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INTRODUCTION

**“There are only four kinds of people in this world—
those who have been caregivers,
those who currently are caregivers,
those who will be caregivers,
and those who need caregivers.”**

Former First Lady Rosalynn Carter

There is no one-size-fits-all model for a caregiver. A caregiver may be the spouse, adult child, another relative or a friend. Both men and women are caregivers, about half work full or part-time, and others are raising children. Many are elderly themselves or live in another city or state. The information in this guide is targeted toward spouses and adult children caring for older adults, but the information may be helpful in other caregiving situations.

Caregiving takes time and effort and often involves personal and financial sacrifice. Both caregiver and care receiver face emotional and intellectual challenges as their roles change and the helper becomes the helped.

At times, caregiving may seem overwhelming, but help is available. Use the suggestions in this guide to make caregiving a rewarding experience for both you and your loved one.



GETTING STARTED

“The hospital called at 2:00 am. Mother had fallen on her way to the bathroom and had just been brought to the hospital by Emergency Medical Services. So began a journey into caregiving that lasted twelve years.”

Caregiving is usually not anticipated or planned and often begins as the result of a crisis. We expect our parents to keep taking care of themselves and may not notice early signs that help is needed. Or perhaps we ignore subtle signals, not wanting to believe our parents and loved ones are no longer able to manage without help.

Is unopened mail stacked up when you visit? Is the home as clean and tidy as usual? Is there a variety of fresh food in the refrigerator? Is personal hygiene consistent with lifelong standards? Does your father make excuses so he doesn't need to leave the house? Does your usually punctual mother arrive late for a family get-together? Have your parents reduced or eliminated activities they used to enjoy?

The best time to plan is before your loved ones need care. Talk with them early and often about their preferences should they need help in the future. What are their concerns? How do they feel about accepting help? Have they considered relocating? Do they expect to move in with you if they need care? Can they afford to pay for care?



BUILDING A CARE TEAM

“When my mom first started to need help with shopping and keeping up the house, I just went ahead and did it. My sister and I never had a good relationship and I just didn't want to mess with her, but it has gotten to be too much. I never have a moment to myself and my kids say I never have time for them.”

You can't do it alone. The time to build a care team is at the beginning. Hold a family meeting with siblings, your spouse, and your adult children and talk about your concerns. If you don't involve others now you may find yourself struggling alone when your parent's needs increase.

The first family meeting may be difficult and should be kept small. Each person comes with their own viewpoint of what your parent needs and what should be done. One may deny there is any need for help and another may insist mother or dad immediately go to a nursing home. Don't try to settle everything in one meeting. Use the time to listen to each other and agree to stick to the reason you are together — to discuss your parent's need for help.

Your loved ones may already have developed an informal or formal network of support. Identify friends, neighbors, agencies or paid caregivers who are involved. Find out what they do now and if they are able to continue.



TALKING ABOUT DIFFICULT ISSUES

“Finances were a big secret with my parents. If I bring up the subject they might think I’m after their money.”

“We never talked about personal issues when I lived at home. Things went the way dad said and that was it.”

“I don’t want to insult them, but mom and dad just aren’t handling things.”

Talking with your parent about finances, health, living arrangements, the need for care, and finally death is not easy, and can be even more stressful if such issues have been off limits for years. However, not talking will not make problems go away. So how do you begin?

Start with a topic you think will be the least sensitive and begin the discussion when you both have time to talk and when you are both calm and relaxed. Express your concerns without stating what you think should be done and then listen.

Your parent has been solving problems and making decisions for years and needs to be heard. You may be surprised at the amount of thought she has given to the subject and you may find she is relieved that she can get her concerns out in the open.

Keep the discussion focused, limited and honest and stop before you become tired or quarrelsome. Back off

at any time your parent makes it clear she is through talking and suggest you talk again at a future date.

You may feel uncomfortable and wish there were no need to discuss difficult issues. In the process of talking, you may open up old wounds and need to do some work to resolve long-standing conflicts.

On the other hand, you may develop a new relationship with your parents as they come to recognize you are a responsible adult, ready and able to help.

