

Orientation to Caregiving



*A Handbook for Family Caregivers
of Patients with Serious Illness*

U.S.

Caregivers Project / Osher Center for Integrative Medicine
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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A Handbook for Family Caregivers of Patients with Serious Illness

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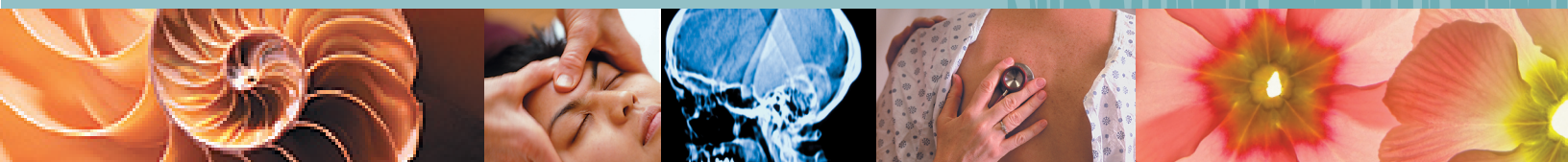
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Chapter 1

A Handbook about What to Expect as a Family Caregiver

There is no work more important, more challenging or more meaningful than caring for a loved one who is ill. About one-quarter of Americans will serve as caregivers to a beloved family member or friend.

Family caregivers quickly become experts at this demanding job but often feel like they have to “re-invent the wheel” in figuring out and prioritizing the many tasks involved.

This handbook has been developed to provide easily accessible and accurate information to family caregivers helping to care for loved ones with serious illness.



Handbook Overview

This information has been developed and reviewed in consultation with Celi Adams, RN, who founded Home Care Companions and Caregiving 101, nationally recognized family caregiver support organizations. Much of the content has been adapted from resources currently available on the Internet and from family caregiving organizations. At the end of each chapter we have noted the source of all borrowed material and appreciate the permissions we have received to present it here.

The handbook covers the full range of issues faced by family caregivers, including managing physical symptoms, caring for your loved one at home and in medical facilities, communicating with health-care providers, managing emotional distress, supporting the caregiver, and handling financial and legal issues.

The handbook is organized into eight chapters with multiple resources and appendices at the end.

- **CHAPTER 1** provides an overview of the handbook.
- **CHAPTER 2** focuses on routine family caregiving at home, including tips to help you manage medications and medical records and coordinate a care team.
- **CHAPTER 3** talks about the critical role of family caregivers at the doctor's office and in the hospital and gives you helpful communication advice when speaking with your medical team.
- **CHAPTER 4** provides helpful tips for communicating with your family.
- **CHAPTER 5** reviews the different types of health insurance, entitlements, and assistance that may be available to help you pay for health care and discusses how you can be an effective advocate for your loved one.
- **CHAPTER 6** introduces you to the legal documentation necessary to secure the patient's wishes for end-of-life care, estate plans, and personal business.
- **CHAPTER 7** describes palliative care options and provides meaningful recommendations for families at the end of a loved one's life.
- **CHAPTER 8** suggests strategies to maintain your own wellbeing and to give you a sense of control, hope, and balance.
- **THE APPENDICES** include a series of resources and more detailed information that you can turn to.

Importance of Family Caregiving

Caring for loved ones with serious illness means that you are dealing with medical issues at the same time that you also are serving as a source of important emotional support for the person who is ill. As a family caregiver, you are called upon to perform a large variety of tasks to provide care for your loved one. For example, family caregivers:

- Organize and administer medications
- Communicate with physicians, nurses, and social workers
- Provide transportation
- Take care of home chores including cooking and cleaning
- Help with dressing changes
- Assist with physical therapy and occupational therapy exercises
- Research and negotiate medical insurance benefits and submit claims
- Attend to business, legal, and financial matters
- Monitor medication side effects

For most family caregivers, responsibilities at work and home do not stop when a loved one gets ill. Your own personal needs for rest and attention to your own health do not go away either. This means that you may find yourself juggling multiple responsibilities, some of which may conflict.

Caring for a loved one who is ill often creates a deepened sense of closeness and connection between the two of you. You may experience increased intimacy, satisfaction, and pride. However, the anxiety that comes with dealing

with a serious illness, combined with the burden of caregiving, can create strain in the relationship and stress for you. At some points you may feel overwhelmed, guilty, resentful, angry, anxious, and even depressed.¹ These varied and complex emotions are common. **It is normal to feel both positive and negative emotions when providing care for a loved one who is ill.**

Sometimes circumstances thrust people into the role of caring for someone, often a relative, with whom they may have a strained relationship. This situation can intensify the usual negative emotions caregivers feel, especially guilt and resentment. Under these circumstances it is important to seek help both for the actual hands-on care and for emotional support.

While no amount of information can eliminate the physical work and emotional challenges of caring for a loved one who is ill, the helpful hints presented in this handbook are designed to ease the frustration and sense of isolation you may feel while doing what can sometimes seem like an impossible job. The handbook provides tips on which situations call for professional help, so you will have a better sense of what you can expect, when to call the doctor, and what you can do at home to help.

You are an instrumental part of your loved one's health care team. Our deepest respect goes to you for the assistance you graciously and lovingly offer.

¹ Gauthier A, Vignola A, Calvo A, Cavallo E, Moglia C, Sellitti L, Mutani R, Chio A: A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology*. 68(12):923-6, 2007.

Chapter 2

In this chapter:

- Identifying Tasks
- Accomplishing Caregiving Jobs
- Getting Organized
- Managing Medications
- Tracking Treatments and Side Effects

Managing Care at Home

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 offers guidance about how to prioritize your caregiving responsibilities and organize supportive family members and friends who may be able to help. Finally, it features an important discussion about organizing medical records, tracking treatments, and managing medications — some of the most critical jobs of a caregiver.



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
- Attend to 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

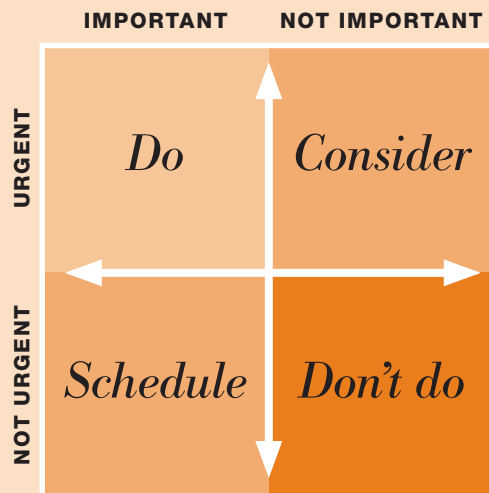
As your loved one's illness changes or progresses, responsibilities for care may change as well. You may find that you can only take on a limited number of responsibilities while you balance your life. As a primary caregiver, you may have the option of caring for your loved one yourself, coordinating 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 & Merrill²

- **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 the illness you are treating 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, cell phone, or email account contact list for phone numbers and contact information of social contacts.
- Contact your loved one's or your family's social organizations such as religious organizations, workplace, and 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.

Coordinate the Care

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:

- 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
 - what the current needs are of the patient and family
 - the roles or tasks each member can take
 - team contact information
 - members' schedules, availabilities, tasks they're willing to do
 - delegation of a "team leader" to make phone calls to team members during emergencies, when there is a change in plans, or to reorganize schedules
- Manage members' schedules on a master calendar that remains at the patient's home.
- Have an easily visible list of important information at the patient's house, including location of pharmacies, grocery stores, medical information, and doctor's contact information.
- Have petty cash available for helpers in case of emergencies and an extra set of house keys.

You may decide to access resources on the Internet, such as Lotsa Helping Hands at www.lotsahelpinghands.com. This site offers free tools to help you organize and manage your community of helpers, with online calendars and message boards. Personalized "Care Pages" at a site like www.carepages.com are personal, no-fee web pages that you create. Developing 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*³:

- **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, and 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, surgery, or chemotherapy — including the dates, side effects, problems, and 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 usage⁴. 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 complementary 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

Treating a serious illness may involve different therapies, such as surgery, radiation, chemotherapy, and drug treatments. It is common for some treatments to cause new symptoms or side effects afterwards. 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 log⁵:

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



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

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

² Covey S, Merrill A, and Merrill R, *First Things First* (New York, NY: Simon & Schuster Inc., 1994).

³ 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).

⁴ Institute of Medicine (IOM), *To Err Is Human: Building a Safer Health System*, 2000, <http://www.nap.edu/books/0309068371/html/>

⁵ Berger MS, personal communication, 2006.

Chapter 3

In this chapter:

- Getting Care at an Academic Medical Center
- A Multidisciplinary Medical Team
- Caregiving in the Hospital
- Caregiving in the Clinic

Tasks of Caregiving in the Hospital and Clinic

As a family caregiver, your critical role isn't limited to the home. You are also an important part of your loved one's care when he or she is visiting the doctor in clinic or is receiving care in the hospital. **This chapter will review the roles of certain staff and doctors, explain what goes on in the hospital and clinic, and provide helpful tools to giving care in these settings.**



Getting Care at an Academic Medical Center

UCSF's Moffitt-Long Hospital is part of a university that trains health care professionals, includes many ongoing research activities, and hosts health students for their clinical training. It is a full-service hospital with many more layers of services than a community hospital. Here patients are cared for by medical students, interns, residents, fellows, and nursing students, under the direction of a primary doctor.

At UCSF, attending physicians generally have continuity of care with patients, meaning they treat the same patient in both the hospital and clinic. However, a resident physician who works in the hospital may not see a patient again after hospitalization. Direct physician communication, inpatient (hospital) charts, and outpatient (clinic) charts serve as communication links between the two services. Be informed about your loved one's medical history, current treatment plan, and, most important, medications, so you can correct inaccuracies if they arise. Remember, all patients have the right to view and have copies of the information in their chart. Ask the nurse or the attending physician for access to them so you can make copies for your files or enter important notes.

The Healthcare Team at a Teaching Hospital

If your loved one is admitted into the hospital, he or she will be cared for by a team of health care professionals. The following is a list of hospital staff members:

- **Physicians** are responsible for managing your loved one's care. If necessary, the doctor may consult other specialists. Your loved one may be seen by a team of doctors, including fellows, residents, interns, and medical students who work with the attending physician.
- **Attending physicians** are leaders of the team that determine and supervise your loved one's medical care. Attending physicians also teach other doctors to care for patients. Your loved one will be assigned an attending physician. They change periodically, so please ask the nurse or doctor about the scheduled rotation of doctors on your unit.
- **Fellows** are physicians who have completed their residency training and are now receiving advanced training in a specialty. Fellows work with an attending physician and help teach interns and residents under the guidance of attending physicians.
- **Residents and interns** are physicians completing their training. Interns are in the first year of training after graduating from medical school. Residents are physicians who have completed at least one or more years of training after medical school. Interns and residents are sometimes referred to as "housestaff." They work under the guidance of attending physicians and fellows and often have to stay overnight in the hospital "on call."
- **Medical students** are third and fourth year students of the School of Medicine who are conducting their clinical rounds prior to their graduation and residency.
- **Charge nurses** are responsible for overseeing the nursing care on your hospital unit during a shift.
- **Clinical nurse specialists** are registered nurses with advanced education in special areas. These nurses help coordinate your loved one's care.
- **Nurse practitioners** are registered nurses with advanced education in special areas. These nurses have training and skills in assessment, physical diagnosis, and management of health needs in their specialty areas.
- **Patient care managers** are responsible for supervising all nursing care on every shift on your unit.

