A Survival Guide for Family Caregivers

Tips For Successful Caregiving

TAKE STOCK:

As problems arise with your aging loved one's health and function, obtain a professional assessment of problems and needs. A geriatrician, a geriatric assessment program or a geriatric care manager are professionals who can evaluate and recommend solutions.

EDUCATE YOURSELF:

Seek information about the following: the normal changes associated with aging, and changes that might indicate a more serious problem. Specific information about any disease or health condition affecting your loved one, and preventive health practices.

PLAN FOR THE FUTURE:

Learn about the range of services in your community that can help provide care in the home, as well as alternative living options. Pre-plan for financial needs (ie.trusts, financial assistance programs). Discuss "end of life" issues with your loved one, and help them execute a will, financial and health care powers of attorney, and a living will.

ENCOURAGE REASONABLE AUTONOMY:

Respect the need of your loved one to make their own decisions and remain in control of their own lives. Limits are often placed on their autonomy due to illness, disability and inadequate financial resources. However, it is usually possible for them to participate to some degree in the decision-making process.

MAKE SMALL CHANGES:

Opt for the smallest amount of change possible at each step. Help your aging loved one understand that accepting a specific service or small amount of help now will actually help preserve their overall ability to remain independent.

BE FLEXIBLE:

Your loved one's condition, and therefore their needs, will change with time. Be prepared to re-evaluate their (and your) situation on a regular basis, and to make changes in the care plan as needed. Waiting until a crisis occurs insures that options will be more limited, and that decisions will have to be made in haste.

SHARE THE WORK:

Don't try to do everything yourself. Share the care responsibility among family, friends, professionals and paid helpers. Knowing your own limits and asking for help is not a sign of weakness, but of strength. It will insure quality of care for your loved one.
SET LIMITS:

You have the right to say "no" to unrealistic demands or requests from anyone, including your loved one. You have the right to make caregiving decisions based upon your own needs as well as those of the person for whom you provide care. Avoid making promises you may not be able to keep, such as promising your loved one that he or she will "never" be placed in a care facility.

FOCUS ON WHAT YOU HAVE DONE WELL:

Too often, caregivers focus only on what they haven't done, or on their perceived mistakes. Remind yourself of the many things you have done well. Ask yourself: "How have I made a difference for my loved one? What have I done that I feel good about?" There will be times when you wish you had done things differently. You are only human. If you make a mistake, admit it, learn from it, and then go on.

TAKE CARE OF YOURSELF:

Caring for another person is the most difficult and stressful thing one can ever do. The welfare of a dependent loved one is directly linked to the well-being of the caregiver. Get adequate nutrition, sleep and health care. Seek regular opportunities for respite and relaxation away from care giving duties. This will allow you to "re-charge your batteries" and will prolong your ability to provide care. Seek out a support group or counselor to help you "problem-solve" and to maintain your emotional strength.

SOURCES:

"Ten Care giver Tips" by Vicki Schmalz, PhD, reprinted in Vol. 2, #2 of the Midlands Chapter of the Alzheimer's Association Newsletter.

"Guideposts for Coping with Aged Parents" by Carter Catlett Williams, M.S.W., ACSW.

INTERNET WEBSITES FOR OLDER ADULTS & FAMILY CAREGIVERS

ADMINISTRATION ON AGING  (www.aoa.dhhs.gov)

AoA's "Elder Page" site contains resources for the elderly and family care givers. There is a nationwide searchable directory to 230 national and local agencies, health associations, and organizations. There are also links to regional and local Area Agencies on Aging.

AGE NET  (www.agenet.com)

Provides information about, and referral to programs and services for older adults and family caregivers. Includes a list of geriatricians in each state.

AMERICAN ASSOCIATION OF RETIRED PERSONS  (www.aarp.org)

Information/advocacy for older adults and caregivers, and links to state and local chapters.
ANSWERS 4 FAMILIES  (www.answers4families.org)
Provides information about community resources in Nebraska for older adults and family caregivers, educational articles and links to local, state and national web sites.

