

The Four Stages of Caregiving

Stage Two: Finding Help

You may have been a caregiver for months or perhaps even for a year or two on a regular basis. It is clear that you are the primary caregiver and that this is not going to be a short-term illness with anticipated quick recovery.

Perhaps you are the spouse of someone whose health situation has changed. When you moved to Florida, both of you may have been healthy, looking forward to travel and other enjoyable retirement activities. You didn't envision yourself becoming a caregiver and the changes that being a caregiver would mean for you.

Perhaps you are an **adult child caring for an aging parent**, and you find that plans you had for your own family have been shelved. Working full-time and caregiving may be exhausting you already, and how many more years of caregiving could lie ahead?

Whether you are a spouse, adult child, or other relative or friend, your caregiving role is still valuable and meaningful. Yet, as a stage two caregiver, you may feel angry, sad, and alone. What do you do now?

This is the time when services for your care receiver and relief for you as the caregiver must be found. Respite care (breaks from caregiving) may come from family and friends, faith communities, and formal services such as home health care and adult day care.

For assistance from most sources, you will need to tell people that you are a caregiver and ask what help they can provide. This may be hard to do, but it is vital if you are to continue caregiving. Yesterday's caregivers sometimes had the advantage of an extended family to help out, people were not living as long with dementia and chronic illness, and fewer people worked outside the home. Your friends and family, faith community, and formal service providers need to hear from you that you are a caregiver. Also, if you are a stage two caregiver who works outside your home, you need to know about options for employed caregivers.

Note: if you are already facing heavy-duty hands-on caregiving, also look through **Stage Three: Heavy Care** for topics you may need.

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 and 727-217-8111 outside of the area.

Stage Two, section 1: Help from Family and Friends

Study the list of family and friends you identified as a beginning caregiver, give specific suggestions to anyone who offers help, and accept all the help you are offered. If something offered isn't anything you can use, make an alternate suggestion. Stage two caregivers need to find and accept informal support.

Asking Your Family for Help

Beginning caregivers were encouraged to hold **family meetings** to ask for help from immediate family and extended family members. If you didn't do that then, consider it now.

If you and your care receiver live in Florida while most of your family members live in other states, your only family support may be telephone calls, cards, e-mails, and occasional visits. Let relatives know how much these mean and keep them informed of changes in the situation you are facing with your care receiver. If they are planning to visit, make certain that you aren't expected to cook for them and entertain them as in the past.

Keep thinking of specific ways relatives can help you while they are visiting and throughout the year. Ask again as your caregiving responsibilities increase. Sometimes relatives will come stay with your care receiver for a week so that you can have time off for a trip to visit your sister, a vacation, or a convention for an organization important to you. If no one offers, it is reasonable to ask someone in your extended family for specific help such as a respite visit to give you a break from caregiving. For more ideas on how to get help from your siblings, see **Stage One, section 1**.

Caregiving can be expensive. You and your care receiver may find yourselves paying for home modifications, services, and medical supplies not covered by insurance or a government-funded program. Sometimes relatives who are not close geographically want to do something but don't know what to do unless you give them specific ideas.

If you hesitate to ask your extended family for financial support, suggest some gifts to save you not only money but also time and strength. For instance, they could give you frozen meals, caregiving books, lawn services, bus passes, and prepaid drug store gift certificates. Some of these can be ordered online or purchased in their state and mailed to you. For more information, see "Gifts for Caregivers" in the **More Resources and Tips** section of this Handbook.

Speaking Up

As a caregiver, there will be many times, with professionals as well as with relatives and friends, when you need to **speak up for yourself and for your care receiver**. This is not easy for many caregivers, who may choose not to make the effort. We believe that the effort is worth it. A good book on this subject is *The Fearless Caregiver—How to Get*

the Best Care for Your Loved One and Still Have a Life of Your Own, edited by Gary Barg, Editor in Chief of *Today's Caregiver Magazine*. This comforting book, which begins with "The Fearless Caregiver Manifesto," will encourage you to "trust your instincts," and to rethink the way you see your role in your care receiver's "care team." For more information, see *Caregiver Books and Videos* in this Handbook.

A number of web sites have information to help caregivers learn to speak up. Read "Ten Tips for Family Caregivers" on the National Family Caregivers Association (NFCA) web site, www.nfcacares.org. While there, you may want to read about or to participate in the National Family Caregiver Story Project. A web site called Empowering Caregivers, www.care-givers.com, offers emotional and spiritual support. (Note the hyphen in this address – without it you go to a different site.) Many other caregiver web sites offer encouragement and tips on how to ask for help. See the list of *Caregiver Web Sites* in this Handbook.

