



Living with Cancer

A collection of observations
and suggestions for
families and friends



Living with Cancer

Introduction

This book is a collection of observations and suggestions from people who have been personally and intimately affected by cancer — patients, family members, friends and caregivers. We hope it makes you feel less alone in dealing with an illness and a process which can be overwhelming.

One of the most important truths about cancer is that each person's diagnosis or experience is different. So, how you use this book depends on how you feel. You may want to dive in or test the water. You may want to read this cover-to-cover, read a single section or pick it up from time to time. You may simply want to pass it along to a friend or family member.

The book is organized into sections addressing a variety of topics and ideas that range from the spiritual to the practical. Included are thoughts about: decision-making, fear, hope, humor, children, friends, finances and more.

Believe it or not, life does go on after a cancer diagnosis. It just goes on differently. What follows is a guide to help you through this new world from the perspective of those who live in it.

The mission of the Cancer Prevention Institute of California is to prevent cancer and to reduce the burden of cancer where it cannot yet be prevented. We look for patterns of cancer in the population, and then try to identify what groups of people are at risk for developing the disease. Our research scientists are leaders in searching for the causes of cancer. CPIC also operates the Greater Bay Area Cancer Registry. Our Community Education Program provides seminars, publications, websites and information resources to help individuals make informed decisions about their health and health care.

CPIC works with agencies, universities and cancer centers throughout the world, and has a formal partnership with the Stanford Cancer Center.

If you have additional comments or suggestions for improving this publication, we would like to hear from you. Please send your comments/suggestions to education@cpic.org, or the address below.



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Dedication

In loving memory of Tessa Thomas Newsom.

In honor of Hilary Newsom Callan and Geoff Callan.



No Lifeguard on Duty

it is difficult
when one is drowning
to wave to the people
on shore

one wants to be
friendly, of course,

but perhaps it is
more important
to keep
swimming

December 1990

Fine Black Lines

Reflections on Facing Cancer, Fear and Loneliness

by Lois Tschetter Hjelmstad
Mulberry Hill Press, 1993

PlumpJack LINK Fund Seminar Series

Several years ago a young couple approached CPIC about supporting breast cancer education and research here at the Institute. They established the PlumpJack LINK Fund at CPIC to accomplish their goal. This booklet is a result of community programs and discussions supported by the PlumpJack LINK Fund.

Thank You for Contributing. . .

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Table of Contents

i	Introduction
iii	Special Thanks
iv	No Lifeguard on Duty~ Poem
v	PlumpJack LINK Fund Seminar Series
1	Suggestions and Observations
4	Doctor-Patient Communications
10	Patients, Families and Friends
16	Partner~ Communications
17	About Fear
17	At the End of Treatment
18	Support Groups
19	Intimacy
20	Recurrence
20	Nutrition
21	Children
26	Laughter, Humor
27	Complementary/Alternative/Integrative Medicine/Herbal Therapy
31	Financial and Insurance Issues
36	Hospice
37	Friends and Caregivers~ More Ideas. What You Can Do
39	Information~ Internet
40	Resources: Phone Numbers, Web Sites, and Books
46	Your Notes and Observations
48	Contact Numbers

Suggestions and Observations

Life is going to change—this is absolutely true. The challenge is to make it change for the better, not for the worse.



Cancer is a family disease. You can't do this alone. Every person in your family (siblings, children, friends, partner, spouse, parents) will have a role to play.



Patients say a diagnosis of cancer is a bittersweet event—it makes you focus on relationships and helps you recognize what is important.



The stress of having cancer or of being the person watching a loved one with cancer makes everything you know useless and everything you need to learn hard. Your brain takes things in differently. As good as your skills were before cancer, things are now harder to do, and it's exasperating. Stress reduction is hard to accomplish because you're scared and that impacts your ability to manage stress.



Cancer is a difficult challenge but it is met more easily with good information, caring friends and families, and supportive health care providers.

Make a list of important names, phone numbers,
activities and needs, even if you don't
need the list or use it.

This is a safety net—a gift to yourself and your family.



One of the hardest things to do is to ask for help.
Do it, though. It feels good to the people you ask
and it's good for you.



There are no stupid questions.



There is such a thing as “survivor guilt”
for those who survive the disease when
you know others who have not.



Everyone who wants to help will try to do so.
Try to be specific about your
concerns and needs.
It's okay to ask for what you want.



When you need care, all the issues of
vulnerability come up and you may get defensive.

