

Chapter 2

Managing Care at Home

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Becoming the primary caregiver for a loved one can be a real challenge. You must learn to balance work, family, and your own needs, while caring for someone else and fulfilling some of the responsibilities he or she used to have. **Caregiving requires skills that you may not be familiar with, and demands the ability to manage your loved one's care almost as if it were a complex business project.** This chapter provides an overview of the different tasks involved in caregiving at home, and features an important discussion about organizing medical records, tracking treatments, and managing medications — some of the most critical jobs of a caregiver. Finally, it offers some guidance about how to prioritize your caregiving responsibilities, and offers tools to organize supportive family members and friends who may be able to help.



Identifying Critical Tasks

Some caregiving tasks are simple and basic, involving household chores and maintenance, while others are more private and involve hands-on patient care. Talk to your loved one about the tasks that need to be accomplished, and involve him or her in doing tasks whenever possible. Also, consider how much work it will take to accomplish each task—is it a one-time task or an ongoing need?

1 Identify tasks that are **routine** and tasks that involve **hands-on patient care**

2 Make a list of what tasks need to be accomplished and maintained

3 Estimate the hours per day, week or month that tasks will require

The Center for Caregiver Training suggests becoming familiar with tasks that may be new for you, but are common for home-care.¹ We've organized them in the chart at right.

Routine Tasks

Food Preparation

- Plan, prepare, and serve meals
- Buy groceries
- Clean kitchen

Managerial Tasks

- Manage finances, banking and bills
- Apply for social services and financial assistance
- Manage insurance
- Legal matters (examples: Advance Health Directives, Powers of Attorney)
- Manage medical appointments

Transportation

- Drive/assist with transportation to appointments and recreation
- Get disabled parking placard from DMV
- Run errands

Assuming a Loved One's Prior Responsibilities

- Care for pets, children and elderly/other family members

Housework

- Laundry
- Garbage removal
- House and yard maintenance

Tasks Involving Hands-on Patient Care

In-home Supervision

- Providing companionship
- Providing safety and comfort at home

Personal Hygiene

- Bathing
- Oral hygiene
- Skin and hair care

Medical/Nursing Care

- Managing and administering medications
- Lifting and transferring in and out of beds and chairs

Recreation

- Recreation and respite activities with family

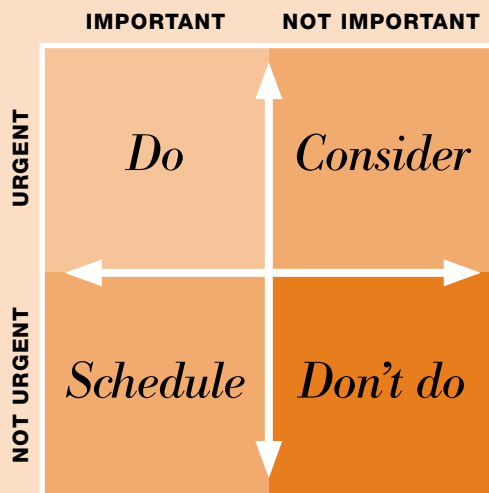
Accomplishing Caregiving Jobs

As your loved one's illness changes or progresses, responsibilities for care may change as well. You may find that you can only take on a limited number of responsibilities while you balance your life. As a primary caregiver, you may have the option of caring for your loved one yourself, coordinating a team of volunteer caregivers to help you, or hiring outside help from various organizations.

1 DOING THE JOB YOURSELF

If you will be doing the actual caregiving work, use these tips to help adjust to the role:

- **Prioritize your time and responsibilities.** Schedule your priorities. Determine which tasks in your life are urgent, which are important, which are both, and which are neither. This allows you to focus only on the necessary tasks to maintain your home and life.



