

# The Four Stages of Caregiving

## Stage One: Getting Started

**When you first become a caregiver for an elderly relative or friend, a party isn't given in your honor the way it is when expecting a child or getting married.** No one sends you flowers to celebrate the gift of love you will be providing. In fact, if your other relatives or friends have anything to say, it may be to insist that the older person is fine and doesn't need care or that you'd have to be crazy to take on a responsibility like that. If you are caring for your spouse, some family members may be supportive. Others may try to stop you from taking on the caregiver role at what they see as a high risk to you. They don't understand that you may find the role of caregiver rewarding and fulfilling or that honoring your vows is most important to you.

**Caregiving is an important role of which you can be proud, but at the same time it can be stressful.** You may not have made a conscious decision to become a caregiver – you may have slipped quietly and unnoticed into the job because you are the spouse and you live with the person who needs care or you are the adult child who lives closest to your elderly parents, the closest child emotionally, or the most responsible one. Perhaps you saw some needs and simply began to fill them, transporting your care receiver to the doctor, helping with bill paying and housework, and leaving extra home-cooked meals in the refrigerator to be heated later.

If you are a **caregiver for your spouse**, you may be experiencing a role reversal and the grief as well as exhaustion that goes with this, for the person who is now frail may have been the one, who used to do the driving, cooked the meals, did the housework, or paid the monthly bills.

If you are an adult **child of aging parents**, you may also be experiencing role reversal, as you've always counted on your parents not only to take care of themselves but to be there for you when you needed advice, comfort, and assistance. You may be part of the "sandwich generation," working outside your home, caring for children of your own, and finding your weekends filling up with chores such as your parent's laundry, while your parent insists that he or she can still host holiday get-togethers and doesn't need any help. Your parent may seem hale and hearty when speaking to your brothers and sisters but present a more frail aspect to you, insisting that only you can provide rides to the doctor. You may even hear glowing accounts of wonderful trips taken by your non-caregiver sister while your parent asks you why you and your spouse never have anything interesting to report.

We hope this information for beginning caregivers will help not only those caring for relatives but also persons helping neighbors, friends, members of a faith community and others. Note: if you have been thrust into heavy hands-on care by a stroke or accident, see **Stage Two and Stage Three**.

# Stage One, section 1: Impact of Caregiving

## You and Your Family

**Consciously realize that you are becoming a caregiver and consider what impact this may have on your life and the lives of your immediate family.** If your care receiver is still fairly independent, take that vacation you and your family have been putting off. If you are an adult child, realize that caring for aging relatives means less attention for your spouse and children. They need a chance to talk about how they feel and to be involved in your decision.

The members of your immediate family should be encouraged to have a role in caregiving. Your teenager may mow her grandfather's lawn, and your children may provide afternoon or weekend respite care visits that will be good for them as well as for the person visited. Your spouse may help with shopping or take care of some of the chores you used to do for your immediate family.

Keep up your friendships, make certain that you maintain contact with your religious (faith) community, and plan time every day and week for something relaxing and enjoyable for yourself. Make a list of your favorite leisure activities, especially ones that can be enjoyed in short increments of time, in case you become so busy as a caregiver later that you forget to include some of these mini-vacations for your mind and body. It is also helpful to schedule a weekly activity with your immediate family that would be fun and not involve caregiving.

## Your Extended Family

**As primary caregiver, it is important to keep your extended family informed as the situation changes and to include them as part of the informal support system.** If possible, let them share in decision making. You may encounter denial or resistance on the part of your brothers and sisters, and, if caring for your spouse, his parents and his siblings.

An extended family meeting can be helpful, with those who cannot come in person contacted by telephone (conference calling service makes this easier) or e-mail. The person needing care should also be part of the discussion if competent. The older person's income available for his or her care needs to be compared to the expenses of caregiving. It will help you to make an informed decision as to whether you can accept the role of primary caregiver if you know what your care receiver's budget will cover and what help you can get from your extended family.

Ask your extended family for specific support. Perhaps different family members can:

- Handle the yard work or pay for the lawn service as a gift,
- Help with financial issues,
- Prepare weekly meals,

- visit your aging parent for a week while your family takes a vacation.

## **Your Friends and Neighbors**

Friends, neighbors, and members of your place of worship or your care receiver's place of worship should be seen as part of your informal support system, also. Make a list of names, addresses, and telephone numbers of people who might assist your care receiver. If anyone has offered specific help, write that by his or her name. This list may be a real help to you at a later time.

If someone makes a vague offer of help, find out more by asking questions like these:

- What can I call on you to do?
- What are you comfortable doing?
- Are there things you would rather not do?
- When are you available?
- How often can you help?