A Multidisciplinary Medical Team

Medical care becomes complex when a person is treated for a serious illness. In addition to the hospital team common at a university medical center, a team of specialists for inpatient and outpatient care may be needed to address all of the patient's needs. When putting together a medical team that will be a good fit for you and your loved one, it may help to consider whether you are comfortable asking the doctor important questions, and whether the doctor gives you the time you need and seems respectful of your loved one's health care needs.

In some cases it may be helpful to get a second or third opinion. Many specialists will support your desire to get other doctors' opinions to ensure that you are comfortable with the treatment options you ultimately choose. Today there are many organizations dedicated to providing information on specific illnesses, with staff to help you choose treatment centers and coordinate members of your medical team.

If you have not dealt with health complications in the past, you may quickly need to figure out how to coordinate communication with a multidisciplinary medical team, as well as your loved one's other caregivers. You will also need to become skilled at managing medical records that are generated by the various providers.

The following list includes many health care professionals who might be involved in comprehensive care for your loved one.

Chaplain — This trained professional, often a member of the clergy, can help support patients in the hospital who are facing serious illness both emotionally and spiritually.

Child-Life Specialist — This is a therapist trained to support children facing serious illness themselves or in their family.

Hematologist — This physician is trained in disorders of the blood and blood-forming organs. This specialty is separate from oncology, though the fields often overlap. Hematologists may specialize in blood cancers, blood transfusions, or bone marrow and stem cell transplants.

Neurologist — This physician specializes in issues related to the nervous system. The field of neurology covers a wide range of diseases, disorders, and injuries related to the functions of the brain or spinal cord. Some neurologists specialize in treating specific neurologic conditions such as Alzheimer's disease or cerebral palsy.

Oncologist — this physician specializes in the diagnosis and treatment of cancer and may have expertise in a specific type. A clinical oncologist is usually trained in one of the three primary disciplines of oncology:

- Medical oncology — treatment of cancer with medicine, such as chemotherapy
- Surgical oncology — surgical aspects of cancer, including biopsy and removal of tumors
- Radiation oncology — treatment of cancer with therapeutic radiation

**Just like choosing a primary care physician who attends to your health care needs, many cancer patients choose their oncologist carefully, sometimes basing this decision on personal values such as treatment goals, location, and expertise in type of treatment offered.*

Pathologist — This doctor identifies diseases by studying cells and tissues (biopsies of tumors, for example) removed by another doctor and sends your medical team a pathology report,

which guides your treatment options. Obtain a copy of this report for your medical files so you can refer to it when determining your treatment options or a second opinion.

Palliative care team — A palliative care team (usually consisting of a physician, nurse, social worker, and chaplain) provides assistance with symptom management and works to improve quality of life for patients and their loved ones. The team focuses on quality of life issues, including pain and other bothersome symptoms, emotional distress (including adjustment to bad news, depression and anxiety), social issues (including social services, family distress, sites of care, and home support), and existential issues (including spiritual distress). The palliative care team can provide support at any point along the course of illness, from the moment of diagnosis, regardless of prognosis.

Primary care physician — This is the local internal medicine or family doctor whom your loved one sees for common health problems when they first arise. This doctor often refers patients to specialists for more complicated or specific problems. (Most insurance companies require you to get a referral from your primary care physician to see specialists). Although this doctor may not be an expert in the treatment of serious illnesses, he or she is familiar with your loved one and can help coordinate the care received from all the specialists. This physician can be seen for urgent care if the specialist is not accessible or to help treat the side effects associated with other treatments.

Psychologist — This mental health professional helps patients identify sources of emotional unrest and offers strategies and counseling to promote mental wellbeing and enhanced quality

of life. It is not uncommon for patients with significant illness to experience depression due to side effects of other treatments and life changes they are adjusting to. Psychologists can help patients and caregivers cope with important issues and life changes that may be overlooked by the doctors who provide technical medical care.

Psychiatrist — This is a physician who specializes in diagnosing and treating mental health disturbances, some of which may result from treatments like surgery or radiation. Psychiatrists are an important part of the medical team because they can prescribe and adjust medication dosages and may also provide counseling to help manage these symptoms.

Radiologist — This doctor specializes in diagnosing and treating diseases with medical imaging technologies such as MRI, CT, PET, and ultrasound. Some radiologists specialize in treating particular diseases, and some doctors who specialize in treating specific illnesses may be trained in using radiation therapy.

Social worker — These are licensed professionals employed by a hospital, treatment center, non-profit organization, and/or through private organizations. They are available to assess patient and caregiver needs (medical, financial, and emotional); develop a plan of care; and help obtain the services needed. You should schedule a meeting with the social worker upon admission to your treatment center or seek a referral to a social worker from an appropriate health care organization (example: The Wellness Community, Cancer Care, Family Caregiver Alliance).

Rehabilitation Therapists

After most major surgeries or injuries, it is common to need some rehabilitation therapies to improve physical strength, coordination, communication, mobility, or mental functioning. These treatments can greatly enhance a person's ability to function and thus improve quality of life.¹ Your loved one's medical team will likely prescribe rehabilitation therapies after surgery or during ongoing treatment. If your loved one is not prescribed rehabilitation that you think he or she would benefit from, you can consult with a nurse or social worker and request these services.

Some of these therapies are available in-patient (while the patient stays at a center) or outpatient (day treatment) at a clinic or your home. Call your insurance company before beginning treatment to determine if they will cover services or if you will need to pay out of pocket. Here are examples of common rehabilitation specialists.

Occupational therapist — This is a licensed practitioner who helps people regain independence in self care, work, and day-to-day functioning, by adapting tasks or the environment (such as incorporating assistive devices) to meet the person's capabilities and level of function.

Physical therapist — This is a licensed practitioner who works with patients following disease, injury, or loss of a body part, to restore physical function and prevent disability. The therapist evaluates physical factors such as pain, endurance, strength, and balance and treats them with exercises and adaptive equipment.

Speech therapist — This therapist specializes in diagnosis and treatment of disabilities in speech, language, voice function, swallowing, and non-verbal communication such as facial expressions.

In addition to your team of specialists, other health professionals help to ensure your loved one receives the care he or she needs:

- **Patient care assistants** are trained to help nurses care for patients. They work under the supervision of a nurse and provide routine care activities but do not give medications.
- **Patient support assistants** help units stay clean and equipped.
- **Unit coordinators** provide clerical support and directions and answer questions for families and visitors.

Caregiving in the Hospital

Hospital Admissions

Before your loved one is admitted to the hospital, an admissions counselor may call to obtain preliminary information, provide important information regarding the hospital stay, and answer questions. The doctor also may schedule routine medical tests, such as laboratory tests or X-rays, before hospitalization. Other routine tests may be done on the day of admission and throughout the hospital stay. Most hospitals have Patient Pre-Admissions Guides to provide families with specific information on the hospital's services. You may obtain a copy of this through patient services.

Medical Team Schedules

Once admitted into the hospital, patients are typically seen by housestaff and attending physicians. After the initial evaluation, patients are generally seen by physicians on a regular daily schedule called "rounds." It is helpful to know your loved one's doctors' rounding schedules so that you can be present to ask questions when they visit.

- Nursing schedules vary; most nurses are on 12-hour shifts.
- Residents commonly make rounds in the early morning, between 6:30-7:30 a.m.
- Attending physicians' rounds vary from mid-day to late in the evening.
- Ask your loved one's doctor a day in advance when he or she expects to be in, and allow a window of one to two hours around that time so you are present when the doctor visits.
- Keep a daily list of any questions you may have for your loved one's doctor, and remember to write down the answers.

What You Should Know about Surgery

Knowing what to expect when your loved one has surgery, including timelines of procedures, tests, and hospital stay, will prepare you and reduce your stresses. The following is a list of questions to ask your doctor prior to undergoing surgery:

- 1 What is the routine timeline to expect for the surgery?
- 2 Will my loved one be in the Intensive Care Unit?
- 3 What do I need to know about the post-operative stage?
- 4 What is the expected length of stay in the hospital?
- 5 Will I receive a pathology report? If so, how long will it take until I receive it?
- 6 What resources are available post-operatively?
- 7 How do I schedule a meeting with a social worker or case manager?
- 8 What condition should the patient be in when leaving the hospital (activity level, ability to eat and drink, pain)?
- 9 What signs or symptoms should I be aware of once we return home?
- 10 Which health care provider do I contact if complications arise once the patient is home?

Preparing for Hospital Discharge

Once the surgery is over, you will discuss discharge plans with your loved one's health care team, including the services and treatments your loved one will need once they leave the hospital. A patient may require nursing care or physical therapy at home after hospitalization. If your loved one is not physically able to return home upon discharge, staying in a skilled nursing facility or rehabilitation hospital may be necessary for some period after hospitalization.

Before leaving the hospital, you can request to schedule an appointment with a medical social worker in the hospital or from your treating doctor's team. These professionals are available through UCSF Care Coordination and the UCSF Cancer Center to discuss what treatments or services the doctor is prescribing as "medically necessary," resources that you may need for home caregiving, and the best ways to obtain services. Other non-profit agencies such as the Family Caregiver Alliance or Cancer Care may offer social work services to families online or via telephone.

Social workers

also provide emotional support in the hospital and help with communication with the medical team. They try to understand each patient and family's unique background, current situation, and future needs to try to help families adjust to and cope with illness and caregiving.

They can help with issues including:

- Rehabilitation
- Skilled nursing facilities
- Nursing homes
- Disability services and finances
- Insurance issues
- Medicaid (Medi-Cal in the state of California)
- Para-transit
- Referrals to counseling
- Short-term lodging
- Discussion of financial issues
- Advance Directives
- Hospice

Caregiving in the Clinic

Doctors' offices and clinics are similar in many ways, except that a clinic is usually the outpatient service of a larger health system like a public health department or university medical center. Clinics, like those at UCSF, often have a variety of health services available such as social workers, physical and occupational therapists, and mental health services. The health facility you visit may be determined by the location of your doctor or your health plan requirements.

Preparing for a Doctor's Visit

Time is limited in busy medical practices for patients with serious and sometimes complex medical issues. Appointment times vary from 30-45 minutes for an initial visit to 15 minutes for follow-up visits. Preparing for your visit in advance will be helpful for you and your loved one's doctor.

The day before your visit, review the treatment log and notes sections of your health care binder (see chapter 2) in case your loved one has experienced significant symptoms, side effects, or pain that you should tell the doctor about. Highlight the important questions you want answered, and leave space to write down responses, whether you ask the questions in person, on the telephone, or via email.

Topics you may want to ask about include:

- The cause of the illness
- Possible treatments
- Time frame for treatments
- Medical tests and procedures involved
- Medical team contact information
- What to expect during and after treatment
- Prognosis and the outcomes of treatment
- Potential lifestyle changes
- How to handle medical emergencies

Communicating with the Medical Team

Although some of these topics may be uncomfortable to talk about, it is almost always very helpful to get the issues out in the open. Some physicians raise serious issues like side effects and prognosis, while others may wait until you bring them up. There are no questions or concerns about your loved one that anyone should consider silly or trivial. All of your questions are important ones.

Keep in mind that *not* all questions can be answered. In the treatment of serious medical illness, even by world-class doctors, some things remain unknown. Your doctors and nurses can help you deal with the ambiguities and uncertainties of medical care.