Adapted from *First Things First*, (1994) Covey, Merrill & Merrill⁵

- **Explore your benefits.** Your employer may provide you with paid or unpaid medical leave for family caregiving. Discuss your benefits with your supervisor or Human Resources representative. If your loved one qualifies as low income, you may be eligible to receive financial assistance for care, or your loved one may be able to receive attendant care through In-Home Support Services.
- **Learn caregiving skills.** There are many organizations that offer one-day workshops and evening classes to teach caregiving skills. Find options by looking online or contacting local social service agencies that provide assistance to people with brain tumors, cancer or other disabilities. Consult a social worker or use the Yellow Pages to find help.

2

GETTING HELP FROM FRIENDS AND FAMILY

Bring family members and friends together, and request their help in caregiving. This may not be easy for you. You might find it difficult to ask for help, because it feels like an admission that you can't handle what you need to do, or because you feel you are imposing on others. Even if people do offer help, it can be difficult to accept.

It is important to get beyond these barriers because there are times when you simply can't and shouldn't do it all yourself. It may help to realize that **most family members and friends appreciate having the opportunity to be helpful**. At the same time, it is important to be sensitive to signs that volunteers are wearing out, in which case new ones need to be found. Sometimes, the "retiring" volunteers can help replace themselves.

Creating a *Care Team* will add support for your loved one and for you. If you choose to create a team of volunteer caregivers, it is critical to ask your loved one which people he or she would like involved, as they may have very personal interactions. The following is a list of ways to identify potential helpers.

Identifying Your Caregiving Team

- Ask your loved one and other family members who would be appropriate helpers.
- Explore your loved one's or your family's phone book or Rolodex for social contacts.
- Contact your loved one's or your family's social organizations such as religious organizations, workplace, social groups/clubs.
- Find professional home-care organizations through the Internet, local newspapers, and the phonebook.
- Consider people's skills, abilities to manage time and projects, and strengths and weaknesses.

Once you have put together a care team, you'll need to coordinate the members so that everyone's efforts are used most effectively.

Here are some suggestions.

Coordinate the Care

- You or a family member (not your loved one) should call to invite the person to help.
- Hold an introductory one-hour meeting for all team members to discuss the specifics:
 - issues regarding the illness and patient's needs
 - what the current needs are of the patient and family
 - the roles or tasks each member can take
 - exchange contact information
 - write down members' schedules, availabilities, tasks they're willing to do
 - delegate a "team leader" to make phone calls to team members during emergencies, when there is a change in plans, or to re-organize schedules
- Manage members' schedules on a master calendar that remains at the patient's home.
- Have an easily visible list of important information at patient's house including location of pharmacies, grocery stores, medical information, doctor's contact information.
- Have petty cash available for helpers in case of emergencies and an extra set of house keys.

You may find it helpful to keep your family, friends, and care team connected by creating a personalized web page at a site like www.carepages.com. "CarePages" are personal and free web pages that anyone can register for. Creating a care page is easy and offers you the ability to share photos, receive emotional support, and have a virtual meeting place.

3

PAYING FOR HELP

If you can afford it, you may want to hire someone to come to your home to help with health and home care. There are many professional agencies that offer home health aide services. You can choose home care providers with qualifications based on your needs. Service providers range from certified nurses, to informal companions, to house cleaners. Below are some suggestions for finding qualified professional help.

Tips for Finding Home Care Services

You can choose to advertise, interview and hire in-home help privately or you can go through an agency.

If you choose to hire privately, the advantage is that you can usually pay less per hour for help. However, this means you are an employer and must adhere to all employment laws including paying payroll taxes and carrying Workers' Comp insurance. The state Employment Development Department will help you set up the necessary paperwork.

The disadvantages are:

- There is no back-up if the attendant is sick or doesn't show up.
- The attendants are usually not bonded.
- You must conduct the interviews and do background checks.

If you use an agency, you will pay more per hour but they assume the employment responsibilities, bond and certify the attendants, and provide substitutes for sick days.

To find an agency:

- Request referrals for services from your doctor or social worker.
- Call the Patient Services department at your hospital for a list of qualified agencies.
- Search on the Internet or in the phone book for local care providers.
- Ask friends and acquaintances in all areas of your social circle for recommendations.



