



100 Tips for Caregivers from Caregivers

1. Take Care of Your Own Health

- ◆ Take note that self care isn't selfish – it's necessary.
- ◆ Remind yourself that if you don't stay healthy, you can't take good care of your relative (if you can't who will?)
- ◆ Schedule at least 15 minutes a day for physical exercise or meditative relaxation.
- ◆ Every day, strive for healthy eating and a good night's sleep.
- ◆ Visit your doctor for annual physicals and preventive tests, like pap smears and blood pressure checks.
- ◆ Use simple safety measures like using night lights to avoid injury.
- ◆ Join a walking group or take a class that will support healthy behavior.
- ◆ Be accountable to a "buddy" who will encourage positive changes and cheer you on.

2. "Learning" to Accept Help

- ◆ Keep in mind that the *best caregiver* is a *rested caregiver*.
- ◆ Recognize that you can't do everything.
- ◆ Acknowledge your feeling that "no one provides care as well as I do" but accept the fact that others can provide *good-enough* care.
- ◆ Understand that your loved one is better off if more than one person knows the ropes.
- ◆ List your loved one's likes and dislikes, tips for eating, medications, etc. to share with helpers.
- ◆ Step back and let your loved one gradually build trust in others.
- ◆ Plan to get out of the house while others provide care.
- ◆ Don't succumb to guilt.

- ◆ Show appreciation for the assistance. A heartfelt “thank you” is all that is needed. Often people truly enjoy helping out.

3. Encourage Family Members to Help

- List the pros and cons of doing it all yourself.
- List the tasks you are doing. Make a second list of those someone else could do.
- Write the names of family members next to the tasks that they would be good at.
- Practice wording your request so that people understand exactly what’s needed.
- Ask for the help you need and explain how it will help.
- If a relative makes an excuse, pleasantly say “If you can’t do that – is there another way you could help me out?”
- Call a family meeting - invite everyone - even those who don’t help.
- Be ready to describe the current situation and prepare a list of problems to discuss.
- Brainstorm possible solutions for each problem.
- Ask someone to take notes and draft a family “caregiving plan.” Keep this plan handy and review it every few months to see how it is working.
- Keep all family members in the loop through email updates and ask for help as needed.
- Personally thank every relative who helps, even if their contribution is small. Keep it simple.

4. What to Do When People Say “*Is There Anything I Can Do to Help?*”

- ◆ Have ideas in mind (shopping, going with you to the doctor, picking up prescriptions, cleaning the refrigerator).
- ◆ Thank the person for the offer and ask, “How do you think you could give me a hand?” and “When are you available?”
- ◆ Keep a calendar or schedule so that you can see helping opportunities at a glance.
- ◆ Start a notebook with names, phone numbers and things that each person has offered to do.
- ◆ Be specific with a small request. Ask at least twice before you give up on an offer of help.
- ◆ Remember that the help can be for you, not just for the ill person. For example, a neighbor could have your car’s oil changed.
- ◆ Keep a list of fun activities you would like to do with another person, and ask if your potential helper would care to join you. Helping you relax is a helpful contribution.
- ◆ Acknowledge even the smallest help with a “thank-you”. Short notes or phone calls are appreciated. You do not need to reciprocate with gifts.

5. Organizing Yourself

- ◆ Keep a list of current medications, emergency contact numbers and DNR documentation on your refrigerator (EMTs look for it there). Bring copies along when you travel.
- ◆ Make a habit of reviewing your calendar. Include time for paperwork and phone calls.
- ◆ Keep phone numbers of medical personnel, family, “friends who offer to help” and repair service people near the phone.
- ◆ Keep a list of “to do” items than can be done by others. When someone offers to help, try having them choose one and schedule it.
- ◆ Use pill boxes to organize medications.
- ◆ Use a personal health notebook to organize health information, questions and appointments for your relatives and yourself.
- ◆ During hospital stays, keep a journal of the day’s events and conversations with professionals. You could then use it to talk with your doctors or to refresh your memory.
- ◆ Be sure someone else knows where to find important financial and personal information.

6. “Partner” With Your Physician

- ◆ Prepare for medical visits and phone calls. Write down symptoms and the sequence of events that occurred. Be concise.
- ◆ Bring your current insurance card and co-pay to every visit.
- ◆ If you have a question that you do not want to ask in front of the patient, call or mail it to the doctor ahead of time.
- ◆ If you want something specific ask in a pleasantly assertive way; don’t wait until the doctor is leaving the room to discuss the real reason why you came.
- ◆ If you like your doctor, but find that he or she sometimes doesn’t listen or include you in decision making, let him or her know. Try saying: *It takes me awhile to explain my situation. I know you are busy, but I am feeling rushed.* Then describe what you want.
- ◆ Discuss, don’t demand, the latest drug or treatment.
- ◆ Take notes. Let your doctor know if you don’t understand something.
- ◆ Before you leave or hang up the phone, say – *Just let me be sure I understand what I am supposed to do.* Then list the steps you think you are supposed to take.
- ◆ Get a second opinion if you feel uncertain.
- ◆ If you have a question that you do not want to ask in front of the patient, call or mail it to the doctor ahead of time.