Asking Your Neighbors for Help

In many neighborhoods today, residents don't visit each other – at the most, they may just wave or say hello. One caregiver told us that all she received from her neighbors was unwanted advice about what decisions they thought she should have made. She added sadly, "Of course, they haven't walked in my shoes." While there is always the chance that one of your neighbors will be insensitive, we believe it is worth the risk to talk to your neighbors about your caregiving needs and how they can help. This could be especially important if you do not have friends or family living nearby.

Caregivers hesitate to ask neighbors for help, thinking that they would be imposing if the neighbors did not offer first; but **most neighbors will not realize that their help is needed unless they are asked**. Try requests like these:

- "I miss my wife's cooking now that she is ill. I'm struggling just to heat frozen dinners, and I know you're a good cook. Could you help me learn to cook a few simple meals or bring us some home cooking once in a while? It would be such a relief to me, and I could pay for the ingredients."
- "I know you and Dad used to see each other when walking your dogs. Dad can't walk Toby now, and I wonder if you might stop by and offer to walk him once a week? I'll give him a walk when I'm in town most Saturdays, so midweek would be good. If you agree, maybe you can help convince Dad to try this plan."
- "You probably heard that my husband is sick. Sometimes I can't leave him to go grocery shopping, and I need someone to go to the store for us or stay with John while I go. May I put your telephone number on my list to call in an emergency?"

You may be surprised to find people willing to do even more than you ask of them once they are alerted to your needs. Also, if your care receiver has a condition that causes wandering, the neighborhood will be alert to help guide him or her home.

If you feel that you just cannot bring yourself to ask people for help if they didn't offer first, at least write down the telephone numbers of the friends or neighbors who did offer to do something and list what they offered. Questions to ask in order to clarify a vague offer of help are included in **Stage One, section 1**.

Now is not the time to say, "No thanks, we can manage." Accept their meals, visits, shopping, and lawn mowing, or suggest other ways they can help.

Finding Ways to Take Breaks

A break from caregiving is called respite care. Encourage friends and neighbors to visit your care receiver for a few hours at a time, sometimes when you are there, but mostly as respite care so that you can get away. In addition to being able to take care of chores like grocery shopping, you need time away from the care receiver to go to the doctor and hair salon, attend caregiver support groups and workshops, and do other nice things for yourself. This could be a drive to the beach or a visit to a library, art museum, or day spa. If there are times of the day such as your care receiver's bath time when you do not want visitors, let your friends and neighbors know that. Perhaps one person can stay with your care receiver while another takes you out for a meal and concert. This gives you a chance to maintain a friendship while taking a break from caregiving. It's also nice for you and your care receiver when a relative, friend, or neighbor takes your care receiver on an outing without you.

It is vital for you to find ways to take regular breaks from caregiving and to stay in touch with the world outside your home. Some caregivers have found relief by actually volunteering for a local charity just to get out in the world and have a change of pace. For more information about volunteer opportunities in Pinellas County, Florida, **call 211** (not the emergency number, 911) or visit the 211 Tampa Bay Cares web site at www.211tampabay.info. This organization refers people who want to volunteer to agencies needing help and helps agencies find volunteers. 211 Tampa Bay Cares is also a resource for information about support groups and agencies that serve people with various needs, and the 211 line is available 24 hours a day with staff trained to help those in crisis as well as those who just need information.

Help from relatives, friends, and neighbors is called **informal support**. Help from faith communities (religious organizations) is also informal support. For more about that, see *Stage Two, section 2*. For more information about **formal services** that can provide a break from caregiving, see **Stage Two, section 5**.

Stage Two, section 2: Help from Faith Communities

Many faiths consider their members and staff to be a faith community in which everyone has a responsibility to the other members and sometimes to the broader community outside. Many congregations are becoming more aware of the needs of their caregiving members. If you and your care receiver have a place of worship, keep staff and friends there informed about your caregiving situation. If you are not affiliated with a place of worship, opportunities for help can still be available.

Help from faith communities may include:

- **Group meetings and outings for seniors.** You and your care receiver may be able to attend some activities together, or perhaps someone can stay with your care receiver so that you can go and enjoy the fellowship and mental stimulation.
- **Tapes of services.** If you miss services while caregiving, ask whether audiotapes or videotapes are available. Some caregivers find a sense of emotional and spiritual comfort by experiencing the service at home.
- **Visitation.** If you would value visits, calls, or cards from staff or members of the faith community, then you need to let them know that this would be appreciated. Let them know that you appreciate their thoughts, prayers, and support. Don't assume that everyone is aware of your situation or feels comfortable initiating contact with you.
- **Caregiving ministry.** Some places of worship are developing caregiving ministries that go beyond visitation, such as providing respite care. Some faith communities are also reaching out to neighbors around their building whether they attend that place of worship or not. You will need to ask about what is available.
- **Counseling.** Many places of worship provide counseling with clergy or other trained counselors by appointment.
- **Television/radio.** Faith based programming is available on local and cable television and is broadcast on the radio.

