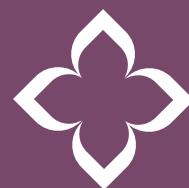


Caregiver Handbook

A Guide for Taking Care of Your
Elderly Loved One – and Yourself



Episcopal Church Home



INTRODUCTION



Caregivers are the unsung heroes of the long-term care system. Each year, nearly 45 million Americans invest more than 35 billion hours into providing unpaid care and assistance for older family members, the disabled, the ill and other individuals who have chronic conditions that hinder them from carrying out their day-to-day activities. Without the selfless help of caregivers, it is estimated that nearly \$450 billion worth of valuable care would need to be replaced with paid services each year.

If you have recently taken on the role of caregiver for an elderly loved one, no doubt you're well aware of how demanding it can be. Not only do you have to assume an entirely new set of responsibilities in addition to those you already have (e.g., work, children, spouse, social obligations, etc.), but your relationship with the person for whom you're providing care will go through a transition as well. It can be challenging and unpredictable at times, and unfortunately many caregivers struggle with excessive levels of stress and anxiety due to the demands of taking on such a role.

That's what this guide is all about. Our goal is to provide you with as many tools and resources as possible to help you successfully navigate the many facets of being a caregiver. We have divided this guide into two main sections based on the two major aspects of caregiving:

**Taking care of an elderly loved one; and
Taking care of yourself.**

By having a plan to address each of these aspects, you can minimize some of the stress associated with caregiving while also improving your ability to provide quality care with balance and effectiveness. So let's get into it!

FIRST THINGS FIRST: WHAT IS A CAREGIVER?

OVERVIEW

A caregiver is someone who looks after or provides assistance to a relative, spouse, friend, or neighbour who is sick, injured, disabled (mentally or physically), or otherwise unable to carry out the basic activities of daily living.

Caregiving can take on a thousand different forms, as the type and degree of care needed can vary greatly from person to person. For example, if you have found yourself assisting an elderly loved one (whether a parent or a spouse) with everyday tasks both big and small, you are a caregiver.

WHAT DOES A CAREGIVER DO?

Truth be told, it would probably be quicker to describe what a caregiver doesn't do, because the list of tasks and responsibilities assumed by caregivers is phenomenally extensive. Below are some of the most common tasks that caregivers provide for their recipients.

- Assist with shopping and buying groceries
- Perform light housekeeping work
- Help with ambulation (i.e., walking assistance)
- Running errands such as paying bills, retrieving mail, making/receiving phone calls, picking up medications, etc.
- Meal preparation
- Pet care
- Provide transportation to meetings, doctor's appointments, social outings, etc.
- Assist the care recipient with getting into or out of bed
- Provide assistance with daily activities such as bathing, dressing, bathroom visits, grooming, administering medications, etc.
- Help with home maintenance
- Provide companionship via personal visits or over the telephone

If you could distill all of the responsibilities and activities of a caregiver into one word, it would be "help." The typical caregiver wears many hats and performs many duties, but at the end of the day, their ultimate goal is to provide whatever assistance is needed to make life a little easier for their loved one. With this thought in mind, let's explore some practical tips and ideas to help you better serve an elderly loved one who has been placed into your care.

TAKING CARE OF AN ELDERLY LOVED ONE

Without proper planning, even the most well-intentioned efforts can be plagued with mishaps and ineffective results. The four-step process outlined below will help you think through the various details involved in taking care of an elderly loved one so that you can successfully provide much-needed assistance in a relevant and effective manner.

1. DETERMINE WHAT TYPE OF ASSISTANCE YOUR LOVED ONE NEEDS.

The first step you should take is to accurately assess and determine the type of care that your loved one will require. Carefully consider how any physical and/or mental disabilities or limitations might hinder them from performing various day-to-day tasks, and then determine the type of services that will be needed to help your loved one manage their basic daily activities.

Keep in mind that the transition into receiving regular care can sometimes be uncomfortable for your loved one, and it can affect them mentally, physically, emotionally, financially, and/or socially. Fortunately, there are several services available that you can leverage to help you and your loved one navigate this new phase of their life.