BENEFITS CHECKUP  (www.benefitscheckup.org)
Provides a questionnaire to complete which will guide the user to a personalized list of financial benefit programs and community resources.

CAREGIVING.COM  (www.caregiving.com)
Information, support and inspirations to persons who provide care for aging relatives.

CAREGIVER ZONE  (www.caregiverzone.htm)
Provides a directory to community resources by locale, product information, and articles on aging and caregiving. Includes links on public policy issues and a wide variety of financial topics as well as human interest stories.

CARE THERE  (www.icdri.org/caregiver/carethere.htm)
Provides customized referral to community resources by locale, a support forum, information on health/wellness, legal and financial planning, and good links.

ELDER CARE ONLINE  (www.ec-online.net)
Information, on-line articles, chat groups and local & national web site links for caregivers.

ELDER WEB  (www.elderweb.com)
Information and resources for family and professional caregivers.

FAMILY CAREGIVER ALLIANCE  (www.caregiver.org)
Information, support and bibliography for family caregivers.

FRIENDLY 4 SENIORS  (www.friendly4seniors.com)
Searches the Internet for useful sites for seniors and their loved ones.

HEALTH AND AGE.COM  (www.healthandage.com)
Provides comprehensive information to seniors and family caregivers on geriatric health conditions, prevention tips and treatment options.

HEALTHFINDER  (www.healthfinder.gov)
The website for the U.S. Department of Health and Human Services. It provides links to online publications, clearinghouses, databases, web sites, and support and self-help groups, as well as government agencies and not-for-profit organizations that produce reliable information for the public.

HOMESTORE.COM  (www.homestore.com)
A national online guide to senior housing and care options (click "Senior Living"). Users can view color photos, floor plans, pricing and amenities of various retirement centers. Also provides links to care management, elder law and health care sites.
LAST ACTS  (www.lastacts.org)
Provides information about end-of-life care and planning through the sharing of ideas and solutions by professional caregivers, educators and consumers. Includes a resource center, news updates, reports on palliative care, service providers, education and training.

LIVING STRATEGIES (www.livingstrategies.com)
Information on and referrals to professional care management services. Has a consumer oriented section on self-planning for care and a private directory of professionals.

MEDICARE  (www.medicare.org)
Information about Medicare and the latest inspection reports for all nursing homes.

MR. LONG TERM CARE  (www.mrltc.com)
An online newsletter for caregivers. Provides information on caregiving issues, on long term care insurance, and has many good links to other health related sites. Has interviews, information advocacy groups, and breaking news on issues related to aging and disability.

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS  (www.naela.org)
N.A.E.L.A. is a non-profit association which assists lawyers, bar organizations and others who work with older clients and their families. This site directs the user to elder law attorneys in each state.

NATIONAL ALLIANCE FOR CAREGIVING  (www.caregiving.org)
Information and resources for caregivers.

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING  (www.n4a.org)
Provides links to Area Agencies on Aging by state and locale

NATIONAL ALZHEIMER'S ASSOCIATION  (www.alz.org)
The Alzheimer's Association is dedicated to funding research into the causes, treatments, prevention and cure of Alzheimer's disease and to providing support to persons with the disease, their families and caregivers.

NATIONAL ASSOCIATION OF PROFESSIONAL GERIATRIC CARE MANAGERS (www.caremanager.org)
N.A.P.G.C.M. is an organization of professionals who assist older people and their families to identify and access community services that provide care and support. This site directs the user to professional care managers in each state.

NATIONAL CITIZENS COALITION FOR NURSING HOME REFORM  (www.nccnhr.org)
Provides information and advocacy for nursing home patients and family caregivers

NATIONAL COUNCIL ON THE AGING  (www.ncoa.org)
Information and publications on community resources and public policy issues.

NATIONAL FAMILY CAREGIVER ASSOCIATION  (www.nfcacares.org)
This site offers information, advocacy, education and support for caregivers.
NATIONAL GUARDIANSHIP ASSOCIATION (www.guardianship.org)
Provides educational, training, and networking opportunities for guardians and promotes values, ethics and standards of excellence for guardianships.