As the caregiver, you have to:

- **Investigate the available faith-based options.**
- **Let people in the faith community know that you are a caregiver and communicate your physical, emotional, and spiritual needs as a caregiver and those of your care receiver.**

Stage Two, section 3: Support Groups

Joining a support group is one of the best things you can do for yourself as a caregiver, truly a way to know that you are not alone.

Participants in support groups often say that being part of a support group saved their lives and sanity. Sometimes group members enjoy social outings together and are almost like an extended family. Even if you never considered yourself a joiner, attending a support group can make a huge difference in the quality of your life. Don't wait until you become a "burned out" caregiver. Start looking for a group fairly early in your caregiving experience. If you are thrust into heavy-duty caregiving by a stroke or accident, look for a support group right away.

Caregivers tell us that it takes several visits to get a feel for whether a group is a good fit. The first time you may feel overwhelmed with the thought of what might be ahead for you and your care receiver. The second time you might hear a guest speaker or caregiver stories that seem less scary, or you may be more ready for a support group then. If you don't feel comfortable after several visits, try a different group. Don't give up on the idea of support groups – different groups have different styles. Most support groups do not charge for services.

What To Expect

If there is a contact person listed for a specific group, it is helpful to call before visiting so that you will know what to expect. Ask questions like these:

- Is this group oriented toward a specific disease, toward caregivers of elderly parents or of spouses, or is it a general group for caregivers of all types?
- Do you have caregivers alone, caregivers and care receivers together, or respite care for the care receivers while caregivers meet?
- Have most people who attend been with the group a long time or do you have a mixture of new and old caregivers?
- What kinds of topics do guest speakers cover?
- When do you meet, and do you have social outings at other times?
- Who leads the group, and what is that person's experience?

Some support groups meet at adult day care centers or a nursing homes, but that does not mean that your care receiver needs to attend that center or be a resident in that home. These groups may be Alzheimer's/dementia oriented or may serve all types of

caregivers, and some have the additional benefit of free respite care for care receivers while their caregivers attend the group.

At caregiver support groups, you have an opportunity to talk about your situation if you want to, but you don't have to talk. You can sit and listen, share feelings and tears you might not be comfortable sharing with non-caregiving family and friends, learn tips from other caregivers or from guest speakers, laugh, hear about research on your care receiver's illness, obtain guidance on where to get additional help, and much more. You can be honest and know that you won't be judged, since many people in the group will have had similar experiences. Often caregivers remain in support groups after their care receivers move to a nursing home or die because the group helps with their grieving process and they can help caregivers who are at earlier stages of caregiving.

How To Find Support Groups

- The caregiving programs of the Area Agency on Aging of Pasco-Pinellas, Inc., may provide you with information. For more about these programs, see "Caregivers REST Project" and "National Family Caregiver Support Program" in the *More Resources and Tips* section.
- **National organizations** for various diseases can be called toll-free. See the list of "Toll-Free Information Lines" in **More Resources and Tips**. Often, they can give you local contact information for support groups associated with their national organization.
- In Pinellas, the Suncoast Hospice recognizes the complexity of caregiving. Commitment, responsibility, tender moments, hope, questions and loss are all part of it. Whether or not the person you care for receives services from Suncoast Hospice, you as a caregiver can find encouragement and information there. Suncoast Hospice offers Caregiver Coffee Breaks at several locations. Here caregivers can share information and tips and get support from other caregivers. Call (727)467-7423 for more information.
- **Alzheimer's Association Florida Gulf Coast** can provide an updated list of affiliated support groups in your area. Call 727-578-2558.
- Call the telephone number 211 which lists community resources for people of all ages including many, but not all local support groups in Florida's Pinellas and Pasco Counties. The 211 database also includes organizations associated with research and assistance to families affected by diseases and conditions. Alzheimer's disease, arthritis, diabetes, multiple sclerosis, Lou Gehrig's disease, cancer, stroke, lupus, Parkinson's disease, lung diseases, HIV/AIDS, mental health problems, alcoholism, hepatitis, fibromyalgia, hearing loss, and blindness are among the choices. You may inquire about "counseling", a service shown to be helpful to caregivers in caring for themselves. For more about counseling,

see **Stage Three, section one**. For Pinellas, visit the 211 Tampa Bay web site, www.tampabaycares.org. Search by the keyword “Support Groups”. Scan the whole support group section, since few caregiver support groups have caregiver in the name. Many have the name of a specific disease.

- Some caregiver web sites offer **online support groups** and other support such as chat rooms, classes, and places where messages and tips can be exchanged. Alzheimer’s Caregiver Support Online, www.alzonline.net, provides free Positive Caregiving Classes. This site is a project of the Florida Department of Elder Affairs and the University of Florida. Caregiving.com, www.caregiving.com, offers seven different support groups to help caregivers who are new, providing hands-on care, male, young adult, alternative (gay/lesbian), transitioning to facility care, or experiencing grief/loss.

