



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 quite 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 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. If you have moved or you are retired to your comfortable home, 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.

Stage Three: Heavy Care

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

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

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

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

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

Stage Four: Letting Go

By now you and your care receiver may have experienced many losses. The shocking diagnosis was followed by loss of dreams for each of you. Then there was loss of companionship as you once knew it. Later you may have been saddened by your care receiver's loss of dignity as he or she needed assistance with the most personal of activities of daily living. The caregiver of a stroke survivor interviewed for an article called "Lives Out Of Sync" in the *St. Petersburg Times*, Sunday, August 11, 2002, summed it up in one sentence when describing how the stroke changed her husband: "He was a project leader who designed the hand controls on a space rocket who can't write his name, who can't say his name."

Now you are approaching your care receiver's last days, either in the home or in a nursing home or other facility. Even if you have found good caregiver support, it is hard to be prepared for the pain that comes with losing someone. The natural reaction to loss of any kind is grieving. A caregiver may grieve for years as the care receiver's illness progresses. Some caregivers grieve deeply after placing the care receiver in a nursing home. They may feel both relief at having fewer hands-on caregiving responsibilities and the loneliness of being in an empty house.

Although Stage Four caregiving involves sadness and grieving for both you and the care receiver, some of the most meaningful moments of your caregiving experience may occur during this time. Tasks for stage four caregiving include resolving relationships, making sure end-of-life decisions are complete, talking openly about death, asking for hospice care, and continuing to care for yourself. After the death, creating memorials to the deceased may give you comfort. Finally, as you reenter regular life, you may find that you have grown and changed, with dreams that you are ready to pursue.

You already know many strategies for coping with the challenges of caregiving. *Stages One, Two, and Three* were full of ideas, and you probably figured out many things on your own. *Stage Four: Letting Go* focuses on meaningful and positive experiences that can be yours and provides ideas for honoring your care receiver in the last months of life and after death.

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 providing care 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 and 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 the primary caregiver, it is important to keep your extended family informed about how things are changing 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. 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. 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 the 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 an older people receiving care in decision making if he or she is 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 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 own 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 recipient'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.

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. 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.

Helplines

The National Alzheimer's Association National Call Center is available for information and support twenty-four hours a day. Call 1-800-272-3900.

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. For Kansas City are caregiver support groups visit www.christiancaregiversupport.com. 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. A resource list of helpful web sites can be found at www.christiancaregiversupport.com. 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.

Caregiver Books and Videos

Take a moment to look through the *Caregiver Books and Videos*. *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. 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.

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.

Government-Funded Care/Case Management

You may feel that services will be needed, but you don't know where to start. Call The **Senior Helpline at 816-444-1122**. 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 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 your care recipient 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. This web site also provides a list of questions to ask when hiring a geriatric care manager.

- If you are a **long-distance caregiver** ask about care management by calling the national toll-free Eldercare Locator telephone number, 1-800-677-1116, refers callers to Elder Helplines throughout the United States. If you prefer, visit the Eldercare Locator website, www.eldercare.gov.
- The National Institute on Aging offers a helpful booklet for long-distance caregivers.: So Far Away:Twenty Questions for Long Distance Caregivers. In addition to information, it also provides websites and toll-free numbers for caregivers. You may access their website at www.nia.nih.gov or call them toll-free at 1-800-222-2225/ TTY 1-800-222-4225.

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, social security numbers for frail older person (and spouse, if appropriate for you to know that), 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. For more about how to ask for help, 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, for a **confidential report on possible benefits** eligibility based on income, assets, etc. Remember that this is just a guideline, and your care receiver may be eligible for other government-funded programs. A similar report plus 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. 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, 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.

The *Older Americans Report* (June 22, 2007) reports on a new online resource for caregivers. Shirley Board, www.shirleyboard.com, is free and provides an online journal, photo keeper, a place to keep prescription information and medical information, and to store important documents. It offers help with organization and is especially useful for caregivers who live a distance away.

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.

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 information on elder law attorneys, read [What Is an Elder Law Attorney?](#) and [Legal Considerations When Facing Incapacity](#). You can 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. 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.
- **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 internment 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 1-877-382-4357. This brochure can be found also on the FTC web site, 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.

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 recipient'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 each 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, and more 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). REGISTRATION FORM 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.
- The **National Weather Service web site**, 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.

Stage One, section 7: Driving Assessment

If your care receiver is still driving, it may be time to look at this issue 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

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

- **The American Stroke Association** has a fact sheet called "Let's Talk About Driving After Stroke" that is available online at: <http://www.strokeassociation.org/presenter.jhtml?identifier=3017279>. 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's toll-free number, 1-888-4STROKE (1-888-478-7653). 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 state vehicle registration site.
- 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 need to use other **transportation services**.
- **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, 1-800-677-1116, refers callers to elder helplines throughout the United States. The Eldercare Locator web site is found at www.eldercare.gov.
- The **AAA Foundation for Traffic Safety** created the Senior Drivers web site, found at 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, offers self tests and driving tips, transportation options after giving up driving, and a booklet called "Driving Safely While Aging Gracefully." Click on Order Publications or on Safety to view.
- **The National Accessible Travelers' Database** lists accessible providers by city for traveling with persons with physical and cognitive (mental) impairments. Find this database under Shortcuts on Easter Seal's Project Action web site, www.projectaction.easterseals.com. You may also call Project Action at toll-free 800-659-6428 or 202-347-7385 (TDD).

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 *ore 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. F

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. For Kansas City area support groups go to the events page at www.christiancaregiversupport.com
- **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 2, 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 have 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 kind 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 have something to offer caregivers who are at earlier stages of caregiving.

How to Find Support Groups

- **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.

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, coming 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, and 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. 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 resources for the same service**. 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 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 needs 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](#).

- **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.
- **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

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.

One VA program that is not well known is Aide and Attendance. Another is respite care for dementia patients. 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.

- 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 *Stage Three, section one* of this Handbook.

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

Stage Two, Section 6: Relief Through Self Expression

Start a personal journal and offer your care recipient a journal. Use a simple notebook or a book with blank or lined pages 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 recipient 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 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 recipient might enjoy art. There are journals with unlined pages, art sketch books 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.

The local recreation departments also offer a variety of 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 blue government pages of the telephone book. Ask whether there are any therapeutic programs for people who are challenged. Many recreation departments have their regular and therapeutic activities listed in brochures they can mail to you. They may also give you the address for their web site if they have one.

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 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.

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

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.

- **Better Business Bureau (BBB) of Greater Kansas City:** <http://kansascity.bbb.org/>, telephone (816) 421-7800 9:00 AM - 4:00 PM. 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.nvc.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 [How Do I Resolve Consumer Complaints](#) or [Caregiver Websites](#).

Stage Three, section 1: Preventing Caregiver Burnout

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

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

If you are so frustrated that you are afraid you will hurt your care receiver if you don't find help right away, see *Stage Three, section 2*. "Avoid Abuse" is near the end of that section.

Resources such as the telephone number of a twenty-four hour crisis and information line and a list of things you can do to cool down immediately are provided. Resources are also provided for suicide prevention, since caregivers and care receivers are among the people at risk of suicide.

