

The Caregiver Guide: An Introduction to Elder Care

Whether it means caring for a parent, spouse, close friend or other loved one, becoming a caregiver is challenging. The responsibility can fall to you suddenly, and you may not feel fully prepared for what lies ahead. Although every situation is different, there are many questions and tasks that all new caregivers must face. There's a lot to cover, and we've put together this guide to cover these topics. Whether you are about to become a caregiver or planning for the future, this guide can help you organize your thoughts, make sure that you're handling all the important tasks, and give you some peace of mind.

Planning Ahead

Have you ever said or heard others say, "I don't ever want to be a burden to my children"? It's a common thought, but what have you done to insure that you won't be? If your parents share these sentiments, now is the time to initiate dialogue with them before it's too late. The inevitable future includes aging for all of us.

Many of us, seniors included, will be called upon as caregivers of our loved ones. The first "baby boomers," the group born after World War II ended, are just entering their 60s. It is likely that this group of Americans may spend more years caring for elderly parents than they spend raising children. They truly exemplify the sandwich generation.

Caregiving can be complicated. Finding resources and making decisions is not an easy task. The entire family should be addressing caregiving issues. If elderly parents are capable, by all means, involve them in an open discussion of issues directly related to their future. If they seem reluctant at first, persist. It's far better to "air" their fears and yours now, while they are still capable. Be sure to involve all siblings in the discussion even the "long distance" children. If they can't be there, keep them well informed, preferably in writing. Informal letters serve well.

Warning Signs

Here are a few warning signs that may alert you that your loved one needs care.

- Loss of mobility, such as trouble walking or standing steadily
- Decline in personal hygiene, such as poor grooming and wearing dirty clothing
- Changes in eating habits, including Weight loss and loss of appetite
- Trouble shopping for groceries, from having no food in the home to having a large amount of expired food
- Loss of interest in your loved one's favorite activities

- Decreased interest in socializing
- Trouble concentrating
- Poor decision making or trouble making any decision at all
- Memory loss and feelings of confusion
- Difficulty taking medications properly
- Chronic fatigue and persistent decrease in energy level
- Changes in personality, increased irritability, mood swings
- Difficulty keeping up with finances and paying bills
- Trouble maintaining the home, from basic housekeeping to more serious maintenance

These issues are only warning signs, and sometimes can be corrected. New health problems in seniors are often drug induced. Furthermore, conditions like dehydration and Vitamin B deficiency can be confused with Alzheimer's disease.

The remainder of this guide will help you take the first steps toward becoming a caregiver. It's broken into the following sections:

1. General Issues
2. Financial and Legal
3. Housing
4. Health and Physical Condition
5. After Death

Each section begins with a few questions for you to think about as you prepare. Each section ends with a list of action items for you to complete. Taken together, this should give you a good start and make you feel much more prepared for the road ahead.

General Issues

Questions to Ask

- Who will be the principal caregiver?
- What involvement will siblings have?
- Which responsibilities can be shared? By whom? (Supervising medications, shopping, doctors, day care, etc.)
- Is communication open and honest between caregiver and elderly person?
- Do family members share feelings and information?

Steps to Take

- Get access to your loved one's date of birth and social security number. This is essential information for being an active caregiver.
- Meet with your family members and have an honest, open discussion. Let everyone express his

or her feelings, and take input and advice. Allow other family members to be involved, assigning tasks as appropriate. This step will help keep communication open and involve everyone in important decision making later on.