The “Caregiver Web Sites” section of this *Caregiver Handbook* or the web site (www.agingcarefl.org/caregiver/Websites) includes other sites that offer online support groups and classes. Some of the national disease-related sites have listings of local affiliates by geographic area.

Stage Two, section 4: Help For Employed Caregivers

If you are an employed caregiver, find out what options you have for providing care while continuing to work.

Employers and Workforce Changes

More than half of all caregivers work full time. Twelve percent work part-time, and nine percent have had to quit their jobs because of caregiving. Many who quit said they would not have made that choice if flexibility in working conditions had been available. As the Baby Boomer generation ages, more and more employees will provide informal care to aging relatives and friends. Employers can help ease the crisis in caregiving by being supportive of caregivers, a growing segment of their workforce.

The U. S. Department of Labor reports that 30% of employed persons are caregivers and that 54% expect to assume that role within 10 years. Some employers may think that the percentage of their workers caring for relatives is low because some caregivers choose not to share this information until they have exhausted their sick leave and have to look at other options. These employers may not know that flexible hours combined with caregiver education and support could improve job performance and reduce employee turnover and the high cost of training new employees.

More companies are offering formal programs with resource materials, counseling, caregiver training, and other services to help caregivers. Some companies or unions have information and referral programs or even care management. Some employers provide caregiver assistance as part of Employee Assistance Programs, and some offer on-site supportive services such as adult day care centers or combination child/adult day care centers.

Talking With Your Employer

The U. S. Administration on Aging (AOA) recommends discussing your needs with your employer. This advice appears in *Because We Care: A Guide for People Who Care* on the AOA web site, www.aoa.gov. Telecommuting, flextime, job sharing, or rearranging your schedule can help minimize stress. Some companies will make special arrangements for an individual caregiver when asked, even if there are no official policies addressing caregiver issues.

You may have used up much of your sick and annual leave providing transportation to medical appointments and other care. Now you may need more time off. The 1993 **National Family and Medical Leave Act (FMLA)**, which allows up to twelve weeks of unpaid leave a year for family caregiving without loss of job security and benefits, may be an option. Find out whether the FMLA applies to your company and whether you qualify. Sometimes even smaller companies, though not required by law, offer similar programs. Look in your personnel manual or ask the human resources department for a copy.

The 1993 National Family and Medical Leave Act does not protect gay and lesbian caregivers (or heterosexual partners who live together but are not married), but some companies extend the same benefits to unmarried domestic partners. Ask what benefits are available at your company. For more about the needs and rights of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers, visit the Family Caregiver Alliance web site, www.caregiver.org, for fact sheets called “LGBT Caregiving: Frequently Asked Questions” and “Legal Issues for LGBT Caregivers”.

Find out about other caregiver-friendly policies offered by your company. If there is little support for caregivers, you may want to show your employer this article and encourage your employer to consider some benefits to help working caregivers. Many of these policies would help other employees as well.

Here are some examples of caregiver-friendly policies:

- **flextime, job sharing, and allowing employees to rearrange schedules** as needs arise or come in on weekends to make up time lost to caregiving tasks, telecommuting from home, etc.
- **eldercare packages** that include services such as caregiver training, care management, information about community resources and caregiver support groups, company-sponsored adult day care programs or financial aid for employees using private-pay adult day care, emergency respite care benefits for caregiving crises, etc.
- **counseling** through employee assistance programs or group health insurance.
- **employee preventive health and fitness programs** that include exercise, nutrition, massage, and stress reduction activities, or financial aid to help with costs of private pay health club, massage, etc.
- **flexible spending plans** (cafeteria plans) for using pretax dollars to pay for medical and other allowable costs associated with caregiving.
- **long-term care insurance** provided by employer or for offered at group rates for employee purchase.

Helpful Resources

- For **statistics on the employment status of caregivers**, see “Selected Caregiver Statistics” on the Family Caregiver Alliance web site, www.caregiver.org. This fact sheet was based on studies such as *Family Caregiving in the U.S.: Findings From a National Survey*, by the National Alliance for Caregiving and AARP, June 1997. Find National Survey results under Reports and Products on the National Alliance for Caregiving web site,

www.caregiving.org. (Please note that the National Alliance for Caregiving and the Family Caregiver Alliance are different organizations with different web sites.)