For more information, see **Stage Two: Finding Help, sections 1 and 2.**

## **Helpful Resources**

- A book that talks about subjects such as sibling stress, shared decision making, and "when siblings don't share" is *Caring for Yourself While Caring for Your Aging Parents—How to Help, How to Survive* by Claire Berman.
- A book that asks you, "Are You Up for This?" and has practical advice for how to conduct an extended family meeting is *The Complete Idiot's Guide to Caring for Aging Parents* by Linda Colvin Rhodes, Ed. D. (Note: this insulting title identifies this book as part of the Complete Idiot's series on how to understand almost anything. If you can get past the title, it has good information inside.)
- A good article on involving others can be found on the AARP web site, [www.aarp.org](http://www.aarp.org). On the home page, click on 'Care and Family', then on 'Caregiving', followed by 'Involving the Whole Family'.
- More articles on involving others can be found on Eldercare Online, [www.ec-online.net](http://www.ec-online.net). Run a Search for 'Family Dynamics'. This web site also includes a Glossary of Eldercare Terminology.
- Also see Caregiver Books and Videos and Caregiver Web Sites. Our Glossary of Aging Terms and Glossary of Acronyms may be helpful, also.

## Stage One, section 2: Dignity and Decisions

**As role reversals take place, allow your care receiver as much dignity and independence as possible.**

### Family Gatherings

If you are an adult child who decides to have holiday celebrations at your home instead of your parent's, incorporate your mother's favorite recipes or family customs meaningful to your dad into the celebration, let your mother advise the second generation cooks, and bring out old photographs or slides from days gone by.

A good activity when the extended family gets together is to make an **audio or video recording** as a reminiscence tape. Someone asks the care receiver about his or her childhood, family, school, holidays, first job, other jobs, travel, life with spouse and children, places lived, the wars, hobbies, greatest challenge and disappointment, achievements, most admired person, things he or she would do differently if given a second chance, and advice for the younger generations.

Suggested questions to ask as part of a reminiscence tape are included in the *Caregiver's Support Kit*, available free to any caregiver by calling the National Caregiving Foundation's toll-free number, 1-800-930-1357. The Caregiver's Support Kit has more than 100 pages of information on caregiving with a focus on Alzheimer's but with general caregiving information to help anyone.

### Care Receiver's Wishes

**Find out what your care receiver's long-term wishes are.** Is he or she insistent on staying at home until the end of life, counting on moving in with you, interested in moving to a retirement community that provides different levels of care, or willing to consider an assisted living facility or nursing home later if needed?

**It is important to involve the care receiver in decision-making if competent.** If your care receiver feels very strongly about staying in his or her own home, you may decide to provide care yourself, bringing in additional services when needed to make remaining in the home possible.

**If you accept the role of primary caregiver, do not make unrealistic promises to keep your care receiver at home no matter what.** Situations change both for the older person and for the caregiver, and the level of caregiving required may be too much for you and your family at some point. Over the years, you could acquire caregiving responsibilities for your spouse and relatives on either side of the family, some of these at the same time, while still working outside the home and caring for your children or grandchildren. When previous generations made promises like this to their spouses and parents, fewer people were working outside the home or living for as many years with multiple chronic health problems or dementia. Also, there were not as many choices for excellent facility-based care.

Sometimes caregivers of an aging parent think that the best solution is to move the older person to the adult child's home. This can be expensive if home modifications other than minor things such as shower grab bars and wider door openings need to be made. In addition, depending on factors such as temperament of the older person, whether children are still living at home, and whether the older person would be isolated from former friends and activities, this may not be the right choice for the person being cared for or for the caregiver's family.

### **Informed Substitute Caregivers**

When other people come into the home to help with caregiving, let them know how your care receiver prefers to be addressed (first name, Mr. or Mrs., etc.), how to help him or her to the bathroom if help is needed, and what food and activities your care receiver enjoys. One way to do this is to write down these preferences and include them in a caregiving notebook that other persons helping with caregiving can read. For more information, see *Stage One, section 5*.

### **Helpful Resources**

- A book that discusses how to determine what kind of assistance your parent needs, whether he or she is still safe at home, and whether having him or her move into the home of an adult child would be a good idea is *When Aging Parents Can't Live Alone* by Ellen F. Rubenson, M.S.W.
- Making educated choices concerning assisted living facilities and nursing homes will be discussed in one of the later stages of caregiving in this Handbook. See **Stage Three, section 3**.

## Stage One, section 3: Educating Yourself

**Start doing research to learn all you can about your care receiver's physical and mental conditions and about resources for frail older persons and support for caregivers.**

Before you begin your research, try to get a **correct diagnosis** of your care receiver's condition so that you will know what you're dealing with, what to expect as the condition changes, what kind of specialist your care receiver should see, and what kind of support groups would be right for you and your care receiver. Educating yourself for caregiving depends, in part, on having the correct diagnosis.

A correct diagnosis of memory loss is very important. Sometimes treatable illnesses such as thyroid problems cause symptoms like dementia. A geriatric assessment will determine whether this is the case. The Memory Disorder Clinics also offer caregiver education and support. For more information about where to get a geriatric assessment for possible Alzheimer's diagnosis, call the Senior Helpline 800-96-ELDER (800-963-5337) or visit the section of the Area Agency on Aging web site that provides information on Alzheimer's, [www.agingcarefl.org/caregiver/alzheimers](http://www.agingcarefl.org/caregiver/alzheimers).