If you are not in a crisis situation but want to avoid or relieve caregiver burnout, consider the suggestions below:

Emotional Support

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

Pain, www.stoppain.org. The "For Caregivers" section of the Stop Pain web site includes "Emotional Needs". Tips for coping follow checklists of feelings and physical symptoms that indicate anxiety, depression, guilt, etc. Find a "Fact Sheet on Caregiving and Depression" on the Family Caregiver Alliance web site, www.caregiver.org.

- Sharing your emotions can provide relief. Write out your anger in your journal as suggested in *Stage Two*. Reading and sharing caregiver stories may help you feel less isolated and alone. If you use the internet, ALZwell Caregiver Support, www.alzwell.com, is an example of a web site that gives caregivers a chance to share their stories and feelings. Look for chat rooms for caregivers on other sites. Many web sites offer tips for preventing caregiver stress and burnout.
- **Counseling.** Consider counseling to deal with the natural feelings that come with caregiving, especially heavy-duty caregiving for someone whose mental and physical health is deteriorating. Among these are anger, frustration, sadness, anxiety, and guilt. Some feelings are part of the grieving process you and your care receiver are experiencing.
- A counselor can help you see things clearly and set goals for maintaining your own life while caregiving. It's a good idea to talk with one while in the midst of caregiving. Unfortunately, many caregivers don't take time for counseling until their caregiving days are over.
- Counselors have a variety of educational backgrounds. They include psychiatrists, who are medical doctors and who can prescribe medications if you need them but who may refer you to a different type of counselor to "talk things over," psychotherapists, psychologists, licensed mental health counselors, licensed clinical social workers, clergy, and more.
- If you are a working caregiver, counseling may be provided as part of your health insurance package even if it is an HMO. Many health insurance providers use a subcontractor to provide counseling services, so you may not see a listing in your health insurance directory. Call your health insurance provider. Employee Assistance Programs (EAP's), for those companies that offer them, may also cover counseling.
- If you are age sixty or over yourself, you may qualify for counseling under the Older Americans Act, Title III-B. Counseling may be available to the person for whom you are caring, also, if needed. These services are usually available without a long wait. There is no charge for services, but donations are accepted.
- The National Family Caregiver Support Program provides counseling for eligible caregivers of any age. This is one of the new caregiver programs described in the *More Resources and Tips* section of this Handbook. Other government funding may cover the cost of counseling for active clients. For information on "Formal Support Services" see *Stage Two, Section 5*.

Respite Care

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

One type of respite care break is when relatives, friends, or volunteers from a faith community stay with the care receiver so that the caregiver can leave the home.

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

- **Adult day care.** Many people think going to an adult day care center will be the same as going into a nursing home, but adult day care programs actually help people remain independent longer. These programs are wonderful both for care receivers and their caregivers, who can get away from caregiving for a day at a time.
- Adult day care programs offer close supervision, lunch, snacks, and excellent activities suited to various levels of participation: lounging in recliners, playing board games, singing, or playing indoor balloon volleyball. For tips on "Dealing With Resistance", see *Stage Three, section 2*.
- Adult Day Care is available through government-funded programs and through agencies on a private pay basis. See *Stage Two, Section 5*. Even if your care receiver is on the waiting list for state-funded programs such as Community Care for the Elderly, you may be able to get a service such as adult day care started through Older Americans Act (OAA) funding. You may also combine OAA-funding with private-pay days. The National Family Caregiver Support Program provides respite, including day care. Some assisted living facilities offer a senior day program at a reasonable rate. Cost depends on how much assistance is needed. The hours are flexible up to twelve per day, and short notice is okay after client information is on file. Some Adult Day Care centers will provide transportation to and from the elder's home.
- **Home Health Care.** There are several reasons to ask for home health care (personal care) as part of respite. Besides the fact that you can leave the house when the home health aide is there, you will be relieved of some personal care such as bathing, toileting, and dressing. These tasks, hard both physically and emotionally, contribute greatly to caregiver burnout. For more about this, including ideas for special garments to protect your care receiver's dignity when being bathed by others, see *Stage Three, section 2*.

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

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

- **Buy respite videotapes.** These occupy a care receiver, including those with Alzheimer's, with something enjoyable while the caregiver takes a break.
- **Ageless Design's Alzheimer's Store**, www.alzstore.com sells sing-a-long to oldie's and memory tapes, beautiful scenes such as fish swimming in an aquarium, spiritual sing-a-long tapes, a videotape showing the four seasons while Handel's Water Music plays in the

background, and more. These can be relaxing and allow an opportunity for singing together and reminiscing. The Alzheimer's Store has other products you might find helpful - alarms, mini-fire extinguishers to attach above the stove, and Alzheimer's activity aprons just to name a few.

- **Innovative Caregiving Resources** sells a different type of respite videotapes. Call toll-free 1-800-249-5600 for a catalogue or use their web site, www.videorespite.com. Sharing Christmas Cheer, A Visit with Maria, and a Kibitz with David are three of the titles. The promotional video shows Alzheimer's patients enjoying their video visitors, speaking to them and singing along. Videos to facilitate exercise, relaxation, and cooperative activities are also for sale.
- **Do something nice for yourself.** No matter how much respite care you arrange from outside sources, also take a short respite break every day by doing something just for you. Use the list of favorite leisure activities requiring little time to enjoy that you made as a beginning caregiver or make a list now if you don't have one. Pick something and do it each day. Then write what you did for yourself in your journal. For days when you can't get away from home long enough to visit a museum or walk on the beach, do something simple at home. Use the checklist below as a daily reminder to choose at least one activity.
 - have a cup of tea or cocoa or a glass of sparkling water
 - read your favorite section of the newspaper
 - pet the dog or cat
 - work in one flower bed or garden patch
 - feed and watch birds or fish
 - read a magazine or one chapter of a book
 - enjoy a bubble bath or shower with music and candles
 - watch escapism movies or television programs
 - spend time in a private spot in the home or yard
 - call a friend
 - meditate for fifteen minutes.
 - use the Internet for fun and to plan outings.
 - One place to find free games and crossword puzzles online is AARP's web site, www.aarp.org/games.
-

Correct Diagnosis

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

Hands-On Caregiving Skills

Learn as much as you can about hands-on caregiving skills. This will increase your confidence while helping you avoid injury and exhaustion that lead to caregiver burnout. Also

help your care receiver to be as independent as possible, reducing your need to assist with heavy tasks. Here are some suggestions:

- **Learn hands-on skills from physical and occupational therapists.** Physical therapists help people recover their strength and range of motion. They also can help patients improve balance, relearn walking, and learn to transfer. PT's evaluate the need for assistive devices such as canes, walkers, wheelchairs, and transfer equipment. Occupational therapists focus on activities of daily living including personal hygiene, bathing, dressing, grooming, toileting, and feeding. The occupational therapist evaluates the need for special equipment such as transfer equipment, feeding devices, and hand and skin devices to help your elder be as independent as possible. Make sure your care receiver's doctor orders physical and occupational therapy if needed.
- **Learn hands-on skills from caregiving books.** A book that describes how to do hands-on caregiving including setting up your home to accommodate a wheelchair, making the home environment safe, preventing pressure sores, caring for someone who is in bed, helping a person get out of bed and into a wheelchair using a mechanical lift or a simple gait belt, and even how caregivers can use tax strategies to save money is The Comfort of Home, an illustrated step-by-step guide for caregivers, by Maria Meyer with Paula Derr, RN. See the *Caregiver Books and Videos* section for more information.
- **Learn hands-on skills from caregiving videotapes.** There are also a number of videotapes that deal with subjects such as protecting your back while lifting or while helping your care receiver to transfer. The Home Care Companion Resources for Caregivers Caregiving Series includes *How to Help Someone Who Uses A Wheelchair Without Hurting Yourself and Personal Care*. These and other instructional videotapes can be ordered from the Home Care Companion web site, www.homecarecompanion.com.
- Another video series that heavy-duty caregivers should find helpful is The Educated Caregiver Video Series, Volumes 1, 2, and 3, a reasonably priced set created by Life View Resources. Call toll free 1-800-395-5433 or visit their web site at www.lifeviewresources.com and click on the box with the picture of their videotapes. Volume 1 is *Coping Skills* such as getting support and being realistic about how much care you can provide; Volume 2 is *Hands-on-Skills* such as bathing, dressing, safety, and bed rest; and Volume 3 is *Essential Knowledge* including medication management, diet, and prevention of infection. You can see sample clips of each video online.
- Caregiver's Marketplace, www.caregiversmarketplace.com offers a free membership that provides discounts on purchases of these videos and many other products available from catalogues and other web sites. You will receive a Caregivers Market membership code to be used when ordering products.
- **Learn hands-on skills from web sites.**

Public Library Resources

Use materials from public libraries to improve your caregiving skills and to get away mentally from caregiving. Many libraries have caregiving books and videos, and more should be available in the future. There are popular and classic movie videos and some new movie DVD's you can check out for several days as well as informational videos you can check out for a week. Anyone with a library card can check out musical CD's and popular books recorded on audiotape. Inter-

library loan is a helpful feature. Materials can be sent over from other libraries within the local system or even borrowed from libraries outside the system. Your local librarian can help with this. **Many libraries offer public access catalog training sessions and basic Internet classes.**

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

Saving Time and Trouble

- **Mobile services.** Save time and the difficulty of getting your care receiver in and out of a vehicle and into stores and offices, where he or she may become confused and frustrated, by using mobile services that come to your home. The mobile medical van's services are covered by Medicare but not by HMO's.
- **Membership medical services.** This is an innovative medical practice concept that has been implemented in some areas. Patients of these physicians pay a membership fee. Membership benefits include easy access to physicians by phone and in person and the availability of home visits.
- **More efficient grocery shopping.** Shopping can be stressful for caregivers. Here are some suggestions to make the chore easier.
- **Here are ideas for making grocery shopping less of a hassle:**
- Ask your store whether they can give you a **printed floor plan** or list showing the aisles where various types of items can be found. If your store's customer service desk can't give you this, suggest the need to the store manager. If you can't get something like this from the store, consider making your own. This may help you and persons who shop for you.
- Ask for other **special help** your store may provide. This can be personal shopping assistance for blind or disabled persons, ride-on grocery carts for persons who have trouble walking, and someone to lift a fifty pound bag of dog food into your cart or help you reach a can on a high shelf. Chances are you will have plenty to load because of stocking up in case you can't get away for a big shopping trip the next week. Ask for help in loading the car.
- **Carry a cell or mobile phone** into the store after giving the number to your care receiver or substitute caregiver. That way you can check on things at home. Knowing that you can be reached in an emergency may give you peace of mind, and your care receiver may worry less. If you are concerned about courtesy to other shoppers, buy one of the new earphone/microphone combinations.
- **Use assistive devices.** Some shoppers bring a grabber tool to reach items on top shelves - this type of tool extends your reach and will hold up to five pounds. Find these in drug stores or order from television commercials, catalogs, or caregiver web sites. See the *Caregiver Web Sites* section.
- **Save time and prevent injury by using a cart** to bring in the groceries. At discount stores you can buy lightweight, inexpensive carts that unfold to look like plastic cubes or baskets with wheels and handles. A moment unfolding the cart can save several extra trips to the car. These carts are handy also when visiting fruit stands that do not have shopping carts with wheels.

- **Keep a grocery list** in a magnetic holder on the refrigerator or in another handy spot in the kitchen to add items as you run out of them. If you write down the specific products that you and your care receiver prefer (brand name or store brand, sugar-free or regular, low-fat or fat-free, gallon or half gallon, etc.), it makes it easier to have a relative, neighbor, or friend shop for you.
- If you need a hard-to-find or new item, **call the store** and ask whether they have it and what aisle it's on. Write the aisle number on your grocery list. Also use the telephone to place deli, meat, or bakery orders for quicker pick up in the store. Consider convenience items such as salad bars, shrimp steamed by the grocery store while you shop, pies and cakes from the bakery, and holiday dinners you can order. Although more expensive than homemade, these items may be worth it for the time saved.
- When you can't get away or are too exhausted to shop, review your list of people who offered help and **ask a neighbor, friend, relative, or volunteer from a faith community to shop for you.** If you feel guilty, remember that you stocked up when you went to the store yourself, which means that the list you give your volunteer shopper will be shorter. For more on how to ask for help, see *Stage Two, sections 1 and 2.*
- If you can afford it, you may want to use **businesses that run errands such as shopping for a fee.** Look up "Errands" in the Senior Resource Directory Subject Index or call the Senior Helpline. Besides errand services, there are homemaker services and transportation providers that also do grocery shopping.
- Most grocery stores do not deliver, but some small specialty markets do provide that service. Compare prices to see if the convenience is worth it, at least for weeks when you can't get away to shop. Private-pay home delivered meals, described below under Protecting Your Health ? Healthy Food, is another option.

Protecting Your Health

- **Preventive medical care.** Visit your doctor regularly. Having mammograms, prostate tests, colon cancer tests, and a pneumonia shot are important. Medicare and private insurance may cover costs. Make sure you put these tests for yourself on your calendar.
- If you and your doctor agree that you need to take medications because of stress, also consider adding some of the other types of support described here:
- **Exercise.** Attend exercise, yoga or Tai Chi classes at local community or fitness centers, exercise at home to a yoga or Tai Chi video tape, swim, dance, garden, lift small weights, walk around the block or on a treadmill, or use an in-home fitness company. Care managers sometimes suggest purchasing this service when Medicare stops covering physical therapy.
- For online exercise videos, visit the National Library of Medicine's Medlineplus, www.nlm.nih.gov/medlineplus/exerciseforseniors.html. An inexpensive exercise video can be found on the web site of The National Institute on Aging, www.nih.gov/nia.
- **Pet Therapy.** Spend time with a pet. Let your dog or cat provide you with comfort and laughs, enjoy a neighborhood walk with your dog, or watch the fish in the aquarium or goldfish pond. Just holding a furry pet is good for your health, and watching fish is relaxing.
- **Meditate.** Even a few moments spent in quiet thought can reduce stress.

