

Chapter 4

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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) charts and outpatient (clinic) charts serve as communication links between the two services. Be informed about your loved one's medical history, current treatment plan, and, most important, medications, so you can correct inaccuracies if they arise. Remember, all patients have the right to view and have copies of the information in their chart. Ask the nurse or the attending physician for access to them so you can make copies for your files, or enter important notes.

The 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. Residents are physicians who have completed at least one or more years of training after medical school. Interns and residents are sometimes referred to as "housestaff." They work under the guidance of attending physicians and fellows, and often have to stay overnight in the hospital "on call."
- **Medical students** are third and fourth year students of the School of Medicine who are conducting their clinical rounds prior to their graduation and residency.
- **Charge nurses** are responsible for overseeing the nursing care on your hospital unit during a shift.
- **Clinical nurse specialists** are registered nurses with advanced education in special areas. These nurses help coordinate your loved one's care.
- **Nurse practitioners** are registered nurses with advanced education in special areas. These nurses have training and skills in assessment, physical diagnosis and managing health needs in their specialty areas.
- **Patient care managers** are responsible for supervising all nursing care on every shift on your unit.

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 Foundation 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 privately. They are available to assess patient and caregiver needs (including 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.

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 life². 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.

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

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

Caregiving in the Hospital

Hospital Admissions

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

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 National Brain Tumor Foundation, 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

Doctor's 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 where your health plan allows.

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 support³. Medical terminology can be complicated, so be sure to ask questions when you don't understand something.

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

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

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

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

On the Day of the Visit

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

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

² National Brain Tumor Foundation; www.braintumor.org, retrieved 2006.

³ National Family Caregivers Association; www.thefamilycaregiver.org, retrieved 2006.