


Information

For Patients Recently Diagnosed with Cancer



Name

Doctor



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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CANCER PREVENTION INSTITUTE
OF CALIFORNIA

Preventing Cancer. Promoting Life.

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TABLE OF CONTENTS

| | |
|--|-----|
| Introduction | iii |
| Valuable Information | i |
| Suggestions from Other Patients and Families | 6 |
| Informational Resources | 8 |
| CPIC Publications | 11 |
| Medications | 12 |
| Outpatient Medication List | 13 |
| A Patient's Bill of Rights | 14 |



INTRODUCTION

Understanding the kind of cancer you have and the treatment that is recommended will help you with medical decisions and communications. You will need to work closely with your doctor and other members of the medical team. Your “team” may include doctors, nurses, nutritionists, psychologists, social workers, physical therapists, and others. And, of course, you.

Treating the “whole patient” is important. Cancer is a disease that affects the mind and the spirit, as well as the body. We hope that the information and questions suggested here will be helpful. We encourage you to ask questions of your doctor(s) and others on your health care team.

Your culture and your family may influence how you think of “cancer,” its treatments and how you make medical decisions. Be aware of this. Discuss this with your doctor.

Once your doctor tells you your diagnosis and treatment plan, you may want to get another doctor’s advice before you begin treatment. This is known as getting a second opinion. You can do this by asking another oncologist to review all of the medical records and materials related to your case. A second opinion can confirm or suggest changes to your doctor’s proposed treatment plan, provide reassurance that you have explored your options, and help answer any questions you may have. Getting a second opinion is done frequently, and most doctors welcome another doctor’s views.

If the medical information is hard for you to understand—due to fear, language, education level, or words used—tell your healthcare provider. Ask for clarification.

CLINICAL TRIALS

Clinical trials are research studies that seek answers to scientific questions. They are used to find improved methods to prevent, screen, diagnose or treat a disease. Participation in a clinical trial is totally voluntary. If you are interested in participating in a clinical trial ask your doctor if one is available for your kind of cancer and what the trial requires.

MEDICAL INTERPRETER

If English is not your primary language and you want a medical interpreter, be sure to inform your doctor or other health care staff. They will help you get the assistance you need.

Notes: _____

VALUABLE INFORMATION

My doctor's name: _____

Phone number: () _____

The receptionist's name and phone number: () _____

The nurse's name and phone number: () _____

Telephone number(s) to call after the doctor's office is closed, on weekends and holidays:

() _____

() _____

My doctor's
office address: _____

Fax: _____ Email: _____

My diagnosis is: _____

My treatment
plan is: _____

Notes: _____



The usual _____
side effects _____
of my _____
treatment _____
are: _____

*(Ask how long your treatment side effects may last.
Ask how to manage them if they occur.)*

Side effects that **need to be reported** right away to my doctor are:

If I have questions or concerns about my medical treatment, I am to call:

at () _____

If I get frightened or anxious and want to talk with someone, I am to call:

at () _____

at () _____

Notes: _____

On weekends, I can call: _____
at () _____

When I am on treatment, my nutritional needs include: _____

When I am on treatment, I should avoid these foods: _____

If I have trouble sleeping, I can try the following: _____

If I decide to attend a support group, I can go to one at: _____

If I want a medical interpreter, I can call: _____
at () _____

Notes: _____



OTHER NAMES AND NUMBERS TO KEEP:

NAME

TELEPHONE

Primary Care Doctor: _____

Surgeon: _____

Medical Oncologist: _____

Radiation Oncologist: _____

Nurse: _____

Nutritionist: _____

Pharmacist: _____

Physical Therapist: _____

Social Worker: _____

Support Group Leader: _____

Insurance Provider or Company: _____

 Contact person: _____

 Insurance Policy Number: _____

Insurance Provider or Company: _____

 Contact person: _____

 Insurance Policy Number: _____

Others: _____

Attach/Tape a copy of your insurance card (front/back) here.

Determine if your insurance company requires pre-certification before medical procedures (example: x-rays).

