

What You Need to Know About Becoming a Caregiver

A caregiver is an individual (family member, friend or health care professional) who assumes care for another person. Basically, there are two types of caregivers: primary caregivers, who assume regular care for an individual, and secondary caregivers, who supplement the primary caregiver's efforts as needed. This guide will introduce you to the role of a caregiver and help you assess your own situation so that you can determine if you are ready to take on the role of caregiver—and in what capacity.

The Role of a Caregiver

Defining the role of a caregiver is not easy. The role and responsibilities of caregiving are as varied and individual as the people who do it. Caregivers perform a variety of tasks, which may involve helping a loved one shop, cook or clean; managing financial, health or legal affairs; or assisting with activities of daily living (eating, bathing, dressing and using the restroom). Each individual situation is unique, but ultimately, caregivers provide support—emotional, physical and sometimes financial—to another person to help him or her live more comfortably.

How Much Help Does Your Loved One Need?

Knowing when to take on the role of caregiver can be a difficult decision that requires careful thought and planning.

Connie works full time, but stops by her mother's house every day after work. "I help my mother as much as I can," Connie explains. "Recently I started paying for someone to cook and clean twice a week, but I'm afraid that soon she'll need more help than I—or a housekeeper—can provide. What are my options?"

While you want to protect your loved one, you also want to respect his or her need for privacy and independence. This balancing act can be difficult, but it is imperative that you carefully assess your loved one's needs—as well as your own—on a regular basis.

If you are living in close proximity to your loved one, check on him or her regularly via phone calls and visits. (If you are caring for a loved one from a distance, please see *A LifeCare® Guide: Caring for Your Loved One From Afar.*) Keep the lines of communication open and ask your loved one to tell you about any specific concerns or needs he or she may have. In addition, take note of his or her living conditions and daily habits. To help assess your loved one's needs, ask yourself the questions on the following page:

Is your loved one able to:

1. Dress and undress without help each day? Yes No
2. Drive or use public transportation without assistance? Yes No
3. Shop for groceries and clothing without help? Yes No
4. Prepare healthy, regular meals? Yes No
5. Take a bath, shower or sponge bath without help? Yes No
6. Get in and out of bed without help? Yes No
7. Be left alone during the day? Yes No
8. Pay bills and manage finances without help? Yes No
9. Clean his or her home or apartment? Yes No
10. Live alone comfortably and confidently? Yes No
11. Remain active and interested in life and hobbies? Yes No
12. Walk, climb stairs, and get around the house easily? Yes No
13. Remember to take medications? Yes No
14. Keep up minimum weight (no diminished appetite)? Yes No
15. Adequately manage household duties? Yes No
16. Continue to care about health and wellness? Yes No
17. Maintain a positive attitude? Yes No
18. Generally take care of him or herself? Yes No

If you answer “no” to even one of these questions, you may need to monitor your loved one more closely and/or he or she may require additional care.

How much care your loved one requires will vary depending on the situation. If, for example, your loved one seems capable of handling most household affairs except for managing finances, simply assisting with this yourself or hiring a bookkeeper or accountant may help. If, on the other hand, your loved one is unable to shop or cook for him or herself, you may need to find more regular care in the form of meal-delivery services or a homemaker. And if your loved one requires help with activities of daily living (such as eating, bathing and dressing), he or she may require additional assistance in the home or, in the case where more care is needed, may need to consider moving into your home or a care facility. Whatever the situation, trust your instincts. If you think your loved one needs more care, you are probably right. *Note*—If your loved one requires 24-hour care, he or she may need more care than you can provide. Consult a doctor immediately and refer to other guides in the LifeCare® Adult Care series for information about professional care options.

Discussing Caregiving Options With Your Loved One

Unless your loved one is unable to physically communicate with you, any caregiving decisions, or changes in his or her living situation, should be made together. Discussions about future care can be challenging, especially when they involve sensitive issues like independence, health, personal information, finances and changing family roles, but by expressing interest in your loved one's health and well-being, you show you care.

In addition to communicating your own concerns, encourage your loved one to tell you about his or her needs, fears and concerns. Many older people express fears of illness, loss, displacement, and of being a burden to their caregivers. Ask for input on what your loved one wants and encourage him or her to be an active participant in all decisions that involve his or her welfare.

