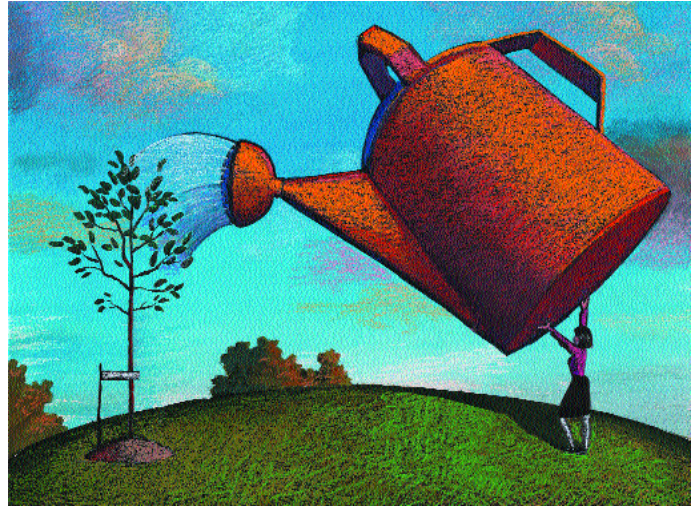


NOW YOU ARE A CAREGIVER

"The caregiver often becomes the critical factor in making the truncated doctor-patient meeting work, preparing questions in order of importance, making sure they are delivered forcefully (perhaps in advance of the visit by fax, Email, voice mail) and that they are answered. Staunch sidekicks are more likely than patients to hang tough as a doctor sighs and looks at his watch."

- Adapted from In The Country of Illness
by Robert Lipsyte



WHAT IS A FAMILY CAREGIVER?



At a time when hospitals are releasing patients earlier, the elderly are living longer, and people are living with many chronic illnesses, more family members and friends have begun to care for loved ones at home. Often, people find themselves having to perform new and unfamiliar tasks. These may include giving medicines, helping with personal care, assisting with meals, and even performing medical and nursing procedures. While there are a host of names to describe this role – “primary caregiver” ... “care-partner” ... “informal caregiver” – the term “family caregiver” may be best. **A “family caregiver” is anyone who provides any type of physical and/or emotional care for an ill or disabled loved one at home.** For this definition, “family” refers to a nonprofessional who is called “family” by the person who is sick. Sometimes, family is whoever shows up to help.

There are different types of family caregivers. Some caregivers are parents of children with physical, mental, or emotional illness. Some are adult children of aging and frail parents who can no longer care for themselves. Others are spouses, life-partners, family members, neighbors or friends, caring for loved ones suffering from an illness or disability. People can become caregivers gradually when a loved one develops a progressive illness that worsens over time, or they can be thrust into the role unexpectedly when a family member has a sudden medical illness, accident or injury.

Regardless of how you became a caregiver, you are about to take on a new role for which you may not feel prepared. It is normal for you to feel nervous or overwhelmed about what is expected of you. You may experience a number of mixed emotions including anxiety, anger, and sadness. At the same time, you’ll probably feel the desire to care for your loved one as best as you can.

This guide is provided to help you feel less alone and overwhelmed, and to aid you in becoming the best caregiver you can be. This means helping you get information, recognize when you need help, ask for and accept assistance from others, and take care of yourself. This guide will also help you be a more prepared caregiver by:

- n Offering practical tips, facts, and advice about caring for a loved one.
- n Providing a way for you to organize resource and medical information.
- n Helping you recognize and attend to your own needs.

Am I a Caregiver?

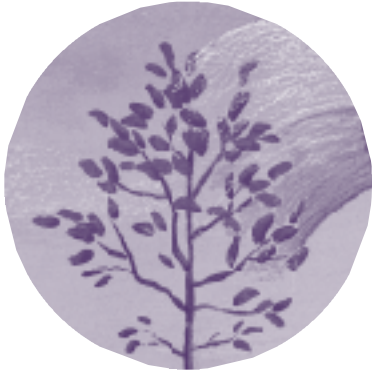
Some people don't think of themselves as caregivers because caring for a loved one seems like second nature or a family duty. However, in many ways, caregiving is like a new job. It may require learning new skills, shifting previous roles, and tackling demanding tasks. In order to best prepare yourself to care for a loved one who is ill, you need to first think of yourself as a caregiver.

You are a family caregiver if you currently or soon will provide unpaid care to an ill, frail, or disabled family member or friend by (check those that apply to you):

- o Assisting with areas of personal care that he/she can no longer manage (dressing, bathing, toileting, feeding)
- o Providing transportation and assistance (for appointments, errands, medical emergencies or crises)
- o Helping with daily activities and maintaining the household (grocery shopping, picking up prescriptions, cleaning)
- o Governing finances (paying bills, managing a bank account, bookkeeping)
- o Participating in medical/nursing care at home (administering medications, performing medical and nursing procedures, communicating with the health care team)
- o Providing emotional support and companionship (talking, reading, and listening)
- o Organizing home health care (clarifying expectations, supervising and communicating with homecare staff)

If you checked any of the boxes, then you are or will soon be a family caregiver. How do you feel? Concerned... Anxious... Angry... Resentful... Guilty... Accepting... Embarrassed... Shocked... Sad? It is completely normal to have many different emotions about taking on this new role. You may even find yourself experiencing a confusing combination of feelings all at once. Most people are not trained or prepared to be caregivers, so the prospect of assuming these responsibilities can be frightening.





Address Your Feelings

Although these feelings are expected and often subside on their own, they can be upsetting.