NATIONAL INSTITUTE OF HEALTH (www.nih.gov/health)
This site shares consumer health information about diseases and health problems on which NIH conducts or supports research. It provides reprints of their most requested consumer-health publications.

NEBRASKA DEPARTMENT OF HEALTH & HUMAN SERVICES (www.hhs.state.ne.us)
Information about programs and services of DHHS, and links to statewide aging services.

NURSING HOME ABUSE (www.nursinghomeabuse.com)
Information on choosing a nursing home, and on spotting and reporting abuse.

SENIOR CAREGIVER SUPPORT (www.seniorcaregiversupport.com)
Website for the Senior Caregiver Support Group in Omaha, NE. Provides information about the support group, and various other information for caregivers of older adults.

SENIOR OPTIONS (www.senioroptions.com)
Directories identify local options for Assisted Living, Residential Care, Retirement Communities, Skilled Nursing, Alzheimer, Hospice and Adult Day Care facilities; local options for senior insurance, healthcare discount cards, and health and professional services such as legal and financial, mental health, home health, and care management.

SENIOR SITE (www.seniors-site.com)
Information on topics of interest to older adults and family caregivers.

SOCIAL SECURITY ADMINISTRATION (www.ssa.gov)
Information about the Social Security Program.

WELL-SPouse FOUNDATION (www.wellspouse.org)
Information, publications, support and advocacy for caregiving spouses.
BIBLIOGRAPHY: CARING FOR AGING ADULTS

BOOKS:


A MOMENT WITH GOD FOR CAREGIVERS: PRAYERS FOR PEOPLE WHO CARE FOR OTHERS. Bruce & Becky Fish. Dimensions For Living, 64 pgs. (1998)


DAILY COMFORTS FOR CAREGIVERS. Pat Samples. Fairview Press, 376 pgs. (1999)


KEEPING THEM HEALTHY, KEEPING THEM HOME: HOW TO CARE FOR YOUR LOVED ONES AT HOME. Ellen Caruso, RN. Health Information Press, 189 pgs. (1998)


A CAREGIVER'S SURVIVAL GUIDE: HOW TO STAY HEALTHY WHEN YOUR LOVED ONE IS SICK. Kay M. Strom. Inter Varsity Press, 156 pgs. (2000)


WITH LOVE: A CAREGIVER’S JOURNAL. Marian E. Wright. iUniverse.com, Inc. 320 pgs. (2000)


THE HOMECARE COMPANION’S QUICK TIPS FOR CAREGIVERS Marion Karpinski & Don Thomas. Healing Arts Communications, 217 pgs. (2001)

ELDER RAGE (OR TAKE MY FATHER.....PLEASE!): HOW TO SURVIVE CARING FOR AGING PARENTS Jacqueline Marcell and Rodman Shankle. Impressive Press, 368 pgs. (2001)

HOW TO FIND THESE BOOKS:

The books listed here are in print at the time this list was prepared. To locate copies of these books, try public libraries and book stores (books not in stock may be special-ordered). The following internet book sellers will mail books to you, or direct you to out-of-print book finding services: www.amazon.com and www.bn.com These web sites offer detailed descriptions of the focus and content of most books.

FAMILY CAREGIVERS: BROCHURES AND NEWSLETTERS

Brochures and other publications on a variety of topics concerning both the elderly and family caregivers are available from the following sources:

AMERICAN ASSOCIATION OF RETIRED PERSONS
601 "E" Street, NW
Washington, DC 20049
Phone: (202) 434-6090 (www.aarp.org)

NATIONAL INSTITUTE ON AGING
Public Information Office
Bldg. 31, Room 5c27
31 Center Drive, MSC 2292
Bethesda, MD 20892
Phone: (800) 222-2225 (www.nih.gov/nia)

CAREGIVER ORGANIZATIONS:

CHILDREN OF AGING PARENTS
1609 Woodbourne Road, Suite 302A
Levittown, PA 19057-1511
Phone: (800) 227-7294 (www.aoa.dhhs.gov/aoa/dir/77.html)