Caregiver Books and Videos

These are just a few of the many excellent books and videos now available, and more on the subject of caregiving are appearing each year. Many of the books and videos listed below can be found in the Pinellas County Library System, and others are available for purchase either online or in local stores. On-line booksellers such as www.amazon.com allow you to search by the name of the book and then read the on-line reviews. Some books and videos are also available from caregiver web sites. Search for books, videos, or magazines on the internet can be achieved by using any of the many search engines, such as “Google”, or “Bing”. Many of these books and videos would make nice gifts for caregivers. See “Gifts for Caregivers” in the More Resources and Tips section of this handbook.

Books

1. **The Caregiver’s Support Kit** is available to caregivers at no charge from the National Caregivers Foundation by calling 800-930-1357. This book focuses on Alzheimer’s but has good information for any caregiver. It comes with several extra goodies such as an audiotape of music and a medication minder pillbox.

2. **How to Care for Aging Parents (A Complete Guide)** by Virginia Morris and Robert Butler, Workman Publishing, New York, c. 1996, is a comprehensive resource guide with special tips in boxes, information on topics from “getting set” (preparing for caregiving) to “in the end.” This book even explains what to expect when you are in the room with someone who is dying, and the section on grieving is good.

3. **The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers** by Maria M. Meyer with Paula Derr, RN, Care Trust Publications, Portland, Oregon, c.1998, won 1999 Benjamin Franklin award in health category – useful and practical, with big print and drawings of caregiving situations and aids (how to arrange furniture to accommodate a wheelchair, how to transfer from bed to wheelchair with and without a transfer belt). Besides giving hands-on care instructions, this book has information such as tax strategies for caregivers.

4. **When Aging Parents Can’t Live Alone** by Allen F. Rubenson, M.S.W., published by Lowell House, Lincolnwood, Illinois, c. 2000 – goes from independent living to hospice, has nice stories about elders and caregivers, explains terms like “activities of daily living (ADL’s)” used in determining eligibility for many programs, has helpful questions to ask to determine whether an elder should move in with adult child, and has a big resource list at end.

caregivers, and describes rewards of caregiving as well as reasons some people should not become hands-on caregivers.

6. **The Complete Idiot’s Guide to Caring for Aging Parents** by Linda Colvin Rhodes, Ed.D., published by Alpha Books, a Pearson Education Company, Indianapolis, IN, c. 2001. If you can get past the title, this book has simple, up-to-date information and wonderful tips in little boxes called, “senior alert,” “geri-fact,” “sage source,” and “silver lining.” There is a good explanation on how to hold a family meeting to discuss sharing the caregiving responsibilities.

7. **The Fearless Caregiver: How to Get the Best Care for Your Loved One and Still Have a Life of Your Own** by Gary Barg, Editor, c. 2001, published by Capital Books Inc., Herndon, Virginia. This book has information from experts, is readable, has celebrity caregiver interviews, poetry, etc. It’s for all caregivers, not just children of aging parents. It is a collection of writing by various writers, many of them caregivers, so it is not a comprehensive information book. It is enjoyable and comforting. This book, edited by the editor of Today’s Caregiver Magazine, is available from booksellers or visit the Today’s Caregiver Magazine website, [www.caregiver.com](http://www.caregiver.com).

8. **The Complete Guide to Alzheimer’s Proof Your Home** by Mark L. Warner, c. 2,000 by Ageless Design ([www.agelessdesign.com](http://www.agelessdesign.com)), Purdue University Press, West Lafayette, Indiana. This book is packed with information, diagrams, and black and white photographs. Each chapter lists resources in the wide margins, and there is a huge listing in the back with addresses, toll-free and regular numbers, and the types of products sold. All types of problems – behavioral, activities of daily living, thinking-related issues, incontinence, mobility, and more are explained and helpful ideas are given. The book shows unusual products like a platform lift where there isn’t room for a ramp and simple ideas such as a brightly colored electrical tape path on the floor from bedroom to bathroom. Some ideas and products look useful for other conditions.

9. **Helping Yourself Help Others** by Rosalynn Carter with Susan K. Golant, c. 1994 by Times Books, a division of Random House, New York. This book is a little older than some, written after surveying the needs of caregivers in the area near the Rosalynn Carter Institute of Georgia Southwestern College. This was one of the first books to talk about the “crisis in caregiving in America,” but it is written in a very warm and personal style beginning with stories about Former First Lady Carter’s mother, who was a lifelong caregiver. The book includes other interesting stories, and the recommendations for what America needs to do to improve the lives of caregivers still hold true today.

10. **Living With Stroke: A Guide for Families** by Richard C. Senellick, M.D., Peter W. Rossi, M.D., and Karla Dougherty, Health South Press, Birmingham, Alabama, c. 1999. This book is used by Health South in working with stroke survivors and their families. It explains what happens with strokes in different parts of the brain, rehabilitation of many types, emotional issues faced by stroke survivors and their families, issues such as sex after a stroke, a stroke stress analysis, and goal setting.

Press, Washington, D.C., c. 2000. This book covers stroke prevention, physical recovery, quality of life issues such as sex and phobias, and technology. It has a nice section called, “Consumers speak out.”


13. **Failure-free Activities for the Alzheimer’s Patient** by Carmel Sheridan, Dell Books, c. 1995. This book offers simple activities which are enjoyable for both caregiver and care receiver.

14. **Caregiving A Step-By-Step Resource for Caring for the Person with Cancer at Home** by Peters S. Housts, Ph.D., and Julia A. Bucher, RN, Ph.D., c. 2000 by the American Cancer Society. This covers topics such as understanding caregiving, getting information from medical staff, emotional issues, making a plan, and when to get professional help. The pain management section is very helpful.

