet is titled the “Health Maintenance Organization Consumer’s Guide” and helps you understand HMO’s and Medicare. Call their toll free number 1-800-640-0886 to request these booklets.

Pinellas and Pasco County residents also have the option of calling the Senior Helpline for referral to a Department of Elder Affairs (DOEA) **SHINE (Serving Health Insurance Needs of Elders)** which can provide books such as these and to help you with health insurance questions and paperwork. The local office of the SHINE Program is located at the Area Agency on Aging of Pasco-Pinellas, Inc. For a description of SHINE see **Stage One, Section 5**. More information on SHINE is available on the “Prescription Assistance” page on the Florida Department of Elder Affairs’ web site, [www.state.fl.us/doea](http://www.state.fl.us/doea).

If you have long term care insurance, check the benefits of your policy as some home health care may be covered under long-term care policies.

Some caregiver web sites have articles about long-term care insurance. See the **Caregiver Web Sites** section of this Handbook or visit the online article, [www.agingcarefl.org/caregiver/Websites](http://www.agingcarefl.org/caregiver/Websites).

## **Back-Up Plan**

Have a contingency plan with someone to serve as temporary primary caregiver in case you have to go away because of another family emergency or are hospitalized yourself.

If your family has funds for it, a **private care management** company can be your emergency contact and arrange fee-for-service respite care and other services. Another resource for information is the web site of the National Association of Geriatric Care Managers, [www.caremanager.org](http://www.caremanager.org). This web site provides a listing of private-pay care managers anywhere in the U.S. For more about care managers, see *Stage One, section 4*.

Some assisted living facilities and nursing homes provide **overnight respite care**. You can pay for this type of care privately, or programs such as The National Family Caregiver Support Program may cover it. If you have no one in the area to serve as a backup, it’s a good idea to visit several facilities and make arrangements in advance so that they can be called in a crisis. Clients of some government-funded programs may receive facility-based respite on a limited basis if funding is available. For more information on government-funded respite see **Stage Two, Section 5**. See **Stage Three** for a discussion of other types of respite options.

Facility based respite for care recipients with **Alzheimer's or other types of memory loss** is available through two sources:

- The **Alzheimer's Association, Florida Gulf Coast Chapter**, will pay for emergency overnight respite care for Alzheimer's caregivers who have no other affordable options. This chapter of the Alzheimer's Association serves Pinellas and a number of other central west Florida counties. Their toll-free number is 800-772-8672.
- The **Veterans Administration** provides overnight respite care for caregivers of eligible veterans who have Alzheimer's or other dementia. For more information about services for veterans, read "Benefits for Veterans" in the *More Resources and Tips* section. Also visit the Department of Veterans Affairs web site, [www.va.gov](http://www.va.gov). If you need help in obtaining veterans' benefits, call the Pinellas County Veteran's Service office at 727-464-8460.

**Ask people in your support group about their back-up plans** and what type of overnight respite care they use.

Remember your informal support system such as relatives, but know that some relatives who might have stayed with your care receiver in earlier stages of the illness might not be willing or trained enough to do so now.

## Preventing Abuse

- If you feel pushed beyond your limits, you may worry that you could lose control and become abusive or neglectful of your care receiver. Before you cross that line, please consider these suggestions and resources:
- **Recognize the signs of caregiver burnout and call for help if you see them.** See *Stage Three, section 1*.
- **If over your limit of frustration, leave the room.** Count to 50, go outside and sit in the car a moment, have a cup of tea, play a game or work a crossword puzzle, call a friend in your support group, or do whatever else is necessary to prevent losing control. Behaviors that signal that you are losing control can include screaming, name-calling, striking, humiliating, or otherwise hurting your care receiver. See *Stage Three, section 1*.
- **Know what constitutes abuse and neglect.** Read "Help Stop Elder Abuse" in the **More Resources and Tips** section.
- If your care receiver is at risk of going into a facility unless you get services right away, read the "At Risk" section of **Stage Two, section 5**.