WHEN TREATMENT IS OVER

When your cancer treatment is completed, you may be told to see other doctors and not your cancer doctor. It is important to have answers to the following questions:

When I am done with my cancer treatment, who will follow my medical issues—are there certain kinds of questions or problems that need to go to my:

Cancer doctor? _____

Primary care doctor? _____

Surgeon? _____

Is a written summary of my treatment plan available for me to have? _____

Is there a written health care plan for me to follow? If one is not available, ask your doctor how to obtain one. _____

Notes: _____

ADVOCACY AND UNDERSTANDING

A diagnosis of cancer can be very scary and remembering everything your doctor tells you can be a challenge. Consider taking someone with you to your appointments to help you remember what was said. Or, you may want to take a tape recorder to help you remember. Not all doctors are comfortable with this, so ask if it's okay. Identify a family member or friend to be your advocate, someone who can interact with the health care system and reduce some of the stress for you.

COMMUNICATIONS

Your health care “team” may be located in several different places and departments. Depending on your treatment, you may be working with many different people—medical oncologist, surgeon, radiologist, pathologist, nurse, social worker, nutritionist, physical therapist, clinic receptionist, and others. You will need good communication skills and patience.

To prepare for your doctor visits, write down your questions. Take them with you to your appointments. Put them in order of importance and ask the most important ones first. You might not get through the whole list, but you will get the most important ones answered. Be respectful of your doctor's time but still meet your needs. Write down the answers you get, and make sure you understand what you are hearing.

Do not be afraid to ask your questions or ask where you can find more information about what you are discussing. Being well-informed is an important task. Be cautious about internet resources.

If you are not comfortable talking with your doctor or do not think you get along well with your doctor, tell your doctor about this. If necessary, you may want to change doctors.

MEDICATIONS

Make a list of all the medicines you are taking. This includes medicines your doctor has prescribed as well as non-prescription drugs such as aspirin, ibuprofen, other pain medicines, cough medicines, cold relievers, vitamins and herbal supplements you are taking, even if they are not related to your cancer diagnosis. There may be drug/chemical interactions that need to be addressed. Some medicines do not work well with others. Some can be harmful when taken together. Your doctor needs to know what you are taking. Bring this list to your doctor so that the two of you can discuss them.

Note: See page 13 in the back of this guide for listing your medications and dosage. It is recommended that you carry this with you to give to any medical care personnel you are working with.



INFORMATIONAL RESOURCES

Some individuals want a lot of information about their cancer and its treatment; others want very little. It's a personal choice. If you want more information about your medical issues, ask your doctor for suggestions. You may also wish to use the list on the next few pages. There are many books, websites and telephone information services available. Only a few of these are listed here. This information is provided to supplement the care provided by your doctor. It is not intended to be a substitute for professional medical advice. Always seek the advice of your doctor or other qualified health care professional before starting any new treatment or medical herb or supplement. Be sure to talk with your doctor if you have questions regarding a medical condition.

Stanford Health Library (with locations in Stanford Hospital, Stanford Cancer Center, Stanford Shopping Center, Oshman Family Jewish Community Center in south Palo Alto, and the Ravenswood Family Health Center in East Palo Alto) has a staff to help you find additional resources.

650.725.8400 • www.healthlibrary.stanford.edu

A few suggestions to start with:

Books

Everyone's Guide to Cancer Supportive Care (A Comprehensive Handbook for Patients and Their Families) by Ernest H. Rosenbaum and Isadora Rosenbaum.

This book includes information about cancer treatment, clinical trials, complementary and alternative medicine, treatment side effects, cancer-related fatigue, stress, cancer and sexuality, cancer and spirituality, nutrition and recipes, rehabilitation and fitness, support groups, planning, and challenges. 2005.

Everyone's Guide to Cancer Survivorship: A Road Map for Better Health by Ernest Rosenbaum, David Spiegel, Patricia Fobair, and Holly Gautier, 2007.

Information about post-cancer treatment issues, including lifestyle changes to improve health and longevity, what survivors need to know following anticancer therapy, how to manage the side effects of chemotherapy and radiation therapy, and how to set goals for the future. 2007.

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

A full-color resource and cookbook for caregivers and patients. Addresses culinary ups and downs resulting from cancer treatment; information and recipes to provide delicious nourishment to cancer patients; practical solutions to taste bud changes and food intake challenges.

Telephone Information Services and Internet Sites

Many patients consult the **internet** for help in understanding their cancer. The information available is immense, but sometimes can be overwhelming, confusing and inaccurate. Be sure to discuss your impressions with your health care team if you are concerned.

Cancer Information Service

1.800.4.CANCER (422.6237) • www.cancer.gov

A nation-wide service of the National Cancer Institute, National Institutes of Health.