- Start learning about resources available in your community. This includes transportation, senior centers, and home health care / adult day options nearby. There's a lot more out there than you may think!
- Consider hiring a care manager, someone to help you better understand the situation facing your loved one and make important decisions.
- Reach out to anyone with experience as a caregiver and talk about your experience. You'll be surprised at the support and great information that you will find. Talking to others can also help when you feel alone or overwhelmed; knowing that someone else has been there before and made it through can make all the difference.
- Take good notes throughout the process, and keep them organized. We recommend creating a spreadsheet on your computer, which is easy to share with family members via email or services such as [Google Docs](#). This approach also makes searching and sorting a lot easier. Important things to track: date, name of the person you spoke to, contact info, and a brief summary of what was discussed.
- Communicate with your senior and do your best to ensure that his or her wishes are honored, within reason. Your goal should be to allow your loved one to maintain as much control over his or her life as possible. It is a challenge for many seniors to transition away from a fully independent lifestyle, but good communication makes the process far easier.
- If your loved one will continue to stay at home, make sure that you and other key family members have keys to the house.
- Create a list of important information and distribute it to your family members.
- Give yourself time to process and work through your emotions. You are doing a great, difficult thing, and you will likely have a wide range of feelings. Take time for yourself and make sure that everything is okay with you, too.

Financial and Legal

Questions to Ask

- What is the person's financial situation?
- Is there a list of assets, their value, their locations?
- Is there a private pension? Is it mailed directly to a bank? Which one?
- What is the social security amount? Is it directly deposited? Where?
- Are there other sources of income? Annuities, stocks, interest, IRA's, CD's, safe deposit box?
- What are the debts? Mortgages, car payment?
- Is there a need to apply for SSI, Supplementary Security Income?
- Is medical coverage adequate?

- Is there a prescription plan? Long term care insurance? Medicare? Medicaid?
- Has anyone consulted an eldercare attorney?
- Has the elderly person transferred any assets?
- What is the “time frame” in your state for transferring assets before being qualified for Medicaid?
- Is there a will, a living will, a power of attorney, a durable power of attorney that lasts beyond incapacitation? Where are they kept?
- Is there an insurance policy? Where is it kept?

Steps to Take

- If your family has not consulted with an eldercare attorney, strongly consider doing so.
- Help your loved one prepare the following documents if he or she has not already done so: living will, durable power of attorney for finances and healthcare, and living will.
- Take a close look at your senior’s health insurance policies and make sure that you understand what’s there and what is not. Fill any gaps as necessary.
- Create an organized list or spreadsheet documenting your loved one’s finances. Consider using of tools like [Mint.com](https://www.mint.com) as well if this helps keep things more organized.

Housing

Questions to Ask

- What housing options are possible? Can the elderly person live alone?
- What about an assisted living facility?
- Is a nursing facility or a personal care facility needed?
- Is senior housing or shared housing an option?
- Is a life care community feasible?
- Has the person or family any “up-front money” available for some period of personal pay in a nursing home?

Steps to Take

- Begin exploring assisted living facilities and other senior living options even if these are not immediately necessary. At the very least become familiar with the different alternatives, and if possible do a basic search and pick out a few communities.

Health and Physical Condition

Questions to Ask

- Has the person had a recent physical? Is there a family doctor? Has a geriatric assessment been ordered?
- What medications are being taken? By prescription? Over the counter?
- Ask the pharmacist or doctor if any medications interactions should be avoided. Ask if any meds should not be taken together. Any foods avoided?

Steps to Take

- Make a list of your loved one's medical providers, from doctors to dentists. You may find it helpful to keep this information in a spreadsheet too. Name, address, phone number, and a few notes are a good start.
- Find out which pharmacy your senior uses and create a note about any arrangements with that pharmacy for discount prescriptions.
- Gather all insurance cards and make copies of the front and back. If applicable (your senior is 65 or older), find and copy his or her Medicare card as well.
- If your senior is eligible for Medicare, strongly consider reading "Medicare & You", a helpful guide located [here](#).
- Make another list or spreadsheet with all of the medications that your senior is taking. Include everything, from prescription medications all the way down to supplements. Name, correct dose, and any special instructions for consumption (for example, after a meal only) are a great place to start. Bring this information with you to all doctor's appointments and share with the health care provider.
- Document the medical conditions and serious illnesses that your senior has experienced. Document the same for his or her parents and siblings to the extent possible.
- Talk to your loved one's doctors about any relevant medical conditions. If you want to find out more information, consider using the library or the Internet for further research. Don't feel pressure to learn everything.
- Keep good, detailed notes and always follow up with healthcare professionals. Though they do their best, these are busy people and sometimes things they promised slip through the cracks. In those cases, it'll be up to you to contact and remind them, ensuring that your loved one gets the best care possible.