- **When you must talk with someone at once** because it is the middle of the night, your care receiver is waking you frequently, and you are beyond your limit of frustration, **dial 211** in Pinellas County, Florida. This is 211 Tampa Bay, a 24-hour crisis and information line for people of all ages sponsored by the 211 Tampa Bay Cares organization. The person who answers the 211 line is trained in crisis counseling and will refer you to community services. For information in several languages and a searchable online database, visit the 211 web site, [www.211tampabay.info](http://www.211tampabay.info).
- If you need **strategies for dealing with a care receiver with dementia** anytime night or day, call the National Alzheimer's Association toll-free information line, 800-272-3900. Counseling, information, and support are provided.
- Some religious organizations offer counseling and telephone support to anyone regardless of religious affiliation, and some also offer online chats with a counselor.

## Preventing Suicide

*Caregiving The Spiritual Journey of Love, Loss, and Renewal*, a book by Beth Witrogen McLeod, tells the story of Jo, a caregiver who was so pushed beyond her limit by years of caregiving for a mother with dementia and hearing loss that one night she contemplated homicide and decided instead that suicide was the only way out of an unbearable situation. Yet as she was taking action to commit suicide, she had the presence of mind to call the police and a hot line. She credited the hotline counselor, who talked with her and referred her to services, with saving her. Jo's story is found in Chapter 8 of this comforting book. Publishing information is included in the *Caregiver Books and Videos* section.

**Risk factors.** Persons sixty-five and older, especially those who are widowed or divorced, and persons who experience loss, illness, and depression are at greater risk for suicide. Heavy-duty caregivers may have some of these risk factors, and care receivers may be at risk, also.

**Pinellas County has the fourth highest number of suicides in Florida.** This is such a serious problem that the Area Agency on Aging of Pasco-Pinellas, Inc. is involved in community education to help raise awareness about suicide. The Area Agency on Aging's web site provides information about the danger of suicide and about resources to help prevent suicide. See *Suicide and Seniors*, [www.agingcarefl.org/aging/suicide](http://www.agingcarefl.org/aging/suicide).

Hopefully, you will never suffer from depression and despair to the point that you contemplate suicide. Community services, support groups, spiritual support, and treatment for depression have helped many caregivers make it through the roughest times.

**If you do find yourself thinking about suicide, here are some valuable resources:**

- **The Geriatric Crisis Response Team of Gulf Coast Community Care** provides free in-home crisis intervention, care management, and other services to help persons 40 and older at risk of suicide or psychiatric hospitalization to avoid suicide or hospitalization. Call 800-380-4303.
- **When you must talk with someone at once** because it is the middle of the night, your care receiver is waking you frequently, and you are beyond your limit of frustration, **dial 211** in Pinellas County, Florida. This is 211 Tampa Bay, a 24-hour crisis and information line for people of all ages sponsored by the 211 Tampa Bay Cares organization. The person who answers the 211 line is trained in crisis counseling and will refer you to community services. For information in several languages and a searchable online database, visit the 211 web site, [www.211tampabay.info](http://www.211tampabay.info).
- **Call 911 immediately if you feel you may act on an impulse to commit suicide.** This is the emergency number for police, fire, and rescue. While they are on their way to your home, someone will continue to talk with you and to reassure you that services can be found to provide relief.
- **Even if your situation seems desperate, you have more choices than you might think.** There are community services and businesses that help caregivers and seniors, Internet resources, information and counseling lines, and faith-based volunteers. When you ask for help, someone will point you in the right direction. **Just make that telephone call.**

## Stage Three, section 3: Facility Care

This is the stage where you must consider whether another living arrangement, which provides daily support and supervision, would be more appropriate for your care receiver. Here are a few of the factors that might lead you to consider facility care such as an assisted living facility or nursing home:

### Risk Factors

- Your **care receiver is falling** frequently.
- You are becoming **physically and emotionally worn out** with the lifting, toileting and incontinence, feeding tube, and being awakened all night.
- Your **care receiver is wandering** dangerously. See “How To Deal With Wandering” in the **More Tips and Resources** section.
- You are having many symptoms of **physical illness yourself**. Your health is suffering. You may even need hospitalization.
- You have **symptoms of caregiver burnout** or need medications for depression and stress. See **Stage Three, section 1**: “Preventing Caregiver Burnout”.
- You are **short-tempered with your care receiver** and are afraid you may be on the verge of elder abuse. See “Stop Elder Abuse” and **Stage Three, section 2**: “Protecting Your Care Receiver”.
- You have tried but have **not been able to get enough in-home services** and respite care to give you the relief you need to keep going. See **Stage Two, section 5**: Formal Support Services.