Some people have trouble adapting to the new situation. It is important to recognize if this is happening to you and, if so, to talk to someone. Friends and family members are a great place to start. Try not to think about being a “burden” on others or hold back in fear of their judgment. You are experiencing a big challenge and it is okay for you to turn to your family and close friends for help.

Sometimes you may not feel comfortable sharing certain feelings with those who also have a relationship with the patient. However, this does not mean that you should ignore or hold these emotions inside. Finding an uninvolved party to listen to your concerns can be very comforting and necessary during this time. The more in touch you are with your feelings, the better you will be able to cope when faced with

the stress of caregiving. There are many places you can turn to find someone who will listen and offer support while you express your feelings:

- n Support group at a local hospital
- n Your church, synagogue, or mosque
- n A psychologist, social worker, or therapist
- n Internet chat rooms with other caregivers (see Appendix G)
- n National caregiver organizations (see Appendix A)
- n National or regional organizations specific to your loved one’s illness (see Appendix B)

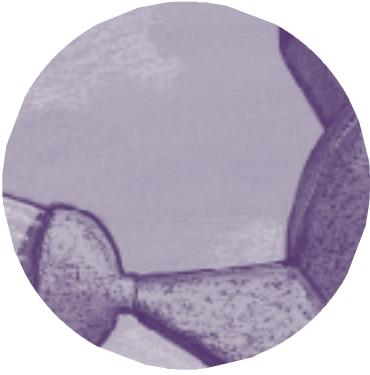
Boost Your Knowledge

Many new caregivers find that learning about caregiving and the patient’s illness helps relieve their anxiety. The remainder of this guide will give you practical information and tips to prepare you as a caregiver. At the end of the guide, you will also find listings of organizations, books, and websites that offer all types of caregiving and disease-specific information.

Helpful Resources for Caregivers (full listing in Appendix A):

- s **National Family Caregivers Association**
Maintains a peer support network that puts caregivers in touch with others in similar situations and offers a newsletter and other printed materials with information and resources.
- s **Well Spouse Foundation**
Provides support to spouses/partners of the ill or disabled through support groups, caregiver networks, and a bimonthly newsletter.

TAKING STOCK



If you are the primary family caregiver for your loved one, it will fall on you to work with the health care team and make sure that all of the patient's needs are met. This can be an overwhelming and strenuous task, especially if you try to handle all of the responsibilities on your own. It may not even be possible for one person to perform all of the duties required in caring for your loved one. In order to gain some control over the situation you must make a plan of action.

There are five main steps in developing a plan of action:

1. Determine the needs of the patient

List the activities that must be done for the patient to be properly cared for. Use the checklist at the end of this section to write down all of the patient's needs, being as specific as possible.

2. Decide which needs you can or would like to meet on your own

Once you see exactly what caring for the patient will require, you can assess your resources. There will be caregiving responsibilities you can handle on your own, and some that will require assistance. On the checklist, check off all of the tasks that you will perform yourself.

3. Determine which needs can or must be met by others

Though you may feel the desire to do everything on your own and not "burden" others, learning to ask for help is vital to minimize exhaustion – a condition called "burnout." This will also ensure that more of your loved one's needs will be met. Circle all of the tasks on the checklist with which you would like or need help.



4. Identify family and friends to whom you can turn for help

Family members and friends may be able to contribute to caregiving in many valuable ways, and are often willing to participate. It helps to know who you can count on to give you a hand. It is also useful to know which of your family and friends have skills in areas that could be of use. On the “Assessing Your Resources” page at the end of this section, list all the family members and friends that you can ask for help. Next to their names, record any specialized skills or resources that they may be able to offer. This may include legal advice, knowledge about medical insurance, cooking, money to spare for a loan, and time to run errands or provide companionship to you or the patient. Be sure to record the person’s schedule and when they are available or have free time.

5. Establish the need for outside professional help

You may find that there are patient needs that require professional assistance, such as nursing care, transportation, or respite care. You should not feel ashamed or guilty if you don’t feel comfortable performing certain medical procedures or need help with patient care. Depending upon your relationship with the patient, it may not seem appropriate to perform some of the tasks yourself. Keep in mind that the patient may also rather have professional assistance for more personal care to help maintain a sense of independence, privacy, and dignity. If this is the case, it is important for you to seek the appropriate assistance. In Appendices C-F, you will find a list of local agencies and organizations that offer such services. Also, if the patient has a social worker from a hospital stay, he/she can be contacted to help you think things through and make arrangements.

HOW TO ASK FOR HELP



Asking family and friends for help can be an awkward and difficult thing to do. In fact, many caregivers avoid asking for help and end up trying to do everything themselves. You may find that once you take the step and ask someone for help, it is much easier than you expect. Many times, family members and friends are willing, but just don't know how to help. You will likely find that once you ask, people are grateful for the opportunity to assist you. You may want to start with a small task, such as asking the person to spend some time with the patient or provide a meal.

Tips for asking family members or friends for help:

- n Sit down with them in person or find a quiet time to speak on the phone
- n Review the list of patient needs
- n Specifically discuss areas in which you think they could help
- n Ask them if they would like to participate

- n Inquire about whether they would like to help out in a particular area
- n Clearly explain the tasks and what they could do to help
- n Make sure that they understand exactly what would be helpful for you, as well as the patient

What you might say when asking for help:

"Jane, I am having some trouble finding time to do everything I need to do to take care of my mom. I could really use some help with the cooking, watching her when I have to go pick up the kids from school, and doing errands. If you would be willing, I think you could help with the errands since you live nearby and pass the shopping center on your way home from work. Do you think you would be able to help out in this way?"