If you have trouble talking with your care receiver's doctors, get tips from the *Eldercare At Home* guide on the American Geriatrics Society Foundation web site, [www.healthinaging.org](http://www.healthinaging.org). Every chapter includes advice about how to talk with professionals about the problem discussed in that chapter, and one chapter focuses on Problems Getting Information From Medical Staff.

Once you have the diagnosis, here are some resources for educating yourself.

### Caregivers REST Project

The Caregivers REST Project, which is described in the **More Resources and Tips** section, produced this *Caregiver Handbook*. Caregivers of seniors in Pinellas County, Florida, are eligible for a free copy. This can be mailed, or a care manager can provide it when meeting with a caregiver to talk about planning services. The web site developed as part of the project is found at [www.agingcarefl.org](http://www.agingcarefl.org).

### Helplines

**The Senior Helpline** maintains a database of information about government-funded agencies and private businesses that serve seniors and caregivers in Pinellas and Pasco County, Florida. Call 800-96-ELDER (800-963-5337) or 727-217-8111 outside of the area. The Senior Helpline publishes the *Senior Resource Directory*, which includes information on Alzheimer's Disease and Related Disorders and Help Pages in addition to a list of service providers.

In other Florida counties, call the **Florida Elder Helpline** at 800-96ELDER (800-963-5337). If you are a long-distance caregiver, call the national **Eldercare Locator's toll-**

**free number**, 800-677-1116 or visit the web site, [www.eldercare.gov](http://www.eldercare.gov). This is a free service of the U. S. Administration on Aging.

For information about support groups, support for families affected by various diseases, volunteer opportunities, and other resources for people of all ages in Pinellas County, Florida, **dial 211** (not to be confused with 911, the emergency number) or visit the web site of 211 Tampa Bay Cares (formerly Pinellas Cares), [www.211tampabay.info](http://www.211tampabay.info). The 211 line also serves as a crisis counseling line, available twenty-four hours a day.

The **National Alzheimer's Association National Call Center** is available for information and support twenty-four hours a day. Call 800-272-3900.

## Support Groups

Another good way to educate yourself is by joining a support group. Support groups offer informational talks, and other caregivers attending share what they have learned. You may get tips on how to manage behaviors, what medical care has proven helpful, how to find services, and more. Find out more about the group by calling ahead, and consider visiting several groups including one for general caregivers. For more information on how to pick a support group, see **Stage Two, section 3**.

## Caregiver Web Sites

Visiting caregiving and disease-related web sites is another way to learn about caregiving. The **Caregiver Web Sites** section of this Handbook, also available online at [www.agingcarefl.org/caregiver/Websites](http://www.agingcarefl.org/caregiver/Websites), includes national, Florida, and local Pinellas County web sites. Under each category, sites are listed alphabetically by the name of the organization or the name of the web site followed by the web address. Each listing has a review that mentions things to look for and how to navigate the site if needed. By using the online version, you can click on the link to visit each site.

You can find many types of web sites on our list: government, non-profit organizations, educational institutions, and commercial sites. There are sites totally devoted to supporting families affected by almost twenty different diseases or conditions as well as general health-related, caregiving, and consumer sites. Here are some examples of what you can find:

- Information about diseases, drugs, and healthy living
- Online support groups, caregiver classes, and prayer circles
- Crossword puzzles for caregivers who need a mental break
- Medical dictionaries and glossaries of Internet and Caregiving Terms
- Nursing home comparisons
- Forms for filing consumer complaints online
- Caregiver magazines and gifts for sale
- Assistive devices and adaptive clothing
- Exercise and respite care videos
- Discounts to caregivers shopping in catalogs and on web sites

Using the Internet is important not just because there are great caregiver web sites but also because publications printed in limited quantities are available for anyone online. For example, the **Florida Department of Elder Affairs (DOEA)** *Elder Update Newsletter*, *Consumer Resource Guide*, and *Making Choices: Beginning to Plan for End of Life Care* can be found under 'Publications' on the DOEA web site, [www.state.fl.us/doea](http://www.state.fl.us/doea).

## Caregiver Books and Videos

Take a moment to look through the **Caregiver Books and Videos** section of this Handbook or online at [www.agingcarefl.org/caregiver/booksVideos](http://www.agingcarefl.org/caregiver/booksVideos). Many of the books and videos can be found in the Pinellas County, Florida, library system or ordered online. An example is *The Fearless Caregiver*, edited by Gary Barg, the editor of *Today's Caregiver Magazine*. This book, with articles and stories by caregivers, provides advice and emotional support. It is available for purchase on the Today's Caregiver web site, [www.caregiver.com](http://www.caregiver.com). Some books such as *How to Care for Aging Parents*, by Virginia Morris, are almost like encyclopedias of caregiver information.

Caregiving videos teach how to make caregiving decisions, how to communicate with someone with Alzheimer's or hearing loss, and how to perform hands-on caregiving skills like personal care and helping someone into a wheelchair. See our list for purchase information or check the library system. For example, the Gulfport, Florida library has a series of videos on communication and caregiving.

