



• Elizabeth J. Clark, PhD, Editor •

TEAMWORK

*The Cancer Patient's Guide To
Talking With Your Doctor*

A publication of the



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

Legal Disclaimer

This publication has been created by the National Coalition for Cancer Survivorship to provide cancer survivors and their loved ones with general information about communicating with your health care team. This publication represents the authors' opinions regarding the subject matter covered. This publication is not designed to provide individual legal advice nor to substitute for professional counsel.

Fifth Edition

Copyright © 2011 by the National Coalition for Cancer Survivorship (NCCS). All rights reserved. No portion of this booklet may be reproduced without permission from the National Coalition for Cancer Survivorship.

INTRODUCTION

This fifth edition of **TEAMWORK** comes nearly 20 years after its first printing in 1991. It also comes at a time when our knowledge about cancer and how to treat it are changing almost faster than we are able to apply the new knowledge. Now, medical breakthroughs, new technologies, and health care reform are making it more important for doctors and patients to work as a team. The new technologies have helped make it easier for both health care providers and the public to get up-to-date knowledge about cancer. This information for doctors and patients gives new meaning to the word “teamwork.”

To work as a team requires commitment from all of the people involved. Patients need to take advantage of the ease with which they can access information to learn about their cancer, its treatments, and the effects that cancer can have on their lives, jobs, and families.

Doctors need to listen closely to their patients and provide more help to educate them and meet the full range of their needs. In **TEAMWORK**, doctors and patients will learn that being aware of how we communicate with each other can result in better ways of dealing with the problems that cancer presents to us. I know you will benefit from this new edition of **TEAMWORK**. I hope you will share it with family, friends, and health professionals.

Hundreds of cancer survivors, nurses, doctors, social workers, mental health workers, and clergy provided helpful comments, insights, and support, so that at last cancer survivors have a clear, useful tool for communicating with their doctors and other members of their health care team. Since 1991, over 500,000 copies of **TEAMWORK** in English and Spanish have been given to people with cancer and the loved ones, friends, doctors and others who care for them.

—Dean H. Gesme Jr., M.D., F.A.C.P.,
Past Chair
National Coalition for Cancer Survivorship

PLEASE NOTE:

- Although the subtitle and text throughout this publication refer to “talking with your doctor,” it is meant to include your entire health care team.
- Words that may be new to you are shown in *blue* type. You can find the meaning of these words on pages 71–81 in a list of cancer terms and a second list of terms related to insurance.

**“With communication comes understanding and clarity;
with understanding, fear diminishes;
in the absence of fear, hope emerges;
and in the presence of hope, anything is possible.”**

—Ellen Stovall,
3-time cancer survivor

ABOUT THE NATIONAL COALITION FOR CANCER SURVIVORSHIP

Founded by and for cancer survivors in 1986, NCCS created the widely accepted definition of survivorship and considers someone a cancer survivor from the time of diagnosis through the balance of life. Its free publications and resources include the award-winning Cancer Survival Toolbox[®], a self-learning audio program created by leading cancer organizations to help people develop essential skills to meet the challenges of their illness. More information is available at www.canceradvocacy.org or 1-888-650-9127.

WHO IS A SURVIVOR? WHAT IS SURVIVORSHIP?

NCCS defined the terms “survivor” and “survivorship” as they are now widely understood and accepted:

NCCS considers a person a cancer *survivor* from the moment of diagnosis through the balance of life.

Whether treatment is being received or has been completed, anyone who has received a cancer diagnosis is a cancer survivor.

Survivorship is the total experience of living with, through, and beyond cancer.

ACKNOWLEDGEMENTS

A group of 25 cancer survivors and health care professionals attended a workshop on *Patient/Doctor Communications* at the 1987 annual Assembly of the National Coalition for Cancer Survivorship (NCCS) in Albuquerque, New Mexico. Several of them met afterward to continue talking about problems with patient/doctor communication. They agreed that even though this communication was crucial to anyone facing a life-threatening illness, no one helped patients learn how to talk with their doctors.

The group decided to do something about this gap, and formed an 11-member Patient/Doctor Communication Committee that wrote the first edition of **TEAMWORK**:

- Larry Moore, M.B.A., C.P.A., Committee Chair
- Leslie Ralston Brusky, C.R.T., C.E.
- Ellen Gacevich, R.N.
- Joanne R. Gambosi, R.N., M.A.
- Paul K. Hamilton, Jr., M.D.
- Mary-Parke E. Manning, M.D.
- Jon Michnovicz, M.D., Ph.D.
- Shirley Miller
- Gene Rudiger
- Natalie Davis Spingarn
- Audrey Wilson

Their research found that no comprehensive guide existed to help cancer survivors to become educated in the often critical business of talking with their doctors. Each survivor struggles with this issue; some become more skilled, others do not.

