

Orientation to Caregiving

THIRD EDITION



A Handbook for Family Caregivers of Patients with Brain Tumors

UCSF

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

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A Handbook for Family Caregivers of Patients with Brain Tumors

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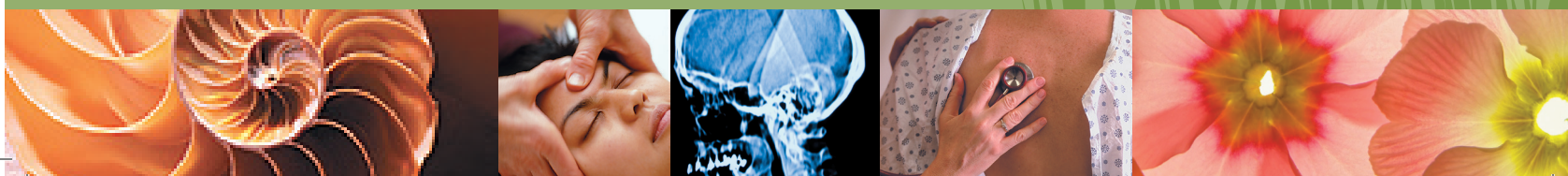
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Chapter 1

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 assist and/or care for loved ones with brain tumors.



Handbook Overview

While much of this handbook provides general information, it has been prepared specifically for family caregivers of patients in the Neurosurgery and Neurological Oncology practices at the University of California, San Francisco. All the contents presented here have been carefully reviewed by Dr. Mitchel Berger, the Chairman of the Department of Neurological Surgery at UCSF and an international expert in the treatment of brain tumors. In addition, 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 back of the book 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 healthcare 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** outlines common brain cancer symptoms, treatment side effects and offers direction about whom to call for help and when.
- **CHAPTER 4** 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 5** provides helpful tips for communicating with your family.
- **CHAPTER 6** 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 7** advises you on important plans you should make to secure quality end-of-life medical care, and estate planning.
- **CHAPTER 8** suggests strategies to maintain your own well-being and to give you a sense of control, hope, and balance.
- **THE APPENDIX** include a series of resources and more detailed information that you can turn to.

Importance of Family Caregiving

Caring for loved ones with brain tumors 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 facing cancer. 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 depressed¹. 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.

In this chapter:

- Identifying Tasks
- Accomplishing Caregiving Jobs
- Tips for Finding Home Care Services
- Getting Organized
- Managing Medications
- Tracking Treatments and Side Effects

Chapter 2

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



Identifying Critical Tasks

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

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

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

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

You may need to become familiar with tasks that are new for you, but are common for home care. 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

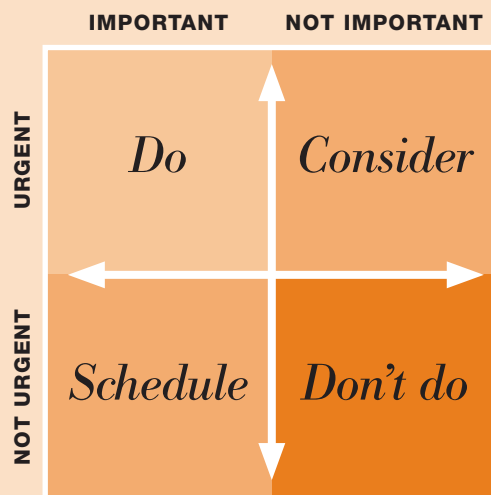
Accomplishing Caregiving Jobs

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 & Merrill¹

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

2

GETTING HELP FROM FRIENDS AND FAMILY

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

It is important to get beyond these barriers because there are times when you simply can't and shouldn't do it all yourself. It may help to realize that **most family members and friends appreciate having the opportunity to be helpful.**

At the same time, it is important to be sensitive to signs that volunteers are wearing out, in which case new ones need to be found. Sometimes, the "retiring" volunteers can help replace themselves.

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

Identifying Your Caregiving Team

- Ask your loved one and other family members who would be appropriate helpers.
- Explore your loved one's or your family's phone book or Rolodex for social contacts.
- Contact your loved one's or your family's social organizations such as religious organizations, workplace, 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.

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

Coordinate the Care

- You or a family member (not your loved one) should call to invite the person to help.
- Hold an introductory one-hour meeting for all team members to discuss the specifics:
 - issues regarding the illness and patient's needs
 - what the current needs are of the patient and family
 - the roles or tasks each member can take
 - contact information
 - team 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 re-organize schedules
 - set up a system for quarterly or other check-in on volunteer availability: "Do you need a break?"

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

- 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.

Declining Help

Sometimes people offer you help you don't need. Thank them for their concern. Tell them that you will let them know if you need anything. Sometimes people offer unwanted advice. They may do this because they don't know what else to say. It is up to you to decide how to deal with this. You do not have to respond to them at all. Otherwise, thank them and let it go. You might tell them that you are taking steps to help your family.²



SEE THE APPENDIX
for more information
on homecare and team
coordination.

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.
- 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.

Getting Organized

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

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

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

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

- **Pathology reports, MRI, and CT scans** — These reports contain the most critical information about the tumor and diagnosis, and will direct the treatment options. Ask your doctor for a copy of scans on a CD-ROM or film, so you can bring them with you if you get second opinions or seek new treatment.
- **Lab reports and blood tests** — Having copies of these on hand will allow you to quickly refer to them without having to ask the nurses or doctors to search for them.
- **Notes and questions section** — This is where you can write notes while at appointments, or keep a file of questions you need answered by the doctors.
- **Medication log** — See the Appendix for a blank medication log on which you can fill in the medications being taken, dosages, dates, side effects, problems, 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, surgeries, 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 usage.⁴ Mistakes in the type of medication taken, the wrong dosage, or an interaction between drugs can lead to severe health consequences or worse yet, death. The best way to prevent this is to keep track of your loved one's medication regimen in an organized way.

Here are important tips for managing medications and preventing errors:

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

Tracking Treatments and Side Effects

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

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

Between physician visits, record the following types of information in your treatment log⁵:

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



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

¹ Covey S, Merrill A, Merrill R. *First Things First*. New York, NY: Simon & Schuster; 1994.

² Adapted from "Caring for the Caregiver," National Cancer Institute, 2007. Available at: <http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver.pdf>. Retrieved 2013.

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. *To Err is Human: Building a Safer Health System*. 2000; National Academy Press, Washington, D.C. Available at: <http://www.nap.edu/books/0309068371/html/>

⁵ Berger MS, personal communication, 2006.