7. Be a Fearless Healthcare Advocate

- ◆ Use the tips on “Organize Yourself”

- ◆ Remember that you know the patient best and are a key partner with other health providers.
- ◆ Learn to be assertive without being confrontational.
- ◆ Ask lots of questions:
What is the problem? What caused it?
What options are there? What are the risks?
What will happen if I do nothing?
- ◆ If you feel rushed, say: *It takes me awhile to explain my situation. I know you are busy, but I am feeling a little rushed.*
Then describe what you want.
- ◆ Before you leave an appointment or hang up the phone, say: *Just let me be sure I understand what I am supposed to do.*
Then list the steps you think you are supposed to take.
- ◆ Don't be afraid to get second opinions.
- ◆ Call 1.866.474.5230 and ask for a copy of **Become a Health Advocate for Yourself and the People You Love.**

8. Taking Over Financial Matters

- ◆ After consulting with a lawyer and thoroughly understanding your obligations, obtain a Power of Attorney. A POA will give you the legal authority to manage the finances.
- ◆ Find out where financial records are kept and organize the files.
- ◆ Develop a list of all bank accounts, investments, loans, credit cards, pension and insurance policies.
- ◆ Learn about monthly income. Be aware of monthly bills and other financial commitments.
- ◆ Strive to maintain the dignity of your relative as their ability to manage affairs changes. Include them as much as possible.
- ◆ Be flexible as circumstances change – what worked before may not work now.
- ◆ Be sure that all insurance policies have the correct beneficiaries listed.
- ◆ Consolidate credit cards. Notify the source and destroy the card.
- ◆ Use convenient direct deposit, automatic and internal bill paying options.
- ◆ If your relative is prone to poor decisions, get a P.O. Box and re-route bills and important documents there. Use a cell phone for important calls, rather than the home number.
- ◆ Depending on your personal situation, get ongoing help from a lawyer, accountant or financial planner.

9. Adjust to Reduced Income

- ◆ Make a list of bills and expenses that you must pay. List other expenses that you might be able to limit.
- ◆ Look at your checkbook and see where your money is going.

- ◆ Check the website *Benefits.com* and call the CHOICES program at 800.994.9422 to identify state and federal programs that can help.
- ◆ Call your human services department (usually in blue pages of phone book) to see what energy assistance, food banks, friendly visiting or other programs are available locally.
- ◆ For entertainment, take advantage of low cost, local activities such as high school sports, plays and concerts.
- ◆ Use the town library for videos, internet access and self-help information.
- ◆ Ask friends to save coupons for you.
- ◆ Arrange for a utility company energy audit.
- ◆ Join membership organizations (such as AARP that offer discounts).
- ◆ Check the local papers and the internet for sales.

10. Overcoming Resistance to Help and Change

- ◆ Be empathic. Try to see the issue from your relative's point of view.
- ◆ Resistance typically is rooted in fear of loss of control. See your role as helping to overcome the fear.
- ◆ Team up with other influential people - have your doctor or trusted friend make suggestions to your relative.
- ◆ Keep "chipping away" at the resistance – persist in a firm but caring manner.
- ◆ Try saying "*I need your help.*" In a loving, gentle, coaxing way, it can be very powerful.
- ◆ Phrase things positively - instead of "You can't handle things alone any more," say "We want you to stay well."
- ◆ Acknowledge that new things take getting used to – you might say, "Try it three times and then we'll decide if it's right for us."
- ◆ Start with small changes and reinforce the positive. If the door slams on the idea, wait a day or two and bring it up in a different way.
- ◆ If your relative is a safety risk and refuses to make necessary changes, you can call your state Department of Protective Services for the Elderly. A social worker will visit and can often exert influence to get the needed change to happen.
- ◆ Do not fear the resistance of your loved one. Remember:
 - a. You are in charge
 - b. Your ability to care for your loved one at home depends on *you* being rested and healthy.
 - c. Keep chipping away at the resistance.