After Death

Questions to Ask

- Are there any pre-paid funeral expenses? Any specific funeral wishes?
- What funeral home? A viewing? A family plot?

- Cremation? Any specific desires?
- Can you discuss death with the person for whom you are caring? Why not? Most of the elderly do not fear discussion of death.

Steps to Take

- Have an open, honest conversation with your loved one. There are cases where this may not be possible, and you'll need to accept that, but in many cases there is initial resistance that wears down as you and your loved one realize the necessity of discussing death. Note his or her wishes and carefully record them

Financial Resources

Health Insurance, Prescription Drug, Medical Care Support and Information Programs

Family caregivers can contact their county or state Department of Health and Human Services, or area social service agencies such as Catholic Charities or the Association of Jewish Family and Children's Agencies, as well as local chapters of voluntary health agencies to find out if they offer any financial support programs and how to apply for them. Don't forget the Medicare and Medicaid websites: www.medicare.gov and www.medicaid.gov. Also, The Center for Medicare and Medicaid Services (CMS), which is the government agency that administers the Medicare Program and works in partnership with the states to administer the Medicaid Program, has a Web site that provides information about the Medicare and Medicaid Programs (www.cms.gov).

Benefits Check-Up and Benefits Check-Up RX

Web sites: www.benefitscheckup.org

A service of the National Council on the Aging, Benefits Check-Up and Benefits Check-Up RX help people over the age of 55 find federal, state, and local public and private programs that may pay for some of their medical care and/or prescription costs.

Medicare Rights Center

1460 Broadway, 11th Floor
New York, NY 10036
888-HMO-9050

Web site: www.medicarerights.org

The Center provides hotlines for direct services, education/training, policy briefs, and a list of discount drug programs. The Web site also has a list of phone numbers for each state's "State Health Insurance Assistance Program and information on the new Medicare law Prescription Drug Cards."

Medicine Program

PO Box 515
Doniphan, MO 63935
573-996-7300

Web site: www.themedicineprogram.com

This program is for persons who do not have coverage either through insurance or government subsidies for outpatient prescription drugs, and who cannot afford to purchase medications at retail prices.

MetDesk

Division of Estate Planning for Special Kids

Web site: <http://www.metlife.com/desk/>

This service links MetLife agents who have special needs children with other parents of special needs children and provides advice on financial planning for the long-term care of special needs children. Visit the Web site for information on workshops, free assistance, and other services.

Patient Advocate Foundation

700 Thimble Shoals Boulevard, Suite 200

Newport News, VA 23606

800-532-5274

Web site: www.patientadvocate.org

The Patient Advocate Foundation serves as a liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relating to a patient's condition.

Partnership for Prescription Assistance

Web site: www.helpingpatients.org/

This is the site of the Pharmaceutical Manufacturers Association and has all the information related to the companies' discount and free programs.

Together Rx Access

1-800-444-4106

Web sites: <http://www.togetherrxaccess.com>

A FREE prescription-savings card for eligible residents of the United States and Puerto Rico who have no prescription drug coverage. Plus information Medicare Part D.

More Resources

- [Caregiver Resources from USA.gov](#)
- [Caregiver Resources from Medicare.gov](#)
- [Caregiving Resources from the CDC](#)
- [Iris Consulting for Seniors](#): For our Canadian visitors, Iris provides seniors, their families and their professional advisors with information, education, advice, advocacy and counseling regarding seniors' needs and issues.