### Facility based care may also be appropriate when:

- You and your care receiver **planned in advance** to use facilities to provide needed care.
- He or she prefers going to an assisted living facility or nursing home rather than having you responsible for activities of daily living such as bathing and toileting.
- **You did not agree to be a hands-on heavy-duty caregiver**, at least not to the extent required now.
- You are an employed caregiver who cannot get a flexible schedule, the unpaid leave under the Family Medical Leave Act is not available to you or has already been used this year, and you **cannot afford to give up your job** in order to put in the hours of service required for heavy care. See **Stage Two, section 4**.

- You are a **long-distance caregiver**, the services you set up with a care manager during your last visit are no longer adequate, and even a revised care plan cannot provide enough support services to keep your care receiver safely in the home.
- **Physicians and other professionals are recommending** an assisted living facility or nursing home.
- Caregiving in the home has become ineffective, your relationship with your care receiver is strained, and it seems likely that **placement in a facility might be positive for both of you.**
- Your care recipient needs ALF or nursing care and you are **financially** able to provide this because he or she has adequate private funds, qualifies for insurance, or meets the eligibility requirements for government funding to cover the costs of facility care.

### **Caregiver's Role**

One of the most important things to remember when approaching the decision to discontinue caregiving in the home and move your care receiver to a facility is that **your role as caregiver will change but will not end.** You probably will visit your care receiver frequently, arrange for visits by friends and family (realizing that some will not come), and monitor care. Start by requesting to see the nursing home's care plan for your care receiver. You are also the person who will bring in photographs and mementos and let the staff know about your care receiver's accomplishments and what he or she enjoys.

One caregiver told us that he visits his wife daily in the facility where she now lives, feeds her dinner, rubs lotion on her arms, and feels more love for her now than when they were courting years ago. He has learned as a caregiver how to share tender, nurturing moments with his wife. Moments like this are possible even when your care receiver does not know that the person providing the hand massage and lotion is you: the beloved spouse, faithful child, or caring friend.

### **Considering a Move**

If you are considering a move to an assisted living facility (ALF) or nursing home, **include your care receiver in the decision if he or she is competent.**

The term "long term care" is often used to describe care in a residential facility, but the term can refer to on-going care needed by frail persons living at home. "Long term care" is one of many confusing terms you may encounter. See the "Glossary" of terms in the **Introduction** of this Handbook.

It helps to **learn as much as possible about your long-term care choices and how to evaluate residential facilities.** Assisted Living Facilities and nursing homes in Florida are licensed by the Agency for Health Care Administration (AHCA). Always ask to see the AHCA inspection report when you visit a facility. Their web site is [www.fdhc.state.fl.us](http://www.fdhc.state.fl.us). There is also a web site that provides information on facilities in each county of Florida. Click on “Facility locator” at [www.floridahealthstat.com](http://www.floridahealthstat.com).

There are several free booklets published which provide information on housing and care options:

Florida’s West Coast Senior Living Guide includes information about continuing care retirement communities, other retirement communities, senior apartments, assisted living facilities, nursing homes, rehabilitation centers and home health services. It is available free at Eckerd Drug Stores, Albertsons Grocery Stores, Wal-Mart stores and other community locations in Pinellas and surrounding counties of Florida. This guide, published twice a year, is called the Yellow Book of senior living options. It includes comparisons of options in each category and a one-page information directory with telephone numbers for commonly requested services.

Another small book with address listings of various options for housing with care is *New Lifestyles, Western Florida*, and one that has advertising for various housing choices is *Mature Living Choices, Florida’s Gulf Coast*.

Note: while you are picking up copies of these free housing guides, look for *Senior Connection*, a free magazine with articles of general interest to seniors and caregivers. Also look for *Seniority*, a special section of the *St. Petersburg Times* Newspaper, for up-to-date articles on subjects of interest to seniors and caregivers. Extra copies of *Seniority* and *Senior Connection* are often available at senior centers.