You have time to make things okay
(between family members, friends, for example).
Make a list of things that have come between you
and your mother, father, sister, brother,
partner etc. and address them.



It's hard to take everything
in when you have a
diagnosis of cancer.
One of the challenges
is how to make it a
manageable task.



Every person experiences
cancer differently.
No one size fits all.



If you are the patient,
make yourself the most important
person in the world for a while.



Cancer helps identify the important issues.

Doctor~Patient Communications

Get a doctor you trust; one who cares, pays attention, listens, treats the entire person, and who knows that you, the individual, is also an intelligent person.



When going to the doctor's, take someone else with you to help remember what was said and to observe the body language used.



When you see the doctor, take a tape recorder and a list of questions. Be patient, persistent and very clear about what you want.

Be sure the tape recorder has fresh batteries and long tapes. It's helpful to have both the patient and a family member there. Families frequently call the doctor and ask the same questions.

If the physician doesn't like the tape recorder, find another physician.



You do not expect the doctor to be unprepared, so be sure you aren't unprepared, either.

Determine how to communicate with your doctor.
Be respectful of his/her time but still meet your needs.
Make a list of your needs and prioritize them.
You might not get through the whole list, but
you will get to the most important ones.
Ask the most important question(s) first.



Think about your life story. “Living happily ever after”
now has a blank page due to a diagnosis of cancer.
How do you want to write your story on this new page?



Everyone has to give up some decision-making
in this process. If a family member says “We need
to call the doctor,” they are usually right. The patient
should not make the decision. If the patient is sick
enough, s/he can’t make the decision. We all try
to manage our problems, but sometimes we
have to give up some decision-making.



Some patients like to include in their medical care
both standard and complementary medicine and
integrative care. Some providers are not comfortable
with these non-traditional practices and techniques.
Inquire, ahead of time, if your medical practitioner
is comfortable with your approach.

You need to find your comfort level and to have confidence in your relationship with the health care team and the physician. There may be a need for a second opinion. Speak up about your relationship with your doctor.



If the doctor gets upset with the idea of a second opinion, then you definitely need a second opinion.



You can request a second opinion for pathology, mammogram, treatment plan, etc. If you are in an HMO, the HMO may frown about a request for a second opinion that diverts from their plan. Be persistent.



Talking with the doctor. . .

When a whole entourage of people accompanies the patient to the doctor's office it may seem supportive to the patient. However, for some patients, it can be threatening. The patient may not be comfortable answering the doctor's questions in front of others—e.g., age at first childbirth, first pregnancy. This history is for the patient and the doctor only.

Consultations help the doctor learn what you understand about the disease, about the diagnosis, prognosis and treatment. It gives him/her an idea of the detail and the technicality required.



All is confidential.

The doctor will try to answer questions from the spouse/partner, with permission from the patient. If the person asking questions is not the patient, the doctor will request the patient's permission before talking with this individual.



A word about genetic testing: Tests for genes such as BRCA I and II raise fears of genetic discrimination. The Genetic Information Nondiscrimination Act of 2008, a federal law, now prohibits the improper use of genetic information about healthy people by insurance companies to deny health insurance or to charge higher premiums, and by employers when making hiring, firing, job placement, or promotion decisions.



Questions. Write them down.

Be sure these are the questions you want answered. The physician needs to ask if it is okay to discuss the questions openly with the family there. Sometimes it is hard for the patient to say “no” if the family is present.

Physicians are not telepathic;
they cannot guess your questions.
Ask your questions clearly.



The patient may be afraid
of the health care provider.
Find a practitioner you can trust,
one whom you trust to take care of you.
This is a new journey, a new concern.
Let the provider know
if things are not working.
This is a two-way street.



Identify existing resources
that can help with transportation to appointments,
medical equipment (such as American Cancer Society,
1.800.ACS.2345). Take advantage of other resources such
as the Cancer Information Service (1.800.4.CANCER),
local cancer groups and support services.



Doctors usually treat diseases, rather than people.
(Look around the room . . . no diseases here, just people.)
You are a human being and deserve to be treated as such.

If you are getting multi-modality treatment, ask whom to call and when. Know that information at the beginning of your treatment. It helps you know what resources you may need before you need them.



Most patients will not experience all the side effects of chemotherapy. Ask your doctor/nurse, “What do I need to know to stay safe? What is the real danger?” For example, chemotherapy creates a poor immune system, which means you are more susceptible to infection. You need to know what to watch out for. What are the most common side effects? What needs to be acted upon?



The first chemotherapy appointment is terrifying for everyone. Take someone with you.