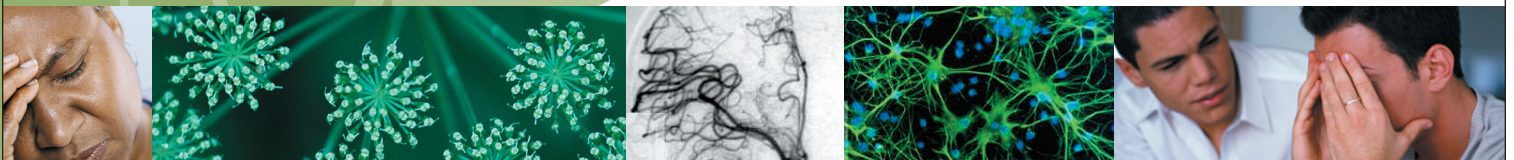
In this chapter:

- What To Do About Common Symptoms
- Identifying and Treating Psychological Symptoms
- Tumor Location and Symptoms
- Common Side Effects of Treatment

Chapter 3

Symptoms Associated with Brain Tumors and Side Effects of Treatment

Unfortunately, it is quite common for brain tumor patients to experience symptoms associated with their tumor, as well as side effects of the treatment. Symptoms and side effects may be the result of the type of tumor, the location and/or size of the tumor, and the type of treatments utilized (see Symptoms Based on Tumor Location, page 3.7). Surgery, radiation, chemotherapy, and drug therapies may all affect the regions of the brain they are directed to as well as alter neurological functions such as the release of hormones and chemicals in the brain. **The symptoms your loved one experiences may change over time. They may include both physical and psychological changes.** This chapter will briefly describe the most common symptoms in people being treated for a brain tumor, and will suggest what to do if the symptoms occur.



Common Brain Tumor Symptoms

The most common symptoms experienced by patients with brain tumors are headaches and seizures. Both may be managed with medication. Loss of sensation and muscle strength may be managed and adapted to with use of occupational and physical therapies. A blood clot or deep vein thrombosis is best managed by preventive measures and early aggressive intervention if those measures fail. Hearing and vision changes may occur throughout treatment and may be treated with specialized interventions. Psychological symptoms such as fatigue, behavioral, and cognitive changes may be treated with cognitive therapy, psychotherapy, and medication¹ (see Psychological Symptoms of Brain Tumors, page 3.6).

Although you should discuss all new symptoms your loved one experiences with your physician or nurse, the table on the following page, “What To Do About Common Brain Tumor Symptoms,” offers some common advice about what to do and whom to call if these symptoms develop.

One symptom that deserves special attention is depression. Current research shows

that symptoms associated with depression are common with brain tumors as well as after surgery to remove the tumor, and may increase over time². Symptoms may include prolonged feelings of sadness, loss of interest or pleasure in things, feelings of worthlessness or guilt, insomnia, decreased energy, and even thoughts of suicide.

Untreated depression can slow rates of recovery from treatments and cause other health problems. Depression affects not only the patient’s quality of life, but also that of the caregiver.

It is important to familiarize yourself with the signs and symptoms associated with depression. Your loved one’s medical team will likely be focused on the treatment of the brain tumor. You may be the first to identify this important symptom. You can alert the doctor to your concerns. The doctor can perform professional formal screening and diagnosis of depression and offer effective treatments such as medication and/or psychotherapy.

Common symptoms experienced by patients with brain tumors include¹:

- Headache
- Seizures
- Sensory (touch) and motor (movement) loss
- Deep Venous Thrombosis (DVT or blood clot)
- Hearing loss
- Vision loss
- Fatigue
- Depression
- Behavioral and cognitive (thinking) changes
- Endocrine dysfunction (hormone/gland changes)

What To Do If Symptoms Occur

The following chart is to help family caregivers understand some common symptoms that their loved one may experience. This chart provides only a rough guide and does not take the place of an in-person assessment by a physician. If there is any question about the seriousness of a symptom, please contact your loved one's physician or get your loved one to an emergency room immediately.

Seizures

DESCRIPTION	WHAT TO DO	WHO TO CALL
Myoclonic ● Single or multiple muscle twitches, jerks, spasms Tonic-clonic (Grand Mal) ● Sudden onset ● Loss of consciousness and body tone, followed by twitching and relaxing muscle contractions ● Might bite tongue ● Lose control of body functions ● Patient may have short periods of no breathing (30 seconds) and may turn dusky blue ● Lasts 2-3 minutes, followed by limpness ● After-effect: sleepiness, headache, confusion, sore muscles ● Patient may have brief weakness or numbness after a seizure	BEFORE: ● If your loved one has medications for when they feel a seizure coming on, or when one starts, ensure that they take the medication DURING: ● Do not panic ● Make sure your loved one is breathing ● Clear area of sharp objects or anything dangerous ● Protect the head from being bumped ● Look at your watch and note the time if you are able ● Don't put anything in the mouth ● Don't attempt to restrain limbs during seizure since it could result in injury AFTER: ● Try to lie person on side, keeping airways open ● Allow time for recovery ● Help with reorientation: tell your name, where you are, what happened ● Encourage the person to rest until he feels like himself again ● May need to adjust dosage of seizure medication ● Maintain record of seizure symptoms	● Seizures in patients with known brain tumors are not necessarily an emergency ● Call your neuro-oncologist or treating physician during business hours to inform them if seizures are a new symptom ● CALL 911 if: ● Person is not breathing or has difficulty breathing ● Injury occurs ● Seizure lasts longer than 5 minutes ● 2nd seizure follows immediately after ● Patient doesn't wake up after first seizure, or has second seizure without

Headaches

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Steady and worse upon waking in the morning and clears up within a few hours ● Persistent non-migraine headache ● May or may not be throbbing, depending on location of the tumor ● May worsen with coughing or exercise or with a change in body position ● Some are associated with new neurological deficits	● Treat with medication prescribed by doctor ● Maintain record of headaches, if they are worsening ● Notify treating physician if prescribed medications are not working ● Ask patient the degree of pain: the worst headache of your life?	● CALL 911 or go the EMERGENCY ROOM if the headache is accompanied by a fever or neck stiffness ● CALL 911 or go to the EMERGENCY ROOM if the headache is the highest degree of pain ● Call local treating physician if you are unsure about what to do

Deep Venous Thrombosis (DVT)

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Swelling and pain in leg ● Skin on leg turns red ● One leg enlarges, and is bigger than the other one ● May indicate a blood clot	● Alert treating physician or neuro-oncologist immediately ● Seek medical care at primary care office or go to emergency room	● Call treating physician or neuro-oncologist immediately to alert them ● CALL 911 if you are unable to reach doctor ● Go to the EMERGENCY ROOM

Pulmonary Embolism (a potential complication of DVTs)

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Chest pain ● Shortness of breath ● Fast heart beat	● Pulmonary Embolism is life threatening and needs immediate attention	● CALL 911