15. **Caregiving: The Spiritual Journey of Love, Loss, and Renewal** by Beth Witrogen Mccloud, New York, John Wiley and Sons, 1999, New York. This book talks about the caregiver’s spiritual and emotional journey, the opening of the compassionate heart and the urge to care, as well as more practical matters. It has interesting caregiver stories and advice for spousal caregivers and children of aging parents. It is a comforting book, and it helps a caregiver see the meaning and value of providing care to another human being. Chapter 8 and 9 address how to get through depression and the low points without committing suicide. Helpful action steps are provided.


17. **The Circle** by Sally Smith. A personal account of the emotional and human side of dealing with dementia. The author has donated the proceeds of sales as a gift to the Medical University of South Carolina to raise awareness and support for research into Alzheimer's disease, Parkinson's disease, dementia, vision and hearing loss and other age-related problems. See a review at [www.musc.edu/pr/circle.htm](http://www.musc.edu/pr/circle.htm). To obtain a copy of The Circle directly, or for other information, contact the Center on Again at [www.musc.edu/aging](http://www.musc.edu/aging) or by calling 843-792-0712.

**Videos**

1. **A Prescription for Caregivers**, produced by Wendy Lustbader, who was also the speaker. Filmed in front of a live audience of caregivers, this presentation is packed with humor and stories from real life. Topics include: heeding resentment as a warning sign of doing too much, varieties of guilt, options for self-care, and figuring out how much care is enough. Available for $30.00 normally or $20.00 for readers of the
National Caregiving Foundation Caregiver’s Support Kit (Caregivers may call 800-930-1357 for free copy of Caregiver’s Support Kit). Add $3.00 for shipping and handling for A Prescription for Caregivers and mail to Wendy Lustbader, 1917 25th Ave. East, Seattle, WA 98112, telephone: 425-462-5722 (not a toll-free call). We thought this presenter gave good advice, but the live workshop style may not be for everyone.

2. Educated Caregiver Video Series, Volumes 1, 2, and 3, created by Life View Resources, 800-395-5433 or www.lifeviewresources.com. Volume 1 is Coping Skills (getting support, being realistic, etc.), Volume 2 is Hands on Skills (bathing, dressing, safety, bedrest), Volume 3 is Essential Knowledge (medications, diet, prevention of infection, etc.). On the web site, click on the photo to go to a screen where you can preview video clips of these. This series is very reasonably priced and has won awards. You may also see these for sale on other web sites for caregivers, but this is the site of the company who developed them.

3. The Family Guide to Long Term Care Video Series, created by Life View Resources (see Educated Caregiver Series above). This set deals with making decisions regarding long term care, choosing an institution, and staying involved. Video previews are available on the web site. The videotapes can be purchased individually or as a series.


5. Video Respite Series by Innovative Caregiving Resources, 800-249-5600 or www.videorespite.com. These tapes entertain Alzheimer’s patients at home or in group settings so that caregivers can get a break. We saw clips of them being shown to Alzheimer’s patients, who were talking to the “visitor,” singing, and clapping. These tapes appear to effectively occupy the Alzheimer’s clients. Some of the titles are A Visit with Maria, a Kibitz with David, Remembering When, and Sharing Christmas Cheer. The tapes may be purchased individually, and this company has also created tapes to help caregivers facilitate exercise, relaxation, and cooperation. **Note:** This web site was off the Internet for construction when this book went to press, but it is supposed to be restored.

6. Video Respite Series, available at the Alzheimer’s Store, found at www.alzstore.com. These video respite tapes include a fish tank scene, nature scenes with Handel’s Water Music, sing-a-longs to the oldies, trips down memory lane to a zoo or a country store, etc. They should be enjoyable for caregivers as well as care receivers. These tapes may be purchased individually and may be available on other web sites.
Caregiver Web Sites

Many web sites offer information and support for family caregivers. Web sites are listed below in alphabetical order under the categories of National, Florida, and Local Pinellas County sites.

We have listed each site by organization or web site name. This is followed by the web address with a link to the site and a short review of what the site offers. Please note that a change of one or more letters, using a different ending (.com or .org), or the addition of a hyphen may take you to a different site. Besides using this list, you may want to try a general search using the word “caregiver,” the name of a disease, or a topic of your choice on any major search engine such as Google.com.

Web site navigation varies, and some sites offer instructions. Some sites are available in several languages, and some offer big print or a choice of print sizes. Some require that you click on health, family issues, caregiver, consumers or a lead article on the home page to go to the caregiver section. Other sites open directly onto a caregiver page. Some do not have a section called caregiver, but caregivers may need the consumer and health information they offer. You can scroll through some sites, but others ask you to click on “next” or “2, 3, 4”, etc. to continue. Some web sites describe and some actually sell or link to sites that sell books, videos, assistive devices, adaptive clothing, gifts for caregivers, and more.

The following domain name extensions may provide clues as to the type of site you are visiting:

- .org (non-profit and voluntary organizations)
- .com (may be a commercial business but it is a commonly used extension)
- .gov (federal government)
- .edu (educational institutions)
- .net (network organizations)
- .mil (military organizations)

While extensions usually indicate the type of site visited, some non-profit and government sites can be reached at “.com” addresses. Both commercial and non-commercial sites offer free information, even if membership or registration with or without a fee is suggested.

You also can find these web sites on the Area Agency on Aging of Pasco-Pinellas, Inc. web site, www.agingcarefl.org. Click on “Caregiver Web Sites” in the For Caregivers section and Links to Aging Resources on the Internet on the main menu – some are in one section and some in the other. A few professional and advocacy organizations that did not offer caregiver information were not included in the Caregiver Handbook, but they are online in Links to Aging Resources.
National Web Sites

AARP:  www.aarp.org.  Web site for the AARP organization.  Click on Care and Family, then on Caregiving.  Site has other information for persons fifty and older, and some caregivers use the Games and Crossword Puzzles section under Travel and Leisure for a break from caregiving.  You do not have to join AARP to use this site, but membership benefits are described.