If you are a Pinellas County resident with a library card, you can reserve library books and videos from various libraries and it can be done online, often having them sent to your neighborhood library for quick pick-up. Visit the **Pinellas County Public Library Cooperative** web site, [www.pplc.us](http://www.pplc.us). Cooperative Libraries provides entrance to local libraries, and Anywhere/Anytime Library covers a broader area. Remember that you can also reserve popular and classical movie videos, although you may have to go to the library that has them to pick them up, and check out time is shorter than for educational videos. Libraries are beginning to offer a few DVD's. The Pinellas County Library Cooperative web site also includes a County Information Page with a link to the Pinellas County Law Libraries.



## Stage One, section 4: Using a Care Manager

**If you need someone to help your family plan informal support and formal services for your care receiver, see a professional called a care manager or case manager.**

### Government-Funded Care/Case Management

You may feel that services will be needed, but you don't know where to start. In Pinellas County, Florida, one choice is to call the **Senior Helpline at 800-96-ELDER (800-963-5337) or 727-217-8111** from outside of the area and ask to meet with a Caregivers REST Project care manager. If you wish, this meeting can include your immediate or extended family and the older person who needs care. The care manager is available at no charge to help lead discussion of assistance to be provided by family and friends as well as by formal services. The care-planning meeting can take place in one of our caregiver resource centers or in your home or office.

The Senior Helpline provides information on services including case management that are available from non-profit agencies and private businesses. One resource may have a waiting list while another is available, so you may have to try several options. For more about case managed programs, see **Stage Two, section 5**. For a definition of terms such as "care manager" and "care plan", see the Glossaries section.

### Private Care Management

**If your family can afford to hire a private care management company, this can sometimes be the right choice** because service will probably be available immediately, case loads for private care managers are low so they have more time for each client, and you may receive a great deal of on-going personal service throughout caregiving transitions such as liquidating a home and moving your care receiver to an assisted living facility or nursing home if needed. Private care managers in Pinellas County, Florida generally charge a flat rate for the initial assessment and then bill per hour after that. In-home services ordered by the case manager are billed separately.

**Service by a private care management company can be as extensive as the family desires and can afford**, from being on-call to assist a local caregiver after the initial assessment is made to making monthly or even daily visits to check on an older person for an out-of-town caregiver. Private care managers arrange and closely monitor in-home services to make certain the companies providing direct care to the older person are doing a good job. Some care management companies send family members e-mails to update them on their care receiver's condition after visits are made.

**If you are a long-distance caregiver, it can be reassuring to know that there is someone to accompany your care receiver to medical appointments and to serve as the local contact person** to meet him or her at the emergency room in the middle of the night. Private care managers can make visits to monitor care in an assisted living facility and nursing home the way you would if you were an in-town caregiver.

## Helpful Resources

- For a private care manager listing by zip code or other area, visit the **National Association of Geriatric Care Managers'** web site, [www.caremanager.org](http://www.caremanager.org). This web site also provides a list of questions to ask when hiring a geriatric care manager.
- If you are a **long-distance caregiver** and the person who needs care lives in Florida but not in Pinellas County, ask about care management by calling the state Elder Helpline number, 800-963-5337. Ask whether services are government funded at little or no cost or whether private with fees for service. The national toll-free Eldercare Locator telephone number, 800-677-1116, refers callers to Elder Helplines throughout the United States. If you prefer, visit the Eldercare Locator website, [www.eldercare.gov](http://www.eldercare.gov).

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

## Stage One, section 5: Information List and Notebook

Learn more about your care receiver by making a list, with that person's permission and assistance, of important family information. Be better organized for caregiving by creating a Caregiving Notebook.

### Information List

Important family information may be needed when applying for benefits and services, handling medical care, enlisting support from others in helping with caregiving tasks, advocating for your care receiver with insurance companies and service providers, and even after your care receiver's death. Leave room in each section to add more information such as: new services such as adult day care or hospice, changes in medications, additional physicians, assisted living facility contact numbers, etc. Make an extra copy of this list to keep at your home if you do not live with your care receiver.

If you are not a close relative or guardian of your care receiver, you may have to work with someone appropriate to prepare this list of important family information. Only the care receiver's family or attorney may know some items. If this is the case, make sure that what you need for caregiving purposes is shared with you.

Here are suggestions for what to include in a list of important family information:

- **Personal information.** Include care receiver's name, address, telephone number, marital status, spouse's name, and social security numbers for frail older person (and spouse, if appropriate to know that), and dates of birth, primary caregiver, and secondary emergency contact.
- **Extended family and friends.** Record phone numbers and addresses of extended family and other possible members of the older person's informal support network including children, siblings, neighbors, friends, religious affiliation and contact person, and condominium or apartment manager if applicable. If anyone has offered to help in a specific way, write that by his or her name. See **Stage Two, section 1**.
- **Service providers.** List telephone number, agency or company name, address, contact person, and service being provided to your care receiver by agencies or businesses. Include contact information for services such as hairdresser, lawn service, pool cleaning service, and utility companies. Remember that when there are hospitalizations, appointments need to be canceled and in-home services discontinued on a temporary basis. Utility bills, etc. still need to be paid.
- **Insurance information.** Include Medicare and, if applicable, Medicaid numbers, private insurance policy company names and policy numbers, long-term care insurance, disability, veterans benefits, home owner's, boat owner's, and car

insurance. Know where the care receiver's Medicare card, insurance cards, and insurance policies are located. Be prepared to gather them in a safe place during a disaster such as a hurricane. Check for waiver of premium on insurance policies. For more information, see **Stage One, section 6: Disaster Planning**.