If you are unsuccessful after several attempts, ask for help from a trusted friend, spiritual advisor, or professional, especially if matters are pressing and quick action is needed. Your parent may find it easier to accept unwelcome news from someone outside the immediate family.



MAKING A PLAN

“With the diagnosis of cancer and Mom gone, I just don’t know how Dad can manage He depended on her so much and I don’t think he has very good medical insurance. Should he be staying in that big house by himself?”

Caregiving will be less stressful for caregiver and care receiver if you know where you are going and have a plan. Begin with an objective assessment of your parent’s physical, mental, environmental, financial and social condition. Involve your parents and other concerned family members and don’t expect to gather all the information in one session.

- Do they need help with activities of daily living such as, bathing, dressing, grooming?
- Are they able to prepare meals, do housework?
- Do they need help with transportation to the doctor or shopping?
- Do physical conditions affect their ability to function?
- Do they have problems with bowel or bladder control?
- Is their hearing or vision impaired?
- Is their thinking ability, memory or decision-making ability impaired?

- Do they show signs of hopelessness, withdrawal, fatigue, lack of concentration?
- Are they able to manage their money?
- Do they have necessary legal documents in place (Wills, Powers of Attorney, Living Wills)?

Answers to these questions will help the family identify what type, amount and frequency of help is needed and who is available to help. Respect your parents’ independence and do only those things they can’t do for themselves.

Once you have identified what is needed, a written schedule may work well for you. Assign responsibility for specific tasks. Some care team members will be better at hands-on care; others do well with paperwork or running errands. One may be excellent at working with health providers, agency staff, and in-home helpers. Keep the entire team involved no matter how little they are able to do. You will need everyone’s support as decisions are made.

Parents need to express how much help they will accept and who they want to be involved in their care. Are they willing to accept help from family, friends or paid caregivers to remain in the home? Would they prefer to move in with a family member? Do they need to relocate to assisted living or a long-term care facility? The Area Agency on Agency can give you a list of senior housing including assisted living facilities. If they are able to remain at home, you will want to make sure the home is safe and comfortable.



CHECKING HOME SAFETY AND COMFORT

“They want to stay in their home, but I don’t know if they can manage there anymore, or if it’s safe there.”

Is the home in good repair, safe and comfortable? Is the neighborhood safe and convenient? Do they have a support network of neighbors and friends nearby? Use this checklist adapted from the series “Aging Parents and Adult Children Together” produced by the Federal Trade Commission in partnership with AARP.

- Are handrails securely fastened on both sides of all stairways?
- Are all areas, including stairways, well lit? Are switches easy to operate?
- Do outside lights illuminate entrances and exits?
- Is a telephone accessible at all times? You may want to suggest a cordless or cell phone.
- Do security locks protect outside doors? Are they easy to operate?
- Are smoke detectors and carbon monoxide detectors strategically located?
- Are batteries replaced on a regular basis?
- Are floors and stairs kept free of cords and loose objects?
- Is safety equipment properly installed in the bathroom? The basics are grab bars for the tub, shower and near the toilet.

- Do the tub and shower have non-slip surfaces?
- Is the hot water heater set to prevent scalding?
- Can you remove tripping hazards, such as cords and throw rugs?
- Is there a night-light?
- Is there a sturdy bedside table with a non-tip lamp and space for eyeglasses?
- Does furniture placement allow a clear path between the bathroom and bedroom?
- Do rugs have non-slip backing?
- Is there a comfortable chair with arms for rest or comfort when dressing?
- Can frequently used items be reached without using a chair or stool?
- Is a fire extinguisher within reach of the stove?
- Is there a work area where a person can sit while preparing food?

Simple inexpensive improvements can make all the difference in an aging person’s ability to continue living at home. Consider installing lever-action faucets in sinks and tubs, lever style door handles, an under-cabinet jar opener and electric can opener in the kitchen, and larger “C” handles to replace small knobs or handles on cupboards and drawers.

More extensive improvements, such as building a wheelchair ramp, widening a doorway to accommodate a wheelchair, or installing a roll-in shower may require professional help.



GATHERING INFORMATION

“Mom handed me her checkbook and a pile of mail. She hadn’t balanced her account for months and I had a mess to unravel.”