Healthy food. Eating right is hard to do when you are so busy. Recommendations include the following:

- **Eat three well-balanced meals** a day, with breads and cereals, milk and cheese, fruits and vegetables, and lean meat, poultry, fish, and eggs. Canned or bottled nutritional drinks may be helpful when you have to skip a meal.
- **Choose healthy snacks** such as fruit, vegetables, yogurt, cereals, crackers, and low-fat cheese and popcorn. For ice cream cravings, there are many low fat and low calorie choices.
- **Limit high sugar and most high fat foods to small servings, but do not eliminate all fat from your diet.** Olive oil, flax seed oil, and the oil in nuts and fish such as salmon are considered healthy fats that should be eaten. Also, chocolate in moderation offers some health benefits, and it's a very comforting food enjoyed by people from childhood to one hundred years and older.
- **Don't self medicate with alcohol.**
- **Avoid food and medication interactions** by being informed. Ask your doctor and pharmacist about interactions. A web site that offers dietary precautions for each medication listed is the National Library of Medicine's MedlinePlus, www.nlm.nih.gov/medlineplus. See the *Caregiver Web Sites* section for others.
- For **nutrition tips** and names of dieticians by area, visit the American Dietetic Association web site, www.eatright.org or call the ADA Consumer Nutrition Hot Line at 1-800-366-1655. This organization provides nutrition tips and names of dieticians in the area where you live.
- If you need to learn how to cook for someone on a **special diet**, your doctor may be able to refer you to a dietician, often within the same medical facility. You may also want to visit the American Diabetes' Association web site, www.diabetes.org or call them toll-free at 1-800-DIABETES (1-800-342-2383). They will mail you materials related to planning meals for diabetic patients.
- If cooking for yourself and your care receiver is becoming increasingly more difficult, consider **home-delivered meals services**. Your care receiver may qualify for government-funded home-delivered meals. Some spouses may also qualify. Meals can also be purchased from both for-profit companies and from government-funded home-delivered meals. Some companies offer delivery of as few as ten frozen meals at a time to your door with choice of menus and special diets at a cost of around \$5.00 per complete meal or \$50.00 per delivery. Food preferences are very individual. You may have to try different companies and different menus to find products that suit your tastes.
- If you are the primary caregiver and your out-of-town relatives want to know what they can do, ask for a care package of home-delivered meals. See "Gifts for Caregivers" in the *More Resources and Tips* section.

Better Sleep

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

- **Exercise daily** but not too close to bedtime unless that is your only opportunity.

- Listen to **relaxation tapes** or do **relaxation exercises** while listening to relaxing **music** just before bedtime.
- **Avoid caffeine in the evenings.**
- **Change your sleep cycle to coordinate with your care receiver's sleep pattern.** In other words, if he or she sleeps during the day but wakes you up a lot at night, try to nap during the day yourself.
- **Get some outside help at night.** Hire a home health agency or recruit a friend or relative to stay over and care for your care receiver while you sleep.
- If confusion and fear of going to the bathroom alone are causing your care receiver to demand your assistance every time, **adapt the environment.** Items that may make the care receiver more comfortable include: grab bars, a raised toilet seat, a bell that the care receiver can ring if he or she has problems in the bathroom, night lights, a sign or picture on the bathroom door, and a tape path on the floor from bedroom to bathroom.
- The tape path idea came from a book called The Complete Guide to Alzheimer's Proofing Your Home by Mark L. Warner, available for purchase on the Ageless Design web site, www.agelessdesign.com. This book lists ways to deal with difficult behaviors by adapting the home. Product suggestions for each problem and information about who makes them are included.
- Find other strategies to help reduce nighttime wandering in "How To Deal With Wandering" in the *More Tips and Resources* section.
- Find out from the doctor whether anything can be done to **reduce the physical need for frequent bathroom breaks.** Changing medications, treating physical conditions such as diabetes, and changing the time that liquids are consumed may reduce the number of times that your care receiver wakes you for help.
- If your care receiver seems to be waking you because of a habit that could be changed, you may want to **try mild behavior modification.** Provide little rewards for letting you sleep more hours at a time or for using the bathroom alone. If you feel your care receiver does not have the capacity to learn new habits at this stage of illness, try the other strategies listed above.

Massage

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

Spiritual Support

Maintain your spiritual life. See *Stage Two, Section 2* for suggestions of support from faith communities. The *And Thou Shalt Honor* web site, www.thoushalthonor.org, was started in connection with the PBS (Public Broadcasting Service) special designed to raise awareness

concerning caregiving, with broadcast date of October 9, 2002. This web site has a section on spiritual caregiving.

Music

Music is good for you and for the person for whom you are caring. Music is called the universal language, connecting us with our inner feelings and with other humans in a way that words alone cannot. Music can be relaxing for you, and it can make working with your care receiver easier. Music is helpful for pain management. Stroke survivors who have lost some of their ability to articulate or use words (aphasia) may get their lost words back by singing. Persons with Alzheimer's disease may play instruments and create songs. Even people with late stage Alzheimer's disease may still respond to music. A person who fights having a shower may follow you to the bathroom if singing, making your life easier. Since music that is invigorating to one person can cause agitation in another, try wireless headphones or personal audiotape, CD or MP3 players with headphones if you and your care receiver like different types of music.

Reminiscing with music may trigger long-term memory. This can be enjoyable for the care receiver and the caregiver. As mentioned in the respite care section above, reminiscence/respite video tapes are available at the Alzheimer's Store, www.alzstore.com, and from Innovative Caregiving Resources, www.videorespite.com, or call toll-free 1-800-249-5600 for a catalogue.

Strategies That Protect Both Your Care Receiver and You

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

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

Help With Personal Care

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

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

Home Modifications

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

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

Help For Vision Loss

Seek help for vision loss, a problem that affects many older adults. One of the main causes of blindness in older persons is macular degeneration, which destroys central vision needed to do tasks such as driving and reading. See "What Is Low Vision?" in the *More Resources and Tips* section. Visit the National Eye Institute web site, www.nei.nih.gov and Lighthouse International's web site, www.lighthouse.org.

Help For Swallowing, Taste, Smell, and Eating Problems

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

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

Guarding Against Dehydration

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

Symptoms of dehydration include the following:

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

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

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

- cracked or shaved ice

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

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

Preserving Communication

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

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

Assistive Devices

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

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

Call ABLEDATA toll-free at 1-800-227-0216 for information about assistive devices and what companies manufacture them. ABLEDATA, www.abledata.com, is funded by the U.S. Department of Education.

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

Another web site with assistive device information is Network of Care, www.networkofcare.org. A resource library and assistive device section provide help for caregivers anywhere.

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

- Dynamic Living: www.dynamic-living.com (note hyphen)
- Elder Corner: www.eldercorner.com
- Alzheimer's Store: www.alzstore.com
- National Stroke Association: www.stroke.org

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

Help For Incontinence

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

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

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

ABLEDATA, 1-800-227-0216 or www.abledata.com, and many of the other web sites that have information about assistive devices, also include incontinence products such as adult undergarments. See *Caregiver Web Sites* in this Handbook. For discounts, visit Caregivers Marketplace at www.caregiversmarketplace.com.

Clients of the Medicaid Waiver programs or the National Family Caregiver Support Program

who cannot afford incontinence products may get help with these supplies. For more about government-funded programs, see *Stage Two, section 5*.