- **Financial resources.** Include income from wages if working, Social Security, Supplemental Security Income (SSI), Social Security Disability Income (SSDI), Veterans benefits, pensions, general assistance, income from interest and investments, and other income; bank(s) used; balance in checking and savings accounts, value of assets including stocks, bonds, CD's, real estate and rental property, other investments; debts including credit cards, loans, mortgages; burial funds if some have been set aside. Find out about location of and keys to safety deposit boxes and home security box or safe.
- After this information has been gathered, you or the care receiver, if capable, may want to visit the Benefits CheckUp web site, [www.benefitscheckup.org](http://www.benefitscheckup.org), for a **confidential report on possible benefits** eligibility based on income, assets, etc. Remember that this is just a guideline. A similar report or general information about benefits for which a person who fits a certain category may be eligible is available at the GovBenefits web site, [www.govbenefits.gov](http://www.govbenefits.gov). Remember that some services, such as The National Family Caregiver Support Program and The Caregivers REST Project available through the Area Agency on Aging of Pasco-Pinellas, Inc., do not have income or asset eligibility requirements and may not show up on a personalized benefits report.
- **Legal information.** Include name of responsible family member, person with Durable Power of Attorney, with Guardianship (if needed), with Health Care Surrogate Power of Attorney; name of family attorney; living will; trusts; and advanced directives such as do not resuscitate order. One source of information about advanced directives is the Project Grace web site, [www.p-grace.org](http://www.p-grace.org).
- **Elder law attorneys** in Pasco and Pinellas counties are listed with the Senior Helpline. The Florida Bar Association at 1-800-342-8060 can also provide a list of elder law attorneys by county. If you prefer, call the local Clearwater Bar Association at 727-461-4869 or the St. Petersburg Bar Association at 727-823-7474.

Elder law attorneys specialize in helping people plan for illness, incapacity, and death. They are knowledgeable in issues such as Medicaid, Medicare, Guardianships, Estate Planning, Trusts, and Advanced Directives. It may be an elder law attorney who helps find strategies to make your care receiver eligible for Medicaid payment for care in a nursing home, something that could be very important to you later if home care becomes too difficult. For information about Medicare-Medicaid laws in Florida, choose that topic on the DOEA web site, [www.myflorida.com/doea](http://www.myflorida.com/doea). You may want to visit [www.floridamedicaid.com](http://www.floridamedicaid.com), also. This commercial site by Medicaid attorneys is updated frequently.

Attorneys can help insure that the care recipient's end of life choices and preferences are honored. This may be especially important if you are the unmarried heterosexual or same sex partner of your care receiver. You may need an attorney to help protect your rights and those of your care receiver. This could be important if the care receiver's relatives have different ideas regarding care and end-of-life decisions. For more on the **legal rights of lesbian, gay, bisexual and transgender (LGBT) older adults** and their caregivers, run a search for "LGBT Caregivers" on the Family Caregiver Alliance web site, [www.caregiver.org](http://www.caregiver.org).

For more information on elder law attorneys, read **What Is an Elder Law Attorney and Legal Considerations When Facing Incapacity** in the *Senior Resource Directory* or on the web site of the Area Agency on Aging of Pasco-Pinellas, [www.agingcarefl.org](http://www.agingcarefl.org). Find Questions to Ask An Elder Law Attorney on the web site of the National Academy of Elder Law Attorneys (NAELA), [www.naela.com/public/QA.htm](http://www.naela.com/public/QA.htm). The NAELA web site also includes Locate an Elder Law Attorney.

- **Medical information.** Include information about primary-care physician, other physicians, agencies providing therapy or other services, suppliers for oxygen, adult undergarments, etc., medical conditions, allergies, medications, pharmacies used, recent hospitalizations, attending physician and surgeon, diagnosis and payment arrangements.
- The Department of Elder Affairs' **SHINE (Serving Health Insurance Needs of Elders) Program**, which has a local office at the Area Agency on Aging of Pasco-Pinellas, Inc., can provide information about prescription assistance and assistance with understanding medical insurance and completing forms. In Pinellas County, Florida, contact SHINE by calling the Senior Helpline, 1-800-96-ELDER (1-800-963-5337). For inquiries from outside of the area call 727-217-8111. SHINE volunteers can answer insurance questions and help complete paperwork. You may prefer to print a copy of the SHINE Prescription Assistance Fact Sheet from the Florida Department of Elder Affairs (DOEA) web site, [www.myflorida.com/doea](http://www.myflorida.com/doea). A new Medicare program, Medicare Part D, has been implemented to assist seniors with their medication costs. A SHINE representative would be able to assist seniors in making a selection.
- **Funeral arrangements.** It may seem too soon to think about funeral arrangements, but pre-planning funerals is a great gift for the family and friends who will be left behind someday. Some people decide everything, even what songs to sing. At a minimum, it would be good to know your care receiver's wishes regarding cremation or burial, type of funeral service desired, place of interment or whether ashes should be scattered, etc. If you are not aware of whether funeral and burial plans have been made and your care receiver is competent, discuss these issues. For help in making funeral plans, order a free pamphlet called *Funerals: A Consumer's Guide* by calling the Federal Trade