The second edition (1998) of **TEAMWORK** was edited by Elizabeth J. Clark, Ph.D., past President of NCCS, with assistance from:

- Judith Blanchard
- Debra Thaler-DeMers
- Susan L. Scherr
- Susan Leigh, R.N., B.S.N.
- André M. Carrington

While most of the work of the original committee remained, new sections and topics such as managed care, fertility, hope, and end-of-life issues were added. The third edition (2004) and fourth edition (2006) included updated information and resources with the same basic format.

This fifth edition (2011) includes the same content as well as access to new cancer print and electronic care planning templates (forms). Care plans—a treatment plan before treatment begins, a treatment summary when treatment is completed, and a follow-up survivorship care plan—are important tools to help survivors work better with their doctors. They provide an opportunity to ask questions and get important information for making decisions. This edition was edited by Elizabeth J. Clark, Ph.D., past President of NCCS, with assistance from:

- Dean H Gesme, Jr., M.D., F.A.C.P.
- Wendy S. Harpham, M.D., F.A.C.P.
- Pamela Milberg
- Mark Gorman
- Ellen Stovall
- Anne Willis, MA

WHY TEAMWORK?

“I hate to take the doctor’s time to answer my questions.”

“I’m so puzzled I don’t know *what* to ask.”

“So many medical terms were used so quickly that I just went away confused.”

If you’ve had these reactions after meeting with your doctor, you’re not alone. Whether you’re a homemaker, retired person, teacher, factory worker, student, or corporate executive, the emotional aspects that accompany cancer, together with the complex details of treatment, can be overwhelming.

You need to know that there are thousands of people just like you!

You need the confidence that comes from a list of sound, practical questions that can be used in **TEAMWORK** with your doctor. You also need to know that it’s OK to ask questions and to expect answers in terms you can understand. The doctor needs to know not just about your cancer, but how the things in your life can either help or hinder your ability to adjust to the diagnosis of cancer and the prescribed treatments that may follow.

That’s why a group of long-time cancer survivors and health care professionals representing the National Coalition for Cancer Survivorship (NCCS) wrote this booklet for you. They’ve had similar experiences.

In essence, **TEAMWORK** allows you to become personal with your doctor. **TEAMWORK** will help you be a stronger, more informed partner with your doctor in the fight against your cancer.

“So many patients are afraid of their doctors and don’t want to bother them because they may feel their concerns are unimportant.”

—Jean Oxford,
Oncology nurse and family member
of a cancer survivor
Houston, Texas

“Sending a patient to do battle with cancer without any training is like parachuting a soldier into the jungle without the benefit of survival training.”

—Michael Lerner, Ph.D., President,
Commonwealth

TABLE OF CONTENTS

	<i>Page</i>
HOW TO USE THIS BOOKLET.....	1
A PLAN FOR YOUR TREATMENT—AND BEYOND	1
USING YOUR CANCER CARE PLAN	2
CANCER CARE PLAN TEMPLATE.....	3
GETTING STARTED:	
UNDERSTANDING HOW TO TALK WITH YOUR DOCTOR.....	8
WHAT SHOULD YOUR DOCTOR KNOW ABOUT YOU?	8
WHAT DOCTORS WISH THEIR PATIENTS KNEW	9
HOW MUCH TEAMWORK DO YOU WANT?	11
KEY QUESTIONS TO ASK	12
ASKING QUESTIONS: WHO, WHEN, HOW?	12
UNDERSTANDING (AND REMEMBERING!) WHAT THE DOCTOR SAYS	14
TEAMWORK IN THE HOSPITAL	15
TEAMWORK BARRIERS FOR THE DOCTOR AND THE SURVIVOR	16
REMEDIES WHEN TEAMWORK PROBLEMS OCCUR.....	18
FINDING CANCER INFORMATION ON THE INTERNET.....	19
CHOOSING A DOCTOR.....	20
BACKGROUND INFORMATION AND STAGING.....	23
BIOPSIES	24
DIAGNOSIS	24
TESTS	26
HEALTH OUTLOOK (PROGNOSIS).....	27
COPING WITH A DIAGNOSIS.....	29
EMOTIONAL ASPECTS OF CANCER	29
MAINTAINING HOPE.....	31
TREATMENT OPTIONS	32
ASKING ABOUT TREATMENT OPTIONS.....	32
CLINICAL TRIALS	37
SURGERY.....	39
UNPROVEN METHODS.....	40
COST AND INSURANCE ISSUES.....	42
COSTS/INSURANCE COVERAGE	42
MANAGED CARE	43

