

Thank You for Caring



Caregiver Planning Guide

Notes

Introduction

What is caregiving? A caregiver provides essential help for a person in need. Caring for a family member or close friend is the most important work in the world. This role may include taking your loved one to medical appointments, helping manage the finances or providing emotional support.

I was a caregiver for my mother, Nancy, for 14 years, who is now deceased. I had many friends, family members, and colleagues who were supportive of me, however, there were many times I felt lonely and stressed out. There are resources and individuals in our world today to help, however, I did not know about many of them, and often didn't have the time to research or use them. Every caregiving journey is unique and will change over time. So, my wish is that you find guidance and support within these pages to make your caregiving experience a better one.

Thank you for doing the most important work in the world.

Karin Pauly - Founder, Caring for Nancy

Begin with a Conversation

It is never too early to plan for the future and to start the conversation with your loved one. Many wait until a crisis occurs to make decisions, and this is often a difficult time as emotions may be running high, assumptions may be made, and you may not have the time to make the best decisions.

Topics around caregiving and management of an aging or chronically ill loved one may be difficult to discuss, so begin by expressing your care and concern. Be sure to use "I" statements, versus "you" statements during the conversation. For example, *"I care about you and love you and plan on looking out for you in the upcoming years. I would like to talk about some of your wishes."* Instead of, *"You are getting older, your health is declining, and you are going to need help, have you even thought about this?"*

Plan Ahead

Creating a caregiving plan will help you and your loved one in the future. Plans may include and should not be limited to: wishes of your loved one, developing a care team, understanding finances and completing legal documents, planning for care in the home or in a long-term care facility, and knowing how to manage medical care for your loved one.

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Care Team

Make a list of family and friends who will participate in the caregiving journey with you. These may include: siblings, a spouse, a parent, a child, or a family friend. Consider, there may be religious, community-based, or other organizations who can help.

Memories

Please, do not let the stress and caregiving steal from the life experience you and your loved ones share together. All things pass, and the reality is no one gets out of here alive. Make sure you take some time to be present in the moment. Take pictures (I regret that I did not take enough of them), listen to and capture your loved one's stories and experiences in writing or video. Hug and forgive when you can.

Caring for Yourself

When we fly, the flight attendant tells us that in an emergency to put on the oxygen mask first, and then assist those around you. Caregiving is similar. If you are not healthy - mentally, physically, and emotionally, you will not be as effective in caregiving. Your health depends on it, as does the health of your loved one. The following are tips to help you care for yourself:

- The Doctor. Go!

Caregiving can be seriously detrimental to your health. If you have something going on, you need to detect it as soon as possible. You might be able to prevent something serious from happening, such as a stroke due to high-blood pressure, or detect early a treatable cancer. To me, this is the most important self-care tip. Just go!

- Exercise. Pick one thing you can do every day or most days

Be realistic and do something you enjoy. If you haven't been walking or running, you likely are not going to take the time to train for a marathon right away. But if walking or running is something you enjoy, commit to walking for 15-20 minutes.

If you are struggling with committing time to exercise, consider signing up for a class that you enjoy, or find a friend who will join you. Consider activities you love, for example, if you are a gardener, it can be a fantastic workout, so you might commit to time outside in your garden regularly.

- Heart-Healthy Diet. Talk to your doctor

The Mediterranean diet and the DASH diet came in as #1 and #2 in the U.S. News and World Report's Best Overall Diets for 2019. Both feature fruits, vegetables, whole grains, lean meats, fish and nuts. The Mediterranean diet reduces the risk of heart disease and decreased the risk of Alzheimer's, Parkinson's disease and cancer.

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The DASH (Dietary Approach to Stop Hypertension) was designed to help manage blood pressure and has many health benefits.

- Nutritional Supplements. Talk to your doctor

My doctor recommended that I always take a high-quality multivitamin no matter what. The effectiveness of supplements is controversial as some manufacturers have made false or over-reaching claims. It is important to discuss any supplements you are taking with your doctor.