A major part of determining what type of care your loved one will need is taking the time to honestly assess what type of assistance you can provide versus what you will have to rely upon family members, friends or service professionals to provide.

A guaranteed way to catapult yourself into burnout is to overestimate your own abilities and underestimate your current time commitments. Be as realistic as possible when evaluating how much time or effort you can contribute.

In fact, it is commonly recommended to give yourself a fairly generous margin of error, so that if any emergency or illness occurs, you can implement an effective backup plan. By establishing honest, realistic expectations, your plan will stand a greater chance of success, and you will avoid potentially putting your loved one or yourself at risk.

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2. GATHER INFORMATION ON SERVICES AND RESOURCES.

After you have determined the type of care your loved one needs as well as what level of assistance you can realistically provide, your next step will be to gather information regarding services and resources in your local area that can assist you with the caregiving process. Below are some of the local services and resources that are commonly used by caregivers to help provide assistance to their elderly loved ones:

- **Home-Delivered Meals:** Look into Meals on Wheels offerings in your area. For more than 25 years now, for instance, Deupree Meals On Wheels has consistently provided warm and nutritious home-delivered meals to elderly individuals living in the eastern portion of Cincinnati. Based in Hyde Park, this service-oriented organization strives to assist caregivers by providing elderly individuals with healthy meals and friendly social contact.
- **Care Management:** Living Well Senior Solutions is a premier provider of practical solutions that can help caregivers make connections with experienced healthcare partners to ensure adequate care for their loved ones. Their services address a wide range of needs, from answering insurance and Medicare questions to helping with assisted living transitions, and everything in between. Their primary goal is to help connect caregivers with the resources they need to provide the best possible care for their loved ones, which can help alleviate stress and increase peace of mind.

- **Health and Wellness Programs:** Parish Health Ministry promotes a variety of health and wellness programs by partnering with local churches to provide blood pressure checks, diabetes screenings, and much more. With an emphasis on a holistic approach to health and wellness, Parish Health Ministry aims to improve the quality of life of individuals through education, advocacy and wellness activities.
- **Home Health Aides:** Caring.com is an excellent resource to help you find and enlist the help of a home health aide who can assist your loved one with basic activities of daily living.
- **Housecleaning and Home Maintenance:** Tender Hearts at Home Senior Care is a premier in-home senior care organization that provides a variety of services (including housekeeping) for elderly individuals.
- **Adult Day Care/Senior Centers:** AgingCare.com can help you find reputable adult day care providers for your elderly loved one.
- **Respite Care:** The threat of caregiver fatigue is a real thing, which is why it is so important to carve out time to take much-needed breaks. A respite care facility can help you accomplish this by ensuring that your loved one is in good hands while you're away. Seniors Guide offers an extensive listing of respite care facilities that provide quality short-term or temporary care.
- **Assisted Living:** Sometimes called personal care, assisted living is for seniors who may need extra help to complete some or many daily living tasks. Examples include preparing meals, taking medications, getting dressed, bathing or grooming. Assisted living options can range from providing limited assistance to providing 24-hour care.

- **Memory Care:** Also referred to as memory support, Alzheimer’s care or dementia care, memory care centers usually involve round-the-clock care for people who have memory difficulties and can no longer complete daily tasks on their own. There are generally specialized activities or programming and specially trained staff. Many memory care centers in nursing homes are secured environments to discourage residents from wandering outside unescorted or getting lost.
- **Long-Term Care:** Long term skilled care is typically the highest level of care that can be provided outside a hospital. Services are provided under the direction of a licensed physician and may include physical or occupational therapies. Long term skilled nursing, often called a nursing home, provide around-the-clock skilled nursing on an ongoing basis.
- **Caregiving Apps:** One of the biggest questions on the minds of most adult children of elderly parents is simply this: “How are Mom and Dad doing?” Work obligations, time constraints, distance, and more can all pose a challenge to performing regular check-ups on your elderly loved ones. Fortunately, ERS has created the How’s Mom app to address these challenges. This innovative smartphone application provides you with daily updates on your loved one’s health, mood, eating habits, social interaction, and personal care, and it can be customized to prioritize the information you want to know right away, as well as how often you want to receive those updates.
- **Other Services:** One of the best resources to help you connect with additional caregiving services is the ElderCare Locator website, which is a public service offered by the U.S. Administration on Aging. You can search by ZIP code, city or topic to locate service providers in your area.