Able Data:  www.abledata.com.  U. S. Department of Education funds this site, which provides information about assistive devices and companies that sell them.

Administration on Aging (AOA):  www.aoa.gov.  Federal agency that provides funding and direction for many programs for seniors and caregivers including the Caregivers REST Project, an AOA demonstration grant that paid for the development of the AgingCareFL web site by St. Petersburg College and the Area Agency on Aging of Pasco-Pinellas, Inc. The Administration on Aging web site describes federal programs such as the National Family Caregiver Support Program in a number of languages. Caregiver publications are available, and the site links to Eldercare Locator, an AOA-funded service to help caregivers find resources in any state.


AL ANON/ALATEEN:  www.al-anon.org.  Organization that provides support to friends and families of alcoholics. Includes publications and contact information for local chapters (notice hyphen).

ALS Association:  www.alsa.org.  National organization concerned with ALS (amyotrophic lateral sclerosis), also called Lou Gehrig’s Disease. Provides advocacy and serves families affected by ALS. Links to products to help with daily living, lists physicians, includes directory of chapters and support groups.

Alzheimer’s Caregiver Support On Line:  http://alzonline.phhp.ufl.edu/. Free Positive Caregiving online classes for dementia caregivers in Florida and nationwide. A project of the Florida Department of Elder Affairs (DOEA) and the University of Florida.

Alzheimer’s Store:  www.Alzstore.com. Sells products such as respite videos, stove-top fire fighters, alarms to alert caregivers to wandering, Alzheimer’s activity aprons.

American Academy of Family Physicians (AAFP):  www.aafp.org. Organization of family physicians. In top corner of home page, search for A Practical Guide to Caring for Caregivers. This article, published in American Family Physician Magazine December 15, 2000, provides a Caregiver Burden test and a checklist for doctors to use with caregivers. Caregivers may want to take these tests. Also click on “Patients” on the AAFP home page or go to the related address www.familydoctor.org for “a to z” health topics and sections on healthy living, self-care, drug information, medical dictionary, etc.
American Association of Homes and Services for the Aging (AAHSA): www.aahsa.org This national organization is made up of not-for-profit nursing homes, continuing care retirement communities, senior housing, assisted living facilities, etc. committed to affordable, ethical long term care. Web site includes consumer information about choices.

American Society on Aging: www.asaging.org Organization committed to enhancing knowledge and skills of those serving older persons and their families. Includes a Resources section.


American Diabetes Association: www.diabetes.org Information about Type 1 and Type 2 Diabetes. Site includes Recipe of the day and Tip of the Day.

American Dietetic Association: www.eatright.org Web site of national organization for dieticians and other professionals provides information for consumers on healthy lifestyle, nutrition tips, and listing of dieticians by area.

American Geriatrics Society Foundation: www.healthinaging.org Click on Eldercare at Home for a free comprehensive online guide to solving caregiving problems. The simple format used for each problem includes advice on how to overcome obstacles such as the older person’s refusal to accept help from anyone but the primary caregiver and examples of what to say when describing problems to professionals.

American Health Assistance Foundation: www.ahaf.org Research and education for Alzheimer’s, glaucoma, macular degeneration, heart disease, and stroke. Offers emergency financial assistance grants to Alzheimer’s caregivers.


American Heart Association: www.americanheart.org National association that provides information and support to persons with heart disease or trying to prevent heart disease. Web site includes Heart and Stroke Encyclopedia and sells heart-healthy cookbooks.

American Liver Foundation: www.liver.org Information about liver health and diseases such as Hepatitis. Site includes contact information for local chapters and support groups.

American Lung Association: www.lungusa.org Advocacy for cleaner air. Education and support for lung problems. Click on “Programs and Events”, then on “Freedom from Smoking” for help in efforts to quit smoking. Covers all types of lung diseases including those caused by AIDS. Includes free profiler tools to help with COPD or lung cancer treatment decisions and local office search.
American Medical Association: www.ama-assn.org Click on “Patients” to find Health Information, Atlas of the Body, Medical Library, and Reference Center.


American Parkinson’s Disease Association: www.apdaparkinson.org Facts about Parkinson’s Disease, chapter and support group information, and publications. Differs from The National Parkinson Foundation.


American Society on Aging: www.asaging.org Membership organization dedicated to improving skills and knowledge of those working with older people. Generations and Aging Today are publications available to public.

American Stroke Association: www.strokeassociation.org American Stroke Association is a division of the American Heart Association. Offers information and free subscription to Stroke Connection Magazine to stroke survivors and caregivers.

Assisted Living Federation of America: www.alfa.org Organization representing non-profit and for-profit assisted living facilities. Web site includes Consumer section with Consumer Checklist (what to look for in a facility).


Beverly Foundation: www.beverlyfoundation.org Research and education in areas of transportation and long term care with goal of improving life for seniors.

Care Guide: www.careguide.com Free mini-assessment of needs helps caregivers locate relevant caregiver information and resources.

Caregiver’s Handbook by San Diego County Mental Health Services: www5.biostat.wustl.edu/alzheimer/care.html This 1990 handbook has some information that is timeless. Click on topics such as Caregiver’s Self-Rating Scale, Personal Care, Mental Stimulation, and Suicide Prevention.

Caregiver’s Marketplace: www.caregiversmarketplace.com Free membership for discounts when purchasing assistive devices, incontinence products, videos, books, and other products from catalogs and various web sites linked to this one. A membership number is used for discounted ordering.
Caregiving.com: www.caregiving.com Includes different types of online support groups including ones for beginning caregivers, male caregivers, alternative lifestyle caregivers, and young adults affected by caregiving. Offers support for professionals and “thinking about you” gifts to purchase online for delivery to caregivers.