**Several types of housing provide facility-based long-term care:**

### **Continuing Care Retirement Communities**

**Continuing Care Retirement Communities (CCRC’s)**, also called **life-care facilities**, provide residents with shelter and health care in return for an entrance fee and periodic monthly fees. Only properly licensed facilities may use the term “Continuing Care Retirement Community” or “life-care” in marketing efforts. CCRC’s may appeal to those who can afford them because of having several levels of care ranging from independent living to nursing home on the same grounds. Residents who need nursing care just move to another part of the facility. There are several different payment plans. Some retirement communities that are not CCRC’s offer several levels of care. Be sure to compare various communities before making a choice.

For more about CCRC’s and a listing of those in Pinellas County, Florida, ask for the Department of Insurance booklet, *Options for Lifelong Care*, available by calling the Florida Department of Insurance Helpline, 800-640-0886.

## Adult Family Care Homes

Adult Family Care Homes (AFCH's) are family-type living arrangements in private homes. These are an option for housing and supportive services for no more than five disabled adults or frail elders. Persons choosing to live in an AFCH must not require 24-hour nursing supervision. These homes must be licensed by the Agency for Health Care Administration as Adult Family-Care Homes unless room, board, and personal care is provided for relatives or no more than two adults who do not receive a state supplement. For more information, see the resources for Assisted Living Facilities listed below.

## Assisted Living Facilities

Assisted Living Facilities (ALF's) provide housing, meals, personal care services and supportive services to older persons and disabled persons unable to live independently. They are called Board and Care Homes in some states. Residents in ALF's cannot have conditions that require 24-hour nursing supervision unless receiving licensed hospice services. Some ALF's have specialty licenses to provide limited nursing services or mental health services, and some specialize in providing services to persons with Alzheimer's Disease. If you are looking for a facility to care for someone with Alzheimer's, there are special questions that you need to ask. See "Residential Care Facilities" in the **Alzheimer's and Related Disorders** section (purple edged pages) of the *Senior Resource Directory*. Find this article on the Area Agency on Aging of Pasco-Pinellas's web site, [www.agingcarefl.org/caregiver/alzheimers/facilities](http://www.agingcarefl.org/caregiver/alzheimers/facilities).

According to the **National Center for Assisted Living Survey** done in 2000, the typical assisted living resident is a woman between 75 and 85 years of age who is mobile but needs help with two activities of daily living (ADL's), which include bathing, dressing, transferring, toileting, and eating. For more Survey results, select "About Assisted Living" on the National Center for Assisted Living (NCAL) web site, [www.ncal.org](http://www.ncal.org). Select "Consumer Information" followed by "Consumer Guide" to find a "Checklist for Consumers and Prospective Residents".

Assistive living facilities charge an average of \$1,873 per month, with prices ranging from below \$1,000 to more than \$3,000 per month. More than two-thirds of residents pay with their own or family funds. Other funding sources are the Medicaid Waiver program, Nursing Home Diversion program, and Long Term Care (LTC) insurance. In Florida, **Medicaid Waiver** funding covers costs of community care or care in an assisted living facility for those who qualify. **Nursing Home Diversion** is a new type of managed care program that can cover care for Medicaid-eligible persons in their home or in a facility. For more about Medicaid Waiver and Nursing Home Diversion, see *Stage Two, section 5*.

Eleven of the leading insurance companies that sell **long term care insurance** offer assisted living coverage. However, most of the people who are sixty or over today do not carry long-term care insurance. If your care receiver does have a policy, be sure to read it carefully. One caregiver thought that when his wife went into a nursing home under the couple's long term care policy, the policy would pay for him to live in the

assisted living facility next door because he had some physical handicaps. He did not meet the policy's requirements for coverage, but he solved his problem by moving into a less expensive senior apartment that offers one meal a day.