- **The METLIFE Study of Sons At Work**, June 2003, surveyed 1400 employed caregivers at three Fortune 500 companies. Researchers found that men were just as likely to be a primary caregiver, responsible for tasks such as grocery shopping but less likely to provide personal care. More men than women reported being long-distance caregivers, and men were less likely to discuss caregiving with coworkers. Both men and women missed some work and would consider a job change because of caregiving. **Two-thirds of men and women did not know about existing corporate eldercare benefits.** This interesting new study can be found at www.caregiving.org under Reports and Products.
- **The METLIFE Study of Employer Costs for Working Caregivers**, another report available at www.caregiving.org, **shows that there is a high cost for replacing those employees who retire early or quit because of caregiving.** Addressing needs of caregivers so that they can continue to work while providing care is a way companies can save money while also having the satisfaction of improving the lives of a growing number of persons within the workforce.

Stage Two, section 5: Formal Support Services

Find community services that enhance your care receiver's quality of life and offer you relief from caregiving.

One thing to remember is that there are **various funding sources for the same services**. One example of a service is adult day care, which provides relief for caregivers and a safe, stimulating daytime environment for care receivers. Adult day care may be purchased privately, sometimes covered by a scholarship if the adult day care center is part of a religious-based organization, or paid for by a variety of federal and Florida state funding sources including Older Americans Act, Community Care for the Elderly, and Medicaid Waiver.

Each funding source has times when funds are available to add new clients and times when funding is limited. Waiting lists are based on the care needs of the client and are not provided on a "first come, first served" basis. Even if there is a waiting list for services, your care receiver may qualify sooner because his or her needs are greater than those of another person who applied at an earlier time.

Funding Provided through the Area Agency on Aging

Here are common types of government funding for community services with eligibility requirements and services paid for by each funding source:

- **Federal Older Americans Act (OAA)** requires a person be sixty or over in order to receive services, but priority is given to low income, minority individuals living in rural areas. Some OAA-funded services may have a waiting list while others do not. There is no charge, but donations are accepted. You may call the agencies that provide these directly. These services are not case managed, and each provider has a specific priority policy developed for that service. To find out what organizations are the designated providers of OAA services, call the Senior Helpline.
- Older Americans Act Title III-C programs include congregate meals served in a group setting and home-delivered meals. OAA Title III-B services include information and referral, adult day care, chore services, homemaker, counseling, emergency alert response, legal assistance, and transportation. Even if you are on the waiting list for state-funded programs such as Community Care for the Elderly (CCE), you can call OAA providers to see if they have OAA hours of service available while you continue to wait for CCE. CCE is discussed below.
- **The National Family Caregiver Support Program**, under Title III-E of the Older Americans Act, is a federal program that pays for services to relieve caregivers: screening and assessment, respite care in the home or in a facility, counseling, chore services, and medical supplies are a few of the services available through this program.

Caregivers eligible for this program must be adults who are providing in-home care for a person over the age of 60 who need help with activities of daily living. As with other OAA programs, these services are not case managed, priority policies are set locally rather than at the state level, donations are accepted, and there may be a waiting list. For more information on this program see National Family Caregiver Support Program. Persons sixty and over who serve as primary caregivers for relatives under 18 may qualify for the **Grandparent Program**.

- **Community Care for the Elderly, or CCE**, is a Florida state-funded program that provides a case manager to assess the needs and determine what services should be provided. In Pinellas County, call the Senior Helpline 800-96-ELDER (800-963-5337) and request a referral to Intake.
- **The Intake process** is based on a telephone screening assessment. This produces a priority score that, along with funding availability, determines whether the caller is on a wait list and how soon a case manager will complete an in-home assessment and develop a care plan, which is required for CCE services. Having a caregiver may lower a person's priority score compared to people living in the community with no support. Persons on the waiting list are reassessed every six months, as a situation may change for the worse, making someone a higher priority. The statewide priority system in Florida was established by the Florida Department of Elder Affairs (DOEA).
- In Pinellas County, if your care receiver's priority score is high enough to receive CCE services, you will have a choice of two agencies: Gulf Coast Community Care or Suncoast. Each of these agencies provides in-home assessments and case management for Florida state-funded services.
- **To be eligible for CCE**, a person must be sixty or over and functionally impaired, needing help with the normal demands of living. There is no income or asset requirement for CCE, however, clients are assessed a co-payment that is based on their monthly income.
- **CCE can provide a variety of services** including case management, case aide, adult day care, chore, companionship, counseling, emergency alert response, emergency home repair, escort, health support, home-delivered meals, home nursing, homemaker, industrial cleaning, pest control, medical therapeutic services, medication management, nutrition counseling, and other services. The consumer has a choice of providers for these services.
- **Community Care for Disabled Adults** is similar to Community Care for the Elderly but targets individuals under sixty. To be referred to the agency that provides this service, call the Senior Helpline.