“Dad called all upset about Mom. He doesn’t think the doctor is helping her and wants me to call. I’ve never met the doctor, but will give her a call and try to sort it out.”

You have made a plan and are ready to help. Now begin gathering important information with the permission and help of your parent. Put together a file of vital information. You need to know where important documents are kept and whether records and legal documents are up-to-date. Be aware that items stored in a safe-deposit box in your loved one’s name are not available upon death. You can record the information in a plain loose-leaf notebook as you go along. Here is a checklist to get you started.

Medical, Financial, and Legal Records

- Names, addresses and phone numbers of doctors, dentists, and other medical providers
- Health care and long-term care plan information and membership cards
- Social Security, Medicare and Medicaid numbers and identification cards

- Names, addresses and phone numbers of their attorney, accountant and banks
- Savings, checking, investment and credit card account numbers
- Retirement accounts (IRA, 401K etc.), pension plans, veteran’s benefits
- Deeds, titles, business agreements
- Records of credit card debt, mortgages, outstanding bills
- List of routine household bills, amounts and due dates
- Insurance policies including life, homeowner’s, liability, accident, auto
- Will, Power of Attorney, and advance directives such as Durable Power of Attorney for Health Care, Living Will and Do-Not Resuscitate Orders
- Burial or funeral arrangements

Support Network

- Names, addresses and phone numbers of friends and neighbors. Note what they are willing to do and when they can be reached. If your parent agrees, leave a key with a trusted person in case of emergency.
- Names, addresses and phone numbers of groups, clubs, religious or service organizations who are helping or may be willing to help
- Names, addresses and phone numbers of individuals, agencies and organizations that are providing care now.



FINDING HELP

The Area Agency on Aging recognizes the vital and major role you and other family caregivers play in meeting the care needs of frail elders. The Agency, a partner in the National Caregiver Support Program, serves caregivers, as well as those needing care.

In the beginning, you and your care team may be able to manage all the care your parents need. However, at some point in your caregiving journey you are likely to need outside help to meet your parents' needs. Explore the services available in your community as soon as possible, preferably before there is a crisis.

Contact the Area Agency on Aging, to get a wealth of information about caregiving and the services offered in your area. Nurses and social workers are available to discuss service options and to develop a personalized plan.

Adult Day Service, Home Care Options and Respite Care can supplement the help you and others are providing and give you the support you need to continue caregiving.

Adult Day Services offer a full or part day program away from home for your loved one, including socialization, supervision and activities.

Home Care Options may include help with bathing or dressing, or help with homemaking activities such as meal preparation, laundry and light housekeeping.

Respite Care benefits both you and the person you care for. Respite Care gives the caregiver a few hours away from caregiving to attend to other errands or chores or to just relax while someone else comes to the home and fills in as caregiver.

Contact the Area Agency on Aging for specifics about services for yourself and your loved one in Champaign, Clark, Darke, Greene, Logan, Miami, Montgomery, Preble, and Shelby counties or for information about services in other Ohio counties.

Phone 1-800-258-7277 or 937-341-3000

Fax 937-341-3005

www.info4seniors.org

In addition to this **Caregiving Guide**, the Area Agency on Aging offers a number of helpful articles on specific caregiving issues in the **Caregiving Series**.

Current topics in the **Caregiving Series** are: *Aging Myths, Caring for Yourself, Dementia, End-of-Life Care, Paying for Care, Legal Issues, Long-Distance Caregiving, and Work and Caregiving.*



MANAGING MEDICAL CARE

“The doctor Mom and Dad had been going to retired last year and they don’t want to start with someone new.”

“Dad has a drawer full of prescriptions and I noticed some of them are several years old. I don’t know what he is taking or what its for, and I’m concerned.”

Medical professionals are key members of your care-giving team. Your loved ones have had their own private relationship with doctors in the past and have managed their own medications but may now need your help. Your loved one may resist your input at first and you may need to express your concern and offer your assistance more than once before it is accepted. If your loved one continues to refuse your help and the problem is serious, you may need to insist on a visit to the doctor or may need to go ahead and call the doctor yourself, even though your parent resists.