Getting help—know whom to call and how to access help. Know what system works within the doctor’s office. For example, during the work week the receptionist takes the note and the nurse or doctor calls back. How do you access someone on the weekend?
On a holiday?

Patients, Families and Friends

You may be surprised by friends' reactions when they learn of your cancer. Some will withdraw, some will step forward. Those who withdraw may do so because they are afraid of cancer or because they feel inadequate about knowing what to do or say; some may fear losing you.



Determine what other people can do for you. Have a list and keep it by the telephone. When someone calls and asks what they can do for you, refer to the list and tell them. They are not calling just to be polite. They want to help. Put on the list the things that you don't like to do or things that you are just too tired to do. For example: taking the kids to school, cooking, folding laundry, grocery shopping, etc.



If you want to help, ask the patient closed-ended questions, such as "I'd like to take care of your children this week. Monday or Thursday works best for me. Which of these days is good for you?" Or, "I'd like to bring over dinner tomorrow. Would you like spaghetti or a tuna casserole?"

Questions with limited answers are easier for an individual or a family drowning in decisions.

Sometimes the well-meant question "What can I do to help?" is just too much.

Identify someone in the family who is the patient's advocate and who can be a consistent interface with the health care system. This is good for both the patient and for the health care provider.



It is important to come together, to share and to support. Take time to be together.



Both the patient and the family need to know the treatment is working; if they don't, they may start second-guessing the treatment or drugs. They may ask, "Should I switch?" or "Whom do I ask?" At the start of treatment, your doctor will order baseline tests, such as a CT scan or a PET scan. Inquire about the time frame for follow-up tests that will be used to compare to the initial baseline tests.



Give yourself permission to have feelings. If you didn't talk as a child, it's going to be hard as an adult to discuss your fears, or your anger. Reach out and ask for help if you are having difficulty coping. Most hospitals and clinics have professional staff, such as social workers, or access to counselors who may assist you.



Everyone heals in his or her own way.

Some side effects of chemotherapy are chronic and long lasting. You need to know how to manage these from a psychological perspective.



A diagnosis of cancer makes us aware of mortality. For most of us it is taboo to talk about death. Force an opening to discuss this. It is hard for both the patient and family; however, decide that it's okay and then do it. We don't die any sooner if we talk about it. Talking about it helps put the patient in control.



When you are diagnosed with cancer, you jump to conclusions, no matter what. You start planning for the end. There are certain tasks to accomplish, like saying "I love you" to those who are important to you, saying "thank you", finding a spiritual peace, thinking about how you want to wrap things up.



Everyone who hasn't had this disease is a civilian. Be patient with them. You may become the educator for your family, friends and coworkers.



Cancer affords an opportunity to make some significant changes. Give yourself permission to live your own life. Take a look at yourself and your relationships.

Give yourself permission to receive. Be conscious of people loving you. Maybe it's time to start loving yourself.



Psychological work is part of your treatment.



Letting others help you is a gift to give to another person—it's both a growth experience and a learning gift.



Let people in if you are the patient and want them involved.
As the caregiver, be aware of involvement
by too many people.



This is a time for growth and intimacy in relationships.



If your life is threatened, do what you need to do to accommodate reality. Use your will, wisdom and heart to identify what is important to you.



Your “team” (medical, family and friends) may be in several locations. You will need good communication skills to share information and receive the support you need.



Treatment is not an all-or-nothing situation. You have options such as second opinions and clinical trials.

Your doctor will talk with you about various “risks” associated with your cancer and your treatment. Understand what “risk and relative risk” mean with regard to this discussion.

Everything in life is a balance of risk and benefit. Your question/decision might be about treatment side effects vs. benefits—you may want to reduce the dose of a chemotherapy drug so that you reduce the negative side effects; however, you may still get side effects but not the total benefits.



There is a sense of betrayal with a diagnosis of cancer. You’ve taken such good care of yourself and now you have cancer. Do not take on the guilt for something you did not do or for which you had no control.



Even the best communication skills fall apart when dealing with cancer. Recognize that all of your feelings are okay. Some will express themselves all the time; some will express themselves some of the time or not at all.



With cancer, the operating theme is “fear”—of the unknown, of what’s to come. Statistics do not provide a crystal ball.



The Hollywood version of the cancer journey is not real. Take time to create your own conversations with your family and other loved ones.

Chronic fatigue can last several years.



There is a letdown when treatment ends. It is replaced with concerns about cancer returning and questions about why you are not back to “normal.” The letdown may be profound. Seek out support through a group, survivorship program, or counseling.