Centers for Disease Control: www.cdc.gov Federal government public health site includes disease information and older adult health section.

Children of Aging Parents (CAPS): www.caps4caregivers.org Children of Aging Parents organization does not list a chapter in Pinellas County, Florida, but you can join the national organization or help start a chapter. Organization’s goal is to raise awareness about the importance of caregiver health.

Consumer: www.ftc.gov Federal consumer information resource covering new products, food, money, health, transportation, home and community, etc. Click on “First Gov” to access other U. S. government public information in easy to read format.

Dynamic Living: www.dynamic-living.com Web site sells assistive devices and other products for persons with arthritis, low vision, and other challenges. Click on “Caregiving” for products such as transfer boards and ramps. Gift ideas are provided by price category (notice hyphen).

Eldercare Locator: www.eldercare.gov Administration on Aging-funded project to help caregivers find resources in any state. Also lists the Eldercare Locator toll-free number which links directly to Elder Helplines throughout the United States for answers to questions about resources in a chosen area.

ElderCare Online: www.ec-online.net Offers free newsletter, bookstore, chat guide, glossary of caregiving terms, teen support, medical research assistant, and articles on topics such as respite care and using family meetings to resolve eldercare issues. Links to ALZwell Caregiver Support (notice hyphen).

Elder Hostel: www.elderhostel.org Non-profit organization provides national and international educational travel programs to persons 55 and over.


Experience Works: www.experienceworks.org A national non-profit organization (formerly Green Thumb) that provides training and employment services for mature workers. Web site lists local contacts, links to Geezer.com (see description below).

Family Care America: www.familycareamerica.com Web site sponsored by company whose business is teaching employers how to support caregivers. Includes information and resources for caregivers.
Family Caregiver Alliance (FCA): [www.caregiver.org](http://www.caregiver.org) National statistics, news about legislation, and fact sheets on caregiving issues such as hands-on caregiving skills and how to manage behaviors associated with dementia.

Federal Citizen Information Center (FCIC): [www.pueblo.gsa.gov](http://www.pueblo.gsa.gov) FCIC distributes consumer-oriented publications from many federal agencies. The telephone number for the National Contact Center, an information line, is included.


First Gov for Seniors: [www.seniors.gov](http://www.seniors.gov) Federal government site for seniors. Choose federal portals such as First Gov or click on links to federal and state agency sites. Includes information about seniors and computers, health and fitness, travel, and legislation.

Generations On Line: [www.generationsonline.com](http://www.generationsonline.com) A non-profit organization promoting Internet literacy for older Americans. Offers online instructional software for those who have never used a computer. Some libraries and senior centers are purchasing this software to make it available.

Gerontological Society of America: [www.geron.org](http://www.geron.org) Membership organization provides aging research information to professionals in the field of aging.


Hard of Hearing Advocates: [www.hohadvocates.org](http://www.hohadvocates.org) Includes report to Congress on hearing loss in elderly, description of types of assistive devices for hearing loss, and list of drugs that can cause hearing loss.

Healing Well: [www.healingwell.com](http://www.healingwell.com) Disease information, coping tips for dealing with emotional aspects of chronic illness, and links to sites for specific diseases or conditions such as Crohn’s Disease, Lupus, and Breast Cancer.

Healthfinder: [www.healthfinder.gov](http://www.healthfinder.gov) Site sponsored by the U. S. Office of Disease Prevention and Health Promotion. Information on diseases, prevention, health care providers, etc. Includes online self tests and medical dictionary.

Healthy Caregiver Magazine: [www.healthycaregiver.com](http://www.healthycaregiver.com) Online site for *The Healthy Caregiver Magazine*, not to be confused with *Today’s Caregiver Magazine*. Target readers are contemporary adults caring for aging parents. Web site offers informational articles.
HIVpositive.com: www.hivpositive.com Information about HIV and AIDS. Includes caregivers section and video library.

Homecare Companion: www.homecarecompanion.com Company has produced videos to teach care for bed rest patient, medication management, safe transfers to wheelchair, communication with Alzheimer's patient and stroke survivor, etc. Also sells caregiving video series plus other support as National Caregiver Training Program. Caregiving books are also available.

Homecare Online: www.nahc.org The National Association for Home Care & Hospice sponsors this site. Click on “Consumers”, then on “How to Choose a Home Care Provider”.

Hospice Foundation of America: www.hospicefoundation.org Education and advocacy regarding dignified treatment of persons during last months of life.

Huntington's Disease Society of America: www.hdsa.org Help for families affected by this genetic disease. Click on “About” and “Getting Help”.

Last Acts: www.lastacts.org Coalition of people devoted to improving end-of-life care. Web site includes links to other end-of-life sites.

Long Term Care: www.ltcplanningnetwork.com Canadian site with information on topics such as home modifications and nutrition that may help caregivers.

Lifeview Resources: www.lifeviewresources.com Creators of award-winning and affordable video series called The Educated Caregiver. Also for sale online is The Family Guide to Long Term Care Video Series. Click on box with photo and go to screen that lets you preview videos online.

Lighthouse International: www.lighthouse.org Publications, low vision equipment, etc. for blind persons and those with low vision.

Long Term Care Living: www.longtermcareliving.com Includes a Glossary of long term care terms and articles on financial options, how to discuss long term care choices with family, etc. This site is sponsored by the American Health Care Association and the National Center for Assisted Living.

Lupus Foundation of America: www.lupus.org Publications, research, support, and chapter locator.