Nausea/Vomiting

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Nausea and decreased appetite can be associated with intracranial pressure ● May be a side effect of medication/ chemotherapy	● Maintain record of symptoms ● Alert treating physician at next appointment if symptom is new/severe	● Call treating physician during business hours if necessary due to symptom severity ● CALL 911 or go to EMERGENCY ROOM if patient is unable to stay hydrated

Motor/Sensory & Language/Communication Problems

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Problems with balance and coordination; impaired coordination of arms, legs, and hands ● Problems with fine motor control (writing, eating) ● Awkward or stiff movements in arms and legs ● Tingling, numbness, or other odd sensations ● Falling ● Asymmetrical (lopsided) facial expressions ● Muscle weakness on one side of body ● Difficulty with verbal fluency: speaking, reading, and/or writing	● Most impairments don't require urgent care ● Maintain record of symptoms ● Some motor changes, especially if they occur suddenly, are symptoms of new stroke and need immediate attention (new difficulty with balance, speaking, swallowing, walking, controlling hands or arms)	● Call treating physician or neuro-oncologist during business hours to inform them of recent changes if they have been developing over days or weeks ● Speak with a social worker, nurse, or neurologist for cognitive rehabilitation or speech and language therapy referrals ● CALL 911 or go to the EMERGENCY ROOM if motor changes have a sudden onset

Vision Loss

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Inability to recognize objects by looking at them ● Hallucinations ● Unusual visual perceptions such as double vision or blind spots in vision	● Maintain record of symptoms ● Alert treating physician or neuro-oncologist at next appointment	● CALL 911 or go to EMERGENCY ROOM if blindness develops suddenly ● Call treating physician during business hours if necessary due to sudden onset or symptom severity

Hearing Loss

DESCRIPTION	WHAT TO DO	WHO TO CALL
● Ringing in the ears ● Decreased hearing ● Dizziness	● Maintain record of symptoms ● Alert treating physician or neuro-oncologist if symptom is new	● Call treating physician during business hours if necessary due to sudden onset or symptom severity

Identifying and Treating Psychological Symptoms

COGNITIVE AND BEHAVIORAL SYMPTOM	DESCRIPTION	TREATMENTS
Emotion and Personality Changes	● Development of psychiatric symptoms: depression, anxiety, obsessive-compulsive behaviors ● Changes in emotional control: irritability, mood swings, withdrawal ● Socially inappropriate behavior ● Denial that behavior is a problem	● Cognitive rehabilitation therapy ● Psychotherapy ● Medication therapies with periodic check-ins to review and adjust regimens as needed.
Learning and Memory	● Difficulty processing, storing, and retrieving information ● Short-term memory loss	● Cognitive rehabilitation therapy ● Speech and language therapy
Attention and Concentration	● Confusion ● Easy distraction ● Difficulty multitasking and planning	● Cognitive rehabilitation therapy ● Medication therapies
Executive Functioning	● Decreased reasoning ability ● Impaired judgment ● Inability to apply consequences from past actions ● Requires frequent monitoring of the appropriateness of one's actions	● Cognitive rehabilitation therapy ● Problem solving therapy

Symptoms Based on Tumor Location

The brain acts as a central control for the body and mind. It is extremely complex, and is made up of many different structures that control specific functions. The symptoms your loved one experiences will depend on the type of tumor, and where it is located in the brain. Here is a list of the major parts of the brain, and some possible symptoms or functional loss that may result from a tumor in that region.

Frontal Lobe

- Weakness
- Paralysis on one side of body
- Mood disturbances
- Difficulty thinking
- Confusion
- Disorientation
- Mood swings
- Organization and Planning
- Seizures
- Memory
- Judgement

Parietal Lobe

- Seizures
- Paralysis
- Problems with handwriting
- Mathematical difficulty
- Motor/Cognitive skill deficits
- Loss of sense of touch

Occipital Lobe

- Loss of vision
- Visual hallucinations
- Seizures

Temporal Lobe

- Seizures
- Perceptual/spatial disturbances
- Inability to understand multi-step commands (receptive aphasia)
- Lack of insight
- Memory

Cerebellum

- Loss of balance (ataxia)
- Loss of coordination
- Headaches
- Vomiting



Common Side Effects of Treatment

Specific drugs and treatments have specific and unique side effects that should be discussed with your doctor. Some of the side effects associated with standard treatments for newly diagnosed brain tumors are listed below. This is not a complete list of possible side effects. Every patient reacts individually to treatment, and your loved one could experience many or very few of these effects. Most patients do not experience all the side effects listed. There is no correlation between the severity of side effects and the effectiveness of the medication or therapy.

Most of these side effects are reversible and will go away when treatment is complete. There are many options to help minimize side effects, which should be discussed with your treating physician.

To help your doctors recognize possible drug interactions, keep a list of all medications, including over-the-counter products.

INTERVENTION	POSSIBLE SIDE EFFECTS	WHAT TO DO
Surgery: Surgical removal is usually the most effective first-line treatment against brain tumors. Surgeons usually aim to remove as much of the visible tumor as possible.	● Headache ● Infection at incision site (redness, swelling, discharge, fever) ● Problems speaking or thinking clearly ● Muscle weakness	Contact your neurosurgeon if these problems appear following surgery.
Radiation Therapy	Short term effects: ● Fatigue ● Hair loss ● Scalp irritation ● Muffled hearing ● Short-term memory loss Long-term effects: ● Memory loss ● Radiation necrosis (a build up of dead brain tissue) ● Neurological impairments (these may vary depending on what part of the brain is most irradiated and how that part normally functions)	Report your symptoms to the doctor caring for you at the time that the symptoms occur. This may be the radiation oncologist, the medical oncologist, the neurologist or your primary care physician.
Chemotherapy — Temodar (Temozolomide) and Gleostine (CCNU): These are oral alkylating agents that are commonly prescribed to patients with newly diagnosed brain tumors.	● Vomiting ● Nausea ● Fatigue ● Loss of appetite ● Headache ● Constipation ● Lowered blood counts	Contact your oncologist or chemo nurse. They can suggest strategies or other medications that may alleviate the side effects.