Having an open, communicative relationship with your loved one's doctors can help you and your loved one make the best choices with the most information.

Practicing good communication techniques will help you develop and maintain an effective relationship with your loved one's medical team. It is important to share your thoughts so that the doctor can address your concerns and provide better support.² Medical terminology can be complicated, so be sure to ask questions when you don't understand something. Patients and

family members often have different needs for information. Some people want to know as much as possible, often to feel in control, while others may feel overwhelmed when they are given a lot of information. Ask yourself, “How much information do I want?” and communicate that with the medical team.

There may be many people in your family with questions about your loved one’s illness and treatment. It is helpful for the doctors to have a single family member collect all the questions and act as the family representative. However, most doctors are happy to speak with anyone in the family who wants to be addressed directly.

As a caregiver, you have a valuable role as a facilitator between your loved one and the doctor. This is a very important role, particularly if your loved one needs help learning how to communicate with the doctor. You can also make sure the doctor’s recommendations will be put into action.

You may be tempted to speak with the doctor directly, without your loved one being present, but this approach may not work. Patient confidentiality considerations may prevent a physician from being candid if your loved one is competent to be in charge of their own health care, but not present at the visit.

On the Day of the Visit

- **Bring** your health care binder with your **questions, treatment log, and medication log** to review with the nurses or doctor.
- At the beginning of the visit, let the doctor **review the list of questions** you have so that he or she knows which issues to address (or can make plans to address them at another time). Your doctor will answer many of your questions during the course of the visit, so you can usually save asking many of your questions until the end of the visit.
- You may find it helpful to **bring an audio recorder** to your appointment so that once you are home, you can review important information discussed. This will also help to remind the doctor that this is new information for you and your loved one. Be sure to ask your physician first if he/she is comfortable with recording the conversation.
- When you feel you need more information than time will allow, ask the doctor or nurse to **recommend reading material or websites** to help you understand.
- Bring questions about insurance claims, billing, and other administrative matters to the **administrative personnel** — avoid using the limited time you have with the doctor to discuss billing and insurance issues.
- **Nurses are valuable** members of your loved one’s medical team and can answer questions about the daily issues you face at home. Get to know them, and don’t hesitate to ask them questions.
- Bring the contact information of your **local treating physician or your referring physician** to your appointments so that the clinic staff can communicate with them about important health information when necessary.
- **Write down contact information** (phone numbers, email addresses, clinic hours) for nurses and physicians you’ll be working with.

¹ National Brain Tumor Foundation, www.braintumor.org, retrieved 2006.

² National Family Caregivers Association, www.thefamilycaregiver.org, retrieved 2006.

Chapter 4

In this chapter:

- How to Speak with Your Children about Cancer
- Helpful Communication Techniques

Communicating with Children about Illness

When someone has a serious illness, it affects the entire family. While some illnesses can be very complicated and hard to understand, it is better to discuss it with your family than to avoid communicating or acting as if life were normal. **Children of almost any age sense when something is wrong, and they need to understand what is happening.**

No matter what their age, there are ways to communicate with children about illness, treatment, and, if necessary, life and death. This chapter will give you strategies for talking with children of various ages about a loved one's illness.



How to Speak with Your Children about Illness

When children witness someone in their family with a serious illness, it is scary for them and it can cause emotional stress. Recent research suggests that children often suspect that something is wrong even before they are told of the diagnosis. It is common for parents to *underestimate* their children's need for difficult information and preparation, resulting in children feeling less control and more afraid.¹

As a parent, you can help your family overcome fears by explaining the situation in ways they understand and keeping them informed. However, the amount of information children want and need varies by developmental level, and can be different for children of the same age.² This section has a chart of children's development by stage, including information about emotional development, communication and play techniques. These are suggestions to help you familiarize your child with what is going on and manage the anxiety they may have.³

Understanding your children's level of emotional development may give you insight into their feelings and behaviors and will help you speak with them about difficult issues. As a parent, you already have an intuitive sense for how much explaining your children want about difficult issues. Pay attention to your children's response to your talks. Be sensitive to the times when they want to know more, as well as to the times when they are less interested or seem overwhelmed with too much information.

With the possibility, or in some cases the eventual reality of a death in the family, children will struggle with many of the same questions adults do. Where does someone go when he or she dies? Why did this disease happen?

Especially for younger children, the worry that they did something to cause their loved one's illness or death is exceedingly common. All families need to deal with these issues.

For many families, religious or spiritual traditions can provide a meaningful framework to help with the ambiguous ideas and painful feelings around illness and death. Discussing these difficult issues from within your family's belief system may bring your kids a reassuring sense of security. If you are a part of a religious or spiritual community, its members may be able to provide suggestions or speak with you and your children together. Whether or not you are religious, paying attention to issues of meaning, values, and relationships remains critically important.⁴

Helpful Communication Tips⁵

- **Describe the illness and treatment.**

Use appropriate language for your children's age. Read picture books to younger children.

- **Practice your explanations.** Your discussions will be most effective if you know beforehand what you are going to say and the words you will use, and if you are calm and able to focus on your children's questions.

- **When you talk to your children, there is no way to predict their response.** They may surprise you with their insight, or they may have their own ideas and explanations. Avoid overcorrecting them and allow them the chance to offer their own explanations as well.

- **Young children may think they (or someone else) may have done something to cause the illness.** If this idea comes up as you talk to your children, reassure them that no one causes diseases to happen. If your children do not raise the idea, then you should avoid talking about fault, as it could lead them to wonder if, in fact, they did have a role.

- **Explain that cancer is not contagious.**

Young children think all illnesses are caught like colds. Assure them that no one in the family will get sick as a result of spending time with the ill family member.

- **Be honest and realistic.** It is best to offer realistic but hopeful information so that children do not feel scared or confused if things happen differently than you suggest.

- **Prepare for treatments.** They can have side effects, such as hair and weight loss, that can frighten children and will make people look different. Prepare kids beforehand, and explain

that treatments are helpful even if they look very unpleasant.

- **Let children help.** Allowing your kids to be involved in small caregiving tasks will make them feel helpful; make sure the tasks you involve them in are appropriate for their age and do not burden them with stress.

- **Use resources and educational material.** There is an abundance of helpful books and websites that will prepare you with age-appropriate language and tools for how to discuss illness and death with children of all ages and levels of cognitive development.

Communicating with Your Child about Illness

DEVELOPMENTAL FEATURES	COMMUNICATION SKILLS OF CHILD	COMMUNICATION TECHNIQUES FOR PARENTS
AGE 2-3 Can differentiate expressions of anger, sorrow, and joy	● Says words, simple sentences ● Can identify simple pictures ● Can follow simple stories	● Communicate using simple words ● Use picture books ● Create simple books with pictures of family members and simple objects that the child understands (hospital, doctor, bed, rest). ● Offer dolls to play with so they can recreate what is happening at home or at the doctor's office
AGE 4-5 More self-secure, can play well with others; tests the rules; 'magical thinking'	● Communicates through play and fantasy ● Can draw simple pictures to express ideas ● Uses complete sentences ● Asks many questions	● Select books with stories that mirror families like yours to help your child relate ● Familiarize your child with pictures of objects and concepts related to medical care and health (hospital, gown, doctors, flowers, bed, coming home from the hospital). ● Incorporate play with a child's 'doctor kit' to familiarize your child and symbolize what is happening



DEVELOPMENTAL FEATURES	COMMUNICATION SKILLS OF CHILD	COMMUNICATION TECHNIQUES FOR PARENTS
AGE 6–7 Capable of following rules; enjoys having responsibility; uncertain of the relationship between cause and effect; parent is primary source of self-esteem	● Tells long stories ● Can read some words ● Beginning to know the difference between fact and fiction; understands truth versus lying	● Use interactive communication—reading books and creating stories with your child ● Help your child create his / her own “this is our family” album and talk about the photographs and memorabilia ● Watch movies with story lines similar to what your family is experiencing
AGE 8–11 Develop a better understanding of logic and cause/effect, less centered on self, able to understand others’ feelings, can empathize	● Language skills and vocabulary becomes more complex and similar to that of adults ● More able to use metaphors, humor ● Wants more facts; needs detailed information about illness and treatment ● Avoids strong emotion	● Listen to your child’s thoughts and opinions ● Ask questions that go beyond yes and no ● Depending on your child’s individual level of development and understanding, speak with direct, reality-based explanations that include facts ● Include the sequence of events involved, and what to expect
AGE 12–17 Experience puberty and physiological changes; seek freedom and independence; acceptance by peers is extremely important; develop more intimate relationships; more thoughtful and empathic	● Verbal communication has matured, but may express themselves more with outward behavior ● May act withdrawn, unemotional, as if they don’t care ● May come off as silent, aggressive, moody, loud 	● Speak honestly and realistically ● Give facts, what is expected to happen, including the diagnosis, prognosis, treatments, and expected outcomes ● Talk with your children, not to them ● Check in and offer time to discuss concerns frequently ● Listen attentively ● Ask open-ended questions (not those answered with ‘yes’ or ‘no’) ● Stay alert for risky behaviors, acting out, or noticeable withdrawal (if this is a new behavior) ● If these new behaviors are present, seek professional help

¹ Cancer Care, www.cancercare.org, retrieved 2006.

² Information throughout this chapter was provided through personal communication with Meryl Botkin, Ph.D, Assistant Clinical Professor, Department of Psychiatry, UCSF.

³ Christ G, Siegel K, Christ A. Adolescent grief: it never really hit me... until it actually happened. *Journal of the American Medical Association*, 288 (10): 1269-1278, 2002.

⁴ Information throughout this chapter was provided by David Becker, MD, Assistant Clinical Professor, Department of Pediatrics, UCSF.

⁵ UCSF Medical Center Patient Information, “Your Health Matters: Helping Children Understand Cancer,” adapted from *Cancer Care Briefs*, http://cancer.ucsf.edu/crc/helping_children.pdf, 2007.

Chapter 5

In this chapter:

- Working with the Insurance Company
- What to Do When Insurance Won't Pay

Paying for Healthcare

As a caregiver, you will confront many choices about treatments, home care, and therapies. You may even find that personal finances and health insurance are the obstacles preventing you from selecting the best care for your loved one. At the point that your loved one requires a particular treatment, it is likely that you will do whatever you can to provide that care, including sacrificing personal finances and compromising your family's stability. But there are ways to avoid having to make these painful choices.



As medicine and health care improve, people are living longer with serious and chronic illnesses. Long-term care has become a part of modern living, and there are resources available to help you plan for this. Start by familiarizing yourself with your loved one's health insurance plan, as well as government entitlements and public assistance.

These are confusing systems to navigate through, but inquiring early on will empower you to obtain the care your loved one needs, when it's needed, at a reasonable price or perhaps for free.

If you approach these important administrative tasks of caregiving early on, you may prevent unnecessary financial pressures and compromises regarding work, housing, and education. Once you get insurance benefits and government assistance in order, you can better attend to your loved one's needs at home and make quality care available. This chapter outlines the basics you should learn about when planning for and purchasing care. It will also give you tips for advocating for your loved one to secure medications, treatments, and services if payment is denied.

Working with Your Loved One's Insurance Company

The two basic categories of insurance are public (government-sponsored insurance) and private (insurance plans purchased by you or provided by an employer). You may have one of the following types of government-sponsored insurance plans — Medicare or Medicaid — or a private plan such as fee-for-service or managed care. Managed care plans include: Preferred Provider Organizations (PPO), Health Maintenance Organizations (HMO), and Point of Service plans (POS).