Multiple Schlerosis Foundation: www.msfacts.org Multimedia library with Multiple Schlerosis (MS) information, support group directory, etc.
National Academy of Elder Law Attorneys (NAELA): www.naela.org  Click on “Public”, then on “Questions and Answers When Looking for an Elder Law Attorney”. The site also provides a listing of elder law attorneys by area.

National Alliance for Caregiving (NAC): www.caregiving.org  Organization that supports caregivers and professionals who work with caregivers. Includes resource guide to caregiving books, etc.

National Alliance for the Mentally Ill (NAMI): www.nami.org  Membership organization which offers support to families affected by mental illness. Site includes information about causes and treatment of depression in the elderly and other conditions. Family to Family, a free twelve week class for families of persons with severe mental health problems, is offered in some areas. Search by zip code for local affiliate organizations.

National Alzheimer’s Association: www.alz.org  National organization supports research and care. Offers resources for Alzheimer’s caregivers including Safe Return program.

National Arthritis Foundation: www.arthritis.org  Information online or by ordering brochures for Arthritis and related conditions such as Fibromyalgia. Site includes local office directory and medication updates.

National Association of Area Agencies on Aging: www.n4a.org  Organization representing the 655 area agencies on aging (AAA’s) and more than 230 Native American aging programs throughout the U. S. Provides advocacy to ensure that services and resources are available to older Americans.

National Association for Home Care and Hospice: www.nahc.org  Association for home care providers offers information for caregivers, also. Click on “Consumers”, then on “How to Choose a Home Care Provider”.

National Association of Professional Geriatric Care Managers: www.caremanager.org  Explains what a care manager is and provides names of care managers anywhere in U. S. Especially helpful if considering a private-pay care manager.

National Center for Assisted Living (NCAL): www.ncal.org  NCAL Survey results and Consumer Guide with Checklist for Prospective Residents

National Center for Elder Abuse: www.ncea.aoa.gov  Provides fact sheets about abuse and neglect, advocacy, and how to report.

National Committee to Preserve Social Security and Medicare: [www.ncpssm.org](http://www.ncpssm.org). Advocacy organization for health and retirement security. Includes Find Your Representatives feature and link to SPRY Foundation site.

National Council on the Aging (NCOA): [www.ncoa.org](http://www.ncoa.org) Membership association that works with organizations and professionals to promote dignity and self determination of older persons.

National Council on Patient Information and Education (NCPIE): [www.talkaboutrx.org](http://www.talkaboutrx.org) Non-profit coalition with goals of educating consumers to make sound decisions regarding medicines, drug safety, etc.


National Fraud Information Center: [www.fraud.org](http://www.fraud.org) Source for information about telemarketing fraud and Internet fraud.

National Hospice and Palliative Care Organization: [www.nhpco.org](http://www.nhpco.org) Order brochures on communicating end-of-life wishes, Medicare hospice benefits, etc.

National Institutes of Health (NIH): [www.nih.gov](http://www.nih.gov) Health information, scientific resources, grants information, etc. Click on “Institutes” for links to various NIH Institutes, Library of Medicine, and Centers for Complimentary and Alternative Medicine, Minority Health, and Research Resources.

National Institute of Mental Health (NIMH): [www.nimh.nih.gov](http://www.nimh.nih.gov) Fact sheets on mental health conditions and emotional aspects of terrorism, etc.


National Multiple Sclerosis Society: [www.nmss.org](http://www.nmss.org) Support for newly diagnosed and those with chronic MS. Research and other efforts to end MS.
National Osteoporosis Foundation: www.nof.org Prevention and treatment of Osteoporosis. Sample articles are “Preventing Falls” and “Fashion Tips.”

National Parkinson Foundation: www.parkinson.org Parkinson’s Disease publications, research information, etc. Click on “Parkinson’s Disease Caregivers Information” for caregiver support.

National Self Help Clearinghouse: www.selfhelpweb.org Collects and distributes information about support and self help groups nationwide. Search Self Help Sourcebook online for sources of support for many different needs.

National Senior Games: www.nsga.com Non-profit organization promoting senior health through competition in Senior Games and Senior Olympics.

National Spinal Cord Injury Association: www.spinalcord.org Includes caregiver section and fact sheets on disabilities caused by spinal cord injuries. Articles range from wheelchair selection to reducing caregiver stress.

National Stroke Association (NSA): www.stroke.org Organization helps stroke survivors and families. Links to sites that sell assistive devices and other products. This is a different organization from the American Stroke Association.

National Women’s Health Information Center (NWHIC): www.womenshealth.gov Health information for women. Also includes sections on health issues for men and for minorities.

Network of Care: www.networkofcare.org California Department of Aging grant funded development of web sites accessible under each county’s name. Includes extensive resource library and assistive device listing helpful in any part of U. S. Click on “Big Print” button if print is too small.

Older Women’s League (OWL): www.owl-national.org Grassroots organization with chapter network that focuses on issues unique to women as the age. Provides research, education, and advocacy. (notice hyphen)

Pain.com: www.pain.com Online pain assessment charts, pain management information, and links to other sites which focus on control of pain.

Personal Care Wear: www.personalcarewear.com Honor Guard clothing to protect a person’s privacy while bathing them was invented by a caregiver who lives in Brooksville, Florida. Reasonably priced garments resemble terry cloth bathing suits with flaps that allow for washing all parts of the body while preserving the person’s dignity. Click on About Us for the story of how caregiving inspired these designs, which are for sale on this site and elsewhere.

Project Action: www.projectaction.easterseals.com This site has FAQ and publications on accessible transportation for persons with disabilities. Information and resources are available Monday-Friday 9:00 a.m.-5:00 p.m. (Eastern Time) at 800- 659-6428 (voice).
The Easter Seals Project ACTION staff can answer questions about ADA rights and responsibilities, direct callers to additional resources, and help members of the disability and transportation communities address diverse accessibility issues.