Managing Medications

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

The Home Care Companion Series video, How to Manage Medications, is very thorough. There are demonstrations of proper use of inhalers, eye drops, and medication dispensers with alarms. Order from www.homecarecompanion.com.

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

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

The Caregiver's Support Kit, available free to caregivers by calling the National Caregivers Foundation at 1-800-930-1357, recommends memorizing the six medication rights." Make sure that:

- the RIGHT PERSON
- receives the RIGHT MEDICATION
- in the RIGHT DOSE
- at the RIGHT TIME
- via the RIGHT METHOD/ROUTE
- followed by the RIGHT CHARTING METHODS

Stage Three, section 3: Facility Care

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

Risk Factors

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

Facility based care may also be appropriate when:

- You and your care receiver **planned in advance** to use facilities to provide needed care.
- He or she prefers going to an assisted living facility or nursing home rather than having you responsible for activities of daily living such as bathing and toileting.
- **You did not agree to be a hands-on heavy-duty caregiver**, at least not to the extent required now.
- You are an employed caregiver who cannot get a flexible schedule, the unpaid leave under the Family Medical Leave Act is not available to you or has already been used this year, and you **cannot afford to give up your job** in order to put in the hours of service required for heavy care. See [Stage Two, section 4: Help for Employed Caregivers](#).
- You are a **long-distance caregiver**, the services you set up with a care manager during your last visit are no longer adequate, and even a revised care plan cannot provide enough support services to keep your care receiver safely in the home.
- **Physicians and other professionals are recommending** an assisted living facility or nursing home.

- Caregiving in the home has become ineffective, your relationship with your care receiver is strained, and it seems likely that **placement in a facility might be positive for both of you.**
- Your care recipient needs ALF or nursing care and you are **financially** able to provide this because he or she has adequate private funds, qualifies for insurance, or meets the eligibility requirements for government funding to cover the costs of facility care.

Caregiver's Role

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

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

Considering a Move

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

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

It helps to **learn as much as possible about your long-term care choices and how to evaluate residential facilities.** Assisted Living Facilities and nursing homes in Florida are licensed by the Agency for Health Care Administration (AHCA). Always ask to see the AHCA inspection report when you visit a facility. Their web site is www.fdhc.state.fl.us.

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

Continuing Care Retirement Communities

Continuing Care Retirement Communities (CCRCs), also called **life-care facilities**, provide residents with shelter and health care in return for an entrance fee and periodic monthly fees.

Only properly licensed facilities may use the term "Continuing Care Retirement Community" or "life-care" in marketing efforts. CCRC's may appeal to those who can afford them because of having several levels of care ranging from independent living to nursing home on the same grounds. Residents who need nursing care just move to another part of the facility. There are several different payment plans. Some retirement communities that are not CCRC's offer several levels of care. Be sure to compare various communities before making a choice.

Adult Family Care Homes

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

Assisted Living Facilities

Assisted Living Facilities (ALF's) provide housing, meals, personal care services and supportive services to older persons and disabled persons unable to live independently. They are called Board and Care Homes in some states. Residents in ALF's cannot have conditions that require 24-hour nursing supervision unless receiving licensed hospice services. Some ALF's have specialty licenses to provide limited nursing services or mental health services, and some specialize in providing services to persons with Alzheimer's Disease. If you are looking for a facility to care for someone with Alzheimer's, there are special questions that you need to ask.

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

Assistive living facilities charge an average of \$3,500 per month, with prices ranging from below \$2,500 to more than \$4,000 per month. More than two-thirds of residents pay with their own or family funds. Other funding sources are the Medicaid Waiver program, Nursing Home Diversion program, and Long Term Care (LTC) insurance. **Nursing Home Diversion** is a new type of managed care program that can cover care for Medicaid-eligible persons in their home or in a facility. For more about Medicaid Waiver and Nursing Home Diversion, see *Stage Two, section 5*.

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

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

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

Nursing Homes

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

- **Skilled Nursing Facilities** provide nursing care on a 24-hour basis. Also included are therapy, diet supervision, activities, and medication management. An RN Supervisor is on-site and a physician is accessible. Medicare may pay for skilled nursing care in a facility if the patient meets the necessary criteria. Medicaid may pay for this type of care for persons who meet the income and asset eligibility. For more information about Medicare, call 1-800-Medicare (1-800-633-4227) or visit the Medicare web site, www.medicare.gov.
- **Intermediate Care Facilities** provide personal care and supervision of dressing, bathing, diet, and self-administered medications. This level of care may be covered by Medicaid for those who financially qualify, but Medicare only pays for skilled nursing and will not pay for what it calls "custodial care" or intermediate care. If a person is on Medicaid, it is illegal for the facility to request more money from the family.

Persons applying for Medicaid coverage of nursing home care must be assessed.

For up-to-date information about Medicaid income and asset limits and planning for Medicaid

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

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

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

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

Things to observe when visiting a nursing home include:

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

Among the questions you should ask when visiting are:

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

Information about how nursing homes compare anywhere in the country is available in print by calling 1-800-MEDICARE toll-free. It is also posted on Medicare's web site, www.medicare.gov. Select *Nursing Home Compare*.

The AARP organization has information to help consumers with long term care decisions. According to AARP, location is an important factor to consider when choosing a nursing home because nursing home residents who have regular visitors get better care. For brochures on choosing a nursing home and protecting a resident's rights, call AARP's toll-free line, 1-800-424-3410. The caregiving section of AARP's web site is found at www.aarp.org/caregiving.

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

Veterans may want to include a U. S. Veterans Administration (VA) nursing home as one of the choices they consider.

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

Coping with Placing Someone

If your care recipient moves to a nursing home, you will experience many emotions. **In Virginia Morris's book, *How to Care for Aging Parents*, there is a list of common reactions to having a parent in a nursing home.** These apply to placing a spouse or friend, also.

TEN COMMON REACTIONS TO HAVING A PARENT IN A NURSING HOME (from *How to Care for Aging Parents*):

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

Many people who go through the transition to nursing home with their care recipients continue with their support group and sometimes join another associated with the facility where their care recipient lives. Those who have been through it can provide information, support and encouragement to those facing the decision.

It can be very healing to talk with other support group members about the emotional pain you may experience because some relatives and friends will not visit your care recipient in the nursing home. Some people cannot stand to see the mental or physical deterioration, some fear their own aging and possible nursing home placement, some just don't know what to do around a person with debilitating mental or physical illness (although you can make it easier for them by giving them ideas), and some don't know the value of being with someone in the last days of life even if the person visited cannot communicate verbally.

Additional Resources

- Find a "Glossary of Long-Term Care Terms" on the Long-Term Care Living web site, www.longtermcareliving.com. Financial options and how to have a family conversation

about long-term care are discussed on this web site, also. Sponsors are The American Health Care Association and the National Center for Assisted Living.