SEE THE APPENDIX

*for more information
on homecare and team
coordination.*

Getting Organized

When it comes to managing your loved one's health care, the more organized you are, the better. You'll be more prepared and have more control when it comes to making decisions, preventing medical errors, and having access to accurate information.

A great way to become organized is by keeping a health care binder. Many caregivers say that these simple books kept them focused, organized, and feeling in control particularly during emergency situations. To create a binder, go to an office supply or drug store and purchase:

- A large three-ring binder in which to keep all information
- Two or three packages of dividers with tabs so you can divide your binder into separate sections
- Two or three storage pouches (8 ½ x 11) that are three-hole punched, one with slots for business cards. One will hold CD-ROMs of your scans, while the one with card slots will hold business cards of your medical specialists, care providers, pharmacy, etc.
- Lined notepads that are three-hole punched so you can take notes on the paper and insert the sheets in the appropriate sections
- A three-hole puncher

Here are some suggestions for organizing your sections, made by Dr. Paul Zeltzer in his book *Brain Tumors: Leaving the Garden of Eden*²:

- **Pathology reports, MRI and CT scans** — these reports contain the most critical information about the tumor and diagnosis, and will direct the treatment options. Ask your doctor for a copy of scans on a CD-ROM or film, so you can bring them with you if you get second opinions or seek new treatment.
- **Lab reports and blood tests** — having copies of these on hand will allow you to quickly refer to them without having to ask the nurses or doctors to search for them.
- **Notes and questions section** — this is where you can write notes while at appointments, or keep a file of questions you need answered by the doctors.
- **Medication log** — see the appendix for a blank medication log on which you can fill in the medications being taken, dosages, dates, side effects, problems, who prescribed them.
- **Treatment log** — see the appendix for this form on which you can fill in the treatments your loved one has received such as radiation, surgeries, chemotherapy — including the dates, side effects, problems, doctor's information.
- **Resources and information** — this is where you can file the information/forms you've received or signed at appointments.
- **Calendar pages** — see the appendix for a blank calendar template that you can copy and fill in with dates — include medical and treatment appointments, home-care and therapy schedules.
- **Health History** — see the appendix for this form on which you can record important health information such as the patient's insurance policy number, emergency contact information, a history of other serious illness, allergic reaction to medications, or another condition that he or she is currently being treated for.



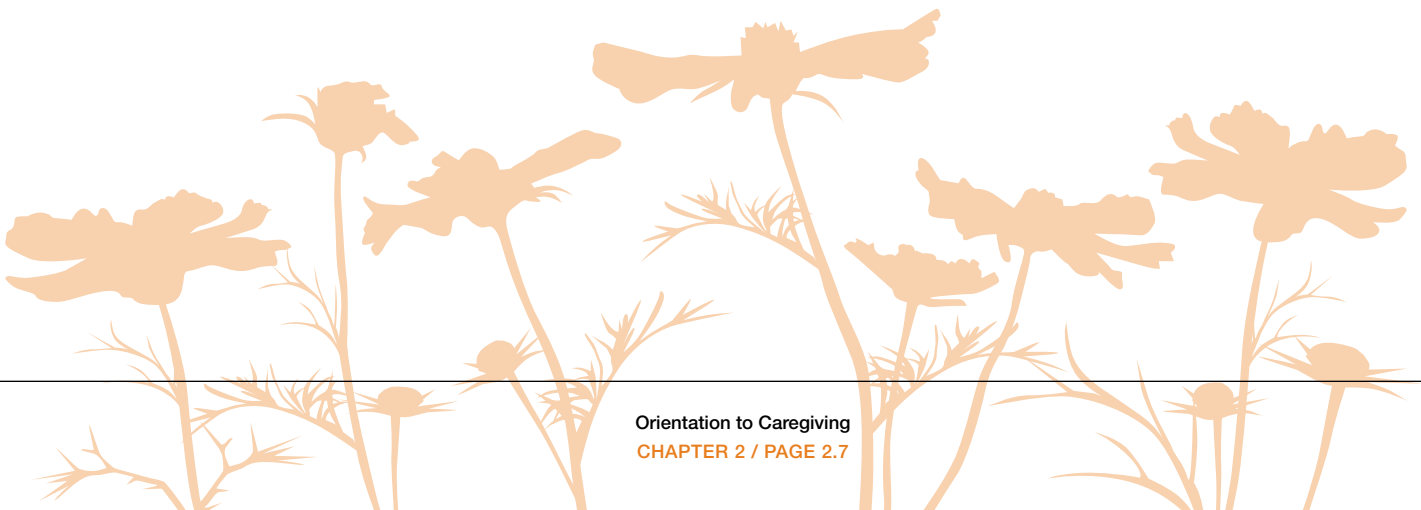
SEE THE APPENDIX for a blank medication log, treatment log, calendar template, and health history form.