**Retirement Research Foundation:** [www.rrf.org](http://www.rrf.org) Large private foundation devoted solely to improving life for aging persons. Includes grant information.

**Science Daily:** [www.sciencedaily.com](http://www.sciencedaily.com) Links to latest research news taken from sources such as scientific and medical journals. Click on “Health and Medicine” to learn more about clinical trial results, etc. Identifies source of each article.

**Senior Net:** [www.seniornet.org](http://www.seniornet.org) Organization whose goal is educating older adults regarding use of computers and Internet. “Learn to Search the Web” and other online courses are free. Web site Includes “Internet Glossary” and listing of local Senior Net centers where persons fifty and over may take low-cost classes.

**Social Security Administration:** [www.ssa.gov](http://www.ssa.gov) Information, available in many languages, about various Social Security benefits such as retirement and disability, tax changes relating to benefits, consumer alerts, and more.

**Spry (Setting Priorities for Retirement Years) Foundation:** [www.spry.org](http://www.spry.org) Foundation dedicated to successful retirement provides research and education.

**Third Age:** [www.thirdage.com](http://www.thirdage.com) A web site for baby boomers. Includes healthy diet tips and stress reduction class, online games, and gifts to order. Click on “Health”, then on “Eldercare” for free class on Parenting Your Parents.

**& Thou Shalt Honor:** [www.andthoushalthonor.org/home/caregiving.php](http://www.andthoushalthonor.org/home/caregiving.php) “& Thou Shalt Honor” is in connection with the PBS television special on caregiving that aired October 9, 2002. Videotapes of program are available, and the site includes other resource information.

**Today’s Caregiver Magazine:** [www.caregiver.com](http://www.caregiver.com) Order subscription to Today’s Caregiver Magazine (print version), and purchase and other books and videos. Read articles and receive free newsletter by e-mail.

**U. S. Department of Justice:** [www.usdoj.gov](http://www.usdoj.gov) U. S. Department of Justice provides information on topics such as elder justice, domestic violence, victims of crime, and faith-based initiatives.

**USAA Educational Foundation:** [www.usaaedfoundation.org](http://www.usaaedfoundation.org) Click on “Order Booklets” for *Driving Safely While Aging Gracefully* or click on “Auto Safety” to view online. Self tests and tips to help you stay in shape to drive and suggestions for other types of transportation after giving up driving.

**Veterans Administration:** [www.va.gov](http://www.va.gov) United States Veterans Administration site has benefits information including health, disability, memorial, etc.
**Video Respite:** [www.videorespite.com](http://www.videorespite.com) Innovative Caregiving Resources has created video respite tapes that entertain Alzheimer’s patients, giving caregivers a break. A number of titles are available including *A Visit With Maria* and *A Kibitz with David*.

**Web MD:** [www.webmd.com](http://www.webmd.com) Click on “Condition Center”, then on “Caregiving”. Site includes extensive disease information plus diet and fitness tips.

**Well Spouse Foundation:** [www.wellspouse.org](http://www.wellspouse.org) Association of spousal caregivers includes a mentorship program linking experienced and new spousal caregivers.
Florida Resources

Agency for Health Care Administration (AHCA):  [www.fdhc.state.fl.us](http://www.fdhc.state.fl.us). AHCA is responsible for the administration of the Medicaid program, for the licensure and regulation of health facilities and for providing information to Floridians about the quality of the health care they receive in Florida. Under “Individuals and Families” are links to health consumer information; outcome and pricing data for nursing homes and hospitals; prescription drug pricing; and Medicaid information.

Claude Pepper Foundation:  [www claudepepper.org](http://www.claudepepper.org). Foundation started by aging advocate Senator Claude Pepper to provide support to the Pepper Center, Library and Institute at Florida State University occasionally funds other projects.

Florida Affordable Assisted Living:  [www.FloridaAffordableAssistedLiving.org](http://www.FloridaAffordableAssistedLiving.org). Site was created by Florida Coming Home Program as a clearinghouse of assisted living information for consumers, operators, and developers. Includes Find a Facility.

Florida Alliance for Assistive Services and Technology (FAAST):  [www.faast.org](http://www.faast.org). Non-profit organization promotes awareness and access to assistive devices and technology to enhance lives of Floridians with disabilities. Web site includes state and regional centers, FAAST toll-free number, disability links, and product recycling center (buy and sell).


Florida Department of Agriculture and Consumer Services, Division of Consumer Services:  [www.800helpfla.com](http://www.800helpfla.com). Florida state agency that serves as clearinghouse for consumer complaints. Learn what types of businesses are regulated by this agency, file a complaint online, learn about scams, use A to Z guide to state agencies by topic, and click on Other Great Consumer Resources for links. Call 800-HelpFla (800-435-7352) for questions not answered on the web site.

Florida Department of Elder Affairs (DOEA):  [http://elderaffairs.state.fl.us](http://elderaffairs.state.fl.us). State agency which oversees many government-funded services to Florida elders. Click on “Reports and Publications” for DOEA’s Elder Update newsletter online, the Elder Law Handbook (information about laws that affect Florida elders), and the Consumer Resource Guide (disease information, caregiver support, etc.). The “Elders and Caregivers” section describes resources, provides information on Medicare, prescription assistance, and long-term care planning through “SHINE” (Serving Health Insurance Needs of Seniors).
Florida Department of Highway Safety and Motor Vehicles:  www.hsmv.state.fl.us. Click on “Driver License”, followed by “Driver License Forms”, then on “Report a Driver” for a form to report a driver whose ability is questionable. Click on “Online Forms”, then on “Disabled Parking Placard” for a form to apply for permit to park in disabled parking spaces. Site lists driver license offices and tax collectors by county.