INTERVENTION	POSSIBLE SIDE EFFECTS	WHAT TO DO
Optune is an FDA-approved medical device that, when turned on, creates low-intensity wave-like electric fields called tumor treating fields (TTF). Using four adhesive patches called transducer arrays, TTFs are delivered to the location of a GBM and interfere with cell division. This action slows or stops glioblastoma cells from dividing and may destroy them.	The most common side effects when using Optune alone are: ● Scalp irritation (redness and itchiness) ● Headache Other side effects may be: ● Malaise ● Muscle twitching ● Skin ulcers	Follow instructions for skin preparation with array changes, Evaluate skin condition for redness or open areas with each array change. Contact prescribing doctor or nurse team when skin changes are observed.
Anti-Inflammatory / Brain Swelling – Monoclonal Antibody: Avastin (Bevacizumab, MVASI) is a monoclonal antibody that is an injectable cancer medication that works by blocking a protein (VEGF) that is important for the formation of blood vessels. Since tumors rely on blood vessels to get the nutrients they need to survive, the drug is thought to work by preventing the formation of new blood vessels that feed the tumor. In addition to being used as an anti-tumor agent, Avastin can also be used to treat inflammation and swelling in the brain.	● Hoarse voice ● Bloody nose, ● Increase in blood pressure ● Increased risk of bleeding ● Impaired wound healing	Contact your doctor's office if you notice increased bruising and/or bleeding, blood in urine, gums, or elsewhere.
Immunotherapy: Keytruda (pembrolizumab) is a type of immunotherapy that has been approved by the FDA for treatment of certain recurrent glioblastomas. Pembrolizumab is in a category of drugs called immune checkpoint inhibitors which bind with the immune checkpoint or the surrounding tumor proteins and prevent the tumor cells from turning off the immune system. These drugs allow the immune system to work as it was designed, specifically , T-cells (immune cells) are able to recognize and attack the tumor cells. www.keytruda.com	The most common side effects that are reported by patients include rash or itchy skin, gastrointestinal disturbances, muscle and/or joint pain, cough, fatigue, and lab abnormalities.	Pembrolizumab has the potential to cause a long list of side effects, most mild to moderate, but on occasion they can be severe. For many the side effects improve with time and are tolerable. If you have symptoms that are severe or persist you should always notify your treating MD.

INTERVENTION	POSSIBLE SIDE EFFECTS	WHAT TO DO
Steroids: These may be prescribed before or after surgery and help to reduce inflammation and swelling in the brain. Common steroids include dexamethasone (brand name Decadron), prednisone, and methylprednisolone.	● Blurred vision ● Headache ● Mood and personality changes ● Swelling of the fingers, hands, feet, or lower legs ● Increased appetite ● Weight gain ● Muscle weakness ● Trouble sleeping ● High blood sugar ● Increased chance of infection ● Steroid myopathy	Patients should never stop taking steroids without talking to their oncologist or a nurse first.
Anti-epileptic Drugs (AEDs): These are prescribed to control seizures. Some common AEDs are Levetiracetam (brand name Keppra), Phenytoin (brand name Dilantin), Lamotrigine (brand name Lamictal), Lacosamide (brand name Vimpat), Carbamazepine (brand name Tegretol), Valproate (brand name Depakote), Oxcarbazepine (brand name Trileptal), Gabapentin (brand name Neurontin) and Topiramate (brand name Topomax).	● Fatigue ● Nausea ● Weakness ● Problems with balance and coordination ● Dizziness ● Drowsiness ● Mood and behavior changes	If possible report your symptoms to the doctor who prescribed the medication for you. If that doctor is not available, report the symptoms to the doctor caring for you at the time that the symptoms occur. Rash, hives, difficulty breathing or swelling of the lips, tongue and jaw may indicate an allergic reaction and you should seek emergency care immediately.

¹ FDA.gov

² Stewart-Amidei, C. Managing symptoms and side effects during brain tumor illness. Expert Rev. Neurotherapeutics 5, (Suppl. 6), 2005.

³ Litofsky N, Farace E, Anderson F, Meyers C, Huang W, Laws E. Depression in patients with high-grade glioma: results of the glioma outcomes project. Neurosurgery 54:358-367, 2004.

⁴ Optune.com

In this chapter:

- A Multidisciplinary Medical Team
- Caregiving in the Hospital
- Caregiving in the Clinic
- What Are Clinical Trials?

Chapter 4

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.**



A Multidisciplinary Medical Team

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) notes, and outpatient (clinic) notes are stored in your electronic medical record (EMR). Your medical record serves 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. Patients have the right to view and have copies of the information in their medical record. Contact Medical Records at 415-353-2221 or visit <https://www.ucsfhealth.org/billing-and-insurance/medical-records> to request copies of medical records.

The Hospital Team

Once admitted into the hospital, your loved one 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. They work under the guidance of attending physicians and fellows.
- **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.
- **Nurse practitioners** are registered nurses with advanced education in special areas. The nurse practitioners work closely with the attending physician to oversee and direct your care. These nurses have training and skills in assessment, physical diagnosis, and management of health needs in their specialty areas.
- **Clinical nurses** are the registered nurses who provide the round the clock care that your loved one needs while in the hospital. They provide routine health assessments, monitor symptoms, administer medications, ensure that doctor's orders are followed, assist with personal care, provide emotional support, and communicate with families and the medical team about a patient's needs and care.
- **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** help units stay clean and equipped.

Specialists

Medical care becomes complex when a person receives a complicated diagnosis like a brain tumor. In addition to the hospital team common at a university medical center, a team of specialists for inpatient and outpatient care is 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. Brain tumor organizations like the National Brain Tumor Society can help you choose treatment centers and coordinate members of your medical team¹.

If you have not dealt with health complications in the past, you may quickly need to figure out how to coordinate communication with a team of specialists 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 specialists.

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

Chaplain — This is trained professional, often a member of the clergy, who has been trained to 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.

Endocrinologist — This specialist treats disorders of the endocrine system, a complex system of organs that secrete and respond to hormones (chemicals which regulate much of our body's functions). Some brain tumor patients may need care from an endocrinologist because they have had surgery or radiation that caused damage to one of the endocrine organs — the pituitary gland located in the brain.

Neuro-Oncologist — This specialist has primary training in either oncology (cancer), neurology (nervous system), or neurosurgery, and has additional training specifically for diagnosing and treating cancers of the nervous system. You will likely see the neuro-oncologist at the clinic or office for follow-up visits, and contact this doctor when experiencing side effects of treatment (such as surgery, radiation, chemotherapy and medication).

Neuropathologist — This doctor analyzes the tumor tissue removed by your neurosurgeon, and sends your team a pathology report that identifies the tumor type and guides your treatment options. Obtain a copy of this report for your medical files so you can refer to it when conducting research, or seeking treatment or a second opinion. You will probably not work directly with the neuropathologist.

Neuropsychologist — This type of psychologist specializes in understanding how the structures of the brain relate to cognition (thinking, reasoning, remembering, imagining, learning words, and using language), emotion, and behavior. Neuropsychologists are trained to assess the cognitive strengths and weaknesses of people who have had illness or an injury to the brain, and offer strategies to improve brain functions for a better quality of life. This psychologist will work with the medical team and the rehabilitation therapists (occupational and speech therapists).

Neuroradiologist — This radiologist specializes in the diagnosis and treatment of diseases of the nervous system (brain, spinal cord, neck) by using radiation technologies.