At the end of treatment, you will find your life has a “new normal”. Don’t expect too much from yourself. The process of recovery is driven by good common sense. There is no formula that fits all. Know yourself and your limits.



Most of us don’t like chaos or the unknown. Sometimes we blame ourselves. Sometimes we blame others for things. We like answers. Blaming, in large part, reduces our fear and chaos. It makes us feel better; however, blame is counter-productive. Be aware of this behavior.



Disease is a stressor. A diagnosis of cancer changes the roles of family members and increases fears. Family members may suffer depression just like patients do. Sometimes their depression lasts longer than the patient’s.



Two common problems for families—doing too much or doing too little.

Talking and expectations. There is no right way to give care or to receive care. People will do what they want done for themselves. For example, one “happy” mom wanted life to go on as “usual” while the patient (her daughter) experienced life differently since her cancer diagnosis. This increased the daughter’s alienation from the family. If you are just a family of smiles, how can you be a family of heart?

Partner~Communication

Loved ones may step back when cancer has been diagnosed. It may be their way of trying to reduce demands on the patient; however, the patient may experience this behavior as rejection. Don’t assume. Ask.



Communication is helpful yet at times, it is difficult. Sometimes, journaling will help sort through the issues prior to opening a conversation.



Post-mastectomy.

Having your significant other participate in changing the wound dressing (in a technical environment) may help diffuse the situation.



Media.

The good news is that there are lots of studies and information about cancer. The bad news is that we don’t know how to respond to it.

About Fear

Even with fear and ambiguity, we can go forward. We have a window of time to do things we like . . . take advantage of it.

At the End of Treatment

Questions to ask:

How am I followed? Whom do I see?

What problems go to what doctor? Where?

Do I see my primary care doctor?

The surgeon? The oncologist?



It is important to go to a doctor who specializes in your problem. Not all primary care doctors do.



It's not over when it's over.

Treatment does not end cancer.

Cards, flowers, meals come in while you're in treatment, and then there's nothing. For the patient, that's the beginning of living with cancer not the end.

There is a tremendous void. Find the words to say "I've got a check-up on (Monday, for example), and I'm scared to death." If you would like someone to go with you to the appointment, ask a family member or friend.



The end of treatment leaves you hanging.
You may get angry at the person(s) you most count on.

Support Groups

There are many different kinds and flavors of groups, depending upon the composition and the facilitator. Try one or more groups and decide if a group is for you, or if one group is more comfortable than another.



There are many patients and many groups. Some people want a group during treatment, some after treatment. Some don't want one at all.



Every patient is an individual. Some individuals like participating in support groups, some do not.



Medical drugs are usually out of your system in 1-2 days. The side effects, however, can last up to or more than a year.

When your treatment ends, you may want to re-/consider a support group to help you feel less isolated.



When there is a change in the routine, you may feel adrift. This is normal.

Intimacy

It's hard to maintain your sex life. Chemotherapy causes fatigue, nausea, vomiting, and irritates the membranes (kissing, sexual intercourse). Libido is affected. Of those couples who have an active sex life before chemotherapy, about 15-20% have an active sex life during chemotherapy.



Sometimes you have to remind people that cancer is not contagious. Hugging and kissing do not spread cancer.



You just don't feel like it. It hurts. There may be psychological aspects related to body changes. Self-image issues are to be expected—who am I now that my body is different?



Need adjustment, rethinking? You feel awful about your partner sometimes. Can you talk about it? Can you talk about sex? If you could not talk about sex before cancer, it's going to be hard to talk about it now.

Recurrence

Recurrences often develop in the bone, skin (chest), and lymph nodes—there might be a rash on the chest, a swollen gland, sore bones (for example: spine, pelvis, thigh bones, ribs).

If any of these symptoms occur, call the oncologist, or call your primary care physician who can respond to you and your symptoms. When calling your primary care doctor, explain first that you have had cancer and then describe your current symptoms and the type of cancer for which you were treated.

Nutrition

This is a real issue during treatment.

Some individuals who receive chemotherapy gain or lose weight. It is important that you take in the necessary nutrients to nourish your body. Discuss this matter with your doctor and/or request a dietary consult with a nutritionist familiar with cancer treatment.

Nutritional needs for individuals with cancer may require adjustments within the family such as a change in meal preparation, frequency of meals and food portions.

Some patients have difficulty with taste, food smells, handling of meat/poultry/fish and the adequate intake of liquids.