Managing Medications

Living with a serious illness usually means taking multiple medications to treat the illness and side effects of treatments. Many patients take herbal therapies, vitamins, and supplements as part of their medical regimen. No matter what type of pills your loved one is taking, it is important to keep track of what is being taken and when. The majority of medical errors in this country are related to mistakes in medication usage³. Mistakes in the type of medication taken, the wrong dosage, or an interaction between drugs can lead to severe health consequences or worse yet, death. The best way to prevent this is to keep track of your loved one's medication regimen in an organized way.

Here are important tips for managing medications and preventing errors:

- 1** When you get the prescription from the doctor, make sure you can read the drug name and dosage clearly. If you can't, ask the doctor to print it out clearly (this will guarantee the pharmacist has the correct information).
- 2** Ask the doctor what it is for, what it does, and what to do if there are side effects.
- 3** Make sure the doctor is aware of all the other medications including supplements and herbal products that are being taken in case there are possible interactions.
- 4** Maintain an up-to-date medication log with all prescription and non-prescription items (including over-the-counter medications like antacids, supplements like vitamins, protein powders, herbs or other "holistic" treatments).
- 5** On your log include the name of the medication, dosages, medication schedule, the doctor who prescribed the drug, what it is for, and any side effects experienced.
- 6** When picking up the prescription, make sure the order has your loved one's name on it, and includes the correct pills at the right dosage.



Tracking Treatments and Side Effects

Once your loved one returns home after having treatments like surgery, radiation, or chemotherapy, symptoms or side effects of the treatments may occur. Some of these issues may be resolved by speaking on the phone with a nurse, and some may require follow up visits with the doctor. It is helpful to keep track of the treatments that were given and the symptoms or side effects that occurred in the treatment log.

If your loved one is experiencing pain at any point, you may want to use the common pain scale included in the appendix to rate the severity, and make note of when it happened so that the doctor can identify the cause and possibly change treatments or follow up with a different procedure.

Between physician visits record the following types of information in your treatment log¹:

- Medical treatments, procedures, and tests with corresponding dates
- Side effects of treatments with the time and date of occurrence
- Frequency of any seizures, brief descriptions, dates of occurrence
- Pain rating scale from 0–5
- Results of tests taken: blood pressure, blood sugar levels, seizure medication blood level
- Any symptoms out of the ordinary: pain, fevers and night sweats, nausea, lack of appetite, insomnia, fatigue, confusion, and anxiety



SEE THE APPENDIX for a treatment log and pain rating scale.

¹ Center for Caregiver Training; www.caregiving101.org; retrieved 2006.

² Zeltzer P, Brain Tumors—Leaving the Garden of Eden: A Survival Guide to Diagnosis, Learning the Basics, Getting Organized and Finding Your Medical Team (Encino, CA: Shilysca Press, 2004).

³ Institute of Medicine (IOM), “To Err Is Human: Building a Safer Health System”, 2000, <http://www.nap.edu/books/0309068371/html/>

⁴ Berger, M. S., personal communication, 2006.

⁵ Covey S, Merrill A, and Merrill R. First Things First (New York, NY: Simon & Schuster Inc., 1994).