3. PRESENT THE INFORMATION YOU HAVE COMPILED TO FAMILY MEMBERS AND MEDICAL PROFESSIONALS AND DISCUSS THE OPTIONS.

It's important to receive input from a variety of perspectives in order to shape a well-rounded care plan. If everyone who has a vested interest in caring for your loved one has the opportunity to provide feedback and suggestions before initiating the caregiving process, you will minimize the risk of misunderstandings or friction later down the line.

4. DRAFT A CARE PLAN AND DISTRIBUTE IT TO FAMILY MEMBERS AND MEDICAL PROFESSIONALS.

The final version of your care plan should include the following items:

- The names of each caregiver along with their contact information (phone numbers, email addresses, fax numbers, street addresses, etc.).
- Important medical contact information including doctor's numbers, 911, the Poison Control Center, etc.
- Instructions for urgent situations such as power outages, inclement weather, medical emergencies, fires, etc.
- Any pertinent schedules or calendar events to be aware of.

Be sure to double-check all of the information on the plan to ensure its accuracy, and then distribute several copies to each caregiver. Ask them to look it over and notify you if anything needs to be updated or corrected.

Once everyone gives it the green light, post your copy of the plan in a conspicuous location (e.g., a bulletin board, the refrigerator, etc.). Be sure to check periodically throughout the year to ensure the accuracy of the information, and make adjustments to the plan as needed.

TAKING CARE OF YOURSELF

Let's face it: Caregiving is a tough job, and even the most resilient among us can grow weary or become burned out over time. The stress and demands of caregiving can drain you physically, mentally and emotionally, which is why it is vitally important for you to prioritize your own health and well-being from the very beginning. You can't effectively take care of your loved one if you're not taking care of yourself, so be sure to pay attention to how you're doing during the caregiving process as well!

Taking Care of Your Mental Health

Just like your physical health, your mental health can have its ups and downs. Excessive stress can hinder your mental well-being, so keep the following steps in mind to help you properly take care of your mental health.

1. SEEK HELP EARLY.

Don't wait until you're on the verge of complete burnout before you begin to seek help. Caregivers who reach out for help early on in the caregiving process are typically able to provide quality care over a longer time frame.

One of the best steps you can take in this regard is to join a support group, such as the one offered by Marjorie P. Lee retirement community. There are a wide range of caregiver support groups available, many of which are categorized by the specific health conditions of care recipients, such as dementia or Alzheimer's disease. Support groups can provide you with a safe place to discuss your concerns, air your frustrations, receive encouragement, and share helpful solutions with other caregivers.

If time commitments or geographic location prevent you from attending group meetings, you can explore groups that offer support via the Internet, such as **Family Caregiver Alliance**, **Caring.com** and **CareGiving.com**.

2. PAY ATTENTION TO YOUR EMOTIONS.

Similar to how hunger alerts you that your body needs food, emotions are signals that can sometimes indicate a need for support or assistance. One of the worst mistakes you can make is to ignore your emotions for the sake of trying to “tough it out,” as this can often be counterproductive to your mental wellbeing.

Whether you feel sad, anxious, frustrated, depressed, or otherwise, keep in mind that it is perfectly normal to experience these emotions during the caregiving process. By seeking help and support early on in the process, you will position yourself to provide a better caregiving experience for both you and your loved one.