Insurance plans have their own distinct systems that may control your choice of health care providers and the services you can obtain. Contact your insurance company or your employer's health benefits manager to learn what the benefits are. Your loved one's coverage plan will determine what treatments will be covered in full, and what portion of the cost you will be responsible for paying.

If your coverage is Medicare or Medicaid, read the free consumer materials that explain your coverage and your rights. You can also contact an advocacy organization such as the National Family Caregivers Association (www.nfca.org; 1-800-896-3650) or the U.S. Department of Health & Human Services (www.hhs.gov; 1-800-575-WELL). These organizations provide educational materials, resources for care, and helpful support networks online and by telephone.

It is common for insurance companies to cover treatments that the doctor prescribes as "medically necessary" or "required medical events." The care prescribed by the doctor may be a combination of services and is based on the complexity of the patient's needs.

Services the doctor prescribes as "medically necessary" may include:

- **Therapies:** speech therapy, occupational therapy, physical therapy
- **Treatments:** radiation, chemotherapy, medications
- **Interim treatment facilities:** rehabilitation hospital, skilled nursing facility
- **Home care services:** professional nursing, social work, nutritional care

Because many tests, procedures, and treatments require authorization by your insurance company, it is best to verify that the service will be paid for by the insurance carrier before receiving it.

Review a copy of your loved one's policy and review it carefully. Find out exactly what services are covered and how the payment system works. Be aware of annual limits and lifetime limits (often \$1 million), and research purchasing additional coverage. Also make sure that you are aware of the policy's regulations on the following:

- Co-payments
- Deductibles
- Referrals to physicians and other clinicians
- Services covered (follow up appointments, MRIs, medications, therapies, treatments, clinical trials, home care, reimbursement for complimentary and alternative services)

The Children's Brain Tumor Foundation recommends taking the following steps in dealing with the insurance company¹:

- Educate yourself. Know about your loved one's illness and why referrals to specialists are needed.
- Many insurance plans and HMOs require that specialized tests, procedures and treatments must be pre-approved and authorized by a primary care provider. You may need this "authorization" when you call to make an appointment with a specialist.
- Ask for one case manager at the insurance company who will always handle your case and answer questions. Ideally you will find someone who is sympathetic to your case and time constraints.
- Document every phone call. Write down the name of the person you speak to, the date and time, and the topic discussed.
- Fill out every form completely. Payment may be delayed or denied if information is missing. You may want to send in claim forms "Return Receipt Requested." Someone of authority will have to sign for it.
- Develop a good working relationship with your loved one's primary physician's office staff because authorizations must come from there.
- Keep a copy of each authorization you receive. Follow up on authorizations and never assume that they are being handled. You may want to tell the specialists that you will get the necessary authorizations yourself.
- Sometimes the referral process to specialists or therapies is slow. You may have to emphasize the serious nature of your loved one's illness in order to get an earlier appointment or referral.
- Don't wait for the doctor's office or insurance company to call you back. Call every day if necessary. Be polite but persistent.

When Insurance Won't Pay

Your options for obtaining services that are not regularly covered by your insurance include:

- Paying out-of-pocket
- Submitting claims to your insurance company
- Fighting denied claims by making appeals with the support of your health care provider (see “Appealing a Decision,” below)
- Using state and non-governmental agencies to help assist insurance complaints
- Applying for social services (county- or state-run) to provide you with services (see “Seeking out Government Entitlements and Private Financial Assistance,” on the next page)
- Obtaining health care services that are offered by charitable or non-profit organizations at reduced or no cost
- Engaging the help of a professional advocate (see “Professional Advocates,” below)

Appealing a Decision

You may find over time that there are services your loved one needs or wants that are not covered, or are denied, by your insurance carrier. Sometimes a denial occurs because of incorrect documentation or other logistic issues. At other times a service may be denied because your policy has exclusions. However, you may appeal to your insurance company to pay for the services that may have been denied. Your insurance company can tell you how to appeal a decision. **In trying to make an appeal, you may ask your doctor or health insurance advocacy organization to help you obtain the services you need by submitting letters of medical necessity.** Your local state legislator can also intervene with your insurance company so that your loved one receives the service for which they are paying insurance premiums.

Professional Advocates

If a service you request is denied, you may obtain the help of an advocacy service to work with your family and doctor to assist you through the appeal process. Examples of professional advocates who are responsible for representing the patient's interest include:

- **Patient Advocates** — assist patients and concerned families and friends. They can get involved in nearly any facet of patient care and are available in most hospitals.
- **Ombudsmen** — advocate for residents of nursing homes, board and care homes, and assisted living facilities. They can be called for any concerns around care or for a referral to a patient advocate. Ombudsmen provide information about how to find a facility and what to do to get quality care. Under the federal Older Americans Act, every state is required to have an Ombudsman Program that addresses complaints and advocates for improvements in the long-term care system.
- **Payment and Billing Advocates** — can investigate and resolve problems concerning insurance payments or Medicare / Medicaid. They are available in the finance departments of medical clinics or hospitals.
- **Social Workers and Discharge Planners** — help patients get in-home support services, equipment, transportation, financial benefits, and community services. They may be available in your medical clinic and are available privately.

Seeking out Government Entitlements and Private Financial Assistance

As a result of illness in your family, you may find that you need to cut back on work hours to give care and help your loved one adjust to life changes. If you are making changes to your employment, inquire with the Human Resources department at your work to learn the policies on sick leave, paid time off, the Family Medical Leave Act, or your flexibility of work hours.

Changes to your employment status can mean lost income and changes to your health benefits. But these changes may also make you eligible to receive entitlements through government programs.

Be aware that there are both government programs and privately sponsored services in place that you may financially qualify for, to help provide your loved one with the needed care.

The following lists are examples of government and non-government programs that offer entitlements, income supplements, low-cost health care services, and financial subsidies. These services may be controlled by the city, county, state, or federal government, or non-governmental organizations. Be sure to speak with a case manager at the hospital or clinic to help you apply for these services.

Government Departments and Programs

- Department of Rehabilitation
- Department of Developmental Services
- Department of Social Services :
 - Social Security Disability Insurance (SSDI)
 - Supplemental Security Income (SSI)
 - Medicaid (Medi-Cal)
 - In Home Support Services (IHSS)
- Department of Aging
- Department of Housing & Community Development
- State Pharmaceutical Assistance Programs

Non-Government Programs

- Clinics or health care providers with sliding scales
- Pharmaceutical programs with discounted prescription programs
- Utility companies offering utility subsidies (based on support of your physician or financial status)
- Food banks, Meals on Wheels, Salvation Army, local churches / synagogues

¹ Children's Brain Tumor Foundation; <http://www.cbtf.org>, retrieved 2007.

In this chapter:

- Advance Care Planning
- Personal Business
- Estate Planning

Chapter 6

Planning for the Future

Most people don't like to discuss their wishes for what will happen at the end stages of their life or directly after death. But there are many important decisions, including what types of health care are wanted toward the end of life and what will happen to one's assets when one dies. **This chapter introduces some of the most important plans for you to help your loved one make, including plans for advanced care, financial plans, and estate plans.**



Advance Care Planning

Part of helping someone live well with a serious illness involves accommodating his or her needs as the illness progresses. **Although you may be dealing with adjustments to daily living, it is important that you and your loved one talk in advance about his or her beliefs, values, and wishes for end-of-life care.** If you wait until your loved one is badly debilitated before getting these affairs in order, it may be too late for him or her to express requests, make rational decisions, and sign important documents.

Advance care planning (for yourself as well as your loved one) includes:

- Learning what life-sustaining treatments are available (artificial nutrition and hydration, extended mechanical ventilators, resuscitation, etc.)
- Deciding what medical treatments your loved one would want if his or her cancer becomes life-threatening
- Communicating with your loved one about his or her personal values and spiritual beliefs about death and dying
- Deciding who your loved one would want to speak for him or her and make decisions about his or her care if unable to do so for him or herself
- Preparing legal documentation of your loved one's end-of-life preferences (advance directives) and giving copies to health care providers

Advance Directives

Advance directives are a set of documents that allow your loved one to identify his or her wishes for care at the end stages of life, in the case he or she is not able to do so at the necessary time — specifically a *living will* and a *medical power of attorney*. Once the advance directives are completely filled out, they should be signed and dated, and copies should be kept at home and also included in the patient's medical records. Once they are signed they become legal, official forms. These documents may vary by the state you live in, and you can obtain your state's version from your doctor, legal offices, or state departments.

Living Will

A living will is the part of the advance directives that document the patient's wishes about the medical care that he or she wants at the end of life. These written instructions are used if the patient is physically or medically unable to communicate wishes at the time. This document is extremely valuable because it protects a patient's rights to accept or refuse care, and it removes the burden of life-or-death decisions from family members or the medical team. It is important to know that someone can decide to refuse "aggressive medical treatment to attempt to cure a disease" but not refuse all medical care. In other words, the patient can specify not to be kept alive artificially, but to be provided with comfort care (pain medication).

Typical information included in a living will:

- DNR (do not resuscitate) orders — instructions to refuse CPR if breathing or heartbeat stops
- Choices about artificial hydration and nutrition
- Choices about life-sustaining equipment (ventilators, respirators)

- Choices about comfort care (pain medications)
- Instructions about being an organ and tissue donor

Medical Power of Attorney

The medical power of attorney is the part of the advance directive that names a patient's health care proxy. A health care proxy is whom the patient designates to make decisions regarding end-of-life care if the patient is unable to do so. Typically this is someone whom the patient knows well and trusts will make decisions that represent the patient's wishes in case they are not well stated. The health care proxy is often a spouse or relative of the patient. The patient should make sure to ask this person if he or she agrees to be the health care proxy, and, if so, the person designated must sign the form.

Personal Business

In addition to the difficult decisions involving physical, emotional and spiritual care at the end of life, most people have personal business that will require management by someone who can be trusted. Naming someone to take charge of financial affairs is called *durable power of attorney for finances*. This is separate from the advance directive described above, but a patient may choose the same person.

Some financial institutions may only recognize the persons named on an account to make decisions about it, so it's important to not wait until the patient is too ill to make changes or add a secondary name on an account. The same goes for other financial assets and legally binding documents such as investments, properties, and car titles. **Adjusting the information on important documents before the patient becomes too ill may prevent years of legal battles and financial burdens.** The following is a list of important topics to become familiar with. If you need to learn more about these you can meet with an associate at your bank, seek advice from a legal service, call your hospital to speak with Patient Relations or a Social Worker, or search the Internet.

- **Bank Accounts** — Pay-On-Death beneficiary designations; do you need to add co-signers?
- **Safe Deposit Boxes** — Where are the keys? Who are the co-signers?
- **Life Insurance Policies** — Who are the beneficiaries? Do they need amending?
- **Health Insurance Policies** — Where are membership cards? What are the ID numbers?
- **Durable Power of Attorney for Health Care** — Has this been signed? Where is the original? Do health care providers have copies?
- **Durable Power of Attorney for Finance** — Who has been designated? What is their contact information?
- **Will and/or Living Trust** — Where are they? What attorney drafted them?
- **Deeds/Property Titles** — Who has ownership of the property? Does "tenancy" need to be designated?
- **Stocks/Bonds** — Who are the beneficiaries? Do they need to be amended?