Everyone may need to adjust.

Children

When you have children, and you have cancer, your priorities come into sharp focus. Two things are important—trust and modeling. It is hellish to give our kids bad news because our job is to protect them. They must be able to trust you so that they can trust themselves. How do you tell the truth without falling apart, and how do you do it honestly?

Do it in increments, not all at once. Be age-appropriate. Kids only need to know what is going to affect them—e.g., mom's hair is going to fall out; dad's going to be sick. Kids know something is going on. They'll make it up if they don't have the truth—e.g., "Mom doesn't want to be with me." Tell them in increments and up front. Tell them definite things. Kids will hear things on TV or from friends' parents, and it may not be the correct information. Make sure they hear information from you first.



They learn by watching you. You can model both getting and giving support. It's scary but they will not have lives without these things. (Your) crying lets them know that sadness is okay. Show them you're scared.

It's our secrets that make us feel sick.



How to express needs? "My medicine today makes me feel really tired. So, I'll need some quiet time, and I need you to play quietly."

Be clear, honest, and truthful.



Cancer surgery may change the way you hug and hold children. Post-surgery time alters interaction with children (For example: hugging/holding/lifting/playing).



If your child leads with a question, ask “Why are you asking?”
Ask an open-ended question to get an idea of what they are thinking.



We want information from the doctor to be able to handle the things we don't know. Kids, too, need information to manage what's happening.



We lose our innocence when something traumatic happens. It motivates us to set priorities, let go of things that aren't important. It's an opportunity to grow, to deal with the reality that bad things do happen. It's not the end of the world, just sad/scary/icky, but not the end of the world.

Cancer is an opportunity to develop life skills.



Cancer brings on intense emotion in a society that is not geared to being emotional. In this day of “positive thinking” we may think that negative feelings are bad for our bodies. This is **not** true. If we don’t show our emotions, negative as well as positive, we model to our kids “don’t show your feelings”. Emotions, when acknowledged or expressed, stimulate the immune system. Support groups, church groups, etc. can help this process.



Acknowledge your feelings—when you are tired or sad, for example. Take care of yourself, nurture yourself and your feelings.



Don’t place your anxieties on your children.
Keep information current, honest.



Help your children by helping yourself.
Give kids the message that one can manage the hard, tough stuff. Honesty creates intimacy in your relationship.
Not talking annihilates trust.

Kids cope better when they can participate in age-appropriate ways. Allow kids to be kids. If they want to help you, assign them tasks that they already do. For example, making their bed(s), cleaning their room(s) or, doing their homework.
Refrain from treating them as adults.



Learn active listening.



Older children may act out with anger; they need honest communication.



When a child is not coping well with the cancer diagnosis of a parent or another loved one, be acutely aware of any changes in behavior including: increased aggressive behavior (such as arguments, backtalk, fighting at school, increased agitation), bedwetting or increased incidences of bedwetting, regressive behavior (such as thumb-sucking), a significant decline in school grades, loss of appetite, or self-harm (such as drug use or sexually acting out).

Three to 18 years of age.

Their baseline experience with death (of a pet) may be their reference point in life. How the family and child cope with those early events will provide the reference points later in their lives. Some children will feel blame.

Some will have a fear that cancer is contagious. Some will have fear of their peers—that they will be different now that their mother or father has cancer.

Some will feel embarrassment, some “different.”

Others may have a fear of being alone; some will worry about how it will affect their routine. And, some will fear upsetting the parent.



Some kids know intuitively not to bring up the topic of cancer because they want to be protective. Children are children, no matter what their size or age. It is easy to forget this.

When talking with them, be age appropriate.

Remember that they need to have normal routines—schools, chores, etc.



Be honest and be open. Speak from the heart. Children need to trust the parent. Build on trust.

Children want honest, open communication. Remember that information and terminology need to be age-appropriate. Use the actual diagnosis.

Anticipate the child's fears and concerns.
Nourish hope with acceptance.
"I'm going to do everything I can to get better..."



Two-way communication encourages understanding and decreases misunderstanding. Have "check-ins" with mom/dad, have a family meeting, talk about what's happened in each other's personal lives. Be willing to share your own thoughts and feelings about the diagnosis.

Laughter, Humor

Laughter and a sense of humor are important.
Timing is important.
Know when to play, when to listen.



What was funny before may not be now.



Endorphins flow with laughter.

Complementary/Alternative/ Integrative Medicine/Herbal Therapy

If you want to use alternative or complementary medicine/products/herbs/techniques, be sure to tell your doctor. It is important that you tell him/her what you want to do or are doing.