The following tips may help you communicate openly and sensitively with your loved one:

- ◆ Respect your loved one. You are not parenting your loved one; rather, you are working with him or her to devise a caregiving plan that benefits both of you.
- ◆ Ask pointed questions that require specific answers.
- ◆ Listen carefully and repeat back what you've heard. Do not jump to conclusions and don't make assumptions. Ask if your understanding of what he or she is saying is correct.
- ◆ Be patient. Allow time for your loved one to formulate his or her thoughts and put those thoughts into words.
- ◆ Allow for negativity. Remember that your loved one is facing life changes that may be difficult.
- ◆ Talk about your own feelings and be personal. Statements such as, "I wish," "I'm worried or concerned," and "I feel," can ease tension and let your loved one know that you're concerned about his or her well-being.
- ◆ Let your loved one know that he or she is not alone and that you are there for support.
- ◆ Take a step back. If you find yourself arguing with your loved one, take a break and come back to the discussion later.
- ◆ Listen to the message beneath the words. Pay attention to body language and facial expressions and make sure you hear all of what is being said (or not said).

By simply communicating with your loved one and sharing your concerns, you should start off your role as caregiver on a positive note.

Caring for Your Loved One—Are You Ready?

Managing the care of an adult loved one can be challenging. Before you make any promises or commitments, decide how involved you're willing and able to be in the day-to-day caregiving of your loved one. For example, are you only available to visit two or three times a week or can you provide full-time care for your loved one? Can you manage the care of your loved one on your own, or will you need help from other family members or professionals? These questions and more need to be addressed before you make any commitments. Ask yourself the following questions, and be honest! If you do not have time to care for your own needs, you will have a difficult time caring for a loved one. These questions should serve as a guideline only. Adapt them to your own needs and ask additional questions as you see fit.

- ◆ How much care does my loved one require per week?
- ◆ How long do I expect this caregiving arrangement to last?
- ◆ How long can I commit to this caregiving arrangement?
- ◆ Will other family members be available to share caregiving responsibilities?
- ◆ In what ways can I reasonably redesign my life, activities and family responsibilities to accommodate the caregiving needs of my loved ones?
- ◆ Can I rearrange my work schedule to accommodate my caregiving responsibilities?
- ◆ Can I afford to take time away from my job to be the primary caregiver for my loved one, if necessary?
- ◆ Are there sufficient funds/resources available to hire a professional caregiver if necessary?
- ◆ Does my employer offer any adult care benefits?
- ◆ Will I be able to give my other family members enough time if I become the primary caregiver?
- ◆ Do my family members feel comfortable caring for my loved one in our home?

When answering these questions, and trying to determine how much time you can devote as a caregiver, remember that numerous resources are also available to help. Before making a definitive decision, investigate respite care—temporary care that can be provided inside or outside the home that provides a break for caregivers and socialization and care for an older person. (For more information on respite care, please see *A LifeCare® Guide: Senior Services and Respite Care*). In other words, try not to make a firm decision about your caregiving role until you explore all of the resources available to you. And remember, if your initial plans or arrangements do not work out, you can always adjust or revise them. Additionally, if you determine that you are not capable of providing the care your loved one needs, investigate professional care options. For more information, please refer to other guides in the LifeCare® Adult Care series.

At-Need Caregiving

Unfortunately, you may not always have time to properly prepare for the role of caregiver. Instead, you may find yourself thrown into the role due to a health crisis or emergency situation. If this is the case, you may need to make fast decisions, sometimes in the midst of a crisis, but do your best to remain calm and think things through clearly and rationally.

If, for example, your loved one is hospitalized, you may need to make arrangements for care after he or she is discharged. At this

point, many caregivers are faced with the decision of whether their loved one should move in with them—or whether he or she would be better off in a care facility such as a nursing home. This is a personal decision that should be made by you, your family members and the appropriate professionals. All hospitals should assign you a social worker, or discharge planner, who can discuss various options and help you find suitable care arrangements for your loved one. Listen carefully to the various options, and investigate as many as possible before making any firm decisions. Hasty decisions made in the face of a crisis may not be the best ones. If you require additional help developing a care plan, consider hiring a geriatric care manager. For more information on geriatric care managers, please see *A LifeCare® Guide: Caring for Your Loved One From Afar*.