- **Grief:** The emotion of grief is often associated with feelings of loss. This isn't limited to the grief you can experience when a loved one passes away, but it can also include feelings of loss based on changes in the relationship you have with your loved one. Don't keep these feelings bottled up inside; be sure to talk about what you're feeling to help you cope with the grieving process.
- **Anger:** Most caregivers are all too familiar with experiencing anger during the caregiving process. There might be times when you feel like you're flying off the handle over the smallest things, and other times you might even experience anger toward the person for whom you are caring. Try talking to a family member or a trusted friend with whom you can vent your frustrations, and recognize that anger is sometimes a mask for deeper feelings of sadness, fear or loss. Do your best to direct the energy provided by anger towards productive ends, such as knocking out a project around the house, exercising or making needed changes in some other area.
- **Loneliness:** Caregivers of elderly persons with Alzheimer's disease often report feeling loneliness due to how the condition has altered their relationship with their loved one. Feelings of isolation and loneliness are not uncommon during the caregiving process, but they should serve as a signal that you need to reach out to friends, family members or your support group for help. You can also try praying or journaling about your experience to help you cope with feelings of loneliness.

- **Inadequacy:** Caregivers can be plagued by feelings of inadequacy, especially when they set very high standards for their own performance. You may feel inadequate because you think you simply can't do enough, or perhaps because your loved one's health condition continues to worsen. You have to remember but there are certain aspects of the caregiving process that are simply out of your control, and you shouldn't beat yourself up for not being able to fix them. Accept and rely on the help of others during your caregiving journey. Practice self-acceptance, and focus on appreciating your strengths instead of magnifying your weaknesses. More than likely, you're doing much better than you think.

3. RECOGNIZE THE SYMPTOMS OF CAREGIVER BURNOUT.

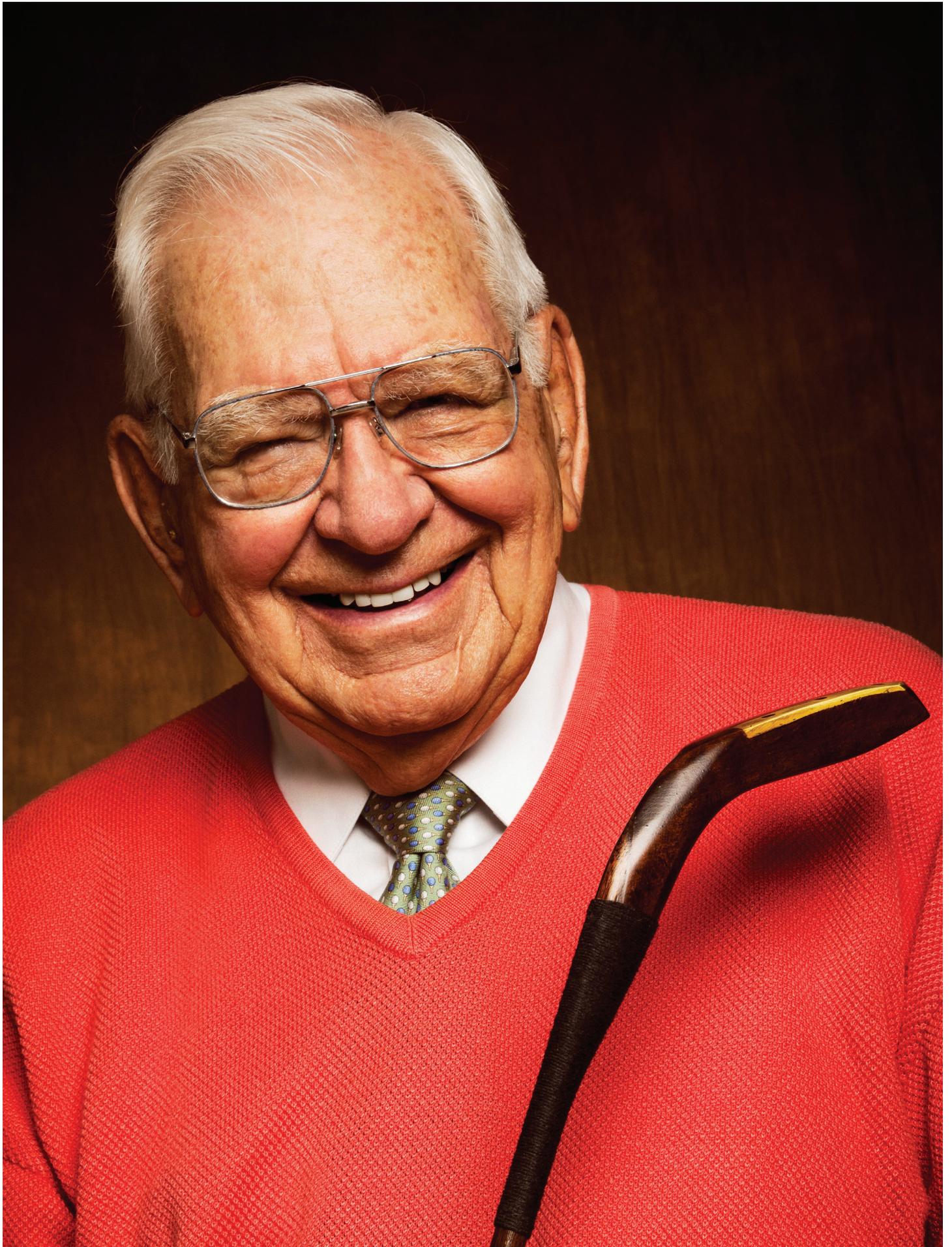
Some of the most common symptoms of caregiver burnout include:

- Noticeable gains or losses in body weight
- A change in personal appearance, or in the appearance of their living conditions
- Frequent bouts of anger or temper flare-ups towards the care recipient, family members, service providers, or doctors
- Feelings of despair, hopelessness or being "boxed in"
- Changes in sleep patterns (insomnia or excessive sleeping)
- Diminished sex drive due to stress
- Depression or listlessness
- Crying for no apparent reason
- Career and/or social life is negatively impacted

If you or someone you know are experiencing symptoms of caregiver burnout, reach out and seek help immediately. Neglecting to address these symptoms will only make the situation worse. Talk with your health professional, contact your local community mental health center, call your local Area Agency on Aging or solicit help from your support group to address this vital issue.

4. SCHEDULE SOME TIME OFF.

No one can provide quality care 24 hours a day, 7 days a week. Make sure you schedule some time off to give yourself a chance to rejuvenate and replenish your mental and physical energy. With careful planning and the help of the resources listed in this guide, you can get some much-needed downtime without neglecting the care of your elderly loved one.



TAKING CARE OF YOUR PHYSICAL HEALTH

Taking care of your body is necessary in order for you to have the energy and stamina you need to carry out your caregiving duties. Below are some handy tips to help you effectively take care of your physical health.

1. EAT WELL.

A poorly nourished body will not perform at its best. Be sure to eat plenty of fresh fruits and vegetables, and try to maintain a balanced diet that includes proteins (e.g., meat, fish, eggs, nuts, and poultry), starches (e.g., bread, rice, pasta, and cereal), and dairy (e.g., cheese, yogurt and milk). And make sure to drink plenty of water every day!

2. EXERCISE.

No doubt your caregiving schedule will keep you busy, but try to squeeze in a minimum of 30 minutes of moderate exercise (e.g., walking, jogging, aerobics, treadmill, etc.) at least five days a week.

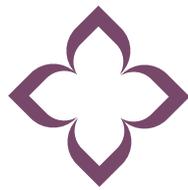
3. SLEEP.

The importance of getting good sleep cannot be overstated. Do your level best to discipline yourself to maintain a bedtime that will allow you to get at least six to eight hours of sleep a night. This will give your body and mind the rest they need to perform at peak levels.

4. SEE YOUR DOCTOR REGULARLY.

Make sure to get regular checkups, including vision and dental exams. Address any symptoms of physical or mental health problems as soon as possible.

If you have any questions, or if you would like
additional information, please contact
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