

The Four Stages of Caregiving

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, considering hospice care, and continuing to care for yourself. After the death, creating memorials to the deceased may give you comfort. Finally, as you re-enter 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.

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

Stage 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, he or she may have 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 photographs and 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 of Pasco-Pinellas, Inc. has a **Medicare and Medicaid Patrol Project** dedicated to reducing errors, waste, and abuse in these programs. If you find errors that are not corrected upon your request, please report these. Call 866-357-6677 and ask for the SMP Project.

Elder law attorneys see **Stage 1, section 5** 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.

- **Project Grace**, an organization that serves Pinellas and Pasco County, offers public education on the subject of advance directives. Visit the Project Grace web site, www.p-grace.org. This web site includes online forms.
- **What Is An Elder Law Attorney?** This article can be found in the Aging Topics section of the Area Agency on Aging of Pasco-Pinellas web site, www.agingcarefl.org/aging/legal, and as one of three legal questions in The HELP Pages at the back of the *Senior Resource Directory*, available free to Pasco and Pinellas County seniors by calling the **Senior Helpline** at 800-96-ELDER (800-963-5337 or 727-217-8111 from outside of the area).
- **Legal Considerations When Facing Incapacity** is another article that can be found in the Alzheimer's Disease and Related Disorders section (purple-edged pages) of the *Senior Resource Directory* and in the Alzheimer's section of the Area Agency on Aging web site, www.agingcarefl.org/caregiver/alzheimers/legal.
- **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.
- A number of elder law attorneys in Florida's Pasco and Pinellas Counties are listed with the Senior Helpline of the Area Agency on Aging of Pasco-Pinellas, Inc. Look up "Legal Counseling/Representation" in the printed *Senior Resource Directory* or call the **Senior Helpline** at 800-96-ELDER (800-963-5337) or 727-217-8111 from outside of the area.
- Call the **Florida Bar Association** toll-free at 800-343-8060 for a listing of elder law attorneys for any county in Florida.
- Many caregiver web sites have articles that may help with end-of-life planning. See **Caregiver Web Sites** in this *Caregiver Handbook* or online at www.agingcarefl.org/caregiver/Websites.

Stage Four, section 3: Hospice Care

As your care receiver 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 800-MEDICARE (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.

In Pasco County there are two Hospice providers. Gulfside Regional Hospice has a website at www.gulfsideregionalhospice.org. Hernando-Pasco Hospice also serves Pasco County. Visit their website at www.hphospice.org. In Pinellas County, Florida, the Suncoast Hospice provides these services in homes, nursing homes, hospitals, and home-like Hospice facilities. They also have a program called Bridges Community Bereavement Services, available to grieving persons in the community whether or not their deceased was a Hospice patient. These grief support groups are offered at various locations throughout Pinellas County. For more information about these services, call Suncoast Hospice at 727-586-4432 or visit their web site, www.thehospice.org. This web site has links to more than a dozen related web sites. 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.
- **Menorah Manor's web site**, www.menorahmanor.org, describes the **Toby Weinman** Jewish Hospice Program. Menorah Manor and Suncoast Hospice are working together to provide hospice and palliative care in a context of Jewish beliefs and cultural practices. The program is available in Menorah Manor and also in the community.
- **The Veterans Affairs (VA)** can also provide palliative and hospice care for veterans. This program is available to all honorably discharged veterans, that are enrolled in the VA system. For more information go to the VA website at www.va.gov.

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.

For more information about bereavement support groups and counseling, see **Stage 4, section 6**.

Stage Four, section 4: Common Concerns Of The Dying

Being aware of the needs of 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, insisting 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 released him or her with love.

Stage Four, section 5: Grieving

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

You will begin to grieve during your caregiving years and grieve again after your care receiver's death, even if you are 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 receiver 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 Suncoast Hospice Web Site**, www.thehospice.org, offers articles about end-of-life personal care, the dying process, and grieving as part of **Practical Caregiver Tips**.
- 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.

In Pinellas County, Florida, **Bridges Community Bereavement Support** is offered by Suncoast Hospice to anyone who is grieving. It is not limited to those whose care receivers used Hospice. Call 727-586-4432 or visit their web site, www.thehospice.org.

Local Funeral Homes such as Moss Feaster and Anderson-McQueen 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.

In Pinellas County, Florida, resources for bereavement support, even support groups for people who have lost pets, may be included in the 211 database.. **Call 211.** The 211 information line is also a crisis counseling line available twenty-four hours a day.

Consider grief counseling if you are overcome with grief that interferes with daily living for a long time. Call the Senior Helpline at 800-96-ELDER (800-963-5337) or 727-217-8111 from outside of the area and 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**). 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 memorials and rituals for remembering and honoring 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, fishpond, 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 your 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, or you might prefer a community organization such as Faith in Action of Upper Pinellas, Hospice, Gulfcoast Community Care, or the local Alzheimer's Association. For contact information call the Senior Helpline at 800-96-ELDER (800-963-5337) or 727-217-8111 from outside of the area.
- **Reconnect with friends and your 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.

Pinellas County colleges are listed in the 211 Tampa Bay Cares database. Call 211 or visit www.211tampabay.info. Many also have web sites. For example, St. Petersburg College's web site can be found at www.spjc.edu. This site includes information about regular and online courses and a career development center.

- **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. This article provides telephone numbers and web sites for resources such as the Pinellas County Department of Consumer Protection, the Better Business Bureau, and the Florida Department of Agriculture’s Consumer Division.

- **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 caregiver 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 care receiver’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, and many of their web sites are listed in the **Caregiver Web**

Sites section and online at www.agingcarefl.org/caregiver/websites.

- **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 too achieve it.