- The **Alzheimer's Disease Initiative Program, or ADI**, is another Florida state-funded program for which eligibility and priority are handled in a manner similar to CCE except that persons must be at least 18 years or older and have a diagnosis of memory or other cognitive loss. Services include case management, caregiving training and support, case aide, and respite care in the home or in a facility. Call the Senior Helpline for more information, and remember that this may be a resource for someone under sixty with Alzheimer's or related dementia.
- **Home Care for the Elderly, or HCE**, can provide a small basic subsidy (stipend) for caregivers of seniors who are eligible for nursing home care under Medicaid but who are cared for at home. Special subsidies are available for reimbursement of supplies, equipment, and services for those who qualify.
- **Medicaid Waiver programs** use federal Medicaid dollars that could have paid for nursing home care. Instead the State has a Waiver to match the federal dollars with State funding to pay for home and community based services for persons who would otherwise be in a nursing home. To be eligible for Medicaid Waiver programs, a client must **meet the current income and asset requirements for Medicaid in a nursing home and must have a level of care that might require nursing home placement if home care options were not provided**. This involves filing an application with the Florida Department of Children and Families and a level of care assessment by the Department of Elder Affairs CARES Unit. For more information, call the Senior Helpline at 800-96-ELDER (800-963-5337).
- **In-home services paid for by Medicaid Waiver** for eligible persons include case management, case aide, companion, attendant, chore, medical supplies, counseling, environmental accessibility adaptations (ramps, grab bars, etc.), escort, family training, health support, home-delivered meals, homemaker, nutritional risk reduction, personal care services, personal emergency response systems, pest control, risk reduction, respite care, skilled nursing, specialized medical equipment, and physical, occupational, and speech therapy. Just as in CCE or ADI, services are purchased for the client based on a care plan completed by the case manager.
- There is also an **Assisted Living for Elders** Medicaid Waiver program that pays for placement in selected assisted living facilities rather than nursing home care.

At Risk Situation

If your care receiver remains on the waiting list for community services so long that you cannot continue home care without services to give you relief, he or she is at risk of placement in a facility. If you want to try to keep your care receiver at home, ask for a reassessment by an intake specialist even if it isn't time for your care receiver's six-

month review. Because your care receiver's situation may have worsened, he or she may now be a higher priority for government-funded services.

If you are at the point of **considering placement** in an assisted living facility or nursing home, you may want to contact the local Department of Elder Affairs (DOEA) CARES Program office located in Largo, Florida. Call CARES at 727-588-6882 for a free assessment to determine long-term care needs and how they can best be met. If the **DOEA CARES Unit** finds your care receiver to be at “**imminent risk**” of having to go into a facility, this will increase his or her priority on the waiting list for community services. For more information of the CARES Unit visit DOEA's web site, <http://elderaffairs.state.fl.us>. Select “Caring For An Elder” followed by “CARES”.

Nursing Home Diversion.

The Nursing Home Diversion Program began in Pasco and Pinellas counties in October of 2003. Clients must be living in the community, must have multiple care needs, and must meet the Medicaid income and asset guidelines. Clients choose a participating Managed Care Organization to provide their services. Offered services and facilities may be different for each company. These companies have contracts with the State to manage the care of program participants. These Managed Care Organizations receive a set monthly fee regardless of how many hours of service are provided and whether the service is provided in the home or facility. Accessing this program depends on the client's priority for service and the availability of funds to add new applicants. Call the **DOEA CARES Unit** (727-588-6882) for more information.

For the current income and asset limits for eligibility for Medicaid coverage of long-term care needs in Florida, visit www.floridamedicaid.com. This site by Medicaid attorneys is updated regularly. If you have more questions, you may want to consult an elder law attorney. See the “legal information” section of **Stage One, section 5**.

Veterans Administration

The Veterans (VA) Administration is an underused resource worth investigating on behalf of your care receiver. Some services that used to be available only to veterans with service-related injuries are now available to other eligible veterans, sometimes with coinsurance payments (co-pays) for those who do not meet low income and asset requirements. Bay Pines VA Medical Center, where eligible veterans can receive services, is located in St. Petersburg, Florida.

One VA program that is not well known is Aide and Attendance. Another is respite care for dementia patients. For help in obtaining Veterans benefits, call the Pinellas County Department of Veterans Services (727-464-8460) or the Pasco Veteran's Service Office (727-834-3282 or 352-521-5172). For more information, see “Veterans Benefits”, in the **More Tips and Resources** section of this Handbook. If you have additional questions, call the Veterans Administration's toll-free line, 1-800-827-1000 or visit the Veterans Administration (VA) web site, www.va.gov.

Private Pay Options

Many of the same services that are available through government-funded programs are available on a private pay basis. Private pay services allow you to tailor the services to your needs and avoid the wait lists frequently found with government-funded programs. Even those receiving some government-funded services such as day care, may supplement with private pay services in order to meet their need.