Herbs—There is no regulatory agency for herbs. Before using any herb, check with your doctor to see if there are any contra-indications.



It is important to say what you think is missing in the treatment plan. Discuss this with your doctor.



Most complementary and alternative medical products have no government regulation. Therefore, their effects, ingredients, quality and effectiveness may be unknown.



Be aware of drug interactions with herbs, vitamins and complementary medicine products.

Recognize the importance of breathing.
Use meditation. Guided imagery and visualization
can be used in a group or by yourself.



A spiritual journey—everyone has one. This disease
changes everything. A gift always results. A spiritual
path helps many people go through this.



Spiritual dimensions.
The power of the spirit is independent
of any manifestation of religion.



Antioxidants.
Vitamins may play a role in tumor growth.
It is important to seek information from
credible sources. Talk with your doctor
before initiating a vitamin program.



Multivitamin preparations are okay.
Large dose vitamins are a concern.

Watch for claims of “a secret formula.”
If you see such claims, question them.
Ask “experts” (doctor, nurse, pharmacist)
if anything is known about this product.



Shark Cartilage.
We often hear that sharks don't get cancer
and that ingestion of shark cartilage protects us.
In truth, sharks do get cancer.



Check your herbs.
Know how much you're taking and how much
you're spending on this. There is a placebo effect for
many of these products. Know the interactive effects
and the potential side-effects. Check the label.
Be sure it states what is in the product
and the recommended dosage.
If this information is not there, be careful.
Many herbs contain additives.



For questions about herbs, botanicals
and health risks, see: www.nccam.nih.gov
or www.medscape.com/drugchecker
(1.888-644-6226), or,
www.ConsumerLab.com

Guided imagery, hypnosis,
visualization—these are health modalities
with no side effects and may be helpful.



Guided imagery uses all your senses.
It reduces muscle tension, respiration and blood
pressure, and affects hope and healing. It can reduce
side effects of treatment and anxiety. It can reduce blood
loss, help with surgical recovery and pain management.



Guided imagery is an effective technique to
reduce stress and relieve pain. There are various
community agencies that offer guided imagery.
Check with your local hospitals and agencies.



Complementary medicine is not
a substitute for conventional medicine.



Evaluate techniques and therapies.
Talk with your physician.
Tell him/her what you are doing and taking.

Financial and Insurance Issues

“DCIS” and “LCIS” are different diagnoses. If a billing person miscodes these, it may create financial problems with your health insurance.



Benefit issues can be confusing and frustrating. Benefit programs and health insurance policies vary in terms of what they provide or cover.

Take time to learn about your benefits.

This will be helpful to you
and will save you
frustration in the future.



Insurance Information: California Department of Insurance

<http://www.insurance.ca.gov>

(Type in “Health Insurance” in the ‘Search’ window or call 1.800.927.4357.)



Benefits are like a dysfunctional family—they make no common sense. They are not logical.



Personal preparation is needed.
Plan, prepare and be practical.

Learn your choices and then make decisions.



Understand your options for financing (health care, rent, and basic living expenses) before you make decisions. Look at long-term care insurance, evaluate the use of income and other assets, learn about life care or continuing care communities.



You can be enrolled in multiple health insurance programs and policies, but be aware that you can be over-enrolled. Ask if you can have extra care before you do so. Not all policies allow this.



Find out which income (Social Security Disability Insurance, State Disability Insurance, or Supplemental Security Insurance) or health coverage benefits you may qualify for.



PPO/HMO

These usually cover home care, hospice, some skilled nursing facility; they almost never cover custodial care.

There are different kinds of care: long term care; acute care; chronic care; skilled care; custodial care. Long-term care policies may or may not include custodial care. Long-term care is not acute care.



Care alternatives include: in-home care, assisted living facility, skilled nursing facility (SNF)/custodial, life care, continuing care.



SNF/custodial care (skilled nursing facility) assists with feeding, with incontinence.



Continuing care/life care is available for life—you can stay there even if you can't pay. Usually this care is provided by not-for-profits—religious or charity-based.



If thinking of home care, your support system is critical when using family members to provide the care.

Private duty nursing and attendant care are usually paid out-of-pocket.



Families frequently use both home health care, private and/or skilled nursing; four to 24 hours/day is typical.