Florida Department of Insurance:  www.doi.state.fl.us. Read consumer guides online or order booklets such as Options for Lifelong Care, Medicare Supplement, and HMO information.

Florida Department of Veterans Affairs:  www.floridavets.org. Goal is stated as advocacy for veterans. Web site includes listing of state veterans nursing homes.


Florida Health Finder:  www.floridahealthfinder.gov. Facility Locator for Assisted Living Facilities, etc. in Florida. Includes Find a Physician guide. Links to the Agency for Health Care Administration’s Nursing Home Guide.

Florida Long Term Care Ombudsman Council:  www.ombudsman.myflorida.com. Advocacy, training of facility staff, and on-line filing of complaints about long-term care facilities such as nursing homes and assisted living facilities in Florida. Includes Residents Rights for persons living in nursing homes and assisted living facilities.

Florida Medicaid.Com:  www.floridamedicaid.com. This site, sponsored by Elderzone, explains eligibility for Medicaid coverage of nursing home care, legal documents to have in place in case of incapacity, etc.

Florida Policy Exchange Center on Aging:  www.fpeca.usf.edu. “The Center conducts research and collects and analyzes information about long-term care, transportation, health care, employment and income security, housing, Social Security, social services, nutrition, and other areas that significantly affect the daily lives of our elders.”

Florida Silver-Haired Legislature:  www.fshl.org. Organization informs public and elected officials about issues critical to seniors. Delegates meet annually to pass resolutions sent to lawmakers. Older Floridians are invited to join FSHL.

My Florida.com:  www.myflorida.com. Click on Find an Agency at the top of the home page to access Florida state agency sites. “Floridian” links to subjects such as Elders and Retirement and on “Visitors” there is information on Florida attractions. There are also links to county governments, a guide to state parks, cultural information, etc.

Pepper Institute on Aging and Public Policy:  www.pepperinstitute.org. The Pepper Institute, located at Florida State University, provides research on aging issues in fields of demographics, social work, regional planning, etc.
Local Resources

**ABC Action News:** [www.abcactionnews.com](http://www.abcactionnews.com). Local ABC television affiliate Channel 11 in Tampa Bay, Florida area. Investigators have helped consumers.

**Alzheimer’s Association, Gulf Coast Chapter (formerly Tampa Bay Chapter):** [www.alz.org/figulfcoast](http://www.alz.org/figulfcoast). Web site of Alzheimer’s Association chapter which serves Pinellas and surrounding counties in Florida. Includes information and support groups by county, Caregiver’s Day Out, Safe Return Program (notice hyphen).

**Alzheimer’s Family Organization:** [www.alzheimersfamily.org](http://www.alzheimersfamily.org). Alzheimer’s Family Organization offers educational programs, respite care, and support groups in Pasco and other central Florida counties.

**Area Agency on Aging of Pasco-Pinellas, Inc. (AAAPP) or AgingCareFL:** [www.agingcarefl.org](http://www.agingcarefl.org). Click on For Caregivers and on your choice of other topics, such as Aging Network and Services and Programs. Includes a way to search by topic. This web site was developed as part of the Caregivers REST Project, a collaborative effort of AAAPP and St. Petersburg College, funded by the U. S. Administration on Aging. Caregivers can also receive replies to their questions sent to the Senior Helpline on the Contact Us page.

**Bay Area Legal Services, Inc.:** [www.bals.org](http://www.bals.org). Receives funds through AAAPP contract to provide legal assistance in Pasco County with priority given to economically and socially needy seniors.


**Better Business Bureau of West Florida:** [www.bbbwestflorida.org](http://www.bbbwestflorida.org). Offers consumer information and assistance in resolving disputes between consumers and companies.

**Caring and Sharing Center for Independent Living:** [www.cascil.org](http://www.cascil.org). Non-profit organization in St. Petersburg, Florida, identifies options for housing, transportation, personal assistance services, equipment for loan, etc. for persons with disabilities. Site lists ADA rules.

**Community Aging and Retirement Services, Inc. (CARES, Inc.):** [www.caresfl.com](http://www.caresfl.com). Receives funds through AAAPP contract to serve as “lead agency” in Pasco County. Provides case management with a variety of support services. Also provides homemaker, health promotion, and other services.

**Creative Clay:** [www.creativeclay.org](http://www.creativeclay.org). Cultural arts organization in St. Petersburg and Safety Harbor, Florida offers therapeutic art classes for stroke survivors and other challenged persons.
Directions for Mental Health, Inc.:  [www.directionsmh.org](http://www.directionsmh.org). Receives funds through AAAPP contract to provide counseling services in North Pinellas County.

Faith In Action Upper Pinellas (formerly Upper Pinellas Interfaith Caregivers): [www.fiaup.org](http://www.fiaup.org). Faith-based organization of volunteers who provide non-medical services such as transportation to home-bound persons in North Pinellas County, Florida. More volunteers are needed to assist others. Use online form to request more information about services, to volunteer, or to provide other support.


Gulf Coast Community Care (Gulf Coast Jewish Family Services, Inc.): [www.gcjfs.org](http://www.gcjfs.org). Receives funds through AAAPP contract to serve as one of two “lead agencies” for Pinellas County. Provides case management with a variety of support services. Also provides homemaker services. Other funds provide HIV/AIDS programs, Geriatric Crisis Team, and support for disabled adults.

Gulf Coast Legal Services, Inc.:  [www.gulfcoastlegal.org](http://www.gulfcoastlegal.org). Receives funds through AAAPP contract to provide legal assistance with priority given to economically and socially needy seniors.

Gulfport City: [www.mygulfport.us](http://www.mygulfport.us). The City of Gulfport, Florida, receives funds for senior center administration and transportation through AAAPP contract and donates space for a Caregivers Resources Center. On the City home page, click on “Departments” followed by Multi-Purpose Senior Center to find their Senior Center.