(Continued on next page)

	<i>Page</i>
TREATMENT PLAN.....	45
MEDICATIONS	45
PAIN RELIEF	46
CANCER FATIGUE.....	50
SEXUALITY	52
FERTILITY	53
MAKING THE TRANSITION OFF OF ACTIVE TREATMENT:	
TREATMENT SUMMARY AND FOLLOW-UP SURVIVORSHIP CARE	55
LIVING BEYOND CANCER	55
YOUR TREATMENT SUMMARY	59–60
YOUR FOLLOW-UP SURVIVORSHIP CARE PLAN.....	61–62
WHEN TREATMENT OPTIONS ARE LIMITED	63
LIVING WITH LOSS	64
RESOURCES.....	65
ADVOCACY AND EDUCATIONAL RESOURCES	66
GLOSSARY OF CANCER WORDS	67
GLOSSARY OF INSURANCE TERMS	76
NOTES	78

HOW TO USE THIS BOOKLET

Hearing that you or a loved one has cancer is overwhelming and stressful, but there are tips and tools to help you adjust to and deal in the best way possible with this diagnosis. One way to begin is to make sure you and your health care team understand each other and that you are an active team member. Everyone is there to work with you, so you need to clearly say what you need from them. By communicating well with your health care team, you stand to be as successful as possible in this situation. Some tips to keep in mind:

- ❑ **Speak openly and honestly with your team.** They need information from you to make sure your needs are addressed.
- ❑ **Make sure your doctor listens and understands your needs and concerns.** Don't be afraid to speak up if you don't think you are being understood. To make sure you've been understood, it is often helpful to repeat back to the doctor what you understood him/her to say.
- ❑ **Ask questions and gather information.** Make sure you understand and that you have the best information you can have to make decisions.
- ❑ **Make a plan with your team for your treatment and care.** Getting that plan in writing or electronic form is ideal but not always possible in every situation. Knowing what to expect can help you feel more at ease and able to address issues better as they arise.

A PLAN FOR YOUR TREATMENT—AND BEYOND

As noted above, one way to help make sure you and your team understand each other is by using cancer care plans. If you were going on a trip, you would likely have a plan of how to get to your destination and what to do when you arrive. In the same way, cancer care plans are roadmaps that make sure you know where you are going and how you will get there. This roadmap should be discussed with your health care team and can be shared with other health professionals you see, such as your primary care doctor, radiologist, surgeon, etc. Cancer care plans are useful whether you are newly diagnosed, making the transition off of active treatment, or changing your treatment course. Cancer care plans should have three parts:

- ❑ ***Treatment Care Plan.*** This plan should be discussed before you begin treatment and can help guide you as you talk with your doctor about what is important to you and any concerns you may have. It will help you talk about treatment options and possible side effects. The treatment plan can be shared with other doctors you might see for your cancer treatment or for any other health care needs.

- ❑ **Treatment Summary.** The treatment summary should be provided once you transition off of active treatment and can be shared with other doctors and health care providers. It provides a list of medicines you are taking, describes any ongoing issues that need to be addressed, and describes the cancer care you received.
- ❑ **Follow-up Survivorship Care Plan.** This plan will help map out your follow-up care when you have completed treatment. Cancer survivors need to be monitored for the rest of their lives and have different health care needs than before they were diagnosed. The Follow-Up Survivorship Care Plan helps to ensure that you and all of the members of your health care team know what follow-up is needed, when it is needed, and who you should see for that care.

USING YOUR CANCER CARE PLAN

On the next pages of this booklet you will find examples of paper-based and electronic cancer care plan templates (forms) that you can tear out or copy and bring to your doctor. You also may want to bring this booklet with you to your appointments. For each section of the cancer care plan, there are lists of questions and tips for communicating well with your health care team. Use this information in this booklet to make sure you understand treatment options, how side effects and symptoms will be managed, and other issues you find important. Once you create your care plan with your doctor, make sure to keep copies of it for you and other health care team members.

**If you are newly diagnosed, you may find the free *Cancer Survival Toolbox*[®] program, *First Steps for the Newly Diagnosed*, to be helpful.
See the *Resources* section of this booklet to learn how to order your copy.**

CANCER CARE PLAN TEMPLATE

The following 3-page Cancer Care Plan template (form) helps you map out your care from before you begin treatment through when your treatment ends.