Hopefully, your loved one will welcome your help and with their permission, you can be present during office visits and communicate with the doctor or nurse yourself on an ongoing basis. Get to know your loved one’s doctors. If a new doctor is needed, find one your loved one trusts and feels comfortable with. The doctor should take time to listen, be easy to talk to, be open-minded and be up-to-date on treatment and medication options. The primary doctor should make all referrals

to specialists as needed and should be fully informed about all your loved one’s medical care and treatment.

Ask whether the doctor accepts the fee payment schedule set by Medicare and accepts your loved one’s secondary or supplemental health insurance. Find out if the doctor is affiliated with the hospital your loved one prefers, who covers patient care during his absence and how to reach him in an emergency.

Compile a medical history and keep it updated to share with the primary doctor. The doctor also needs to know about lifestyle issues that may affect treatment choice such as abuse of alcohol or other drugs, smoking, or poor nutrition. Address problems such as memory loss, confusion, depression and refusal to follow instructions that may interfere with the patient’s ability to follow a treatment plan. Let the doctor know if your loved one still drives.

Take a list of questions to each doctor visit and bring a notebook or tape recorder to record answers. Ask, what the problem is, what the treatment plan is, whether there are other options, what tests and/or medications are recommended, what are they for and what should be expected from the treatment plan. Keep asking until you understand. Set up a file for Medicare and all other medical insurance paperwork and keep it up to date. Forms and appeals must be filed on time if there is a problem.

Medical professionals have the expertise you and your loved one need. Be a team player. Remain involved,

polite and constructive to get the best service and the attention your loved one needs.



CAREGIVER STRESS

“I can’t remember when I last had a day to myself. I just get so tired.”

“I really love my Mom, but she is so hard to please. I am sick of trying.”

Caregivers experience mixed emotions. Love for your family member and the satisfaction you get from helping may coexist with feelings of resentment about the time and effort you spend caregiving. You may find it hard to accept the decline of the special person you are caring for and may feel frustrated about your lack of control over what is happening. If your loved one lives with you, you may feel resentful about the loss of privacy and the many adjustments you must make.

Your feelings will depend on several factors, among them; your past relationship with your loved one, the extent of your responsibilities as a caregiver, whether you are holding down a full or part time job in addition to caregiving, your other family obligations and how important your own social and leisure activities are to you.

To help yourself, you can start by acknowledging your feelings. All feelings are legitimate, even those that are disturbing to you, including anger, frustration, and sadness. Your feelings have a lot to do with the way you cope with caregiving.

Your responses to the following statements will help you become aware of your feelings and the kinds of pressures and stress you currently feel. Respond to each statement with either: **seldom true, sometimes true, often true, or usually true.**

_____ I find I can't get enough rest.

_____ I don't have enough time for myself.

_____ I don't have time to be with other family members.

_____ I feel guilty about my situation.

_____ I don't get out much anymore.

_____ I have conflicts with the person I care for.

_____ I have conflicts with other family members.

_____ I cry every day.

_____ I worry about having enough money to make ends meet.

_____ I don't have enough experience or knowledge to give good care.

_____ My own health is not good.

_____ I have trouble sleeping.

_____ I am eating much more or much less than usual.

If you responded **usually true** or **often true** to one or more of these statements, it is time to look at ways to reduce your level of stress. Do you need more help because your loved one's care needs have increased? Have your other responsibilities increased? Are you trying to do it all, thinking no one else can do things as

well as you can? If so, begin to set realistic goals, let others know you need help and accept the help offered. Use community resources such as adult day services, or home-delivered meals. Bring in a few hours of home health service to help with a bath, do the laundry or tidy up the house. Avoid overuse of alcohol or other drugs. Turn to family members, friends, clergy, or professional helpers. Many caregivers benefit from support groups and sharing their experiences with other caregivers. If you don't take care of yourself, you will not be there for your loved one.

Material for "**Caregiver Stress**" was drawn in part from "The Caregiver's Handbook: Assisting both the Caregiver and the Elderly Care-receiver" produced by the San Diego County Mental Health Services, San Diego, CA 92110, Robert Torres-Stanovik, LCSW, Editor, and used with permission.