- **Birth Certificate** — Know where your loved one was born in case you need to order one.
- **Military Papers** — If applicable, where are the discharge papers?
- **Social Security Papers** — Where are these documents?
- **Benefits Forms** — Have copies of all forms (SSI, SSDI, GA, MediCal, Food Stamps, etc.).
- **Loan Papers** — Keep payment contracts and credit card statements organized.
- **Vehicle Registrations** — Who is listed as the owner and where is the certificate?
- **Income Tax Returns** — Keep returns for the last five years and the accountant's contact information.
- **Funeral Instructions** — Is there a contract with a funeral home? Are wishes written down?

Estate Planning

Many people have things that they want to leave for their loved ones to remember them by — some form of a legacy — usually identified in a will. These inheritances can be in the form of financial gifts, family heirlooms, objects of sentimental importance, or even personal memoirs. Helping prepare a legacy with your loved one is a way to bring you closer by providing support that they may not know to ask for.

If your loved one does not specify who is to inherit his or her belongings, each state has a formula that will disperse property out to your next of kin after a lengthy and costly process. If a person dies *intestate* (without a formal will) the state takes control of the property, determines the legal nearest blood relatives and disburses the estate to them. Many times property is sold, all the expenses are paid and what is left goes to the heirs.

There are many issues involved in estate planning that you should be aware of. The best way to become educated on these topics is to seek legal advice or refer to a social worker at the hospital for references. The Internet can be very helpful because it will lead you to many resources and references, but make sure that the information has been written by a legitimate source such as a government or nationally known organization. Also, guarantee that the information you read is current and relevant to the state you live in.



Chapter 7

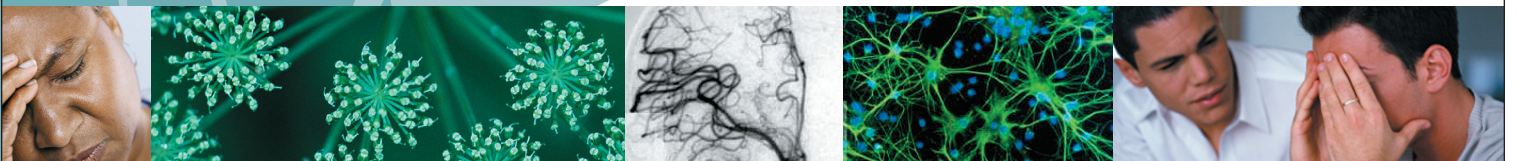
End-of-Life Care

In this chapter:

- The Difference Between Palliative Care and Hospice
- Choosing the Right Care for Your Loved One
- Bringing Hospice into the Home
- Your Loved One Is Dying, What Can You Do?

Despite excellent care and the best medical treatments, some patients with serious illness may face the possibility that medical treatments can no longer cure or even control their illness, and their life is ending.

Many patients in this situation wish to focus entirely on their comfort, rather than continuing burdensome and costly treatments that do not provide benefit. During this time, often referred to as end-of-life, family caregivers play a very important role.



The Difference between Palliative Care and Hospice

Palliative Care

Elsewhere in this book we have mentioned “palliative care,” and it is important to understand the difference between palliative care and “end-of-life care.” Palliative care is medical treatment used to relieve pain and manage distressing symptoms such as nausea, fatigue, and loss of appetite. It is not dependent on prognosis and can be delivered at the same time as curative treatments, from the point of diagnosis on. Palliative care can help a patient tolerate medical treatments and maintain quality of life, while living with a serious illness. The goal is to reduce a patient’s suffering. Palliative care is not always the same as hospice or end-of-life care. However, when curing the disease is no longer possible and someone is dying, palliative care may become the only focus.

Hospice

Hospice is a well-known provider of palliative care for patients who are no longer seeking cure. This model of care is reserved for people whose disease is expected to lead to death within six months. Approximately one-third of Americans who die each year do so under hospice care. It is appropriate for you, as the caregiver, to discuss hospice with your loved one and his or her medical team at any time when facing a potentially life-threatening illness. Ultimately, however, your loved one will make the final decision about starting hospice care. If the disease goes into remission or a cure becomes available, a patient can stop hospice and begin aggressive curative attempts again.

Choosing the Right Care for Your Loved One

Hospice care can take place at a hospital, an in-patient hospice center, a skilled nursing facility, or the patient’s home. Choosing whether to receive hospice care, and where to receive it, are challenging and emotional decisions. These choices can be made easier if you have the right information. Speak with your loved one, the medical team, or a social worker to understand what type of care would be most appropriate for your loved one and to recommend some local options.

The Joint Commission is an independent, not-for-profit organization that evaluates health care facilities in the United States. They suggest you talk with representatives from your potential care providers, and use the following questions to help you make an informed decision¹:

- What types of services does the organization provide? Does it offer services for children?
- How long has the facility, home care, or hospice been in business?
- Does it accept payment from Medicare and Medicaid? Does it have a list of its fees and services? Can they help you find financial help if you need it?
- How does the organization train and manage its staff? Does a supervisor come to the patient’s home to review the care being given? Are home care workers licensed and bonded?

- Is the home care or hospice prepared in case of an emergency like a power failure or a natural disaster? Will it still be able to deliver the services you need?

Please note that all of the questions above are acceptable to ask of agencies providing hospice care as well as non-hospice home care.



SEE THE APPENDIX for a *Home Healthcare Primer* to learn more about hospice and choosing quality home care.

Bringing Hospice into the Home

For patients who choose to receive hospice care at home, family caregivers can continue to provide care under the guidance and support of trained hospice nurses, social workers, health aides, and physicians who visit the home regularly. Hospice care is comprehensive and includes physical, psychological, and spiritual care to address the needs of patients and their families. These services include:

- Physician services
- Nursing services
- Home health aides
- Medical appliances and supplies
- Spiritual, dietary, and other counseling
- Continuous care during crisis periods
- Trained volunteers
- Bereavement and grief services for the family

Hospice is covered by Medicare nationwide, as well as by most insurance companies. Speak with your insurance carrier to determine your loved one's coverage and co-pay. If coverage is unavailable, the hospice team may be able to access community or foundation funds to provide services.²

Your Loved One Is Dying; What Can You Do?

At the end of life, family caregivers typically provide the same types of care they were providing previously—assisting their loved ones with medications, household chores, and managing the emotional stresses of illness. However, at the end of life, in anticipation of great loss, these issues may become significantly more intense. While all the principles and recommendations in this book apply during the end of life, a few issues deserve special attention.

Symptom management

It may be easier to manage symptoms once patients are no longer spending great amounts of energy pursuing disease treatments that cause painful side effects and complications. Palliative care teams and hospice teams can be of great help in controlling and managing bothersome symptoms.

Nutrition and hydration

In every culture and in almost every family, food and feeding are meaningful because they represent nourishment and love. At the end of life, however, patients may not be able to eat nor enjoy eating. Often, patients lose weight (regardless of how much they eat) as their disease drains them of their nutrition and energy. It can be a great gift from family members not to insist that dying loved ones eat if they are not hungry, but rather to offer other demonstrations of love and affection.

Depression

It is understandable that patients express difficulty adjusting to the end period of their life. But some patients develop a deep sense of hopelessness, helplessness, sadness, and an inability to experience pleasure. These may be signs of depression and should be brought up to your loved one's physician or hospice team. Depression at the end of life can be treated.

Delirium

A waxing and waning level of consciousness (level of being awake) with difficulties in thinking and confusion that often includes hallucinations is delirium. Unfortunately, delirium is very common in the last days of life. If the confusion is bothersome to the patient or to loved ones, sedating medications can be used to control the symptoms.

Hope

We do not always hope for a cure at the end of life. When curing a disease becomes impossible, hoping may shift to other things that still are possible. Even at the end of life, patients and loved ones may have hopes for other things — such as relief from pain, moments of pleasure or discovery, achieving closure of important relationships, or a sense of peace.

Relationships

At the end of life, relationships must come to a close. Those who have had experience caring for patients at the end of life have observed that there are a number of things that must be said between a dying person and their loved ones. If you are having difficulty figuring out what to say or how to begin a difficult conversation with your dying family member, you might consider saying one or more of the following:

Forgive me

I forgive you

Thank you

I love you

Good-bye

Some add a sixth statement, *“I’ll be okay without you”* as an effort to give permission for the patient to move on when it is time.

Guilt

It is nearly inevitable among family caregivers to experience guilt. Despite the amazing work that most family caregivers provide, everyone worries that they did not do enough. This feeling of guilt is common and understandable. But death is not a failure. Ultimately, it is a profoundly sad, but deeply natural event in the human life cycle.



Grief

It is part of life. These feelings of sadness are often intense. They may vary greatly in the days, weeks, and months after someone you love has died. People who are grieving often talk about having “bad days” mixed with “good days.”

Over time, people eventually find ways to integrate the loss of their loved one back into their life. This process of re-integration can take many months (often up to 6 months). Although you may go back to work and establish new relationships, things are never the same. You do not forget.

If you are finding that the intensity and frequency of grief does not begin to improve by six months after the death of your loved one, you should see your own physician to discuss possible treatment for a condition called “Complicated” or “Traumatic” grief. In both normal and complicated grief, bereavement support groups can be very helpful.

¹ The Joint Commission, www.jointcommission.org, retrieved 2009.

² Hospice Net, www.hospicenet.org, retrieved 2007.

Chapter 8

In this chapter:

- Focus on What Matters
- Realign Your Goals
- Finding the Benefits
- Meaningful Moments
- Allowing Laughter

Caring for the Caregiver: Maintaining Well-being

As the caregiver, you already know how a loved one's serious illness can cause intense and prolonged psychological stress. **The signs of stress are well known: worry, anxiety, sadness, and other negative emotions begin to color each day.**

You may have trouble with sleep, and during the day you may be tired, find it hard to concentrate, especially on tasks that seem irrelevant. Because of the effects of stress on the immune system, you may also experience more physical problems, including colds, flu, and other upper respiratory illnesses.



Surprisingly, even when things are going badly and stress is intense, people do have moments when they experience positive emotions such as joy, happiness, love, and compassion. And, in fact, except when the situation is truly dire, these upbeat moments occur surprisingly often over the course of a day or week.¹

These positive moments are often fleeting, but they are very important because they help you sustain your wellbeing in the midst of stress. They can do this in several ways. They provide a “breather” from the distressing emotions that accompany stress. Many of these positive moments help motivate us and keep us going by reminding us of what matters. They can also help to reduce the harmful effects that can occur when the body is under stress for a long time.

These positive moments sometimes just happen, but at other times, you can make them happen with specific coping strategies. These strategies don't make the stress of caregiving go away. But they can provide respite, renew purpose, and restore psychological resources that are often depleted by the stress of caregiving.

These coping strategies do not require extensive training. You simply need to think about them to make them happen.

Here are five strategies to help maintain your own wellbeing in the midst of stress:



FOCUS ON WHAT MATTERS.

Focusing on what matters can strengthen your sense of purpose and meaning in your life. It can help direct the choices you make and can help sustain you when the going gets tough.

As a caregiver, you can get caught up in responding to day-to-day demands and easily lose sight of why these activities matter. As a result, your resources can become depleted and you can burn out.