You can tear out the care plan in this booklet, or you and your health care team can create an electronic plan for you using *Journey Forward*. The *JourneyForward.org* website has paper-based and electronic templates to make sure you understand your options and to make sure your team understands what is important to you. These templates can help you and your health care team create your *Cancer Care Plan*, which includes your *Treatment Plan*, *Treatment Summary*, and *Follow-Up Survivorship Care Plan*.

Following the template, you will find sections of this booklet related to the topics in the cancer care plans. For example:

- The *Background Information and Staging* section of this booklet will help you better understand your diagnosis and how the extent of the cancer is determined. You can find the right questions to ask to learn more about biopsies, diagnosis, and tests.
- Cancer also takes an emotional toll. It can cause you to feel sad, depressed, stressed, or anxious. You can learn more about how to cope with a diagnosis in the *Coping with Cancer* section.
- Find tips for talking with your doctor to understand your treatment options in the *Treatment Options* section. This includes discussing the options, surgery, clinical trials, and unproven methods as well as knowing your insurance plan and understanding the costs.
- The *Treatment Plan* sections will help you know your medications and their side effects and talk with your doctor about a plan for addressing any side effects.
- As you transition off treatment, your doctor can help provide you with a summary of your treatment and provide a roadmap for your continued health care needs. Learn more in the *Making the Transition Off of Treatment: Your Treatment Summary and Follow-Up Survivorship Care Plan* section.
- Your treatment plan may change at some point in your care, and you may want to reread the *Treatment Options and Treatment Plan* sections. If you are considering making the transition off of treatment, read the *When Treatment Options Are Limited* section.

In addition, sections of the booklet show again the part of the Cancer Care Plan template related to the topics being discussed.

NOTE: The Cancer Care Plan template may contain some terms that are new to you. Medical terms on the templates are defined in the back of this booklet beginning on page 67.

TREATMENT PLAN AND SUMMARY TEMPLATES - PAGE 1 OF 3

Below is a paper-based template from the American Society of Clinical Oncology (ASCO) that can be used with any type of cancer. You can **tear** these pages out and take with you to your doctor. ASCO also has Treatment Summary templates for breast cancer, colon cancer, diffuse large b-cell lymphoma and small-cell lung cancer.

Insert Practice Name/Info Here:					
<i>The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.</i>					
Patient name:			Patient ID:		
Medical oncology provider name:			PCP:		
Patient DOB: (__/__/__)		Age:		Patient phone:	
Support contact name:					
Support contact relationship:			Support contact phone:		
BACKGROUND INFORMATION					
Symptoms/signs:					
Family history/predisposing conditions:					
Major co-morbid conditions:					
Tobacco use: <input type="checkbox"/> No <input type="checkbox"/> Yes, past <input type="checkbox"/> Yes, current (If current, cessation counseling provided?: <input type="checkbox"/> Yes <input type="checkbox"/> No)					
Cancer type/location:			Diagnosis date: (__/__/__)		
Is this a new cancer diagnosis or recurrence?: <input type="checkbox"/> New <input type="checkbox"/> Recurrence (date: __/__/__)					
Surgery: <input type="checkbox"/> None <input type="checkbox"/> Diagnosis only <input type="checkbox"/> Palliative resection <input type="checkbox"/> Curative resection					
Surgical procedure/location/findings:					
Tumor type/histology/grade:					
STAGING					
Study	Date	Findings			
T stage: <input type="checkbox"/> T1 <input type="checkbox"/> T2 <input type="checkbox"/> T3 <input type="checkbox"/> T4 <input type="checkbox"/> Not applicable N stage: <input type="checkbox"/> N0 <input type="checkbox"/> N1 <input type="checkbox"/> N2 <input type="checkbox"/> N3 <input type="checkbox"/> Not applicable					
M stage: <input type="checkbox"/> M0 <input type="checkbox"/> M1 <input type="checkbox"/> Not applicable			Tumor markers:		
Stage: <input type="checkbox"/> I_ <input type="checkbox"/> II_ <input type="checkbox"/> III_ <input type="checkbox"/> IV_ <input type="checkbox"/> Recurrence			Alternative staging system:		
Location(s) of metastasis or recurrence (if applicable):					
TREATMENT PLAN			TREATMENT SUMMARY		
<i>White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy</i>					
Height: in/cm		Pre-treatment weight: lb/kg		Post-treatment weight: lb/kg	
Pre-treatment BSA:		Treatment on clinical trial: <input type="checkbox"/> Yes <input type="checkbox"/> No			
Name of chemotherapy regimen:					
Chemotherapy start date: (__/__/__)			Chemotherapy end date: (__/__/__)		
Chemotherapy intent: <input type="checkbox"/> Curative, adjuvant or neoadjuvant <input type="checkbox"/> Disease or symptom control					
ECOG performance status at start of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4			ECOG performance status at end of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4		
Chemotherapy Drug Name	Route	Dose mg/m2	Schedule	Dose reduction	# cycles administered
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
Major side effects of this regimen: <input type="checkbox"/> Hair loss <input type="checkbox"/> Nausea/Vomiting <input type="checkbox"/> Neuropathy <input type="checkbox"/> Low blood count <input type="checkbox"/> Fatigue <input type="checkbox"/> Menopause symptoms <input type="checkbox"/> Cardiac <input type="checkbox"/> Other					