11. Avoid a Crisis

- ◆ Be alert to signs of a possible crisis
 - Sores that won't heal
 - Frequent falls or accidents

- Severe behavior changes such as unusual suspicion, anger outbursts, crying
 - Very aggressive or physically threatening behavior
 - Frequent hospitalizations and worsening health problems
 - Signs that your relative doesn't have bowel or bladder control
 - Comments from friends, family or doctors that things seem worse
- ◆ Recognize signs of "burnout" in yourself (irritability, not sleeping, unwillingness to let anyone help, exhaustion, depression).
 - ◆ Ask a friend how the situation looks from the outside.
 - ◆ Get a professional opinion of your relative's situation from a family doctor, VNA or geriatric assessment center.
 - ◆ Build a support system with family, friends, neighbors and professionals.
 - ◆ Develop a "Plan B" in case your relative's health gets worse. Current living arrangements may not suffice.
 - ◆ Follow other tip cards for using outside help, financial matters, making health decisions and staying organized.

12. When Family Members Disagree

- ◆ Plan to hold a family meeting. Invite all key people. Long distance family members can be included on a speaker phone.
- ◆ If possible, have a neutral mediator run the meeting (social worker or counselor).
- ◆ Ask those with strong opinions to write down their concerns.
- ◆ Before the meeting, develop a clear statement of the problem decide on a goal (what needs to be accomplished).
- ◆ Designate someone to take notes and to distribute the notes after the meeting.
- ◆ Start the meeting by sharing background information and listing things on which you agree.
- ◆ If you do not agree, try to develop alternatives. Brainstorm solutions.
- ◆ Discuss the situation with patience. Don't take things personally. Listen openly.
- ◆ Don't be discouraged if the first meeting doesn't run smoothly.
- ◆ Afterward, keep everyone in the loop, regardless of their participation. Widely communicated periodic updates and emails are useful.

13. Coping With Depression

- ◆ Recognize the symptoms of depression:
 - Feeling sad and hopeless most of the time
 - Difficulty sleeping
 - Feeling powerless
 - Crying frequently
 - Persistent fatigue
 - Considering suicide
- ◆ If two or more of the symptoms persist for more than two weeks, seek help from your doctor or a therapist. Clinical depression is beyond lifestyle changes and requires professional help.

- ◆ Dispel the stigma myth. Depression is not a sign that you are weak- it is often a biochemical response to overwhelming stress.
- ◆ Depression is most often treatable. Recognize untreated depression can get in the way of your ability to be a good caregiver.
- ◆ Find a doctor or therapist with whom you can communicate easily.
- ◆ Work with your doctor to find the right medication. Often a trial and error process must take place to find the right drug and dose for you.

14. When Friends Come To Visit

- ◆ When friends ask if they can visit, suggest a time that is helpful to YOU. “Could you stop by early Wednesday afternoon while I run an errand?”
- ◆ You don’t have to be the “hostess with the mostess.” Every visitor doesn’t need lemonade and cookies.
- ◆ Whenever possible, take time for yourself when you know your relative is with friends.
- ◆ If shorter visits are best, tell friends ahead of time “It would be wonderful if you could stop by before lunch for a short visit. A 15 minute visit gives Ted such a lift.”
- ◆ When someone drops in unexpectedly, don’t be afraid to say “Thank you for stopping over, but right now isn’t the best time.”
- ◆ Some friends give you energy and some drain it. Encourage the **energy boosters!**

15. Celebrating While Caregiving

- ◆ Continue to celebrate holidays and family events even if things must be done differently. Just dimming the lights and lighting a candle can be a celebration.
- ◆ When you receive an invitation, respond by asking whether you can stop by for part of the celebration. On the day of the party you should feel comfortable to make a short or long visit.
- ◆ Work out a way to go to celebrations even if your relative isn’t able to attend.
- ◆ Share your feelings and thoughts with someone outside your daily circle of support who might be able to help you find alternative ways to attend the celebration.
- ◆ Leave guilt at home. Remember that attending a gathering can be a break from on-going demands and will refresh you. Also, missing events may cause you to grow resentful of your caregiving role.
- ◆ Find ways to include your relative in some of the fun – bring home photos, flowers or a piece of dessert.

Top Ten Things You Must Do

1. Take care of your own health first. The best caregiver is a rested caregiver.
2. Learn about your relative’s health problems and medications.

3. Find a doctor who will help you manage your relative's health.
4. Organize health and financial records. Have living Will and Health Representatives documents in place.
5. Have Power of Attorney in place.
6. Keep emergency numbers and medication information on your refrigerator and in your car.
7. Modify your home for safety and independence.
8. Find at least one other person to be a back-up and support for you.
9. Join a caregiver support program.
10. Keep a positive attitude and laugh every day.