- The *Introduction to the Caregiver Handbook* includes a "Glossary of Terms" and "Glossary of Acronyms", and these are also available online at www.agingcarefl.org/services.
- ***The Family Guide to Long-term Care*** is a series of six videos available from Lifeview Resources. Call toll-free 1-800-395-5433 or visit the website, www.lifeviewresources.com. Two of these are called *Making the Right Choice and Staying Involved*. View video clips online before purchasing. If you are a caregiver, you can buy these and other caregiving videos at a discount by using your free membership number from the Caregivers Marketplace web site, www.caregiversmarketplace.com.
- ***How to Care for Aging Parents***, by Virginia Morris, is a comprehensive guide to caregiving. This book has chapters called "Home Away From Home," "A Good Nursing Home," and "Paying The Way"?. For reviews of other caregiving books that may be helpful, see the *Caregiver Books and Videos* section.
- Also check the **public libraries**, as some locations are adding new caregiver books and videos to their collections.
- ***Residential Care: A Guide for Choosing a New Home*** is a National Alzheimer's Association publication to help families make choices about residential care for persons with Alzheimer's. For a free copy, call the national toll-free number, 1-800-272-3900, or select "Resource Center" followed by "Fact Sheets" on the Alzheimer's Association web site, www.alz.org.
- **American Association of Homes and Services for the Aging (AAHSA)** is a national organization made up of not-for-profit nursing homes, continuing care retirement communities, senior housing, assisted living facilities, etc. committed to affordable, healthy, and ethical long term care. Visit their web site, www.aahsa.org, for information about types of facilities ranging from government-funded senior housing to nursing homes, contact information for state affiliates, and a directory of members.

Stage Four, section 1: Resolving Relationships

Resolving relationships is one of the most important tasks for end-of-life caregiving.

Bonding affectionately with the care receiver can help make for a better grief experience following his or her death. It may be easier to bond if you tell each other what being related or being friends has meant over the years and share moments together when you are spouse, child, or friend again rather than caregiver.

Resolving anger and guilt helps a caregiver prepare for the eventual death of the care receiver. It is good to forgive your care receiver for past wrongs and for difficulties in your life caused by his or her illness. You also may need to forgive yourself if you feel you did not live up to your expectations or those of your care receiver, no matter how unrealistic. You may need to seek forgiveness from your care receiver for things he or she felt you did wrong. For example, if he or she opposed nursing home care and you had to make that decision for your mutual good. It is important to realize that both of you did the best you could.

If resentment and anger are keeping you from expressing affection toward your care receiver during his or her last months, it may help to talk with people in your support group and to a counselor. For more information about support groups, see *Stage Two, section 3*. For information about counseling resources, see *Stage Three, section 1*.

If your care receiver suffers from Alzheimer's or related dementia and no longer recognizes you, you may have worked on resolving your relationship before the disease progressed to this point. In your last days together, it may be worthwhile to share **simple activities in the present moment**. Music, a visit from a friend from the distant past, or looking at mementos from important times in your care receiver's life many decades ago may trigger long-term memories... or they may not. Even a person who cannot communicate may sense your presence, feel soothed by the sound of your voice, and enjoy your touch.

Just spending time with a person during the final days of life is a way to honor him or her. It is a gift of the spirit for the person receiving your companionship and may be one for you, also.

Stage Four, section 2: End-Of-Life-Decisions

Make sure plans are in place for end-of-life decisions.

- **Personal information**
- **Emergency contacts and informal support network**
- **Formal service providers and utility companies**
- **Insurance information**
- **Financial information**
- **Legal information**
- **Medical information**
- **Funeral arrangements**
- **Plans for care of pets**

To the information collected earlier, add **payment arrangements**. You will probably be the person who will notify providers of care that services are no longer needed. You may also be the person who pays final hospital bills, nursing home bills, bills for therapy or durable medical equipment, etc. after your care receiver is deceased. If you are not, you may need to supply information to that person, who may be executor of the estate.

Note: Following the death of your care receiver, you may want to review **the final Medicare Summary Notice (MSN)**. Take a few moments to look at this to make sure that procedures billed to Medicare were performed prior to your care receiver's death. If your care receiver had an HMO, there may not be a copy of the Medicare Summary Notice, but HMO's can furnish a breakdown of charges if requested. Caregivers have sometimes found that Medicare was being billed for months after the patient's death. Sometimes there is actual fraud or deliberate effort to cheat, but often it is accidental over-billing. The Area Agency on Aging has a **Medicare Patrol Project** dedicated to reducing errors, waste, and abuse in these programs.

Elder law attorneys (see below) can help with end-of-life decisions, advance directives, wills, trusts, and other legal documents. Please be aware that even if your care receiver has had legal documents in place for years, changes may be needed. For example, Florida has a new **Pet Trust** law that makes it legally enforceable to set up and fund pet care to take place after one's death.

Helpful Resources

- Select "End-of-Life Choices" on the Florida Department of Elder Affairs web site, www.state.fl.us/doea for Making Choices: Beginning To Plan for End-of-Life Care. This book discusses issues such as Do Not Resuscitate Orders, communicating end-of-life wishes to physicians, hospice care, and the advantages and disadvantages of various decisions regarding advance directives.
- **What Is An Elder Law Attorney?**
- **Legal Considerations When Facing Incapacity** is another article that can be found in the Alzheimer's Disease and Related Disorders.
- **The National Academy of Elder Law Attorneys (NAELA)** web site, www.naela.org, provides a listing of attorneys by area and has tips for choosing a good elder law attorney.

Stage Four, section 3: Hospice Care

As your care recipient nears the end of his or her life, consider the comprehensive care provided by hospice.

Medicare offers a hospice benefit that will cover almost all the costs of caring for a dying person during the last six months of life. To be eligible, your care receiver must have Medicare Part A, the doctor and medical director of the hospice must confirm a life expectancy of less than six months, and the person to receive services must agree that no more attempts to cure illness will be made. Call 1-800-MEDICARE (1-800-633-4227) or visit the **Medicare web site**, www.medicare.gov to get Medicare Hospice benefit information.

Having hospice care may mean that your care receiver can remain at home or in an assisted living facility if it coordinates with hospice rather than having to move to a nursing home. It will free you from some caregiving responsibilities, giving you more time to spend with your care receiver just enjoying each other's company. Hospice also provides support for you as a caregiver before, during, and after the death of your care receiver.

Here are two examples:

- **The National Hospice and Palliative Care Organization**, www.nhpco.org, offers consumer brochures called "Communicating Your End of Life Wishes" and "Medicare Hospice Benefits." View online, request a copy online, or call 1-800-658-8898. This site provides nationwide hospice information.

Note: The words "palliative care", when used in connection with hospice care and pain management, implies care meant for comfort rather than to cure a disease. Palliative care seeks to address not only physical pain but also emotional, social, and spiritual pain to achieve the best quality of life for patients and their families.

Stage Four, section 4: Common Concerns of the Dying

Being aware of needs that people who are dying should make it easier to help your care receiver meet these needs.

A study by the Veterans Affairs Medical Center in Durham, North Carolina, found that terminally ill patients and their families are concerned about the following:

- **Prevention of pain** is most important. Dying in pain is feared more than death. People need reassurance that pain management is available.
- Patients want to be **involved in decisions** regarding their treatment.
- Patients and their families want to know **what to expect** from the fatal condition and treatment.
- Dying persons and their families **search for meaning in their lives** and relationships at the end of life. Practicing one's faith, life review, and saying goodbye are important activities.
- People who are dying want to **contribute to the well-being of others**. They find peace in helping loved ones come to grips with their impending death in order to let them go. They also like to leave behind means to care for the needs of their survivors.
- Patients want to be **seen as a whole person, not a disease**.

