ELDER CARE: A SURVIVAL GUIDE FOR FAMILY CAREGIVERS

Updated: July 2023

Prepared by:

The Home Instead Center for Successful Aging Nebraska Medicine 730 S. 38th Ave., Omaha, Nebraska

https://www.nebraskamed.com/geriatrics

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 reevaluate their (and your) situation on a regular basis, and to make changes in the care plan as needed. Waiting until a crisis occurs ensures 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 ensure 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 Caregiver Tips" by Vicki Schmalz, PhD

"Guideposts for Coping with Aged Parents" by Carter Catlett Williams, MSW., ACSW.

INTERNET WEBSITES FOR OLDER ADULTS & FAMILY CAREGIVERS

AARP https://www.aarp.org/caregiving/?intcmp=GLBNAV-PL-CAR

The American Association of Retired Persons provides information/advocacy for older adults and caregivers, and links to state and local chapters.

ANSWERS 4 FAMILIES <u>https://www.answers4families.org/</u>

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 <u>https://www.benefitscheckup.org/</u>

Provides a questionnaire to complete which will guide the user to a personalized list of financial benefit programs and community resources.

CARE PATHWAYS https://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.

CAREGIVER ACTION NETWORK https://caregiveraction.org/

Information, advocacy, education and support for caregivers.

CAREGIVER SUPPORT SERVICES http://caregiversupportservices.com/

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

DEPARTMENT OF VETERANS AFFAIRS https://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 LOCATOR https://eldercare.acl.gov/Public/Index.aspx

A public service of the United States Government Administration on Aging, it connects you to services for older adults and family caregivers in your locale.

FAMILY CAREGIVER ALLIANCE https://www.caregiver.org/

Information, support and educational resources for family caregivers.

HEALTHFINDER https://healthfinder.gov/

The web site 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 health information for the public.

https://www.medicare.gov/ MEDICARE

The official web site for Medicare. Provides detailed information and permits you to compare Medicare medical and drug plans, and provides access to inspection reports for individual nursing homes.

https://www.medicare.org/ MEDICARE

A web site not affiliated with Medicare, that provides information about Medicare and other health care insurance options.

NATIONAL ACADEMY OF ELDER LAW ATTORNEYS https://www.naela.org/

A national directory of attorneys who specialize in elder law issues.

NATIONAL ALZHEIMER'S ASSOCIATION

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 CENTER ON ELDER ABUSE https://ncea.acl.gov/

Information about, and links to state and local resources for elder abuse.

4

https://www.alz.org/

NATIONAL CONSUMER VOICE FOR QUALITY LONG TERM CARE

Information and advocacy for nursing home patients and family caregivers. <u>https://theconsumervoice.org/</u>

NATIONAL COUNCIL ON THE AGING https://www.ncoa.org/

Information and publications on community resources and public policy issues.

NATIONAL INSTITUTE ON AGING https://www.nia.nih.gov/

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

NEBRASKA DEPT. OF HEALTH & HUMAN SERVICES <u>https://dhhs.ne.gov/Pages/default.aspx</u> Information about programs and services of DHHS, and links to statewide aging services.

SOCIAL SECURITY ADMINISTRATION <u>https://www.ssa.gov/</u> Official website of the Social Security Administration.

ELDERCARE PODCASTS & WEBINARS

National Public Radio (NPR) Podcasts by and for family caregivers: https://www.npr.org/podcasts/1045670834/twenty-four-seven-a-podcast-about-caregiving

Family Matters https://familymattershc.com/best-caregiver-podcasts/

Family Caregiver Alliance

https://www.caregiver.org/resource/fca-webinars/

Apple Podcasts

https://podcasts.apple.com/us/podcast/elevate-eldercare/id1524700411

ONLINE CAREGIVER SUPPORT GROUPS

Caregiver support groups offer a safe and welcoming environment for caregivers to seek and provide emotional support, and to share helpful tips and coping skills.

https://www.aplaceformom.com/caregiver-resources/articles/caregiver-support-groups

RECOMMENDED READING FOR FAMILY CAREGIVERS

These and other books about caregiving issues are available at 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

ARE YOUR PARENTS DRIVING YOU CRAZY? GETTING TO "YES" WITH COMPETENT

<u>AGING PARENTS</u> Joseph Ilardo, Ph.D & Carole R. Rothman, Ph.D. VanderWyk & Burnham Press, 265 pgs. (2005)

WHEN YOUR AGING PARENT NEEDS HELP: A GERIATRICIAN'S STEP-BY-STEP GUIDE TO MEMORY LOSS, RESISTANCE SAFETY WORRIES & MORE Paula Spencer Scott. Better Health While Aging LLC, (rev. 2023)

<u>THE CAREGIVER'S TOOLBOX: CHECKLISTS, FORMS, RESOURCES, MOBILE APPS</u> <u>AND STRAIGHT TALK</u> Carolyn P. Hartley, MLA and Peter Wong. Taylor Trade Publishing, 256 pgs. (2015)

<u>CRUISING THROUGH CAREGIVING</u> Jennifer L. Fitzpatrick, MSW. Greenleaf Book Group Press, 316 pgs. (2016)

<u>THE FAMILY GUIDE TO AGING PARENTS: ANSWERS TO YOUR LEGAL, FINANCIAL</u> <u>AND HEALTH CARE QUESTIONS</u> Carolyn Rosenblatt, RN, JD. Familius Publishers, 313 pgs. (2015)

HOW TO CARE FOR YOUR AGING PARENTS (3rd Ed.) Virginia Morris. Workman Publishing Co. 653 pgs. (2014) STAGES OF SENIOR CARE: YOUR STEP-BY-STEP GUIDE TO MAKING THE BEST DECISIONS Paul & Lori Hogan. McGraw-Hill Publishers, 268 pgs. (2009)

WHEN YOUR PARENT MOVES IN: EVERY ADULT CHILD'S GUIDE TO LIVING WITH AN AGING PARENT David Horgan & Shira Block, MA. Adams Media Corp., 196 pgs. (2009)

YOU AND YOUR AGING PARENT: A FAMILY GUIDE TO EMOTIONAL, SOCIAL, HEALTH AND FINANCIAL PROBLEMS Barbara Silverstone and Helen Kandel Hyman. Oxford University Press, 370 pgs. (rev.2008)

LONG TERM CARE: HOW TO PLAN AND PAY FOR IT Joseph Matthews, JD. NOLO Press, 337 pgs. (2020)

CAREGIVERS SURVIVAL GUIDE: CARING FOR YOURSELF WHILE CARING FOR ALOVED ONERobert Yonover, Ph.D and Ellie Crowe. Skyhorse Publishing, 176 pgs. (2018)

THE CAREGIVER'S SURVIVAL HANDBOOK: CARING FOR YOUR AGING PARENTSWITHOUT LOSING YOURSELFAlexis Abramson, Ph.D and Mary Ann Dunkin.TarcherPerigee Publishers, 288 pgs. (2011)

<u>I'LL BE RIGHT THERE: A GUIDEBOOK FOR ADULTS CARING FOR THEIR AGING</u> <u>PARENTS</u> Fern Pessin. Publish Your Purpose Press, 342 pgs. (2019)

You may download and print a copy of this and other patient education documents from the resources link on our Internet web site: <u>https://www.nebraskamed.com/geriatrics/resources</u>