Medi-Cal (Medicaid)—There are over ninety different categories/types in California
<http://cms.gov>

Medicare
www.medicare.gov



Know what your health insurance covers and does not cover.
Some policies will go “outside of benefit” to help.
Call, don’t give up. Get an advocate to help with the insurance questions.



What’s available in the community?
Home health care—to recover from surgery or an accident—is usually short term care. It includes Durable Medical Equipment (DME) and visits from registered nurses, social workers, home health aides, and physical therapists. Payers include Medicare, Medi-Cal, and private insurance.

Meals-on-Wheels
depends upon existing
community agencies and availability.



Advance Health Care Directive— designate whom you want to represent you if you are unable to do so for yourself. These are available from many sources including: the California Medical Association, elder care organizations, your hospital, family law attorneys, and estate planning attorneys.



The number of people over 65 years of age will double from 35 million to 70 million in the next 30 years. This has tremendous implications for health care.



Warning: Reverse annuity mortgages are available but it may mean losing your house. This option is not for everyone. Investigate it carefully.

Hospice

Hospice works with skilled nursing facilities (SNFs), people at home or in the hospital.



You can call hospice yourself. Inquire. Sometimes doctors are uncomfortable with the discussion. You can call and explore your options, get some questions answered.



Hospice care—people get nervous. Matthew Fox, a theologian, said, “Hospice is a moment of hope at a time of despair.”



Hospice is usually a home service, although occasionally there is an inpatient unit.



The Palo Alto, California Veterans Administration hospice is open to both veterans and non-veterans.



Veterans Hospice Resources
Palliative care and Hospice care for veterans.
www.nhpc.org

Friends and Caregivers ~ More Ideas. What You Can Do

When you don't know what to say to your friend who has cancer, acknowledge it to yourself and to him/her. Sometimes it's helpful to say "I don't know what to say or do. I wish I knew how to help."



This is someone else's journey, not yours. Remember they have limited energy. Don't take it personally. Give them time to cocoon with their family.



A suggested telephone message for the recorder—"We're glad you called. If you want to see how we're doing, call (name) at (telephone number; time). He/she will let you know."



"On call" buddy—these are friends whom the patient can call if he/she needs assistance. Assign days to be "on call."



Be cautious about imposing your own ideas.



Recognize that the patient's energy dissipates easily.

Show up—write a message,
send a joke, an email. Be present.
You don't need to fix it; you can't fix it.
Never underestimate the importance
of being present.



Practical things don't require worry.



Cecily Saunders, MD, founder of the modern hospice movement, said something to this affect: “Whenever we have a blank page, it can be a time of intense individual achievement and accomplishments for family, friends, and colleagues. It is an opportunity.”



A note for caregivers: It is important that you take care of yourself as well as your loved one.
Do not wait to get assistance for yourself.
If you wait until you get fatigued you can't give care.
You might even get sick yourself.
Don't be afraid to call/ask for assistance.



Knowledge is power—educate yourself.

Information~Internet

It's important to have a plan.
The Internet can be helpful, but it can
also put you on sensory overload.
At some point, you may ask yourself,
“What was I looking to answer?”



Avoid cancer chat rooms on the Internet.



There are lots of books, agencies and Internet
information. A word of caution: Information
is frequently broadly written. For example,
there are lots of side effects that may
not apply to you. The descriptions can be
valuable but may also be very frightening.
They also may be inaccurate.
Use trusted resources.

Resources: Phone Numbers, Web Sites, and Books Organizations

Advance Health Care Directive

California Medical Association Publications

PO Box 7690, San Francisco, CA 94120-7690.

www.cmanet.org or, check with your medical institution

Cancer Information Service: 1.800.4.CANCER

www.cancer.gov

English/Spanish. M-F, 8 am - 8 pm, Eastern time.

Internet instant messaging is available M-F, 8 am - 11 pm, Eastern time. (click on “LiveHelp”)

Sponsored by the National Cancer Institute.

Publications are available by telephone, fax-on-demand, “LiveHelp” and the Web site.

National Cancer Institute (NCI)

1.800.4CANCER (1.800.422.6237)

www.cancer.gov

Coordinates the National Cancer Program; conducts and supports research, training, health information dissemination; information about clinical trials, research statistics and additional cancer links. (English and Spanish). The NCI operates the 1.800.4CANCER Information Service (see listing above).

National Center for Complementary and Alternative Medicine (NCCAM)

(A Center within the National Institutes of Health)

P.O. Box 7923, Gaithersburg, MD 20898

1.888.644.6226

1.866.464.3615 (hearing impaired)

info@nccam.nih.gov

www.nccam.nih.gov

Information about complementary and alternative medical therapies.