This confidential bi-lingual site (English and Spanish) is constantly revised and updated to reflect changes in treatment, clinical trials, and supportive care. The bi-lingual telephone service (English and Spanish) is available M – F, 8 am–8 pm (Eastern time). NCI also offers an “instant messaging” service called LiveHelp (also bi-lingual), M – F, 8 am to 11 pm, Eastern time.

Cancer Response Service

1.800.ACS.2345 • www.cancer.org

A nation-wide service of the American Cancer Society, providing cancer information and community resources.

Clinical Trials

www.cancer.gov/clinicaltrials

A website of the National Cancer Institute, providing current and completed clinical trials, clinical trial results, educational materials about clinical trials, information about safety monitoring, and more.

Healthfinder.gov

www.healthfinder.gov

This site is sponsored by the Office of Disease Prevention and Health Promotion, U.S. Dept. of Health and Human Services. It provides a comprehensive and concise quick-reference guide for health education, resources, libraries, consumer guides, health organizations, and more. In English and Spanish.

Complementary and Alternative Medicine (CAM)

National Center for Complementary and Alternative Medicine

National Institutes of Health

P.O. Box 7923 • Gaithersburg, MD 20898

1.888.644.6226 • TTY: 1.866.464.3615

<http://nccam.nih.gov>

Information, research, clinical trials, herbs, supplements, products, health information, and CAM training. In English and Spanish.

Drug and Drug Interactions

Drug Digest

www.drugdigest.org

A non-commercial, evidence-based, consumer health, drug and herb information site.

Publications available from Community Education, Cancer Prevention Institute of California (formerly Northern California Cancer Center) are listed below. For more information or to request copies, please contact education@cpic.org or 1.888.315.5988.

ENGLISH

A Guide to Developing and Sustaining Spanish Speaking Support Groups

For Latinas who have Breast Cancer

A practical reference for organizations and facilitators.

Estates: Planning Ahead *A personal manual for estate planning.*

A book to assist with financial and legal matters related to estate planning.

Living with Cancer: A collection of observations and suggestions for families and friends

Suggestions from patients, families, friends and health care professionals.

Information for Patients Recently Diagnosed with Cancer*

A booklet for newly diagnosed patients to help organize cancer treatment information, contacts and questions.

Using the Internet for Medical Advice

General guidelines and suggestions for finding and using qualified websites for medical information.

Working with Breast Cancer: Workplace Guidelines and Solutions For Employers and Employees.

Addresses employment law and breast cancer.

ESPAÑOL

Patrimonios: Planificación Anticipada *Una guía personal para la planificación del patrimonio.*

Un libro para asistir con los asuntos financieros y legales relacionados con la planificación de sus bienes/estado.

Guía Para el Desarrollo y Sustento de Grupos de Apoyo en Español

Para Latinas con Cáncer del Seno

Una referencia práctica para organizaciones y facilitadores de grupos.

Información para Pacientes Recién Diagnosticados con Cáncer*

Un folleto para pacientes recién diagnosticados para ayudarle a organizar información sobre su tratamiento de cáncer, contactos y preguntas.

Viviendo con Cáncer

Una colección de observaciones y sugerencias para familias y amistades que viven con cáncer.

Sugerencias de parte de pacientes, familiares, amistades y profesionales de salud.

**** Also available in Chinese.***



MEDICATIONS

Things you should know about your medication(s):

What are the brand and generic names of the product?

What is the purpose of the medication?

What does the medication look like?

What is the dosage?

How should I take this medication?

How often should I take this medication?

What if I miss a dose?

Does this medication have any side effects? What are they?

What should I do if they occur?

What side effects must I report to my doctor?

Does this medication interact with any other medications? With foods?

What should I avoid while taking this medication (for example, alcohol, herbs, certain foods)?

How should I store this medication?

Are there restrictions for certain daily activities (e.g., driving) while taking this medication?

Do you have allergies (food, medications)? If yes, be sure to tell your doctor.

Do you use over-the-counter medications? If yes, be sure to tell your doctor.

Allergy relief, antihistamines

Antacid

Aspirin, Tylenol, Ibuprofen

Cold, cough medicines

Diet Pills

Herbals, dietary supplements

Laxatives

Sleeping Pills

Vitamins and Minerals

Other: _____

If you have any questions about your medication(s), be sure to ask your doctor.

Notes: _____

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