TREATMENT PLAN AND SUMMARY TEMPLATES - PAGE 2 OF 3

Insert Practice Name/Info Here:			
<i>The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.</i>			
TREATMENT PLAN (CONTINUED)			TREATMENT SUMMARY (CONTINUED)
Non-chemotherapeutic Agents	Route	Purpose/Goal	Comments
Reason for stopping treatment: <input type="checkbox"/> Completion <input type="checkbox"/> Toxicity <input type="checkbox"/> Progression <input type="checkbox"/> Other: _____		Response to treatment: <input type="checkbox"/> Complete <input type="checkbox"/> Partial <input type="checkbox"/> No response <input type="checkbox"/> Progression <input type="checkbox"/> Not measurable	
Treatment-related hospitalization required: <input type="checkbox"/> Yes <input type="checkbox"/> No		Serious toxicities during treatment (list all):	
Ongoing toxicity at completion of treatment: <input type="checkbox"/> Yes (enter type(s) and grade(s) _____) <input type="checkbox"/> No			
ADDITIONAL THERAPIES PLANNED			
Drug name	Comments		Date started (or to start)
			(_/_/_)
			(_/_/_)
			(_/_/_)
Radiation therapy: <input type="checkbox"/> Not planned <input type="checkbox"/> Planned <input type="checkbox"/> Administered Region treated: _____ Radiation dose: _____ Date initiated: (_/_/_) Date completed: (_/_/_)			
ONCOLOGY TEAM MEMBER CONTACTS		SURVIVORSHIP CARE PROVIDER CONTACTS	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	

© 2011 American Society of Clinical Oncology. All rights reserved.

Important caution: this is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

TREATMENT PLAN AND SUMMARY TEMPLATES - PAGE 3 OF 3

Insert Practice Name/Info Here: <i>The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.</i>		
FOLLOW-UP AND SURVIVORSHIP CARE		
Follow up care	When/How Often?	Coordinating Provider
Medical oncology visits		
Lab tests		
Imaging		
Potential late effects of treatment(s): 		
Call your doctor if you have any of these signs and symptoms: 		
Needs or concerns: <input type="checkbox"/> Prevention and wellness: _____ _____ <input type="checkbox"/> Genetic risk: _____ _____ <input type="checkbox"/> Emotional or mental health: _____ _____ <input type="checkbox"/> Personal relationships: _____ _____ <input type="checkbox"/> Fertility: _____ _____ <input type="checkbox"/> Financial advice or assistance: _____ <input type="checkbox"/> Other: _____ _____	Referrals provided: <input type="checkbox"/> Dietician <input type="checkbox"/> Smoking cessation counselor <input type="checkbox"/> Physical therapist or exercise specialist <input type="checkbox"/> Genetic counselor <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Psychologist <input type="checkbox"/> Social worker <input type="checkbox"/> Fertility specialist or endocrinologist <input type="checkbox"/> Other: _____	
COMMENTS		

© 2011 American Society of Clinical Oncology. All rights reserved.

Important caution: this is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

JOURNEY FORWARD SURVIVORSHIP CARE PLAN BUILDER

You and your health care team can also download Journey Forward's Survivorship Care Plan Builder, which is based on the ASCO templates on pages 4–6. This free tool has electronic templates for breast cancer, colon cancer, lymphoma, and other cancers. It also includes options to make it easier to fill out, such as a built-in regimen library, BSA (Body Surface Area) and BMI (Body Mass Index) calculators, and checklists. It also has a library of information on survivorship care that can be attached to each care plan. The screen below show the generic template that can be used for any type of cancer.