- Communicate. Seek out support

Share your caregiver story with friends, family, co-workers, and community organization members. Don't be afraid to be honest about your difficulties.

- Have Fun

Make the time to do something you love to do at least once per week. I like to laugh, so while caregiving, I tried to watch comedies. Don't be afraid to see the humor in life and spend time with people you like and try to reduce the amount of time spent with people you don't.

- Sleep. Commit to going to bed

If something can wait until later and it is time to go to bed, go to bed. Sleepiness causes accidents. Sleep loss can lead to serious health problems, and reduces the ability to think critically or learn. Of course, this is easier said than done with the demands of caregiving. For me, I needed to reduce screen time before bed and put my phone down. I was so worried I would receive a call about my mom, that the phone itself stressed me out and kept me up. If the techniques you are trying are not helping your sleep time, make sure to talk to your doctor as she may be able to help.

- Mindfulness and Mental Health Management.

Pick one activity you can do every day or most days. Ideas include deep breathing, reframing negative thoughts, practice positive self-talk, meditation, humor, and socialization. Do not be afraid to seek professional counseling if you believe it will help you.

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Checklists for Your Caregiver Plan

Care Receiver Personal Information Checklist

- Social Security Card/Number
- Birth Certificate
- Marriage Certificate
- Death Certificate (for a deceased spouse or loved ones)
- Military Records
- Divorce Papers
- Driver's License/Organ Donor Card/ID
- Passport/Citizen Papers
- Contact Lists (friends, family members, colleagues, contacts)
- Community and Church Membership
- Personal Care (hairstylist, barber, manicurist)
- Lawyer
- Passwords

Care Receiver Financial and Legal Information Checklist

- Will
- Trust
- Health Care Directive/Living Will/Do Not Resuscitate (DNR)
- Physician's Order for Life-Sustaining Treatment (POLST)
- Power of Attorney
- Health Insurance Policy
- Prepaid Funeral Expenses
- Medicare (Include prescription drug coverage)
- Medicaid/Waiver/State Assistance
- Veterans
- Life Insurance
- Long-Term Care Insurance
- Disability Insurance
- Car Insurance
- Property documents or rental information (titles, insurance, home security, utilities)
- Investments and Banking
- Debts and Expenses
- Passwords

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Care Receiver Health Information Checklist

- Medications (dosage and schedule, pharmacy contact information)
- Diet (examples - DASH, vegetarian, low-cholesterol)
- Primary Physicians (names, addresses, phone number, email, online communication)
- Healthcare Specialists (names, addresses, phone number, email, online communication)
- Health Insurance Information (reference Financial and Legal Information checklist)
- Long Term Care (assisted living, nursing, memory care) information

Care Receiver History and Preferences Checklist (document for professional caregivers and the care team)

- Entertainment (television, movies, computer or pad use, live entertainment)
- Telephone use (landline, cellphone/keypad or smartphone)
- Reading (vision challenges, print size, audiobooks)
- Musical preferences
- Hobbies
- Conversation (religion, politics, interests)
- Sleeping preferences (blankets, pillows, sleepwear, socks/slippers)
- Clothing
- Food likes and dislikes
- Temperature
- Professional/work history
- Personality (examples – determined, out-spoken, quiet, calm, listening skills)

Care Receiver Goals and Wishes Checklist

- To stay in own home for as long as possible
- To move into a residence with assistance
- To remain active and maintain hobbies
- To be around friends and family members
- To visit friends or family/ to travel
- Pets
- Legacy planning (photos, storytelling, obituary, eulogy, funeral)

Notes

Sources:

- *AARP Family Caregiving Prepare to Care. A Planning Guide for Families*
- *Caregiver Resource Guide, Minnesota Board on Aging*
- *The Caregiver Helpbook, Third Edition, Powerful Tools for Caregivers, 2013*
- *VA Caregiver Support, U.S. Department of Veterans Affairs*
- *The Alzheimer's Association*

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