Neurosurgeon — This surgeon treats many disorders of the nervous system, and also deals with nonsurgical issues such as prevention, diagnosis, evaluation, treatment, critical care, and rehabilitation. You are most likely to meet the neurosurgeon during emergency care, or before and after surgery in the hospital. If you are seeking out a neurosurgeon, look for one who specializes in treating the type of tumor your loved one has.

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 brain tumor treatment, 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 the brain tumor treatment.

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 brain tumors to experience depression due to structural changes in the brain, side effects of medication, 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 tumor 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 like brain tumors, and some doctors who specialize in treating specific illnesses may be trained in using radiation therapy.

Radiation oncologist — This oncologist is trained to treat cancer patients with radiation therapy. Once the patient completes the course of radiation therapy this doctor will not likely be a part of your loved one's active medical team. Because radiation is known to have short- and long-term after-effects, this doctor may continue to follow up if problems arise.

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 support from a social worker at a brain tumor or cancer organization.

Palliative care specialists — This health care team works with the primary treating team in providing relief from the pain symptoms, side effects, and emotional difficulties associated with having a brain tumor. Some members of a palliative care team also provide spiritual support for patients and their families.

Pharmacists — These licensed healthcare professionals work in hospitals and pharmacies to dispense prescription medication. They are a great resource and provide information and education on the safe and effective use of medications.

Rehabilitation Therapists

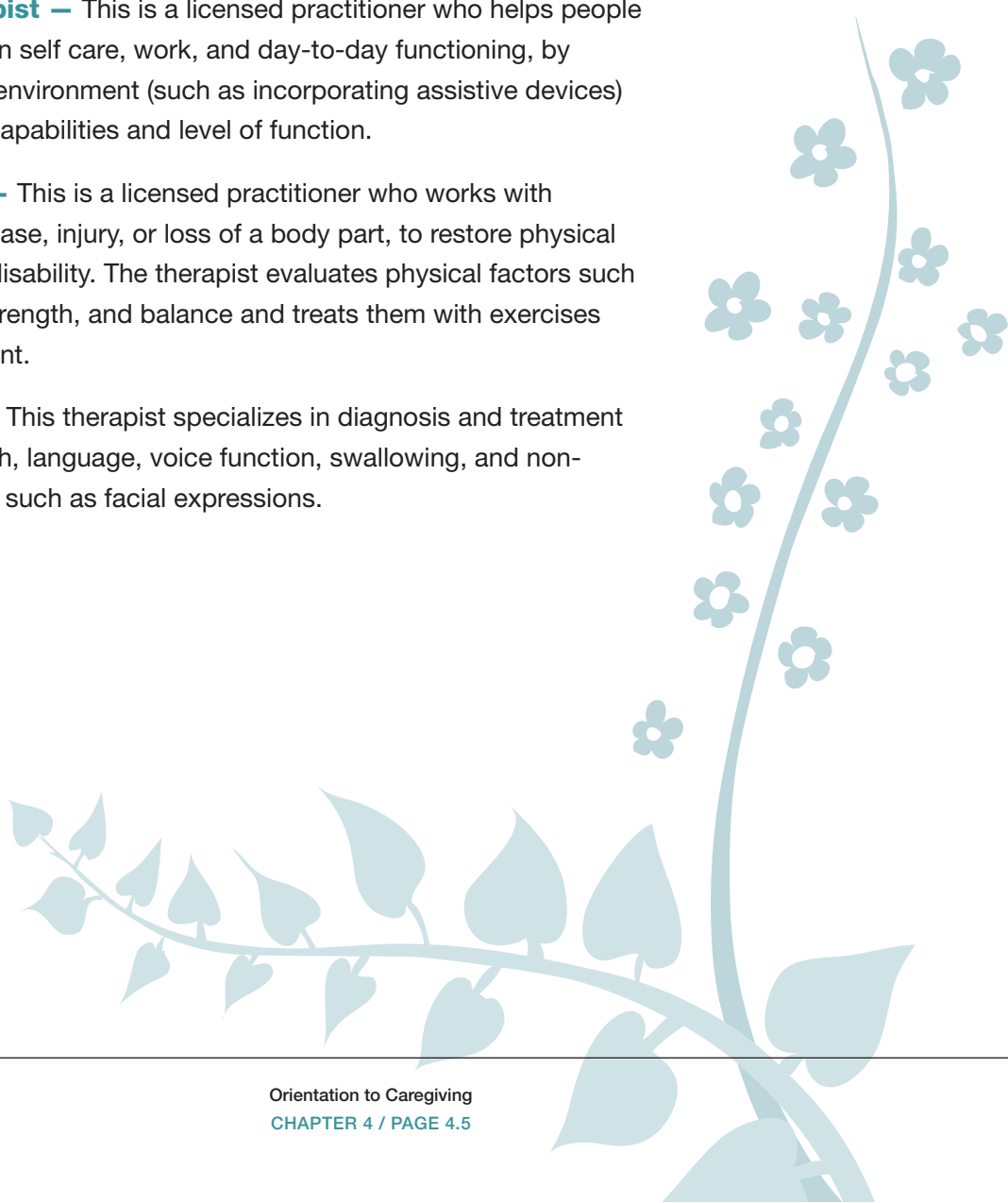
After most major surgeries or injuries, it is common to need some rehabilitation therapies to improve physical strength, coordination, communication, mobility, or mental functioning. These treatments can greatly enhance a person's ability to function and thus improve quality of life. Your loved one's neurosurgeon or neuro-oncologist 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.



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 to Expect When Your Loved One Has 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 what a patient's pre- and post surgery may look like:

- 1 The patient is admitted to the hospital the morning of surgery.
- 2 The patient goes into the Intensive Care Unit (ICU) after the surgery.
- 3 The patient is often transferred out of ICU to a regular floor bed the next day.
- 4 The patient should be eating and increasing activity levels as he or she is able.
- 5 There typically will be a post-operative MRI (magnetic resonance imaging) within 48 hours of surgery.
- 6 The Neuro-Oncology doctor will see and discuss their role after surgery.
- 7 The patient may return home in about three days if:
 - pain is controlled on oral pills
 - he/she is eating food, drinking fluids, going to the bathroom and walking safely independently
- 8 Patients routinely go home before receiving a pathology report on their tumor (the extent of the tumor and whether it is cancerous, or malignant).
- 9 Neuro-Oncology doctors will contact the patient when the final pathology is known and treatment plan is formulated.
- 10 The Neuro-Oncology team sees the patient typically within two to three weeks and assumes care, except for issues related to the surgical incision.