General information about ALF's and the Assisted Living for Seniors Medicaid Waiver is available online at [www.state.fl.us/doea](http://www.state.fl.us/doea), the Florida Department of Elder Affairs (DOEA) web site. A new web site, [www.floridaaffordableassistedliving.org](http://www.floridaaffordableassistedliving.org), was developed as part of DOEA's *Coming Home Project* to be a clearinghouse of information for developers, operators, and consumers. Ask about several new facilities that were built as part of this project.

If you are a caregiver (especially a long distance caregiver) for someone who needs help in making the transition to a residential facility, you may want to hire a care manager or placement service. For more about care managers, see **Stage One, section 4.**

## Nursing Homes

**Nursing homes** provide more care than assisted living facilities. There are two levels of nursing homes, Skilled Nursing Facilities (SNF) and Intermediate Care Facilities (ICF).

- **Skilled Nursing Facilities** provide nursing care on a 24-hour basis. Also included are therapy, diet supervision, activities, and medication management. An RN Supervisor is on-site and a physician is accessible. Medicare may pay for skilled nursing care in a facility if the patient meets the necessary criteria. Medicaid may pay for this type of care for persons who meet the income and asset eligibility. For more information about Medicare, call 800-Medicare (800-633-4227) or visit the Medicare web site, [www.medicare.gov](http://www.medicare.gov).
- **Intermediate Care Facilities** provide personal care and supervision of dressing, bathing, diet, and self-administered medications. This level of care may be covered by Medicaid for those who financially qualify, but Medicare only pays for skilled nursing and will not pay for what it calls "custodial care" or intermediate care. If a person is on Medicaid, it is illegal for the facility to request more money from the family.

**Persons applying for Medicaid coverage** of nursing home care in Florida must be assessed by the Florida Department of Elder Affairs (DOEA) CARES (Comprehensive Assessment Review and Evaluation Services) office. See page 47 of this Handbook. The DOEA web site [www.state.fl.us/doea](http://www.state.fl.us/doea) also contains information on the CARES Unit. Select "Caring for an Elder" followed by "CARES. Note: the DOEA CARES Unit is not to be confused with CARES, Inc. (Community Aging and Retirement Services), a "lead agency" for case managed programs and provider of services for older persons in Pasco County, Florida.

For up-to-date information about Medicaid income and asset limits and planning for Medicaid eligibility for long-term care, visit the **Florida Medicaid.com** web site, [www.floridamedicaid.com](http://www.floridamedicaid.com). This commercial site by a number of Florida Medicaid and elder law attorneys explains things like **Qualified Income Trust (QIT)**, which allows persons whose income is too high for Medicaid but too low to afford nursing home care to qualify for Medicaid.

**Choosing a nursing home** can be complicated and emotional. Sometimes a choice is dictated by what homes have beds available that day. However, if time allows, it is good to learn what to look for in a nursing home and to compare various local nursing homes.

The Florida Agency for Health Care Administration (AHCA), the agency that licenses and inspects nursing homes, publishes regional *Nursing Home Guides* and provides the same information on its web site. There are several ways to obtain a copy:

- Call AHCA toll-free at 888-419-3456 and ask for the *Nursing Home Guide for Central Florida*, which includes Pasco and Pinellas Counties.
- Write AHCA at the following address: Agency for Health Care Administration, Bureau of Consumer Protection, MS #27, 2727 Mahan Drive, Tallahassee, FL 32308.
- Visit the AHCA web site, [www.fdhc.state.fl.us](http://www.fdhc.state.fl.us) or visit [www.floridahealthstat.com](http://www.floridahealthstat.com). You may want to read *How to Select a Nursing Home* and *Alternatives to Nursing Homes*. Select "Search by Region" and choose Region 5 (Pasco and Pinellas) on the Florida map to pull up a list of local facilities. Click on each one for the same information and rating found in the printed version of the *Nursing Home Guide*. You can search by characteristics you are looking for in a nursing home if you prefer. There is also a link from the AHCA home page to *Nursing Home Watch*, which lists nursing homes with particularly bad AHCA inspection reports.

Inside *The Nursing Home Guide* is general information ranging from choosing a nursing home to planning enjoyable activities when visiting someone in a nursing home. There is a glossary of nursing home terms and a comparison of nursing homes in the region. A rating system is used to evaluate the facilities.

