CARING FOR AN AGING LOVED ONE: A SURVIVAL GUIDE FOR FAMILY CAREGIVERS

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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 (i.e. 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 care giver. Get adequate nutrition, sleep and health care. Seek regular opportunities for respite and relaxation away from care giving duties. This will allow you to “recharge 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 Cattlet 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.

CARE PATHWAYS  www.carepathways.com
Provides information on health maintenance and home care for the elderly, as well as other caregiving information. Provides links to local care resources.

CHILDREN OF AGING PARENTS  www.caps4caregivers.org
Non-profit organization that offers reliable information, referrals and support to family caregivers.

DEPARTMENT OF VETERANS AFFAIRS  www.va.gov
The official website of the United States Department of Veterans Affairs. Information on eligibility and application for health, disability, pension and death benefits.

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.

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
Directs the user to a list of attorneys in each state who specialize in elder law issues.

NATIONAL ALLIANCE FOR CAREGIVING  www.caregiving.org
Non-profit coalition of organizations for family caregivers. Reviews and highlights books, articles, videos, websites and other media of interest to 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
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
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 http://health.nih.gov
This site shares consumer health information about the diseases and health problems on which NIH conducts or supports research. It provides reprints of their most requested consumer-health publications.

NATIONAL INSTITUTE ON AGING http://nia.nih.gov
Health information, publications and related links for seniors, caregivers and professionals.

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

NEBRASKA HEALTH INSURANCE INFORMATION, COUNSELING & ASSISTANCE PROGRAM www.nol.org/home/NDOI
Official site of the Nebraska Department of Insurance. Through it's Nebraska Senior Health Insurance Information Program page it provides downloadable brochures and newsletters highlighting issues such as Medicare, supplemental insurances, fraud warnings, legislation and regulations.

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

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)


MOVING MOM & DAD: WHY, WHERE, HOW AND WHEN TO HELP YOUR PARENTS

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  http://nia.nih.gov

CAREGIVER ORGANIZATIONS:

Children of Aging Parents
1609 Woodbourne Road, Suite 302A
Levittown, PA  19057-1511
Phone: (800) 227-7294  www.caps4caregivers.org

National Family Caregivers Association
10400 Connecticut Ave. #500
Kensington, MD 20895-3944
Phone: (800) 896-3650  www.nfcacares.org

Family Caregiver Alliance
690 Market St., Suite 600
San Francisco, CA 94104
Phone: (415) 434-3388  www.caregiver.org

Well Spouse Foundation
30 E. 40th St., PA
New York, NY 10016
Phone: (800) 838-0879  www.wellspouse.org

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