A family caregiver who participated in an important research project on stress in caregiving helps us understand the importance of reflecting on what matters. This man's partner had advanced AIDS during the time before effective treatments were available. He described a night that was much like most other nights when his partner experienced severe night sweats. The caregiver had to change the bed linen, sponge his partner and help him into fresh pajamas. This caregiver reported that he usually had to do this about four times during a night; the previous night, however, it had been eight times. And what got him through this night after night? He focused on what mattered to him — the underlying love they had for one another and how these efforts were an expression of that love.

For some caregivers, what matters may have to do with love. For others it may have to do with a sense of what is right and moral, of what a “good” person does. It might have to do, for example, with valuing compassion and being able to reduce suffering.

The most important thing is to be aware of what matters to you. Remind yourself of it, especially when things are going badly.

Some people find it helpful to create a “matter-ing” list. *What would be on your list? Why do these things matter to you?* What are the deeply held beliefs and values, the deeply held fundamental truths, that guide you and that underlie your list?

2

REALIGN YOUR PERSONAL GOALS ACCORDING TO WHAT MATTERS TO YOU.

One of the reasons a diagnosis of a serious illness is often a shattering experience is that it means that the big life goals we had previously held no longer fit our changed reality. These big life goals, even those that we were not entirely conscious of, rise to the surface as we realize they are no longer realistic or they no longer seem to be as important as they once were.

The awareness that life goals need to be changed can create intense stress. Putting important goals on hold, or even having to give them up, involves loss. It is not unusual for caregivers to feel sadness, anger, and resentment about this loss.

But as a caregiver, you need to identify new goals in order to address the demands of your loved one's illness. Identifying realistic goals that matter *now*, in relation to your changed reality, can renew your sense of purpose, creating a heightened sense of energy that can motivate and direct you. It can help you marshal your resources to do what needs to be done.

Here are three steps that can help with “resetting” goals:

- Think about the goals you had before your loved one became ill. They may have to do with goals you had for your family or at work. Some of these goals will no longer matter. Others will still matter, but are no longer realistic. Let go of goals, at least for now, that no longer matter or that are no longer realistic. This will reduce frustration, anger, and anxiety. At the same time, this may make you feel sad and possibly resentful and angry.
- Identify new goals that matter and that are realistic. Many of these will be related directly or indirectly to your role as a caregiver.

- Think about why these new goals matter. Which of your underlying values do they represent? Knowing why they matter will reinforce your sense of purpose and your awareness of meaning in your life.

Initially, it can help to focus on near-term goals over the next days or weeks. These can be very concrete goals, the kinds of things that you'd put on a To-Do list for the day. And, in fact, it is often helpful to make up a daily To-Do list that includes tasks that you are likely to get done that day or the next. Try to make these near-term goals as realistic as possible. If you set yourself up to be successful, you'll feel more capable and in control.

In caregiving, long-term goals are often shared between the caregiver and the person who is ill. If possible, talk together about your shared long-term goals, what it is that you each want for the other and for yourself. These conversations can clarify what matters to your loved one, which is likely to shape your new goals. These conversations can increase intimacy and intensify feelings of affection and love. They can also decrease anxiety for both of you.

3

BENEFIT FINDING AND BENEFIT REMINDING.

Research on coping with stress shows that many people discover that they have benefited from their stressful experiences. Caregivers, for example, talk about how they've gained knowledge and skills that make them much more competent. Some caregivers talk about the increased intimacy that they experience with their loved one that comes from talking openly with one another or from appreciation the patient expresses for the caregiver's efforts. Other caregivers feel they have gained wisdom or that

they have experienced deepened spirituality or religiosity. Some report that the family has become closer.

Take time to reflect about ways in which you've grown, the skills and knowledge you've acquired; deepened spirituality or understandings of the world and your place in it; changes in relationships with your loved one, family members, and friends; or other benefits that have come from your caregiving experience. Then remind yourself about these benefits when you are feeling down.

4 INFUSE ORDINARY EVENTS WITH MEANING.

In a sense, this strategy is something like the old adages, “take time to smell the roses” or “don’t just do something; sit there.” Positive moments occur throughout the day. They can be something as ordinary as not getting stuck in traffic, having a salesperson greet you in a friendly manner, or seeing a beautiful sunset. When such a moment occurs, take advantage of it. Dwell on it, reflect on why it makes you feel good. If you have the opportunity, tell someone about it. These moments give you an emotional time-out from anxiety and worry. They can help reduce your stress and restore you.

You might want to reflect on a day’s positive moments just before you go to sleep. This can help quiet distress and create an upbeat mood that can help you fall asleep.

5 ALLOW YOURSELF TO LAUGH.

“Humor is one of the healthiest and most powerful methods to help provide perspective on life’s difficult experiences, and it is frequently shared during periods of crisis.”² To help find humor during a stressful time, think about what typically can make you laugh and bring it into your day. Don’t feel guilty about your laughter — enjoy the moments of levity and know that they will help restore your energy and perspective.

There is a body of research showing that humor and laughter can be very therapeutic and assist in the psychological recovery from crisis.² Laughter and humor have been shown to provide relief and even facilitate survival. It may at first feel like a challenge to find humor during a hard time, but take comfort in knowing that if you can not laugh today, you may be able to tomorrow.

Bottom line: Positive moments and positive emotions are a part of the experience of stress. This may sound counterintuitive, but a lot of research supports this observation. Take advantage of these moments. They can help keep you focused on what matters and sustain you when things are especially difficult. Know what creates positive moments for you, and use some of the strategies described above or others that work for you so that you can make the most of these often fleeting, but very important, moments.

¹ Folkman S. & Moskowitz, J. Stress, positive emotion, and coping. *Current Directions in Psychological Science*, 9, 115-118, 2000.

² Sultanoff S. Levity defies gravity: using humor in crisis situations. *Therapeutic Humor*, 9 (3): 1-2, 1995.

Appendix

Calendar Templates:

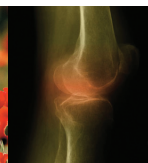
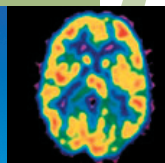
- Monthly
- Monthly / Weekly

Forms and Checklists:

- Caregiving Checklist
- Treatment Log
- Medication Log
- Health History Form
- Personal Care Team Member Information Form

Information Sheets:

- Pain Rating Scale
- Home Healthcare Primer
- How to Communicate Your Loved One's Symptoms Regarding Overall Wellbeing, Pain, and More
- How to Communicate Your Loved One's Symptoms During a Crisis
- How to Communicate with Insurance Company Personnel
- Resources



[illegible]

Caregiving Checklist

Caregiving Task	Hours Per Week	Who Can Help
In-Home Supervision / Companionship		
Meal Planning		
Grocery Shopping		
Meal Preparation		
Dishwashing / Kitchen Cleanup		
Bathing		
Other Personal Hygiene (care of skin, mouth, hair, nails, etc.)		
Scheduling Medical Appointments		
Managing Medications		
Coordinating In-Home Care		
Hands-On Medical Treatments / Exercise		
Medical Recordkeeping		
Transportation for:		
Medical Appointments		
Support Groups and Counseling		
Shopping and Errands		
Rest & Relaxation / Recreation Activities for:		
The person who is ill		
The primary caregiver		
Family members / visitors		
Child Care		
Elder Care		
Pet Care		
Laundry		
House Cleaning / Trash Removal, etc.		
Home Maintenance and Repairs		
Yard Care & Gardening		
Banking		
Paying Bills and Financial Recordkeeping		
Managing Insurance Claims		
Handling Legal Matters		
Securing Government and Community Services		
Care Team Meetings / Dinners		

TOTAL HOURS PER WEEK:

Treatment Log

Date	Time	Treatment	Treating Doctor	Notes

Medication Log

[illegible]

ALLERGIES:

NOTE: When you list ALLERGIES, we recommend that you use RED INK to draw attention to them. When you discontinue a medication, we recommend that you use a highlighter to cross it off the list.

Health History Form

Name	
Date of Birth	
Social Security or Insurance ID Number	
Medical Insurance Company Name and Phone Number	
Name of Emergency Contact	
Phone Number of Emergency Contact	
Primary Doctor's Contact Information	
Name and Phone Number of Preferred Hospital	
Location of Advance Directives	
Allergies or Reactions to Medications	
History of Medical Problems (indicate if you have had or are treated for any)	☐ Heart Disease ☐ High Blood Pressure ☐ High Cholesterol ☐ Diabetes ☐ Asthma / Lung Disease ☐ Thyroid Problem ☐ Kidney Disease ☐ Cancer (Specify): _____ ☐ Depression ☐ Other (Specify): _____ _____

Personal Care Team Member Information Form

Full Name:

Daytime Phone:

Evening Phone:

Cell Phone:

Email Address:

Mailing Address:

I can help provide care (please fill in all that apply):

Sundays from _____ to _____

Mondays from _____ to _____

Tuesdays from _____ to _____

Wednesdays from _____ to _____

Thursdays from _____ to _____

Fridays from _____ to _____

Saturdays from _____ to _____

I can help in the following areas (please fill in all that apply):

☐ In-Home Supervision /
Companionship

☐ Meal Planning

☐ Grocery Shopping

☐ Meal Preparation

☐ Dishwashing /
Kitchen Cleanup

☐ Bathing

☐ Other Personal Hygiene
(care of skin, mouth,
hair, nails, etc.)

☐ Scheduling Medical
Appointments

☐ Managing Medications

☐ Coordinating
In-Home Care

☐ Hands-On Medical
Treatments / Exercise

☐ Medical Recordkeeping

Transportation for:

☐ Medical Appointments

☐ Support Groups
and Counseling

☐ Shopping and Errands

Rest and Relaxation/ Recreation Activities for:

☐ The Person Who Is Ill

☐ The Primary Caregiver

☐ Family Member/Visitors

☐ Child Care

☐ Elder Care

☐ Pet Care

☐ Laundry

☐ House Cleaning /
Trash Removal, etc.

☐ Home Maintenance
and Repairs

☐ Yard Care and Gardening

☐ Banking

☐ Paying Bills and
Financial Recordkeeping

☐ Managing
Insurance Claims

☐ Handling
Legal Matters

☐ Securing Government and
Community Services

☐ Care Team Meetings /
Dinners

Pain Rating Scale

The Wong-Baker Faces Pain Rating Scale is used in most doctors' offices, and is particularly helpful for patients who may be cognitively impaired. It offers a visual description for those who don't have the verbal skills to explain how their symptoms make them feel. You can explain that each face shows how a person in pain is feeling. That is, a person may feel happy because he or she has no pain (hurt), or a person may feel sad because he or she has some or a lot of pain.

Helpful Instructions

- Point to each face using the words to describe the pain intensity.
- Have your loved one choose the face that best describes how he or she feels.
- Make note of the pain, with the date, and any other symptoms that occurred and keep this information in your medical records or journal.
- Bring your notes to your next appointment, or refer to them when on the phone with the nurse.

You may find it helpful to fold this paper here and use the scale
↓ with your loved one to gauge his or her pain.



0
NO
HURT



1
HURTS
LITTLE BIT



2
HURTS
LITTLE MORE



3
HURTS
EVEN MORE



4
HURTS
WHOLE LOT



5
HURTS
WORST

Face 0 is very happy because he or she doesn't hurt at all.

Face 1 hurts just a little bit.

Face 2 hurts a little more.

Face 3 hurts even more.

Face 4 hurts a whole lot.

Face 5 hurts as much as you can imagine, although you don't have to be crying to feel this bad.

Home Healthcare Primer

What Is Home Care?