Additional information provided in the *Nursing Home Guide* includes number of beds, minimum costs, payment forms accepted, affiliations, languages spoken, whether for profit or non-profit, and availability of special services such as respite care, pet therapy, and hospice. While looking for a home that will meet your care receiver's needs and that gets a good review is important, other factors such as whether the home is close enough for family to visit frequently should also be considered.

AHCA recommends one or more visits after making comparisons using the *Nursing Home Guide*. One of these should be scheduled with an opportunity to talk with staff and take a tour. Drop in another time without scheduling an appointment to make certain that the facility still seems attractive and treatment of residents seems the same. Be sure to look at floors above the first floor.

**Things to observe when visiting a nursing home include:**

- Do residents appear happy, comfortable, and at home?
- Is the facility clean, odor-free, and well staffed?
- Are residents being taken care of in a timely manner?
- Are the rooms decorated with personal furnishings and belongings?
- Do the residents have adequate privacy?

**Among the questions to ask when visiting are:**

- What deficiencies, if any, were cited during the last inspection? (Ask to see the survey, which is AHCA's inspection report.)
- How many residents does each nurse and nurse's aid care for during each shift?
- What do they do about medical services and special therapies?
- What transportation arrangements for residents are available?
- What special training does the staff have?
- What are the policies regarding deposits, refunds, and bed holds?
- How much advance notice is given before increasing charges?
- How are personal possessions safeguarded?
- What activities are available? (Ask to see calendar.)
- What are the visiting hours, and are exceptions allowed?
- Does the nursing home limit the use of physical restraints?

Information about how nursing homes compare anywhere in the country is available in print by calling 800-MEDICARE toll-free. It is also posted on Medicare's web site, [www.medicare.gov](http://www.medicare.gov). Select "Nursing Home Compare".

The AARP organization has information to help consumers with long term care decisions. According to AARP, location is an important factor to consider when choosing a nursing home because nursing home residents who have regular visitors get better care. For brochures on choosing a nursing home and protecting a resident's rights, call AARP's toll-free line, 800-424-3410. The caregiving section of AARP's web site is found at [www.aarp.org/caregiving](http://www.aarp.org/caregiving).

When considering legal and financial issues involved in long-term care decisions, many people find it helpful to consult an elder law attorney, an expert in counseling, educating, and advocating for seniors regarding illness, incapacity, and death. Learning what financial decisions to make and avoid if Medicaid will be needed for nursing home care is just one of many reasons to visit an elder law attorney. See **Stage 1, section 5** for more information on elder law attorneys.

**Veterans** may want to include a U. S. Veterans Administration (VA) nursing home as one of the choices they consider. The Baldomero Lopez Veterans' Nursing Home is located in Land o' Lakes in Pasco County, Florida. This is a 120-bed facility with 60 beds dedicated to serving mobile Alzheimer's patients. To be eligible, a veteran must have been a Florida resident for at least one year, honorably discharged, and need nursing care. Costs vary depending on income.

To locate a VA nursing home anywhere in Florida, visit the Florida Department of Veterans Affairs web site, [www.floridavets.org](http://www.floridavets.org). For more about several types of VA benefits often overlooked by older veterans, see "Benefits for Veterans" in the **More Tips and Resources** section and visit the national Veterans Administration (VA) web site, [www.va.gov](http://www.va.gov).

## Coping With Placing Someone

If your care receiver moves to a nursing home, you will experience many emotions. In Virginia Morris's book, *How to Care for Aging Parents*, there is a list of common reactions to having a parent in a nursing home. These apply to placing a spouse, also. This is a humorous look at what can be a gut-wrenching experience.