Commission (FTC) toll-free at 877-382-4357. This brochure can be found also on the FTC web site, [www.ftc.gov](http://www.ftc.gov).

- **Plans for care of pets in case of incapacity or death.** A frequently overlooked issue is what a person hopes will happen to pets should the owner move to a facility that does not allow pets or following the death of the owner. If an older person dies without a surviving spouse who is able to care for a pet and without making provisions in a will or at least by telling relatives while alive, families may argue about what to do with the surviving pet, especially if it doesn't work out for a family member or friend to take the pet. This can be stressful for the grieving family and a sad fate for the pet, which may end up in an animal shelter with few hopes of adoption. This is probably the last thing the owner would have wanted.

**Discuss plans for pets while your care receiver is alive and can be involved in the decision. Also let him or her know about the option of a Pet Trust.** January 1, 2003, Florida pet trusts became legally enforceable, meaning that the Trustee has to spend the funds on the owner's pet with funds remaining after the pet dies distributed to heirs or charities as the owner chooses. This is something for you and your care receiver to discuss with an elder law attorney. One elder law attorney who serves Pinellas County, Florida, is working on a pet trust web site, to be found soon at [www.pettrust.net](http://www.pettrust.net). You may also want to run a general Internet search for "Florida pet trusts".

## Caregiving Notebook

Besides having a list of important family information, it is helpful to create a caregiving notebook in a 3 ring binder. Adding to this Caregiver handbook works well. Your goal is to have information needed to arrange and keep up with your care receiver's care.

Here are some of the uses for your caregiving notebook:

- This is a place to **record medications and changes in health.**
- A **calendar** with your care receiver's appointments can go in here.
- Special **diet information** and **pamphlets about medical conditions** can be kept in the pockets of the notebook.
- Decide whether to include the entire important **family information** list or keep it private and make a smaller list for the notebook, which may be used by friends, family, and service providers helping with care.
- The caregiving notebook should include **a list of emergency contacts**, doctors' numbers, family and friends and the type of help they can provide, and contact people for services for anyone staying with your care receiver to use in an emergency. You will be more comfortable taking breaks from caregiving if you

know that your substitute caregivers have this information, and they will be more comfortable, also.

**While keeping up with your care receiver's care, don't forget your own care:**

- Keep a **calendar for yourself** including your support group meetings, medical appointments, caregiver workshops you want to attend, and scheduled breaks from caregiving.
- Remember to **schedule your annual medical exams** and tests such as mammogram or prostate test, etc.
- **Make sure your doctor knows that you are a caregiver.** Discuss your situation and any depression, anxiety, and insomnia that you may experience. Medications can be helpful for these conditions if needed, but non-drug choices can also help you avoid or postpone the use of medications to deal with caregiver stress.
- **Alternative stress reducers** include joining a support group, finding ways to take breaks from caregiving, eating right, exercising, volunteering, writing in a journal, expressing yourself through art, watching popular and classical movie videos or DVDs checked out of the library, and working puzzles or playing free games on the Internet. For more on these topics, see **Stage Two and Stage Three.**

## Stage One, section 6: Disaster Plan Update

**Your care receiver's disaster plan may need to be reviewed and updated whether or not you live in the same home.** Perhaps in the past he or she stayed at home during a hurricane or other disaster because of living in a non-evacuation zone. Perhaps he or she gathered storm supplies and put plywood or other window coverings on prior to each storm but cannot do that now.

Here are suggestions to help with disaster planning:

- **Consider having your care receiver stay with you at your home**, if different, or having your family stay with the care receiver, looking at factors such as evacuation levels of each home, which home can be better prepared for a storm, and responsibilities to other adults, children, and pets as well as to the care recipient.
- Find out whether family members, neighbors, or persons for hire are available to help **cover windows and doors** before a storm. If not, try to protect windows using a method that does not require manual installation and removal.
- Look for an interior, windowless room that can be used by your care receiver as a **safe room** to wait out the storm.
- Make certain that glasses, medications, water, food, flashlights (candles are dangerous), other supplies, and **important paperwork** including the family information list, insurance policies, etc. are available and protected. For what to include in a family information list, see **Stage One, section 5: Information List and Notebook**.
- Evaluate your need to evacuate to a **shelter**. There are some special needs shelters, which provide services such as oxygen. Some caregivers living in an evacuation zone decide that staying in a relative or friend's home in an area that does not have to evacuate is much more comfortable. Make special provisions for oxygen, dialysis, or other services that may be affected.
- If your care receiver will require pick up by the County for evacuation to a public shelter, special needs unit, or hospital, **register with County Emergency Management in advance**. Transportation is not provided to evacuate to homes of friends or relatives, and Medicare covers only medically necessary hospitalization (arrange in advance if required). In Pinellas County, register with Emergency Management by calling 727-464-3800 or completing the form found under "Evacuation Assistance Program" in the **Local Preparedness** section of Pinellas County Emergency Management's web site, which can be found at [www.pinellascounty.org/emergency/Local/htm](http://www.pinellascounty.org/emergency/Local/htm). In Pasco, you may call the Office of Disaster Preparedness. The phone number for New Port Richey is 727-847-8137; Land of Lakes is 813-996-7341 and Dade City is 352-521-5137. The Pasco County Office of Emergency Management has a website which is



[www.pascocountyfl.net/oem/index.asp](http://www.pascocountyfl.net/oem/index.asp). You can also register by contacting the fire department. The American Red Cross, Tampa Bay Chapter offers disaster preparedness assistance. The numbers in Pinellas are 727-446-2358 in Clearwater and 727-898-3111 in St. Petersburg. In Pasco, the number is 727-862-8685 in Hudson. Most shelters do not allow pets, so make plans for pets to be cared for by relatives or friends or boarded in a non-evacuation zone. Pinellas County can now offer an alternative to pet owners who must seek public shelter during a mandatory evacuation with its first pet-friendly shelters. Pre-registration will be required. For questions or to have a PET FRIENDLY SHELTER REGISTRATION FOR mailed to you, call 727-582-2150.

- Take essential items if you are leaving home: two week supply of medications, cash, personal hygiene items (soap, toothbrush, toothpaste, deodorant, etc), special dietary foods, identification, important papers, personal aids (glasses, hearing aides, dentures), and items like pain relievers or anti-acids.
- Take provisions that will make your stay away from home more comfortable: linens (including towels and wash cloths), sleeping bag or blankets, change of clothing, radio, flashlight, batteries, lawn chair, books or magazines.
- In Florida's Pinellas and Pasco Counties, you can obtain a copy of the Florida Department of Elder Affairs (DOEA) *Disaster Preparedness Guide for Elders* from the Senior Helpline by dialing 800-96-ELDER (800-963-5337). This Guide has general information about all types of disasters including terrorism and floods. It is available under Disaster Preparedness on the DOEA web site, [www.state.fl.us/doea](http://www.state.fl.us/doea). Also look for information about a Family Disaster Plan and Disaster Supply Kit there.
- ***The St. Petersburg Times Hurricane Guide*** for North or South Pinellas, Pasco, and surrounding Florida counties is published as a special section in the *St. Petersburg Times* newspaper just prior to Hurricane Season, which starts June 1st. *The Hurricane Guide* includes an official evacuation map, tips for preparing for storms, and advertisements for various types of window protection such as hurricane resistant film and permanent storm shutters, if you and your care receiver are considering purchasing these. Find the *St. Petersburg Times Hurricane Guide* online on Pinellas County Emergency Management's web site: [www.pinellascounty.org/emergency/Local.htm](http://www.pinellascounty.org/emergency/Local.htm). Evacuation information is available for North and South Pinellas, Pasco, and several other counties.
- The Public section of the Florida Division of Emergency Management's web site, [www.floridadisaster.org/DEMPublic.htm](http://www.floridadisaster.org/DEMPublic.htm), provides Florida residents with **emergency information** such as road status by event and telephone number of the toll-free Florida Emergency Information Line (FEIL), 800-342-3557, an information service activated during a disaster. The site also lists the telephone numbers for the Federal Emergency Management (FEMA) National Tele-registration Center (800-621-3362 or 800-462-7585 (TTY). Registering with

FEMA is the first step for individuals or businesses that need FEMA assistance after the President declares a disaster area.

- The **National Weather Service web site**, [www.nws.noaa.gov](http://www.nws.noaa.gov), has local forecasts and warnings, radar and satellite images, maps, etc. Local radio and television stations provide this type of information, also, on the air and online. For web sites of local television stations and newspapers in the Tampa Bay area, visit the Links to Aging Resources section of the Area Agency on Aging of Pasco-Pinellas's web site, [www.agingcarefl.org/links/local](http://www.agingcarefl.org/links/local).

## **Stage One, section 7: Driving Assessment**

**If your care receiver is still driving, it may be time to evaluate their driving skills and consider a driving assessment.**

Among the conditions that could cause concern about a person's ability to continue driving are problems with eyesight and coordination, Alzheimer's and related dementia, Parkinson's, and stroke. Medications and alcohol may also affect driving, and drug interactions can multiply impairment.