Homecare is a general term that represents a wide range of community-based services to support someone that is recuperating from an acute situation, such as a hip fracture, or services needed by persons with ongoing chronic conditions, such as stroke or cerebral palsy. The skills and duties of home care personnel vary, but all have one thing in common — they make it possible for care recipients to remain at home in a safe environment and, in some cases, have more independence than they did before. In the process, they also provide family caregivers with a chance to replenish their depleted physical and emotional reserves.

Homecare personnel include:

- **Registered nurses (RNs)** — that provide skilled medical care, including giving medications, monitoring vital signs, dressing wounds, and teaching family caregivers how to use complicated equipment at home.
- **Therapists** — that work with patients to restore or maintain their motor, speech, and cognitive skills.
- **Homecare aides** — who provide personal services such as bathing, dressing, toileting, making meals, light cleaning, and transporting patients to the doctor.
- **Companion/homemakers** — who help with chores around the house but usually do not perform personal duties for the care recipient.

Getting Started with Homecare

If you are considering getting homecare help to assist you with your caregiving responsibilities and/or to get some time for yourself, there are a number of things you need to consider, and also things you need to know.

- The first step is to make sure you and your loved one are comfortable with the idea of someone else taking on some of the tasks that you've been doing by yourself. There are many care recipients that are totally opposed to the idea, and some negotiations will need to occur before any plan can be put in place. It is important for all concerned to understand what is prompting the need for homecare and the personal issues that lie beneath the refusal to consider it. Getting beyond objections isn't necessarily easy and you might need some guidance on how to go about it, perhaps from other family caregivers that have dealt with the issue or from professionals that counsel family caregivers.
- Defining the tasks that need to be done by the homecare worker will help you determine exactly what type of homecare is most appropriate in your situation. Do you need a nurse to clean and bandage wounds and monitor equipment, a homecare aide to help your loved one get showered and dressed, or would a companion / homemaker be more appropriate in your circumstance?
- Once you know what type of assistance you need, and all parties agree that it is necessary or desirable, the inevitable questions about where to find homecare services, how much they will cost, and whether any of the cost is covered by insurance or provided by govern-

ment programs must be asked and answered. Some federally funded programs, insurance companies, and health maintenance organizations (HMOs) do provide for some home health care services, but the coverage provided may not fit your needs. To be sure whether or not you have any coverage at all, it is imperative that you review your insurance benefits.

- If you're like the majority of family caregivers you need the most help with personal care tasks — the very type of care that is not typically covered by private health insurance programs or Medicare. So unless your loved one had the foresight and the funds to purchase long-term-care insurance prior to becoming ill, your access to homecare will be limited by what you can afford. You may be able to get some help from state programs that take into account your ability to pay, and the age or extent of disability of your care recipient, but the sad reality is that more often than not the costs of homecare services will have to come out of your own pocket.

Choosing the Right In-Home Care

How do you find the right homecare solution for your family, the one that provides the services you need at a price you can afford? There are several ways of tapping into the homecare network.

Here is a look at some of the most common ones and what you need to think about when considering them:

Home Care Agencies

Home Care Agencies are companies in the business of meeting homecare needs. Not all home care agencies provide the same variety and level of service, however, so make sure the agency you are considering can provide all the services you need. The issue isn't bigger or smaller but rather which one meets your criteria.

If your care recipient is approved for skilled care that Medicare will pay for, it's vital that the agency be Medicare certified. This ensures that the agency has met federal minimum requirements. If your loved one only requires personal care or companion / homemaker care, Medicare certification need not be a factor in your decision. Some companies actually have two agencies that are legally separate but work together, one that is Medicare certified and one that is strictly private pay.

Some agencies are accredited in addition to being certified. Well-known accrediting organizations are the National League for Nursing, the Joint Committee for Accreditation of Healthcare Organizations, and the National Foundation of Hospice and Home Care. This type of certification tells you that the agency conforms to national industry standards, and there is always comfort in knowing you are dealing with an organization that has proven its worth to its peers.

What do home care services cost through an agency? Some agencies charge flat fees ranging from \$100 to \$120 per visit. Others have a minimum two or four-hour fee. The actual hourly rate will vary depending on the services you require and the part of the country you live in, but don't be surprised to find rates ranging anywhere from \$13 to \$35 per hour.

Questions to Ask Any Agency You Are Thinking of Working With

- Is the agency certified for participation in Medicare and Medicaid programs (where applicable)?
- How long has the agency been serving the community?
- Is the agency accredited by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) or Community Health Accreditation Program (CHAP) or other recognized accrediting body?
- Does the agency provide an initial assessment to determine if the patient would be appropriate for home care and what those services might be?
- Does the agency provide all of the services you need? Can they provide flexibility to meet the patient's changing health care needs?
- How does the agency choose and train their employees? Are background checks made? Does it protect its caregivers with written personnel policies, benefit packages, and malpractice insurance?
- Does the agency provide literature explaining its services, eligibility requirements, fees, and funding?
- Does the agency have arrangements in place for emergencies? Are the agency's caregivers available 24 hours a day, seven days a week? How quickly can they start service?
- Are references from former clients and doctors available?
- What types of programs does the company have in place to assure quality care is provided?
- Will the agency go to bat for you if your insurance company or Medicare fail to cover a claim you and the agency thought should be covered?

Privately Employed Home Caregivers

Instead of using a home care agency, you may wish to hire a home care worker on your own, especially if you are not looking for skilled medical care, but rather for someone to act as a companion or personal aide on a regular, long-term basis. In those situations, bypassing commercial agencies can often result in significant financial savings. You can start your search by putting the word out to friends and neighbors that may know of a homecare worker. Also check with the nursing staff in your doctor's office, a hospital discharge planner, or community-based social service agencies for reliable candidates.

Things to Think about If You Plan to Hire Private Homecare Help

- You yourself must do substantial background checks to ensure that the employee has no record of criminal activity or abuse.
- You must be prepared to do all the paperwork necessary to comply with tax and insurance laws affecting employees.
- You may not get candidates with the same level of training and licensure as those who work for home care agencies.
- You do not have the guarantee of substitute help if your home caregiver is ill or on vacation.

Home Care Registries

A good middle ground between home care agencies and hiring help on your own is a home care registry. Registries are somewhat like an employment agency. They screen, interview, and reference-check workers they refer to clients so you don't have to, but just as with homecare agencies you need to ask a lot of questions to assure yourself that they can provide the right personnel to meet your needs. Because members of a registry are independent contractors, their services are available at prices that are usually lower than agencies.

Government In-Home Aide Services

Many states and counties offer homecare services to residents who are aged or disabled. Some even offer services to family caregivers. Applications for aid are evaluated by state social workers that rank a candidate's needs according to a number of objective criteria, including whether the care recipient lives alone and what activities he or she can perform. Care recipients who qualify are provided with home care aides that can give personal (not medical) care, do light cleaning, change linens, prepare meals, and transport or escort the patient to the doctor. The aides are trained and licensed by

the state. Fees are usually set on a sliding scale and can range anywhere from \$1 to \$20 / hour, depending on the care recipient's ability to pay. To find out what services your state offers, call your state Department of Human Resources or state Health Department. But be forewarned: usually these agencies are overwhelmed with applications and the waiting list can be long.

Hospice

If you are caring for a loved one with a terminal illness, Hospice offers a number of services that can help. To qualify for in-home hospice care, you must have a doctor certify that your loved one is no longer seeking curative treatments and that he or she has "months rather than years to live." Depending on your situation, Hospice will provide a social worker, a nurse who comes regularly to check medicines and vital signs, volunteers to sit with your loved one while you while you run errands or just get some rest, and home health aides who will bathe and clean the patient, tidy up the room, and fix a meal if necessary. Payment is usually through Medicare or private insurance. When you call your local Hospice office, a home health care coordinator will work with you to arrive at the best combination of services for your situation.

How to Communicate Your Loved One's Symptoms Regarding Overall Wellbeing, Pain, and More

Overall Wellbeing

- Is the patient eating well? Any sudden changes in diet or fussiness about eating? Any sudden cravings?
- Is his weight stable? If not, what is happening?
- Is he sleeping well? Unable to fall asleep? Wakes up and is unable to go back to sleep? Has nightmares? Sleeps restlessly?
- Is he getting some kind of exercise? Suddenly doing more or less than typical?
- Is there any sign of abuse or neglect that you've noticed? If so, what is it?

General Condition

- Does the patient seem to have "slowed down" noticeably since the last visit? If so, in what way?
- Does he have any unusual bleeding? Where? How much?
- Does he seem to be breathing easily? If not, what is the quality of the breathing?
Rapid Shallow Gasping Rattling
Other _____
- Does he cough when he eats or drinks?
- Is his digestive system working well? If not, what seems to be the matter?
Excessive gas Heartburn Diarrhea
Constipation Other _____
- Are his limbs moving as they usually do? Is he struggling to handle things?
- Have any rashes or welts appeared recently? Where? What do they look like?
- Has a mole changed shape or become dark? Has a new one appeared somewhere? If so, where?

- In general, does the treatment plan seem to be working? If not, what seems to be wrong?
- Is a particular problem the reason for this office visit? If so, what are the major symptoms or concerns?

Pain

- Is the patient complaining about pain? What does he say it feels like?
Sharp Stabbing Dull Pounding
Achy Tingling Other _____
- Where is it located?
All over Headache Abdomen Limbs
Other location _____
- On a scale of 1–10, with 1 being no pain and 10 being the worst pain imaginable, how does the patient rate his pain?
- How long has the pain lasted?
- Does it move around or stay in one place?
- Does it come and go, or is it there all the time?
- Does the pain seem to occur in relation to something else (e.g., eating, standing up suddenly, while reaching for something overhead)?
- Is there anything that makes the pain better or worse?
- Does pain medication help? If so, how much?

Medications

- Is the patient taking his medications on time? At the prescribed dose? If not, what seems to be going wrong?
- Is he complaining about or suffering from any side effects? If so, what are they (drowsiness, hyperactivity, etc.)?

- Does anything seem to have suddenly changed in his response to medication? If so, what is it?
- Did he stop taking a medication for any reason? If so, why and what happened as a result?

Emotional and Mental Wellbeing

- Does the patient seem to be as mentally sharp and alert, or has there been a noticeable decrease in mental function? What are the symptoms?
- How is his memory, both long term and short term? Has it changed recently? If so, in what way?
- Can he still do and enjoy activities as in the past? Has something suddenly become boring or unpleasant?
- Does he feel responsible for being ill and / or angry about his condition?
- Does he fear the truth and put off doctor visits based on what he thinks the doctor may say about his problem?
- Is he able to laugh and enjoy life?
- Does he seem to be more emotionally overwrought than usual? In what way?
Anxious Depressed Fearful
Sad Hyped-up Excitable
Other _____

Spiritual Wellbeing

- Are there any restrictions on treatment that need to be considered due to the patient's spiritual beliefs or practices? If so, what are they?
- Has the patient continued his usual spiritual practices (e.g., going to church, meditation, saying the rosary, prayer, using a home altar)? If not, what has changed?
- Has he started expressing doubts about faith or spiritual practices?
- Does he seem more reflective and quiet than usual? If so, does this seem to be okay?
- Is he starting to talk about wanting to "go home" in the sense of dying?

Other Conditions

Each illness has its own set of unique symptoms. Ask your doctor if there are particular symptoms that should be monitored.