In the first two to three weeks after surgery, call your neurosurgery team with questions or concerns. From that point on, call either the neuro-oncology team, your local treating oncologist, or the radiation MD. You may call and ask for the surgical coordinators first, so they can help you figure out whom to speak with.



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 schedule an appointment or ask to page your neurosurgery team's social worker or case manager. These professionals are available through the Neurosurgery Department, 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 American Brain Tumor Association, American Cancer Society, and 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
- Medi-Cal
- 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.

NOTE: 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.

What Are Clinical Trials?

“A clinical trial provides the means by which your doctors can evaluate an important scientific question relating to your cancer. In most cases, the question of interest is whether a new drug or novel treatment approach is better than an existing treatment or at least worthy of further evaluation.”

– Paul Hesketh, MD, Lahey Clinical Medical Center.

A clinical trial is a research study that has progressed from a scientific question through laboratory testing and is now ready for human volunteers. Clinical trials are critical to the development of new brain tumor treatments. These new treatments may include drugs, surgical procedures, and new ways to manage side effects. The clinical trials process is overseen by the Food and Drug Administration (FDA), a local institutional review board (also known as an ethics committee), and a physician specifically trained to manage clinical trials.³

What are the potential benefits of clinical trials?

Participating in a clinical trial may have several potential benefits for patients. By participating in the trial, a patient will:

- Play an active role in determining the direction of his/her health care
- Have access to new treatments before they are widely available
- Receive expert medical care at leading health care facilities
- Help others by contributing to medical research

What are the risks of clinical trials?

Before your loved one agrees to participate in a clinical trial, he or she should talk to your oncologist and the doctor in charge of the trial to make sure he or she understands the possible risks. The treatment being used may not be better and side effects may be worse than the standard treatment. Because the treatment is new, the

healthcare team may not know all of the side effects that may be experienced. A clinical trial may require more time and attention from the healthcare team and from the participant than would a non-clinical trial treatment regimen. This extra time may include trips to the cancer center, more treatments, hospital stays and complex dosage requirements.

When do I ask the healthcare team about participating in a clinical trial?

Any time a patient is facing a treatment decision, he or she should ask about clinical trials that might be appropriate. Clinical trials are not just for advanced stage brain cancer – clinical trials are available for all stages of brain cancer. Ideally, the entire healthcare team will be available to talk about new treatments that may be available. For example, the oncologist, radiologist, and surgeon may each have access to information about different clinical trials. Once a patient knows about clinical trials that might be appropriate, he or she should discuss the options with the team, who can help explain the benefits and risks based on the specific tumor and health status.

How can I find clinical trials?

There are several clinical trials in the U.S. available to the brain cancer community. However, not all clinical trials will be available in every area. Clinical trials may be open at only one cancer center; others may be open in hundreds of cancer centers across the country. The number of participating centers depends on the disease being studied, the phase of the clinical trial, and the complexity of the clinical trial.

If your loved one is interested in participating in a clinical trial, there are many sources of information. The two best sources of information are:

- The healthcare team (e.g. oncologist, radiologist, pulmonologist, etc.) – Ask the healthcare team if a clinical trial is appropriate at this time and what clinical trials are available at your center. If no trials are available at your center, ask the oncologist which investigational drugs or procedures might be right for the patient. With this information, you can search the government database for clinical trials in your area.
- U.S. National Institutes of Health (NIH) website of clinical trials located at <http://ClinicalTrials.gov>. There are many other internet sites with information on clinical trials, but these sites are generally built on information from the NIH website. This website lists both federally funded and privately supported clinical trials.

Another good site for brain tumor patients is Trial Connect, the American Brain Tumor Association's clinical trial matching service. Emergingmed.com/networks/ABTA

The Four Phases of Clinical Trials

Phase I: Is it safe?

Phase II: Does it work?

Phase III: Is it better than what we have now?

Phase IV: What else can happen?

Questions to Ask

Questions to ask the oncologist and healthcare team about the clinical trial under consideration:

- What do you hope to learn from this clinical trial?
- Has the experimental treatment/procedure been studied before?
- What phase is this clinical trial?
- Who will be in charge of care during the trial?
- Will the care change based upon response to the treatment during the trial?
- What are the risks and benefits?
- How long will the trial last?
- Who pays for the trial?
- Will insurance cover the treatment?
- Will the patient be paid?
- Can the patient be forced or asked to leave the trial?
- Can the patient learn the results of the trial?
- What is the time commitment to participate in a clinical trial?
- Are there extra visits required if I participate in the trial?
- If so, how many extra visits to the study center are required?

¹ National Brain Tumor Society; www.braintumor.org. Retrieved 2013.

² Caregiver Action Network; caregiveraction.org. Retrieved 2013.

³ "What are Clinical Trials?" was adapted with permission from: "Navigating Lung Cancer 360° of Hope," Bonnie J. Addario Lung Cancer Foundation. Available at: www.lungcancerfoundation.org/patients/newly-diagnosed/. Retrieved 2013.

In this chapter:

- How to Speak with Your Children about Cancer
- Helpful Communication Techniques
- Discussing Relationship and Intimacy Issues

Chapter 5

Communicating with Children and Your Partner about Illness

When someone has brain cancer, it affects the entire family. Though it is a complicated disease to understand and describe, 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 cancer, 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. **Cancer can also cause difficulties in your relationship with your partner or spouse.**

Here you will find some suggestions for how to be open with one another during this time.



How to Speak with Your Children about Cancer

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 afraid¹.

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 age². 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 have³.

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 important⁴.

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 cancer.** If this idea comes up as you talk to your children, reassure them that no one causes cancer 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 cancer 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

Communicating with Your Partner⁶

Nearly all caregivers and their partners feel more stress than usual in their relationship. They must handle many decisions and changes. Some couples feel that the diagnosis and disease bring them closer together, while others find that they become disconnected. The most important thing you can do is be open about your stress and the causes.

- Allow times to talk about how you feel
- Share how you are coping
- Look for things that are causing you both stress
- Talk about choices you can make together
- Try to be grateful for each other
- Make time to focus on things besides the tumor

Talk with your partner if you find that your sex life is different than it used to be. There can be many causes:

- You or your partner is tired
- Your relationship is strained
- If your partner is the patient:
 - Either of you may not feel so good about how your partner looks
 - You may be afraid to hurt your partner
 - The treatment might be affecting your partner's ability to perform. He/she may be in pain or depressed.

You can still be close as a couple in spite of these issues. Staying close is about sharing feelings and understanding. You can:

- Talk about your closeness and your sex life
- Talk about your hopes for the future
- Try not to judge each other
- Protect your time together
- Be patient and take things slowly
- Talk to a counselor or your support group

¹ Cancer Care, www.cancercare.org. Retrieved 2013.

² 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.