- There are many businesses in Pinellas County that provide in-home services such as help with house keeping and respite care. Take care of yourself and consider paying for at least four hours of relief a week.
- Meals can be delivered to your home, ready for you to warm and eat when you are ready. Private case managers can help coordinate care. There are also physicians and other health care providers who will make home visits.
- Licensed home care agencies can provide assistance with personal care such as bathing your care receiver. Some agencies require a four-hour minimum visit, but others will come for fewer hours at one time. Services do not have to be purchased on a daily basis and the agencies will help you design a schedule that fits your needs.
- Adult day care is available on a private pay basis. Some assisted living facilities offer Senior Day Programs that are similar to adult day care. You can drop your care receiver off for 4 to 12 hours, and the cost depends on how much care is needed – Alzheimer’s care is more expensive than independent care. Facilities are able to charge a reasonable rate because they already have adequate staff and there is little additional cost for the day care client.

For more detailed information on these private pay options see *State Three, section one* of this Handbook.

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

Helpful Resources

- A **Family Caregiver Alliance Fact Sheet** comparing using a home care agency with hiring someone privately is called “Hiring In-Home Help”. It can be found on the www.caregiver.org web site.

- **How To Choose a Home Care Provider** is a consumer guide that can be found at www.nahc.org/Consumer/Coninfo.html on the web site of the National Association for Home Care (NAHC). This guide lists types of services available, who come into the home to provide various services, and who pays for them.
- Services and programs information is available on the Area Agency on Aging of Pasco-Pinellas web site, www.agingcarefl.org/services. Also select “Community Services” in the *Alzheimer’s Disease and Related Disorders* section of the web site, www.agingcarefl.org/caregiver/alzheimers. For resources for diagnosis of a memory disorder such as Alzheimer’s, which may result in better planning for services, select “Clinical Evaluation and Research”.
- **The Senior Helpline**, serving Pasco and Pinellas Counties call 800-96-ELDER (800-963-5337) or 727-217-8111 from outside the area.

See **Stage One, section 3**, for more information.

Stage Two, section 6: Relief Through Self Expression

Start a personal journal, and offer your care receiver a journal. Use a simple notebook or a book of blank or lined pages with a lovely cover.

Your journal may serve as a place to:

- keep a **daily diary** of your experiences. Include anything of interest to you - some caregivers even include the weather and what was going on in the world that day.
- **list enjoyable activities** you can do to reward yourself or to get away from caregiving for short periods of time. Record something nice you did for yourself every day, choosing ideas from the list of enjoyable activities.
- **vent rage or write poetry** – a private book in which you can write down your feelings of disappointment, sadness, anger, and fear.
- **record or glue inspirational verses and stories** you find in a daily text, magazines, or caregiver newsletters.
- **write down advice from other caregivers** you meet in your support group.
- **glue, tape, or staple in comic strips or copies of other humorous things** you have seen and want to look at again when you need cheering up.
- **record moments in which love between you and your care receiver is expressed through quiet experiences you share** – watching the fish in your fishpond, feeding birds, or looking at an old photograph album together.

The person for whom you are caring may be physically challenged but mentally capable. Having a journal as a private place to express the feelings of helplessness, sadness, and frustration that accompany the condition that has completely changed his or her life and dreams could be **emotionally healing**. If your care receiver has trouble writing, consider a tape recorder. There are small, inexpensive tape recorders that are fairly easy to use. Some are voice activated.

If your care receiver hesitates to express feelings in a personal journal, he or she might like to write down or record **stories and memories from his or her life**. Your care receiver might enjoy leaving this behind as a gift for family and friends, and recording these stories might lead to opening up to express other thoughts.

Art

In addition to journaling, you and your care receiver might enjoy art. There are journals with unlined pages, art sketchbooks with bigger pages, and paper, canvas, and other materials for drawing and painting. Other types of art such as working with clay might be helpful, too, and can be done by people with conditions such as dementia. Art could be an activity you do together. If your care receiver is able, many of the senior centers offer art classes. If you live in Florida's Pinellas or Pasco Counties, see our list of "Senior Centers", part of *More Resources and Tips*.

The local recreation departments also offer art classes, and some activities are offered for those who are physically or mentally challenged. Look for parks and recreation department or leisure services under your city in the government pages of the telephone book. Ask whether there are therapeutic programs. Many recreation departments list their activities in brochures they can mail to you, and they may have a web site.

Creative Clay Cultural Arts Center in St. Petersburg and Safety Harbor, Florida, provides classes in pottery, watercolor, poetry, sculpture, voice lessons, etc. Creative clay is certified to work with persons with physical and or developmental challenges. Grants and private sponsors fund them, and their therapeutic art philosophy has proven useful in rehabilitation centers and nursing homes. They had a resource table at a local Stroke Conference. Call 727-825-0515 or visit their web site, www.creativeclay.org.