How to Communicate Your Loved One's Symptoms During a Crisis

When your care recipient is in a medical crisis, your ability to observe symptoms carefully and report accurately might be, quite literally, life-saving. But that is also a time when it may be difficult to function clearly. Here is a list that will help you remember what to look for during a crisis. You may want to read it ahead of time and then tuck a copy in your patient file for later reference.

- What time did the problem start?
- What was he doing when the problem started?
- Do you know or suspect what might have caused the problem?
- What was the first symptom that you noticed?
- What other symptoms / complaints do you remember?
- Did the symptoms come on abruptly or gradually?
- Was he given any medication or medical treatment just before the problem started? If so, what was it?
- Did the patient say anything about how he felt when the problem started and / or has it progressed? What was it?
- Does he have a history of this kind of problem? If so, what was the previous diagnosis?
- What did you do to try to help him between the time the problem arose and the time you arrived in the ER or the doctor's office?
- Did something work well? Seem to make things worse?

When to Call for Help

When is a crisis a crisis? When should you call someone else for help? Get help when your care recipient is in some kind of medical distress and you aren't sure what to do.

Call your local rapid-response number (e.g., 911) or an ambulance if the person you are caring for:

- Is unconscious
- Has unexplained chest pain or pressure
- Is having trouble breathing or is not breathing at all
- Has no pulse
- Is bleeding severely
- Is vomiting blood or bleeding from the rectum
- Has fallen and may have broken bones
- Has had a seizure
- Has a severe headache and / or slurred speech
- Has pressure or severe pain in the abdomen that does not go away
- Is unusually confused or disoriented

Also call for help if:

- Moving the person could cause further injury
- The person is too heavy for you to lift or help
- Traffic or distance would cause a life-threatening delay in getting to the hospital

How to Communicate with Insurance Company Personnel

Before you pick up the phone to speak to a claims representative, you need to gather some information. Be prepared to give the person you talk with:

- Your name and your relationship to your care recipient,
- Your care recipient's birth date,
- The insurance policy number,
- The name and address of the organization that sent the bill,
- The total amount of the bill,
- The diagnosis code on the bill, and
- The Explanation of Benefits (if you are questioning an insurance payment).

When you start the conversation, ask for the name and telephone extension of the individual who is handling your phone call. If you need to call again, you will want to try to speak with the same person. Keep in mind that billing office personnel and insurance claims representatives are there to serve you. You are the customer. Be assertive. You should expect to:

- Be treated with respect and consideration,
- Have your concerns clarified,
- Have your questions answered with accurate and timely information, and
- Be informed of any steps you need to take to move things along.

Communication Tips

Here are some tips for communicating effectively with people who work in the health insurance system.

- **Be Prepared.** Before you call an insurance company, write down a list of the questions you have so you can handle everything in one phone call.
- **Take Good Notes.** Take notes about your phone conversations, including the name of the insurance representative, the date of the call and the information you were given. For convenience, put this in your care recipient notebook.
- **Be Clear and Concise.** State clearly and briefly what your question or concern is, what you need, and what you expect.
- **Be Patient.** Health insurance issues can be frustrating and time-consuming. Accept that you will spend a certain amount of time navigating through automated telephone menus, waiting on hold, and waiting for the claims process to be completed.
- **Be Considerate.** Most insurance personnel want to do their jobs well, and they have a tough job to do. Thank them when they have been helpful. Speak to them kindly. Assume that they are trying to help you.
- **Follow Through.** If the insurance company asks you to do something or to send additional information, do it right away. Don't let it slide. This will help them get the bill paid. Above all, be persistent. Stay in touch. Keep after an issue until it is resolved.

Resources

Cancer Organizations

American Cancer Society

<http://www.cancer.org>

1-800-ACS-2345 (or 1-866-228-4327 for TTY)

A voluntary organization that offers a variety of services to patients and their families. The ACS also supports research, provides printed materials, and conducts educational programs.

Cancer and Careers.org

www.cancerandcareers.org

Email: ksweeney@cew.org

Provides a free workbook, educational resources, support, and information for cancer patients and survivors, coworkers, managers, CEOs, and human resources personnel about cancer patients and survivors working through their treatment and returning to work.

Cancer Care, Inc.

275 7th Avenue, Floor 22

New York, NY 10001

www.cancercare.org

Email: info@cancercare.org

1-800-813-HOPE (4673)

Offers support, information, financial assistance, and practical help to people with cancer and their loved ones. Services are available in person, over the phone, and through the agency's website.

Cancer Hope Network

2 North Road, Suite A

Chester, NJ 07930

www.cancerhopenetwork.org

Email: info@cancerhopenetwork.org

877-HOPENET (877-467-3638)

Provides individual support to cancer patients and their families by matching them with trained volunteers who have undergone and recovered from a similar cancer experience.

CURE:

Cancer Updates, Research & Education

www.CUREtoday.com

1-800-210-CURE (2873)

Provides online education, publications, educational events, and a comprehensive list of resources on specific cancers, issues for families, financial help, and integrative therapies.

National Cancer Institute (NCI)

1-800-4-CANCER (800-422-6237)

www.cancer.gov

bethesdaclinicaltrials.cancer.gov

A comprehensive site for people wanting to know more about cancer, including prevention, definitions, clinical trial information, recipes, links to cancer centers, and more. Resources for patients, families and health care professionals.

National Comprehensive Cancer Network (NCCN)

215-690-0300

www.nccn.org

A non-profit alliance of the world's leading cancer centers. The primary goal of all NCCN initiatives is to improve the quality, effectiveness, and efficiency of oncology practice. To order patient guidelines call 888-909-NCCN (6226).

The Wellness Community

888-793-WELL (888-793-9355)

www.thewellnesscommunity.org

Provides free psychological and emotional support to cancer patients and their families. They offer support groups on stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Caregiver Organizations

Caregiver.com

<http://www.caregiver.com/>

1-800-829-2734

Caregiver Media Group is a leading provider of information, support, and guidance for family and professional caregivers

Care Pages

www.carepages.com

CarePages websites are free blogs, created by patients and families, that connect friends and family during a health challenge.

Family Caregiver Alliance

<http://www.caregiver.org>

1-800-445-8106

Offers information, education, services, research, and advocacy to support and sustain the work of families nationwide, caring for loved ones with chronic, disabling health conditions.

Lotsa Helping Hands

www.lotsahelpinghands.com

Provides a simple way for friends, family, colleagues, and neighbors to pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during a crisis. It uses a free, private group calendar, specifically designed for organizing helpers.

National Association for Hospital Hospitality Houses

<http://www.nahhh.org>

1-800-542-9730

A non-profit corporation serving facilities that provide lodging and other supportive services to patients and their families when confronted with medical emergencies. Each facility assures that a homelike environment is provided to persons who must travel to be with a patient or to receive necessary outpatient care.

National Family Caregivers Association

<http://www.nfcares.org>

1-800-896-3650

Educates, supports, and empowers caregivers nationwide. Provides services to all caregivers independent of patient diagnoses, relationships and life stages, to help transform family caregivers' lives by removing barriers to well being.

There With Care

303-447-CARE (2273)

www.therewithcare.org

A non-profit organization providing a range of services for children and families facing critical illness in order to ease the burden of day-to-day obligations during a medical crisis.

Visiting Nurse Association of America

<http://www.vnaa.org>

617-737-3200

A national, nonprofit association of Visiting Nurse Agencies (VNAs) and home healthcare providers. The mission is to support, promote, and advance the nation's network of VNAs who provide cost-effective and compassionate home care to vulnerable patients. Services include advocacy, education, collaboration, and provision of products, resources, and support to members.

Well Spouse Foundation

<http://www.wellspouse.org>

1-800-838-0879

A nonprofit membership organization that advocates for, and addresses the needs of caregivers of chronically ill and / or disabled spouses / partners. Offers peer-to-peer support and education for health care professionals and the general public.

Complimentary Care Organizations

Consortium of Academic Health Centers for Integrative Medicine

612-624-9166

cahcm@umn.edu

<http://www.imconsortium.org/home.html>

An organization of 42 highly esteemed academic medical centers across the US. The mission is to help transform medicine and healthcare through rigorous scientific studies, new models of clinical care, and innovative educational programs that integrate biomedicine, the complexity of human beings, the intrinsic nature of healing and the rich diversity of therapeutic systems. Many of the Consortium's academic medical centers offer clinical services.

National Center for Complementary and Alternative Medicine (NCCAM)

888-644-6226

www.nccam.nih.gov

The leading government agency for scientific research on complementary and alternative medicine (CAM). One of the 27 institutes and centers that make up the National Institutes of Health (NIH) within the U.S. Department of Health and Human Services. Provides the latest news, research, events, and clinical trials in complementary medicine.

Pine Street Foundation

415-455-5878

www.pinestreetfoundation.org

Website that provides information on evidence-based research on integrative care. Publishes a quarterly newsletter called Avenues.

UCSF Osher Center for Integrative Medicine

www.osher.ucsf.edu

415-353-7700

A university-based clinic and research center, whose mission is to transform the way medicine is practiced by conducting research on integrative approaches to health, educating students, health professionals, and the community, and treating patients with compassionate care — addressing the physical, psychological, social, and spiritual aspects of the patient.

Hospice Resources

Hospice Education Institute

<http://www.hospiceworld.org>

1-800-331-1620

An independent, not-for-profit organization, serving members of the public and health care professionals with information and education about the facets of caring for the dying and the bereaved.

National Hospice and Palliative Care Organization

<http://www.nhpco.org>

1-800-658-8898

A national nonprofit membership organization representing hospice and palliative care programs and professionals. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of enhancing quality of life for people dying and their loved ones.

Medication Assistance Organizations

Drug InfoNet

www.druginfonet.com/
1-315-671-0801

A website that provides drug and disease information. Provides a Manufacturer Information page to link to pharmaceutical company pages.

National Council on the Aging — BenefitsCheckUp

www.benefitscheckup.org

The National Council on the Aging developed BenefitsCheckUp — a comprehensive Web-based service to screen for benefits programs for seniors with limited income and resources. Benefits include health care, energy/utility assistance, tax relief, prescription drug benefits, food, housing, transportation, and more.

NeedyMeds

www.needymeds.com

An on-line organization that provides information on patient-assistance programs designed to help with the cost of medicine and health care.

Pharmaceutical Research and Manufacturers of America (PhRMA)

202-835-3400
www.phrma.org
www.innovation.org

A directory of patient-assistance programs offered by pharmaceutical companies.

Patient Advocacy

Legal Resource Guide for Cancer Patients

www.tyla.org/cancer_guide

The Guide covers legal issues concerning privacy, informed consent, insurance, clinical trials, employment law, disability, liability, guardianship, estate planning, and end-of-life decisions. The Guide is intended to be an informative resource upon which cancer patients and their family members and friends can rely to answer legal questions.

National Patient Advocate Foundation

725 15th Street, NW, Tenth Floor
Washington, DC, 20005
1-800-532-5274
Email: action@npaf.org
www.npaf.org

A national, non-profit patient-advocacy organization for assistance in improving access to, and reimbursement for, high-quality healthcare through regulatory and legislative reform at the state and federal levels.

Patient Advocate Foundation

700 Thimble Shoals Blvd., Suite 200
Newport News, VA 23606
help@patientadvocate.org
1-800-532-5274
www.patientadvocate.org

Provides no-fee professional case management to individuals facing barriers to healthcare access for chronic and disabling disease, medical debt crisis, and employment-related issues.