Involving Immediate Family Members in Caregiving Arrangements

If you plan to be the primary caregiver, discuss what it means to your immediate family, especially if your loved one will be living with you. Remember, this is a change for everyone involved, and transitions can be difficult. Call a family meeting to discuss your options. If you acknowledge your concerns, and give your family the opportunity to voice their feelings, you will all adjust more easily to the changes. Here are some suggestions for making the transition as smooth as possible.

- ◆ Explain your loved one's needs and your decision to take on the role of caregiver. Review all the positive aspects of caring for your loved one: renewing or beginning a relationship, strengthening family ties and/or allowing your loved one to live in a home environment for as long as possible.

- ◆ Create a plan for integrating your loved one into your family. Discuss roles and responsibilities, determine who will do what and when and also consider roles of other caregivers (family members or professional caregivers).
- ◆ Pick a time to meet as a family on a regular basis. Simply knowing that you have a forum to talk about how you feel will help to ease the transition.
- ◆ Be willing to revise your plan each time you meet. Caregiving roles can change as a loved one's needs change.
- ◆ Make lists of your needs and problems as they arise to help clarify the kind of help that you may need.
- ◆ Provide support to one another on an ongoing basis.
- ◆ Give yourself the freedom to make mistakes. This is a time of transition, and you will be experimenting with what works and what doesn't.

Remember, it's important to acknowledge the difficulty of change and to continue to be loving and supportive of each other, despite the difficulties. The more you work together as a family, the stronger you will become.

Sharing Caregiving Responsibilities With Siblings

Many caregivers depend on siblings for support—physically, emotionally and financially. Unfortunately, however, siblings don't always respond as you might hope, and the stress of caregiving can reignite old conflicts and create new conflicts. Generally, one sibling ends up assuming a majority of the caregiving responsibilities for various reasons—he or she may be closer to your loved one geographically or emotionally, or he or she may have fewer responsibilities and/or more time

to give. In any case, if you are sharing caregiving responsibilities with your siblings, there may be times when you disagree on the best course of action. Try to keep in mind that you all want what's best for your loved one.

The following tips may help you and your sibling(s) work together without straining your relationship:

- ◆ Call a family meeting. Get together with your sibling(s) to discuss your loved one's situation, what needs to be done and how you can work together to accomplish it. Allow each other to air concerns and tensions, but try to avoid bringing up old conflicts.
- ◆ Divide up caregiving responsibilities. Draw up a list of tasks that need to be done—doing paperwork, making phone calls, researching home health care, talking with a lawyer—and divide them up among you and your sibling(s). This will ease the caregiving demands placed on the primary caregiver and help the others provide valuable help and input.
- ◆ Write and call siblings at least twice a month to apprise them of your loved one's current situation and future needs. Be sure to ask for their input—regardless of whether they respond. Keep a copy of all correspondence to avoid future conflicts over any decisions made relating to your loved one's care.
- ◆ Consider hiring a geriatric care manager to help divide up responsibilities or guide decisions about your loved one's care, especially if you and your sibling(s) cannot agree. Sometimes you might all be more willing to listen to a neutral third party if emotional tensions between you and your sibling(s) run high.

Remember that sharing caregiving responsibilities with your siblings can also be a positive experience. It may be a chance to bond with your siblings despite busy schedules, long distances and different life interests. You may be pleasantly surprised by the renewed and/or strengthened relationships that develop.

Helpful Resources

Children of Aging Parents

1609 Woodbourne Road, Suite 302A
Levittown, PA 19057
800-227-7294
215-945-6900

This national, nonprofit organization provides information about caregiving, support groups and other resources. Membership offers enhanced services.

Family Caregiver Alliance

Market Street, Suite 600
San Francisco, CA 94104.
415-434-3388
www.caregiver.org

This organization serves as an information clearinghouse for caregivers and sponsors education and training programs nationwide.

National Family Caregivers Association

10400 Connecticut Avenue, #500
Kensington, MD 20895-3944
800-896-3650
www.nfcacares.org

This organization's goal is to support family caregivers and promote self-advocacy and self-care for caregivers. It provides caregiving tips, educational materials, and a caregiver newsletter.

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