Research from this study and others indicates that it is **helpful to talk openly about death and to give your care receiver a chance to talk about death**. If he or she gives you an opening such as, "When I'm gone" or, "I need to get my finances in order," take it. If you miss your chance and it doesn't come up again, ask a question such as, "Are you afraid of dying?" You can also talk about funeral plans and any advanced directives or other legal matters that have not been completed.

It is not helpful to argue with your care receiver that he or she can recover and is not going to die. Your care receiver will be more peaceful if you make it known that you have accepted his or her death and release him or her with love.

Stage Four, section 5: Grieving

The grieving process is something that both you and your care recipient will experience.

You will begin to grieve during your caregiving years and grieve again after your care receiver's death even if temporarily relieved after years of caregiving. Allow yourself to have this experience in order to heal.

Before Death

Based on the studies of Elizabeth Kubler-Ross, caregiver grief can be seen as having stages similar to those of other grief experiences. Not all caregivers go through every stage, and some may have grief reactions a number of times during the course of caregiving, as there are losses all along the way. **Here are the five stages of caregiver grief:**

- **Denial:** not believing the diagnosis, pretending everything will be fine.
- **Anger:** which may be directed anywhere, at the care receiver, other family members, physicians, God.
- **Bargaining:** searching for new therapies, going to medical specialists.
- **Depression:** illness and death of patient is understood as inevitable, and the caregiver may experience physical illness, despair, and social isolation.
- **Acceptance:** living each day as well as possible, knowing that the death of the loved one is imminent.

When your care receiver is facing death, he or she will also go through stages of grief. Here are things you can do to make this process easier and the last months of life more meaningful and enjoyable:

- Provide materials for expression through art.
- Provide a journal or tape recorder.
- Offer some of his or her favorite things. For example, if your care receiver loved bird watching but is now confined to the house, try to place his bed or chair near a window with a view of birds.
- If applicable, make use of the comprehensive care and support offered by hospice.
- Provide a "life review book". This is a big scrapbook with a person's life story including photographs and memorabilia if desired. Family, friends, or Hospice volunteers may have time to help with this project. Ask visitors who are willing to add comments and memories. Some people prefer to have visitors put their comments in a journal or notebook that is kept in the room.
- Let your care receiver know how proud you are of his or her accomplishments as well as how much you will miss him or her. People who feel they lived successfully may die more peacefully.
- If you made the reminiscence videotape suggested in *Stage One, section 2*, you and your care receiver might want to look at it together. If you didn't make one, you may want to

make it now. If you are unable to make a videotape, try an audiotape. The sound of your care receiver's voice after he or she is gone can be a treasure.

- Request visits from clergy for spiritual guidance and sometimes for reconciliation.
- Call other relatives and friends to give them a chance to visit, make peace if needed, and say goodbye. Realize that some will not come. Unfortunately, fear robs some people of the privilege of spending time with a dying friend or relative. Some people may not come because of prior conflicts, even though reconciliation makes for an easier grieving process after the person is gone. For more about the value of visiting persons who are close to death, see *Stage Four, section 1*.
- A dying person who is unable to communicate may still be able to sense on another level that he or she is being honored for the gifts his or her life provided to the world. Even if your care receiver suffers from dementia, it will mean a lot to the survivors to read comments, funny stories, and expressions of gratitude from people who knew your care receiver at various times of his or her life.
- If your care recipient has Alzheimer's or other cognitive impairment, give him or her a chance to grieve, also. Smells, touches, and music may be helpful in reaching a person with dementia to allow for grieving.

After Death

After the death of your care receiver, you will grieve again even if you first feel relief that the struggle is over. Having support for your grieving is helpful, especially from others who have experienced a similar loss of a parent or spouse. If this death represents the loss of your only living parent, you may feel like an adult orphan. When you realize that you are no longer anyone's child, that you are on your own without a safety net, you may feel adrift without a rudder. This can lead to new growth and greater independence, but at first it feels like an empty hole.

Spouses who are widowed sometimes become preoccupied with the deceased spouse, thinking about them constantly and having dreams or nightmares about them. It is normal for people who are grieving to think they see or hear their deceased loved one.

People who are bereaved may lose weight, have trouble sleeping, become irritable or listless, and feel short of breath. It is important to go through the process of grieving and "feel the pain" rather than numbing it with alcohol or medications.

Even a ninety-year-old survivor needs to grieve the loss of a loved one. According to "Ideas from Loss in Later Life," a teleconference sponsored by the Hospice Foundation of America April 24, 2002, society discounts losses that old people experience because death of relatives and friends is expected at that age. A comment such as, "Your spouse lived a good life and is at peace" does not acknowledge the survivor's pain. The loss is still tragic to the elderly widow or widower. It still needs to be grieved, and the survivor needs the support of family and friends. Visit Hospice Foundation of America's web site, www.hospicefoundation.org.

Participating in rituals related to death is beneficial. Nursing homes used to hide death, drawing the drapes and taking out bodies while the residents were at dinner. This is changing now as the importance of acknowledging the death is realized. Some nursing homes work with funeral homes to have afternoon viewings, with transportation provided for residents. Many offer monthly memorial services at the nursing home.

Some nursing homes offer special ceremonies. A June 9, 2002 *St. Petersburg Times* Special Report called "Alone Together - A Year in the Life of an Alzheimer's Support Group" described a service offered by Bon Secours Maria Manor in St. Petersburg, Florida. "When staffers think a resident will die within three days, they begin a ceremony they call 'Angels Passing By.' Aides stay in the room round the clock. They bring a CD player for soft music, an angel pin for the pillow, lotions for rubbing, and a journal so people can write messages." Other nursing homes may be trying equally innovative approaches to honoring the dying person and comforting the grieving.

Helpful Resources

- [How To Care for Aging Parents-A Complete Guide](#) by Virginia Morris devotes forty pages to end-of-life, death, and grieving. The dying process is described.
- The **AARP web site**, www.aarp.org, includes a *Grief and Loss* section with information for spouses, adult children, men who are grieving, employers of persons who are grieving, and others. The *End of Life* section of the web site includes a "Final Details Planner".
- **Network of Care:** www.networkofcare.org. Created by the California Department of Aging, this web site may help caregivers anywhere. The "Library" includes *End-of-Life Care*. "Checklist After a Death" is one of the articles.

Stage Four, section 6: Caring for the Stage Four Caregiver

You must take time to care for yourself during your care receiver's last days and after his or her death. Here are suggestions:

- **Remain in your support group** after your care receiver's death. Besides receiving on-going support from people who know you well, you have your experience as a caregiver to share with newcomers.
- **Continue writing in your journal** during your care receiver's last months and following his or her death. Sometimes people like to write letters to the deceased person in their journals. Your journal will be a source of solace for you later. Tape recording your thoughts is also an option.
- **Continue relaxation and spiritual practices** such as prayer, meditation, yoga, art, feeding the birds, listening to music, and getting a massage.
- **Lighten your schedule** to allow quiet times to be alone with your grief.
- **Take advantage of community bereavement programs.** This may be a short-term group that meets a limited number of times or it may be on-going.
- Local Funeral Homes offer **grief support programs** that assist survivors in adjusting to the loss of a loved one. These programs are available to anyone in the community.
- **Consider grief counseling** if you are overcome with grief that interferes with daily living for a long time. Ask about bereavement counseling for people any age and Older Americans Act (OAA) counseling of any type for seniors. Free OAA counseling services are available to persons sixty or over. (See *Stage Three, Section 1*, page 57). Check with your health insurance provider about available counseling.