Photographs and Videos

While you may feel that there are no reasons to take photographs, nothing to celebrate anymore, it is a good idea to keep cameras handy and be ready to make a record of this time spent together. Photographs may be a source of peace for you and meaningful to family and friends. Consider organizing these into a photo album or scrapbook. Digital photographs may be e-mailed to relatives and friends and can also be printed.

An audiotape or video recording (VHS or DVD) can be a treasure, too, especially if you record your care receiver's voice. For more about making a reminiscence tape, read "Family Gathering" in *Stage One, Section 2*.

Stage Two, section 7: Relief From Telemarketers

At this stage of caregiving, your care receiver may be at home all day, a prime target for telemarketers including dishonest ones. If you and your care receiver have had enough of irritating and potentially dangerous sales solicitation calls from telemarketers, **add your telephone numbers to the National or Florida Do Not Call Lists**. This is a good idea for several reasons:

- It is annoying and time consuming to be interrupted by telemarketers all day.
- Sales solicitations calls interfere with meals and other important activities.
- Frail older people may be talked into paying fees for “prizes” they think they won and ordering products they don’t need and cannot afford.
- There is a risk of revealing social security numbers, credit card numbers, and other personal information to thieves including those involved in identity theft.

The new **National Do Not Call List** is a function of the Federal Trade Commission. There is no cost to enroll in the program. Call the Federal Trade Commission’s toll-free number, 1-877-FTC-HELP (1-877-382-4357), or visit their web site, www.ftc.gov. Select “National Do Not Call Registry”. For information on identity theft and other consumer issues, select “For Consumers”. There are a few exceptions to the national list, including calls from charities and political candidates.

The Florida Department of Agriculture and Consumer Services also maintains a **Florida “No Sales Solicitation Calls” List** for residential, mobile, or telephonic paging device telephone subscribers. Business numbers cannot be included in this list. Most commercial telemarketers are prohibited from calling anyone on this list. Also, callers must accurately identify themselves and their business name so that anyone receiving such a call will know who is calling. **Solicitors may still call under these circumstances:**

- In response to an express request of the person being called
- In connection with an existing debt or contract
- Any person with whom the solicitor has an existing or previous business relationship
- If it is a newspaper in connection with newspaper business
- If requesting a contribution or donation for a charitable organization
- On behalf of political candidates and political parties

The Florida list requires you to pay a fee. The list is updated quarterly, and your payment must be received at least two months prior to the beginning of the quarter. The fee for the first year is \$10.00, with a \$5.00 fee for renewal each year. Enrolling in the State program automatically enrolls you in the National program as well. The State list is legally very effective for callers based in Florida. For more information, call the Department of Agriculture and Consumer Services’ toll-free hotline, 1-800-HELP-FLA (1-800-435-7352), or visit their web site, www.800helpfla.com.

Instructions for applying and forms for filing complaints are included on the web site, as is other information for Florida consumers. After being added to the list, you are encouraged to report violators by getting as much information as possible about the caller before filing a complaint online or on a preprinted postcard sent to subscribers as part of the “No Sales Solicitation Calls” service. Complaints from consumers are helping Florida stop violators.

With crimes like identity theft growing at an alarming rate, it is important to reduce the opportunities to be a victim. See “Resolving Consumer Problems” in the *More Resources and Tips* section. This article also describes resources such as the Senior Victim Advocate Program of the Area Agency on Aging of Pasco-Pinellas, Inc. and legal assistance, two resources for victims of crimes.

More Resources

- **Pinellas County Department of Consumer Protection:** www.pinellascounty.org/consumer, telephone 727-464-6200. Database of consumer complaints against businesses, online complaint form, consumer tips and brochures.
- **Better Business Bureau (BBB) of West Florida:** www.bbbwestflorida.org, telephone 727-535-5522 (24 Hours) / Toll Free: 1-800-525-1447. Database of companies, online complaint form, help in resolving consumer problems, BBB locator.
- **Consumer:** www.consumer.gov. Federal information resource covers new products, food, money, health, transportation, home and community, etc.
- **Consumer Identity Theft:** www.consumer.gov/idtheft. Prevention and recovery, online complaint forms.
- **National Center for Victims of Crime:** www.ncvc.org. This site provides a toll-free helpline, a virtual library, and information about public policy, civil litigation, and related information for victims of crime.
- **National Fraud Information Center:** www.fraud.org. This is a source for information about telemarketing and Internet Fraud.
- **U. S. Department of Justice:** www.usdoj.gov. This site includes information on elder justice and victims of crime.

In addition, some local newspapers and television news departments offer **consumer investigators**, and sections of their web sites are dedicated to consumer issues. For a listing of these and other useful web sites, see the *Caregiver Web Sites* in this Handbook or online at www.agingcarefl.org/caregiver/Websites.