Web Sites

www.cancer.gov

National Cancer Institute (NCI).

1.800.4CANCER (1.800.422.6237)

Information, statistics, additional cancer links (English and Spanish), “Live Help” available.

www.caregiver.org

Family Caregiver Alliance/National Center on Caregiving

1.800.445.8106

Information, education, and on-line discussion groups, and the Family Care Navigator, a state by state directory of programs, support and services for caregivers and loved ones.

www.drugdigest.org

Drug Digest

Evidence-based consumer health and drug information site.

Includes herbs, drugs, drug interactions.

(continued)

www.growthhouse.org

Growth House, Inc., San Francisco

Education and information for the general public and health care professionals, including free access to over 4,000 pages of education materials about end-of-life care, palliative medicine, and hospice care.

www.healthfinder.gov

Healthfinder.gov

Sponsored by the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Comprehensive and concise quick-reference guide for herbs, pharmaceutical drugs, drug interactions, health education, resources, libraries, consumer guides, health organizations and more (English and Spanish).

www.hospicedirectory.org

A subsidiary of Hospice Foundation of America

A consumer website of hospices, contact information, locations and services.

www.hospicefoundation.org

Hospice Foundation of America

Provides hospice listings, information and education for patients, families and health care providers.

1.800.854.3402

www.insurance.ca.gov

Insurance Information California State-mandated regulatory agency. Its responsibilities include legal enforcement, licensing, consumer protection, and criminal investigations. It also offers a Consumer Communications Bureau (Hotline) 1.800.927.HELP (4357). (English and Spanish)
Outside California 1.213.897.8921

www.medscape.com/drugchecker

Medscape provides medical information and educational tools for health care practitioners. The “drug checker” looks at drug-drug interactions for two or more drugs.

www.nlm.nih.gov

National Library of Medicine (NLM)

Health information from the world's largest medical library. Services include Clinical Trials, NIHSeniorHealth, Tox Town, Household Products Database, Genetics Home Reference, LocatorPlus Online Catalog, MEDLINE/PubMed, and Bioethics Information Resources.

e-books

Stanford Health Library

www.stanfordhospital.com/healthLib/atStanford

Books

Suggested by cancer patients and families

100 Questions and Answers About Lymphedema

By Saskia R.J. Thiadens, Paula J. Stewart, and Nicole L. Stout, 2009.

Another Country: Navigating the Emotional Terrain of Our Elders

By Mary Pipher, 2000.

Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer

By Michael Lerner, 1996.

Dr. Susan Love's Breast Book, 3rd edition

By Susan M. Love, MD, Marcia Williams and Karen Lindsey, 2005.

Estates: Planning Ahead—A Personal Manual for Estate Planning

By Cancer Prevention Institute of California, 2010.

(formerly Northern California Cancer Center)

(English and Spanish).

(Patrimonios: Planificación Anticipada—Un Guía Personal Para la Planificación de Patrimonio)

Everyone's Guide to Cancer Therapy: How Cancer is Diagnosed, Treated and Managed Day to Day

By Ernest Rosenbaum, Malin Dollinger, and Andrew Ko, 2007.

Everyone's Guide to Cancer Survivorship: A Road Map for Better Health

By Ernest Rosenbaum, David Spiegel, Patricia Fobair and Holly Gautier, 2007.

Fine Black Lines: Reflections on Facing Cancer, Fear and Loneliness
By Lois Hjelmstad, 2003.

Jane Brody's Guide to the Great Beyond: A Practical Primer to Help You and Your Loved Ones Prepare Medically, Legally, and Emotionally for the End of Life
By Jane Brody, 2009.

Living Well Beyond Breast Cancer
By Marisa Weiss, MD and Ellen Weiss, Revised 2010.

Mayo Clinic Book of Alternative Medicine: The New Approach to Using the Best of Natural Therapies and Conventional Medicines,
Produced by Mayo Clinic, 2010.

Supportive Cancer Care: A Comprehensive Guide for Patients and Their Families
By Ernest Rosenbaum and Isadora Rosenbaum, 2005.

The Cancer-Fighting Kitchen: Nourishing, Big-Flavor Recipes for Cancer Treatment and Recovery
By Rebecca Katz and Mat Edelson, 2009.

Working With Breast Cancer: Productive Solutions for Employers and Employees
Breast Cancer and Employment Law.
By Cancer Prevention Institute of California, 2007.
(formerly Northern California Cancer Center)



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