³ Information throughout this chapter was provided through personal communication with Meryl Botkin, Ph.D, Assistant Clinical Professor, Department of Psychiatry, UCSF.

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

⁵ Adapted from "Helping Children Understand Cancer: Talking To Your Kids About Your Diagnosis," Cancer Care Fact Sheet, 2013. Available at: http://media.cancercare.org/publications/original/49-fs_children_eng.pdf

⁶ Adapted from "Caring for the Caregiver," National Cancer Institute, 2007. Available at: <http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver.pdf>

Chapter 6

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 MediCal — 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 American Brain Tumor Association (1-800-886-2282) and the National Brain Tumor Society (1-617-924-9997). 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,” at right)
- 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, or a health care advocate at an organization such as the National Brain Tumor Foundation, to help you apply for these services.

Government Departments and Programs

- Department of Social Services:
 - Social Security Disability Insurance (SSDI)
 - Supplemental Security Income (SSI)
 - Medicaid (Medi-Cal)
 - In Home Support Services (IHSS)
- Department of Aging
 - https://www.aging.ca.gov/How_Do_I/Make_Home_Modifications/
 - https://www.aging.ca.gov/Care_Options/
- Private or non-profit assistance agencies
 - 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
 - American Cancer Society treatment travel stipend

¹ Children's Brain Tumor Foundation; <http://www.cbtf.org>. Retrieved 2013.

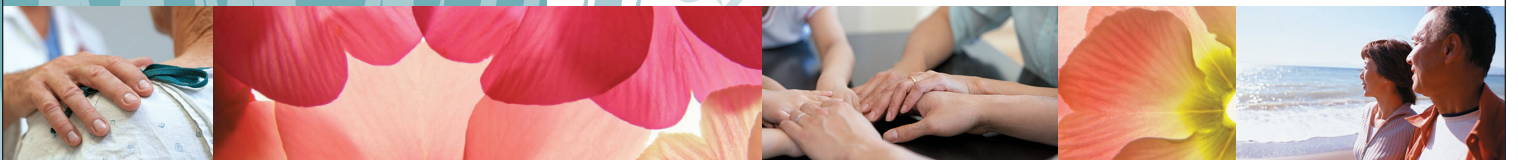
In this chapter:

- Advance Care Planning
- Personal Business
- Estate Planning

Chapter 7

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 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 mentally 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.

Palliative Care

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious and/or life-threatening illnesses. Palliative care focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness. The goal of palliative care is to improve quality of life for both the patient and their family.

Palliative care is provided by a team of doctors, nurses, social workers, and other health professionals who work together with a patient's care team to provide an extra layer of support to the patient and their family. Palliative care is appropriate at any age and any stage of a serious illness, and can be provided alongside curative treatment. In fact, many organizations recommend that palliative care be initiated early in the illness and that it be an integral part of the treatment plan.

Palliative care focuses on symptoms such as pain, fatigue, constipation, nausea, difficulty sleeping, anxiety and depression. By successfully managing these symptoms, patients are ideally able to more fully participate in and enjoy daily life. Palliative care can improve your loved one's ability to tolerate medical treatments. It can also help them better understand their treatment choices and feel an enhanced sense of control around their medical care.

Palliative care teams are present in some hospitals; an increasing number of outpatient palliative care clinics exist as well. If you are interested in seeing a palliative care doctor, ask your oncologist about services available in your area.

Hospice

It is important to note that palliative care and hospice care are not interchangeable terms. Hospice is a specific type of palliative care aimed at patients with life-limiting illness. Hospice is a model of care that emphasizes comfort and management of pain and symptoms, when an illness is expected to lead to death within six months and curing it is not an option. It is appropriate for you, as the caregiver, to discuss hospice with the medical team and your loved one at any time when facing a potentially life-limiting 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.

If a patient decides to begin hospice care, he or she can be admitted to an in-patient hospice center or remain at home and have regular visits from the hospice staff. Hospice care is comprehensive and includes physical, psychological and spiritual care to address issues such as pain management, adjusting the home to meet the patient's needs, providing necessary medical equipment, and counseling and grief services for the patient and family. Most insurance companies cover hospice care, and it is covered by Medicare nationwide. 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 use community or foundation funds to provide services¹.

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 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?
- **Password Keeper** — Where does your loved one keep this information? While certainly private, it is important to know where this information lives for emergency situations.

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.

¹ Hospice Net, www.hospicenet.org. Retrieved 2013.

Chapter 8

In this chapter:

- Self-Care Strategies
- Focus on What Matters
- Resetting Goals
- Finding the Benefits
- Meaningful Moments
- Allowing Laughter

Caring for the Caregiver: Maintaining Physical Health and Well-being

In order to provide the best care to your loved one you need to be as healthy as possible. Caregiving can not only be a full-time job, but 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 or 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 and flu, and other upper respiratory illness. It is easy for caregivers to put their own needs and feelings second or aside, but it is crucial to take care of yourself.



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 week¹.

These positive moments are often fleeting, but they are very important because they help you sustain your well-being 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 six strategies to help maintain your own well-being in the midst of stress:

1 PRACTICE SELF-CARE STRATEGIES.

- Caring for your body and staying active: If possible, get at least 30 minutes of moderate-to-vigorous exercise per day, pay attention to what you are eating, get enough sleep, rest regularly (deep breaths, meditation, gentle stretching), and keep up with your own checkups, screening, and medications.
- Making time for yourself: Develop and maintain planned episodes of pleasurable self-renewal. For example, go to the movies, be by yourself, read a book, watch TV, visit with friends, or take a leisurely walk. Find something pleasurable and enjoy it.
- Joining a caregiver support group: In addition to providing information, support groups give you the opportunity to talk with others who are going through a similar situation, and may help you feel less alone.



2 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 “mattering” list. *What would be on your list? Why do these things matter to you?*

3 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.

4 **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.



5 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.

6 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.³ 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.