**Here are some indicators of impaired driving from various causes:**

- Getting lost in familiar places
- Failing to observe and obey traffic signs and speed limits
- Poor or slow decision making in traffic
- Trouble navigating turns or judging distance
- Not anticipating actions of other drivers
- Drifting across lanes
- Getting confused at exits
- Stopping before intersections
- Parking inappropriately
- Hitting or driving over curbs
- Anger, confusion or frustration while driving
- Scrapes on car, garage, or mailbox
- Car accidents or near misses
- Needing instructions from passengers

**In Pinellas County, Florida, there are two formal resources that involve assessing a person's driving skills:**

**The Bayfront Medical Center Driver Evaluation Program** utilizes an occupational therapist who offers an evaluation to individuals needing to determine if they are safe on the road and what adaptive equipment can be used to allow them to return to driving again. It is a two part evaluation. Part one is a clinical assessment of eye-hand-foot coordination, reaction time, visual scanning ability, and other cognitive and motor functions. The second part, if needed, is a road test of driver safety, awareness of laws, and training needed. There is a charge for the assessment. For more information call 727-553-7132. Staff will arrange for required documents, including the required prescription from their health care provider. They must have a current driver's license, 20/40 corrected vision in one eye, and be seizure free for 6 months. Contact:

The Driver Evaluation Program  
Occupational Therapy Department  
Bayfront Medical Center  
St. Petersburg, FL 33701  
727-553-7132

**Please remember that effective January 1, 2004, all drivers 80 years and older who are in the process of renewing their driver licenses are required to pass a vision test.** Driver's License offices provide these tests, preferably by appointment, at no cost. Another choice is to be tested by a family doctor or eye specialist, who has to complete a form. For more about this new law, see *Mature Driver Vision Test* on the Florida Department of Highway Safety and Motor Vehicles web site.

Having to give up a driver's license represents a great **loss of freedom and mobility** and can be difficult emotionally, as it is symbolic of loss of control over one's life. As is true of other losses, it causes grieving. It can also lead to increased isolation and secondary losses such as loss of friends and activities. As one older person described it, "It's the hardest thing to have to give up your license, because then you're grounded."

Referral to community resources for transportation may be helpful. Please be aware that these services may have eligibility guidelines, mileage limits, and call-ahead policies. To the person having to give up the license, using transportation programs cannot erase the pain of having lost the freedom to drive anywhere anytime. **Counseling to get over the loss may be needed.**

### **More Helpful Resources**

- To access the services or programs described in this Handbook, call the Senior Helpline at 800-96-ELDER (800-963-5337) in Pinellas or Pasco counties or 727-217-8111 outside of the area.
- The **American Stroke Association** has a fact sheet called "Let's Talk About Driving After Stroke." Warning signs of unsafe driving after stroke are provided, and stroke survivors are encouraged to talk with their doctors and occupational therapists and to get tested through a driver's assessment program. Call the American Stroke Association, 888-4STROKE (888-478-7653). Also ask for information packets for caregivers and for stroke survivors (several different packets are available) and a free year's subscription to *Stroke Connection Magazine*.
- If your care receiver needs a **disabled parking placard**, whether driving alone or being transported by family or friends, see "Florida's Disabled Parking Program" in the **More Resources and Tips** section of this *Caregiver Handbook*.
- You may not be able to leave your job or other activities to transport your care receiver as often as he or she would like to be transported. Your care receiver may qualify for other **transportation services**. Call the Senior Helpline at 800-96-ELDER (800-963-5337) for more information.
- **Long distance caregivers** may want to use the Eldercare Locator, a free service of the U. S. Administration on Aging, to find resources for driver evaluation, counseling, and transportation. The Eldercare Locator's toll-free information line, 800-677-1116, refers callers to elder helplines throughout the

United States. The Eldercare Locator web site is found at [www.eldercare.gov](http://www.eldercare.gov). Residents of any Florida county may call Florida's Elder Helpline number, 800-96ELDER (800-963-5337) for direct connection to a local elder helpline.

- The **AAA Foundation for Traffic Safety** created the Senior Drivers web site, found at [www.seniordrivers.org](http://www.seniordrivers.org). Find exercises and refresher tips, in a choice of web page or video format, to help older drivers stay in shape for driving.
- The **USAA Insurance Company Educational Foundation** web site, found at [www.usaaedfoundation.org](http://www.usaaedfoundation.org), offers self-tests and driving tips, transportation options after giving up driving, and a booklet called "Driving Safely While Aging Gracefully." Click on Order Booklets or on Auto Safety to view.
- **The National Accessible Traveler's Database** lists accessible providers by city for traveling with persons with physical and cognitive (mental) impairments. Find this database under **shortcuts** on the Project Action Web site, [www.projectaction.com](http://www.projectaction.com). You may also call Project Action toll free at 800-659-6428 or 202-347-7385 (TDD).
- **The Florida Senior Safety Resource Center**, developed by the University of Florida and found online at [www.floridaseniorsafetyresourcecenter.php.ufl.edu](http://www.floridaseniorsafetyresourcecenter.php.ufl.edu), provides driving knowledge test, transportation options by Florida county, and links to national driving resources.