**"Ten Common Reactions to Having a Parent in a Nursing Home"** (from *How to Care for Aging Parents*):

- Guilt that you are not doing enough for your parent
- Anxiety that the nursing staff won't do enough for him or her
- Guilt because you promised you would never put him or her in a home
- Anxiety about whether you will end up in a nursing home
- Guilt that your parent isn't in a nicer, more expensive home
- Anxiety over the high cost of the nursing home he or she is in
- Guilt that you don't visit him or her more often
- Anxiety about having to visit so often
- Guilt for feeling relief that your parent is in a nursing home
- Anxiety that it won't work and you'll have to devise another plan

Many people who go through the transition to nursing home with their care receivers continue with their support group and sometimes join another associated with the facility where their care receiver lives. Those who have been through it can provide information, support and encouragement to those facing the decision. Support group members may discuss the emotional pain experienced when some relatives and friends will not visit the care receiver in the nursing home. Some people cannot stand to see the mental or physical deterioration, some fear their own aging and possible nursing home placement, some just don't know what to do around a person with debilitating mental or physical illness (although you can make it easier for them by giving them ideas), and some are unaware of the value of being with someone in the last days of that person's life even if the person visited cannot communicate verbally. For more on this subject, see **Stage Four, section 1** "Resolving Relationships".

## Additional Resources

- **Florida's Long Term Care Ombudsman Program (LTCOC)** offers a web site, [www.state.fl.us/ombudsman](http://www.state.fl.us/ombudsman), and a toll-free number, 888-831-0404. This Department of Elder Affairs-sponsored citizen's group strives to improve conditions for residents of long term care residential facilities. Rights. Lists of Nursing Home, Assisted Living, and Discharged Nursing Home Residents Rights are available. Complaints against facilities may be filed online or by calling the toll-free number.
- If a complaint against a nursing home or assisted living facility involves abuse or neglect of a resident, any person can report this by calling the **Florida Abuse Hotline on the toll-free number, 800-96-ABUSE (800-962-2873)**. The TDD (Telephone device for the Deaf) Abuse Hotline number is 800-955-8770. The Abuse Hotline is available 24 hours a day seven days a week for confidential reporting of abuse and neglect of any type. For more about abuse, see **Stop Elder Abuse and Stage Three, section 2**.
- Find a "Glossary of Long-Term Care Terms" on the Long-Term Care Living web site, [www.longtermcareliving.com](http://www.longtermcareliving.com). Financial options and how to have a family conversation about long-term care are discussed on this web site, also. Sponsors are The American Health Care Association and the National Center for Assisted Living.
- The *Introduction to the Caregiver Handbook* includes a "Glossary of Terms" and "Glossary of Acronyms", and these are also available online at [www.agingcarefl.org/services](http://www.agingcarefl.org/services).
- *The Family Guide to Long-term Care* is a series of six videos available from Lifeview Resources. Call toll-free 800-395-5433 or visit the website, [www.lifeviewresources.com](http://www.lifeviewresources.com). Two of these are called *Making the Right Choice* and *Staying Involved*. View video clips online before purchasing. If you are a caregiver, you can buy these and other caregiving videos at a discount by using your free membership number from the Caregivers Marketplace web site, [www.caregiversmarketplace.com](http://www.caregiversmarketplace.com).
- *How to Care for Aging Parents*, by Virginia Morris, is a comprehensive guide to caregiving. This book has chapters called "Home Away From Home," "A Good Nursing Home," and "Paying The Way". For reviews of other caregiving books that may be helpful, see the **Caregiver Books and Videos** section.
- Also check the **public libraries**, as some locations are adding new caregiver books and videos to their collections. To search the catalogs and reserve books online in Pinellas County, Florida, visit the Pinellas County Public Library Cooperative web site, [www.pplc.us](http://www.pplc.us).

- *Residential Care: A Guide for Choosing a New Home* is a National Alzheimer's Association publication to help families in make choices about residential care for persons with Alzheimer's. For a free copy, call the national toll-free number, 800-272-3900, or select "Resource Center" followed by "Fact Sheets" on the Alzheimer's Association web site, [www.alz.org](http://www.alz.org).
- **American Association of Homes and Services for the Aging (AAHSA)** is a national organization made up of not-for-profit nursing homes, continuing care retirement communities, senior housing, assisted living facilities, etc. committed to affordable, healthy, and ethical long term care. Visit their web site, [www.aahsa.org](http://www.aahsa.org), for information about types of facilities ranging from government-funded senior housing to nursing homes, contact information for state affiliates, and a directory of members.

**To access the services or programs described in this Handbook, call the Senior Helpline at 800-96-ELDER (800-963-5337) or 727-217-8111 from outside of the area.**

