

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

Prepared by:

Susan V. Murray, CMSW, LMHP
Division of Geriatrics & Gerontology
Department of Internal Medicine
University of Nebraska Medical Center

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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 (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:

Often, caregivers focus only on what they haven’t done, or on 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 Catlett Williams, MSW., ACSW.

INTERNET WEBSITES FOR OLDER ADULTS & FAMILY CAREGIVERS

ADMINISTRATION ON AGING www.aoa.gov

Resources for the elderly and family care givers. Has a nationwide searchable directory to 230 national and local agencies, health associations, and organizations. Also provides links to regional and local Area Agencies on Aging.

AGE NET www.agenet.com

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

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

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 <http://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.

HEALTH AND AGE.COM www.healthandage.com
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.

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

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS www.naela.org
State-by-state directory of attorneys who specialize in elder law issues.

NATIONAL ASSOCIATION OF AREA AGENCIES ON AGING www.n4a.org
Links to state and local Area Agencies on Aging.

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
Information about professional care management services. Has a state-by-state directory of professional care managers. www.caremanager.org

NATIONAL CENTER ON ELDER ABUSE www.ncea.aoa.gov
Information about, and links to state and local resources for elder abuse.

NATIONAL CONSUMER VOICE FOR QUALITY LONG TERM CARE
Information and advocacy for nursing home patients and family caregivers
<http://www.theconsumervoice.org/>

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
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>

Consumer information about diseases and health problems on which NIH conducts or supports research. It provides reprints of consumer-health publications.

NATIONAL INSTITUTE ON AGING www.nia.nih.gov

Health information, publications and related links for seniors, care givers and professionals.

NEBRASKA DEPARTMENT OF HEALTH & HUMAN SERVICES

Information about programs and services of DHHS, and links to statewide aging services. www.hhs.state.ne.us

SENIOR CAREGIVER SUPPORT www.seniorcaregiversupport.com

Website for the Senior Caregiver Support Group in Omaha, NE. Provides information about the group, plus access to local resources.

SOCIAL SECURITY ADMINISTRATION www.ssa.gov

Official website of the Social Security Administration

WELL-SPOUSE ASSOCIATION www.wellspouse.org

Information, publications, support and advocacy for caregiving spouses.

BOOKS: CARING FOR AGING ADULTS

To locate copies of these and other books about dementia and caregiving, 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 providers. These web sites offer detailed descriptions of the focus and content of most books. They also sell downloadable e-book versions: www.amazon.com and www.bn.com

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

CHANGING PLACES: A JOURNEY WITH MY PARENTS INTO THEIR OLD AGE. Judy Kramer. Putnam Publishing Group (2000)

IT TAKES MORE THAN LOVE: A PRACTICAL GUIDE TO TAKING CARE OF AN AGING ADULT. Anita G. Beckerman & Ruth M. Tappen. Health Professions Press (2000)

SELF-CARE FOR CAREGIVERS: A TWELVE-STEP APPROACH. Pat Samples. Hazeldon Informational and Educational Service (2000)

WHEN AGING PARENTS CAN'T LIVE ALONE: A PRACTICAL FAMILY GUIDE. Ellen Rubenson. Lowell House Publishing Co. (2000)

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

ANOTHER COUNTRY: NAVIGATING THE EMOTIONAL TERRAIN OF OUR ELDERS Mary B. Pipher. Berkley Publishing Group (2000)

MY MOTHER'S KEEPER: A MIDDLE-AGED SON'S EXPERIENCE AS A CAREGIVER Bob Apperson. Authority Press, Inc. (2001)

A DAUGHTER'S LAMENT: THE TRIALS AND TRIBULATIONS OF A FAMILY CAREGIVER Eden Rosen. Xlibris Corporation (2001)

THE COMFORT OF HOME: AN ILLUSTRATED STEP-BY-STEP GUIDE FOR CAREGIVERS Maria Meyer & Paula Derr. Care Trust Publications (2001)

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

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

AND THOU SHALT HONOR: THE CAREGIVER'S COMPANION Rosalynn Carter. Rodale Books (2003)

ARE YOUR PARENTS ARE DRIVING YOU CRAZY? HOW TO RESOLVE THE MOST COMMON DILEMMAS WITH AGING PARENTS Joseph Ilardo. VanderWyk & Burnham Press (2001)

TAKING CARE OF PARENTS WHO DIDN'T TAKE CARE OF YOU: MAKING PEACE WITH AGING PARENTS Eleanor Cade. Hazeldon Information Education (2002)

HANDBOOK FOR LONG DISTANCE CAREGIVERS Bob Rosenblatt & Carol Van Steenberg, MSS. Family Caregiver Alliance (2003)

ELDERCARE FOR DUMMIES Rachelle Zukerman, Ph.D. Wiley Publishers, Inc. (2003)

HOW TO CARE FOR YOUR PARENTS' MONEY WHILE CARING FOR YOUR PARENTS Sharon Burns and Raymond Fogue. McGraw-Hill Publishers (2003)

HOW TO CARE FOR AGING PARENTS Virginia Morris & Robert M. Butler. Workman Publishing Co. (2004)

A GUIDE TO ELDER PLANNING: EVERYTHING YOU NEED TO KNOW TO PROTECT YOURSELF LEGALLY AND FINANCIALLY Steve Weisman. Prentice-Hall Books (2004)

THE CAREGIVERS SURVIVAL HANDBOOK: HOW TO CARE FOR YOUR AGING PARENTS WITHOUT LOSING YOURSELF Alexis Abramson. Berkley Publishing Group (2004)

CROSSROADS AT MIDLIFE: YOUR AGING PARENTS, YOUR EMOTIONS AND YOUR SELF Frances Cohen Prayer. Praeger Publishers (2004)

THE HARD QUESTIONS FOR ADULT CHILDREN AND AGING PARENTS Susan Piver. Gotham Books (2004)

CARING FOR YOURSELF WHILE CARING FOR YOUR AGING PARENTS: HOW TO HELP, HOW TO SURVIVE. Claire Berman. Henry Holt Publishers (2005)

THE ELDERCARE HANDBOOK: DIFFICULT CHOICES, COMPASSIONATE SOLUTIONS Stella Mora Henry & Ann Convery, Harper Paperbacks (2006)

NAVIGATING THE JOURNEY OF AGING PARENTS: WHAT CARE RECEIVERS WANT Cheryl Kuba. Brunner Routledge Publishers (2006)

ELDERCARE 911: THE CAREGIVER'S COMPLETE HANDBOOK FOR MAKING DECISIONS Susan Beerman & Judith Rappaport-Musson. Prometheus Books (2008)

CARING FOR YOUR AGING PARENTS: THE COMPLETE FAMILY GUIDE Hugh Delehanty & Elinor Ginzler. AARP Books, Sterling Publishing Co. (2008)

STAGES OF SENIOR CARE: YOUR STEP-BY-STEP GUIDE TO MAKING THE BEST DECISIONS Paul & Lori Hogan. McGraw-Hill Publishers (2009)

WHEN YOUR PARENT MOVES IN: EVERY ADULT CHILD'S GUIDE TO LIVING WITH AN AGING PARENT David Horgan & Shira Block. Adams Media Publishers (2009)

THE COMPLETE ELDERCARE PLANNER: WHERE TO START, WHICH QUESTIONS TO ASK AND HOW TO FIND HELP Joy Loverde, Crown Publishing Group (2009)

Susan V. Murray, CMSW, LMHP
Division of Geriatrics & Gerontology
Department of Internal Medicine
University of Nebraska Medical Center