

Chapter 1

A Handbook about What to Expect as a Family Caregiver

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

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

This handbook has been developed to provide easily accessible and accurate information to family caregivers helping to care for loved ones with 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, emotional distress, support of the caregiver, and financial and legal advice.

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.