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

Appendix

Calendar Templates:

- Weekly
- 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
- Cancer and Caregiving Resources



MONDAY		TUESDAY		WEDNESDAY		THURSDAY		FRIDAY	
8		8		8		8		8	
9		9		9		9		9	
10		10		10		10		10	
11		11		11		11		11	
12		12		12		12		12	
1		1		1		1		1	
2		2		2		2		2	
3		3		3		3		3	
4		4		4		4		4	
5		5		5		5		5	
6		6		6		6		6	
EVENING		EVENING		EVENING		EVENING		EVENING	

MONDAY		TUESDAY		WEDNESDAY		THURSDAY		FRIDAY	
8		8		8		8		8	
9		9		9		9		9	
10		10		10		10		10	
11		11		11		11		11	
12		12		12		12		12	
1		1		1		1		1	
2		2		2		2		2	
3		3		3		3		3	
4		4		4		4		4	
5		5		5		5		5	
6		6		6		6		6	
EVENING		EVENING		EVENING		EVENING		EVENING	

SUNDAY		MONDAY		TUESDAY		WEDNESDAY		THURSDAY		FRIDAY		SATURDAY	
MONDAY		TUESDAY		WEDNESDAY		THURSDAY		FRIDAY					
8		8		8		8		8		8			
9		9		9		9		9		9			
10		10		10		10		10		10			
11		11		11		11		11		11			
12		12		12		12		12		12			
1		1		1		1		1		1			
2		2		2		2		2		2			
3		3		3		3		3		3			
4		4		4		4		4		4			
5		5		5		5		5		5			
6		6		6		6		6		6			
EVENING		EVENING		EVENING		EVENING		EVENING		EVENING		EVENING	

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
MONDAY		TUESDAY		THURSDAY		FRIDAY
8		8		8		8
9		9		9		9
10		10		10		10
11		11		11		11
12		12		12		12
1		1		1		1
2		2		2		2
3		3		3		3
4		4		4		4
5		5		5		5
6		6		6		6
EVENING		EVENING		EVENING		EVENING

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

Date Started	Product Name	Dosage / Strength	Times Taken Daily	Purpose of Medication	Prescribed By	Additional Comments

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.



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.

From Wong, D.L., Hockenberry-Eaton M., Wilson D., Winkelstein M.L., Schwartz P.: Wong's Essentials of Pediatric Nursing, ed. 6, St. Louis, 2001, p. 1301.
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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

government 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 \$25 to \$40 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.

Adapted from: Communicating Effectively with Healthcare Professionals, Caregiver Action Network.
Available from: <http://my.brainshark.com/Saturing-Communicating-Effectively-With-Healthcare-Professionals-962681677>.
Retrieved 2013.

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?

NOTE: Although not a 911 call, it is usually a good idea to notify the doctor caring for the patient by phone if the patient is having an increase in symptoms such as weakness, difficulty speaking, or increased confusion or disorientation.

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 that lasts more than 5 minutes or has a second seizure before regaining consciousness after the first.
- Has a severe headache and/or slurred speech
- Has pressure or severe pain in the abdomen that does not go away

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

Adapted from "Communicating Effectively with Healthcare Professionals," Care Giver Action Network, caregiveraction.org.

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.

Adapted from "Communicating Effectively with Healthcare Professionals," Care Giver Action Network, caregiveraction.org.

Cancer and Caregiving Resources

Brain Tumor Organizations

Acoustic Neuroma Association
<http://www.anausa.org>
1-877-200-8211

American Brain Tumor Association
<http://www.abta.org>
1-800-866-2282

Brain Science Foundation
<http://www.brainsciencefoundation.org>
1-617-852-5230

Brain Surgery Information Center
<http://www.brain-surgery.com>
1-212-263-7481

The Healing Exchange Brain Trust
<http://www.braintrust.org>

Brain Tumor Society
<http://www.tbts.org>
1-800-770-8287

National Brain Tumor Society
<http://www.braintumor.org>
1-617-924-9997

Support for People with
Oral, Head, or Neck Cancer
<http://www.spohnc.org>
1-800-377-0928

The Tug McGraw Foundation
<http://www.tugmcgraw.org>

Cancer Organizations

American Cancer Society
<http://www.cancer.org>
1-800-227-2345

Cancer and Careers.org
<http://www.cancerandcareers.org>

Cancer Care, Inc.
<http://www.cancercare.org>
1-800-813-HOPE (4673)

Cancer Hope Network
<http://www.cancerhopenetwork.org>
1-800-552-4366

Cancer Support Community
<http://cancersupportcommunity.org>
1-888-793-9355

CURE: Cancer Updates, Research, and Education
<http://www.CUREtoday.com>
1-800-210-CURE (2873)

National Cancer Institute
<http://www.cancer.gov>
1-800-4-CANCER (1-800-422-6237)

National Coalition for Cancer Survivorship
<http://www.canceradvocacy.org>
1-877-622-7937

National Comprehensive Cancer Network
<http://www.nccn.org>
1-888-909-NCCN (6226)

Pediatric Brain Tumor and Cancer Resources

American Childhood Cancer Organization
<http://www.acco.org>
1-855-858-2226

Brave Kids
<http://www.bravekids.org>
1-800-568-1008

Childhood Cancer Lifeline
<http://www.childhoodcancerlifeline.org>
1-603-645-1489

Children's Brain Tumor Foundation
<http://www.cbtf.org>
1-866-228-4673

Cure Search
www.curesearch.org
1-800-458-6223

National Children's Cancer Society
<http://www.thenccs.org>
1-800-5-FAMILY

Okizu Foundation Camps
<http://www.okizu.org>
1-415-382-9083

Pediatric Brain Tumor Foundation of the United States
<http://www.curethekids.org>
1-800-253-6530

Ronald McDonald Houses
<http://www.rmhc.org>
630-623-7048

Caregiver Resources

Caregiver.com
<http://www.caregiver.com>
1-800-829-2734

Caregiver Action Network
<https://caregiveraction.org>
1-855-227-3640

Care Pages
www.carepages.com

Center for Caregiver Training
<http://www.caregiving101.org>
1-415- 563-9286

Drug InfoNet
<http://www.heretoserve.org/drug-infonet>
1-315-671-0801

Elder Care Locator – US Administration on Aging
<http://www.eldercare.acl.gov>
1-800-677-1116

Family Caregiver Alliance
<http://www.caregiver.org>
1-800-445-8106

Help for Cancer Caregivers – An Online Self-Care Tool
<https://helpforcancercaregivers.org>

Healthcare Hospitality Network
<http://www.nahhh.org>
1-800-542-9730

Hospice Education Institute
<http://www.hospiceworld.org>

Lotsa Helping Hands – Online Caregiver Support
<http://www.lotsahelpinghands.com>

Medicare Home Health and Nursing Home Compare
www.medicare.gov/homehealthcompare
1-800-633-4227

National Association for Hospital Hospitality Houses
<http://www.nahhh.org>
1-800-542-9730

National Family Caregivers Association
<http://www.nfcacares.org>
1-800-896-3650

National Hospice and Palliative Care Organization
<http://www.nhpco.org>
1-800-658-8898

Net of Care – Information and Resources for Caregivers
<http://www.netofcare.org>

UCSF Cancer Resource Center Caregiver Peer Support Program
<http://www.cancer.ucsf.edu/crc/peer-support>
1-415-885-7801

Well Spouse Association
<http://www.wellspouse.org>
1-732-577-8899

This image shows a full page of blank, lined paper. It features approximately 20 evenly spaced horizontal grey lines across the entire width of the page, providing a guide for handwriting or typing. The background is a clean, solid white color.