Stage Four, section 7: Memorials to the Deceased

Many people find it helpful to create their own grieving rituals and memorials to the deceased person. Here are suggestions:

- **Read through the life review book, look at the reminiscence videotape or listen to the audiotape, and read notes** that friends and family wrote in the journal or notebook you or the nursing home provided visitors during your care receiver's last days. If you don't have any of these things, read sweet notes that people sometimes include in their sympathy cards and letters.
- **Look at old slides, home movies, and photo albums.** If photos are not in an album, arrange them and make one now. If you wish, take one of those classes on how to make scrapbook-like photo albums with written comments and acid-free paper.
- **Start a scholarship or contribute to a charity in his or her honor.**
- **Participate in a fundraiser or become a volunteer** for an organization that provided support to your family during your caregiving days.
- **Create an indoor or backyard memorial.** Make a **memory box** or have family members make special **memory ornaments** for the tree.
- **Plant a tree, a rose garden, or other living reminder** of the deceased.
- **Make a quilt, collage, or teddy bear from some of his or her clothes.**
- **Spend private time reading or praying in a peaceful location that helps you feel connected to the deceased.** This might be a bedroom he or she used, the car he or she drove, or a beautiful spot in nature, perhaps near the bird feeders, fish pond, or garden you used to look at together.
- **Host a celebration in a favorite restaurant on the anniversary of his or her birth or death.** Invite relatives and friends. Share things such as the photo album, life review book, and notebook in which friends and family wrote their stories and appreciation.
- **If you took over responsibility for your care receiver's pet, treat the pet with tenderness.** Try to recreate some of the activities your care receiver and pet used to do together. These might include going for walks, watching television together, and having snacks.
- **Provide memorial flowers at place of worship and your care receiver's place of worship.** Buy your care receiver's favorite flowers for your home.
- **Pass on traditions** such as cooking special holiday foods to other members of the family.
- **Visit your care receiver's favorite places,** locally or places you have traveled.
- **Give important possessions of the deceased a place on honor** in your home or in current family traditions.
- **Write stories or poetry about the deceased.** Share stories about the deceased with the next generation.
- **Share the old home movies, slides, and videos that show the deceased during his or her life.** Old movies and slides can be professionally transferred to newer formats such as videotape or DVDs. Pass these on to the next generation rather than letting them be sold in estate sale boxes or thrown away because the equipment to show them is not made anymore.

Stage Four, section 8: Reconnecting

At some point, you may sense that even though you still miss and grieve for the person who is deceased, you are ready to reconnect with the world outside. Here are some suggestions for making the most of the period following caregiving and bereavement:

- **Offer support to other caregivers.** Stay in your support group for as long as you are comfortable, both for yourself and for what you can offer to caregivers who are at earlier stages of caregiving. If you want to use skills and understanding gained while caregiving, become a volunteer caregiver. (Before volunteering, give yourself time to grieve and to focus on yourself and your immediate family.) You might like the caregiving ministry started by your place of worship,
- **Reconnect with friends and place of worship.** Now you have time to take classes at your place of worship or to sing in the choir, or you can just enjoy services without making additional commitments.
- **Take classes at your local college, senior center, or recreation center.** A list of "Senior Centers" is included in *More Resources and Tips*. If you are a Florida resident age sixty or over, you may take certain undergraduate or graduate college classes on a non-credit, space available basis without exams, grades, or tuition fees.
- **If you are a surviving spouse, try to give yourself a year or more before making major decisions** regarding the house, investments, etc. If you do decide to sell your home and liquidate many possessions, consider having the antiques appraised to help you price them, or sell them through an auction house. Another choice is to hire a professional estate seller. This can be advantageous even though you have to pay a percentage of what is earned on the sale. A good professional estate seller has an established clientele who go from sale to sale. Also, if the sale is at a home that is for sale, networking with real estate professionals may occur. Check out your estate seller. Get references and a written contract that lists services provided.
- Before hiring professionals such as an estate seller, home improvement company, and realtor to help with this process, read "Resolving Consumer Problems" in the *More Resources and Tips* section. You will have fewer consumer problems to resolve if you check out the companies in advance.
- **Try to release the caregiver role, at least for a few years.** If you are an adult child who was caring for an aging parent, give your spouse and children more of your time now. Plan things you can do together for family fun. Sometimes when one of two elderly parents dies, the adult child who did much of the caregiving has a tendency to over-care for the surviving spouse. After that spouse recovers from grief, he or she may be capable of independence at a greater level than before the death of the spouse. Your parent needs your love and support, but too much dependence on you because you are used to being a caregiver should not be encouraged.
- **Consider your current work situation and whether it is right for you.** This may mean returning to school for more training, returning to work full-time, continuing part-time work, or remaining out of work long enough to take a trip or fulfill some other dream that might have to be put on hold once you return to work full-time. If you continued full-time work throughout your years of caregiving, you may want to talk with your family

members about planning something special together - perhaps a vacation. Some caregivers have been influenced by the caregiving experience to train for a career they had not imagined for themselves before - nursing, for example.

- **Continue any positive activities that helped you care for yourself while you were a caregiver.** These might include exercise, yoga, massages, meditation, prayer, eating right, art, writing in a journal, volunteering, gardening, using the Internet, and using the library system. If you were not able to do these activities as a caregiver, you may enjoy them now. You deserve to take care of yourself.
- **Enjoy the activities you may not have been able to do while caregiving.** Visit your out-of-state relatives, go to religious or civic club conventions, attend concerts on the beach, go boating, ride your bike, play golf, play bridge, dance, go on picnics, pursue a hobby.
- **Get involved in advocacy, awareness, and training efforts** by organizations trying to improve the lives of caregivers or of people with the disease that led to your loved one's death.
- National advocacy groups are always looking for interested members. One example is www.lastacts.org. Last Acts is a coalition of people dedicated to improving end-of-life care. "Toll-free Information Lines" in the *More Resources and Tips* section lists organizations dedicated to helping families affected by various diseases .
- **Give yourself credit for the wonderful job you did as caregiver** and for making sure that your care receiver's last days were filled with as much dignity and meaning as possible. You did your best and you deserve love and praise.
- **Review your life so far** with its high and low points, accomplishments and disappointments, joys and sorrows. Looking back, you may see that some things that seemed the most difficult, perhaps the low points at the time, may have changed the course of your life for the better. Look at your caregiving experience and see that **through your devotion and the things you had to learn and do, you are more confident and more compassionate now.**
- **Make plans for your future.** Are there dreams you have had your whole life that have never been fulfilled? Do you have new dreams and goals that surfaced during your caregiving years? It is not too late to start. You can begin by gathering information about what is needed to accomplish your dream. Once you set a goal, take steps to achieve it.