Menorah Manor Jewish Hospice: [www.menorahmanor.org](http://www.menorahmanor.org). On the home page, click on “Jewish Hospice” for information about hospice services within the context of Jewish cultural practices and beliefs provided through the collaborative efforts of Menorah Manor and the Suncoast Hospice.

Neighborly Care Network (formerly Neighborly Senior Services, Inc.): [www.neighborly.org](http://www.neighborly.org). Pinellas County agency receives funds through contract with AAAPP to provide adult day care, transportation, home-delivered meals, and congregate meals. Other services are available.

News Channel 8:  [www.wfla.com](http://www.wfla.com). NBC Television local affiliate News Channel 8 in Tampa Bay, Florida area. Investigators have helped consumers.

Pasco County Government:  [www.pascocountyfl.net](http://www.pascocountyfl.net). On the Pasco County government home page, click on “Departments”, then on “Public Transportation”, “Emergency Management”, or “Elderly Nutrition”. The Public Transportation section offers bus routes and schedules. The Emergency Management section includes a personal disaster plan checklist, information about disasters from sinkholes to terrorism, important telephone numbers, and links to related sites. Elderly Nutrition includes a description of a program providing government-funded congregate dining sites and
home-delivered meals for people sixty and over and fee-for-service Meals on Wheels for persons any age.

**Pinellas County Consumer Protection:** [www.pinellascounty.org/consumer](http://www.pinellascounty.org/consumer). Direct route to this Pinellas County government department. Consumer brochures, database of consumer complaints, and online complaint form.

**Pinellas County Emergency Management:** [www.pinellascounty.org/ema](http://www.pinellascounty.org/ema). Click on “Local Disaster Preparedness” at the top of the page. Information includes *St. Petersburg Times* Hurricane Guide, facts about bioterrorism, etc. Other Pinellas County information can be accessed by clicking on “Home”.

**Pinellas County Government:** [www.pinellascounty.org](http://www.pinellascounty.org). This is the Pinellas County Government home page. Pinellas County Human Services (formerly Social Services) receives funds for Energy Assistance for the Elderly (EHEAEP) through AAAPP contract. Click on “Departments”, then on “Human Services”. Other departments can be accessed on the Departments page.

**Pinellas County Public Library Cooperative:** [www.pplc.us](http://www.pplc.us). Click on *Cooperative Libraries* to access the card catalogs of Pinellas County, Florida libraries or choose *Anywhere-Anytime Library* for larger system. Use your local library card number to search catalogs by topic, author, or title. Reserve books and videos on caregiving or for escape from caregiving (mysteries, romance, action movies, travelogues, etc.). Most selections can be sent to your neighborhood library for quick pick-up if ordered that way online.

**Project Grace:** [www.p-grace.org](http://www.p-grace.org). Project Grace, with an office in Clearwater, provides community education regarding making end-of-life decisions in advance. Includes online forms for recording wishes.

**St. Petersburg College:** [www.spjc.edu](http://www.spjc.edu). St. Petersburg College (formerly St. Petersburg Junior College) web site includes information for regular and online courses, college library online, and career development center for students and others. These resources may be helpful for staying mentally active, working on a certificate or degree, or considering a career change during or following caregiving.

**St. Petersburg Times:** [www.sptimes.com](http://www.sptimes.com). Web site related to the *St. Petersburg Times* newspaper. Read the news online, find Coupon Book and Restaurant Guide in the *Marketplace* section, and review the *Weekend* section for interesting outings to plan as an escape from caregiving.

**Suncoast Alzheimer’s and Gerontology Center:** [www.health.usf.edu/medicine/suncoastalzheimers](http://www.health.usf.edu/medicine/suncoastalzheimers) Alzheimer’s research and caregiver education by the University of South Florida, which is located in Tampa, Florida but serves a broader area.

**Suncoast Center for Community Mental Health, Inc.:** [www.suncoastcenter.com](http://www.suncoastcenter.com). Receives funds through contract with AAAPP to serve as one of two “lead agencies” for
Pinellas County. Provides case management with a variety of support services. Also provides counseling in South Pinellas County area.

**Suncoast Hospice**: [www.thehospice.org](http://www.thehospice.org). Organization providing hospice care (end-of-life) in Pinellas County, Florida area also offers bereavement support, caregiver education, and other services for the public and training of professionals. Web site links to various end-of-life sites.

**211 Tampa Bay Cares**: [www.211tampabay.org](http://www.211tampabay.org) Online database for 211 Tampa Bay Cares organization (formerly Pinellas Cares) lists many local support groups, volunteer opportunities, organizations that help people with various diseases, and other resources. Available in multiple languages for Florida’s Pinellas and Hernando Counties. Pinellas County information may also be requested by dialing the telephone number 211 (not 911, as in emergencies).

**Tampa Bay 10**: [www.wtsp.com](http://www.wtsp.com). CBS local affiliate Channel 10 Television News in Tampa Bay Area of Florida offers Health, Ask the Doctor, Around the Bay, and more.

**Tampa Bay Online/Tampa Tribune (TBO.com)**: [www.tbo.com](http://www.tbo.com) Web site related to the Tampa Tribune newspaper and Channel 8 News in Tampa Bay area of Florida has Consumer section with stories about investigations of consumer complaints, etc. Health section includes “Caregiver Guide”.

**University of South Florida (USF) Public Television**: [www.wusf.usf.edu](http://www.wusf.usf.edu) Public Television Channel 16 in Tampa Bay, Florida area. Education, public affairs, news, arts, and culture. Links to web site of USF Public Radio 89.7 fm, home of the volunteer Radio Reading Service for print-impaired listeners.