File Edit Tools Help

Cancer Survivorship Care Plan Builder

Care Plans
New
Open
Save
Print

Tools
Regimens
Library
Preferences
User Guide
Contact Us

Journey Forward

Survivorship Care Plan

General information | Background information | Treatment plan | Treatment summary | Follow-up care

Height in
Pre-treatment weight lb
Treatment on clinical trial Yes No
Chemotherapy regimen
Chemotherapy start-date

Chemotherapy

Agents	Route	Dose	Schedule
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/> X
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/> X
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/> X

Add agent

Non-chemotherapy

Agents	Route	Purpose/goal
<input type="text"/>	<input type="text"/>	<input type="text"/> X
<input type="text"/>	<input type="text"/>	<input type="text"/> X

Add agent

Chemotherapy intent
ECOG at start of treatment
Possible side effects of regimen
Pre-treatment comments

< Previous Next >

MCM0000233700

GETTING STARTED: UNDERSTANDING HOW TO TALK WITH YOUR DOCTOR

Before you make treatment decisions or start your treatment, there is some information you should share with your doctor. There also are things you should know about your doctor, and about how to communicate effectively, how to ask the right questions, and how to work with your health care team to make sure you remember and understand what you discuss.

WHAT SHOULD YOUR DOCTOR KNOW ABOUT YOU?

“Your doctor should know a good deal more about you than the facts of your illness.

Medicine is often an inexact science, and often several approaches are equally appropriate — whether it is in making a diagnosis, prescribing therapy, or following up a particular problem. In deciding the approach to take in your particular case, your doctor will gauge your personality, your general philosophy about your health, and your ability to understand and cope with illness.”

—Janet R. Maurer, M.D.

in How to Talk to Your Doctor

Cancer treatment is tailored to your individual circumstances. Likewise, for effective teamwork, the relationship between you and your doctor also must be based on your situation. You probably will want your doctor to know that you are “not just another cancer patient”— your lifestyle and your hopes have a special importance for you.

Types of personal information that may be helpful to your doctor:

- Your type of work and the degree of physical work or mental stress it involves.
- Close relatives who have had cancer, and their cancer types.
- An idea of how much you know about cancer and its treatment.
- How much you are affected by family problems, money problems, work-related stress, or other issues.
- Your hobbies and other interests.
- Your goals for your quality of life during and after treatment.

- Whether you might want to have children in the future.**
- Any important cultural beliefs.**

If you prefer that some of the information not go beyond your doctor, request that the doctor not write it down. (Once information is entered in your medical records, it may be available to parties such as insurance carriers and others.)

WHAT DOCTORS WISH THEIR PATIENTS KNEW

**“One thing that should be emphasized is
that some questions just don’t have answers.”**

*—Francis Jenkins,
Breast Cancer Survivor,
Atlanta, Georgia*

About Doctors

- Doctors are human.** They have feelings, stresses, hopes, and needs.
- They’re only human.** They see many patients in a week’s time. Sometimes it’s difficult to remember details about a specific patient’s case if the medical chart isn’t readily available. Sometimes they may not be able to answer a particular question because there may not be an answer, or at least no answer now. Just as cancer treatment is individualized, your response to that treatment also is individualized.

About How to Make Sure That Your Medical Preferences Are Honored

Doctors want to know your medical preferences. How can you help ensure that your preferences are honored?

- It might be helpful to choose one person to help you communicate your needs.** If you want a family member or friend to help you communicate, discuss this role with that person early on and tell your health care team how you want this person involved. Having many people who communicate different messages is confusing and may make it harder to work with your team to make decisions and solve problems.
- Whether you have cancer or not, you can’t predict the future.** But each of us should think about how decisions should be made and who should make them if we become too ill to do so ourselves. Your doctor or hospital can give you information on preparing

a document, called an *advance health directive*, that is legally recognized in your state. Common forms of this document are the *durable power of attorney* (also known as the *health care proxy*) and the “*living will*.” Many people have questions about these documents, such as:

- **What is a durable power of attorney?** A *durable power of attorney* is a legal document that lets you appoint someone to speak for you. It allows you to transfer your legal right to make a health decision to someone you choose as your “agent” or “proxy.” “Durable” means that your agent can make decisions for you only when you become unable to do so for yourself. Your agent need not be an attorney; most people choose a close family member or friend.
- **Why would I need a durable power of attorney?** A durable power of attorney lets you appoint someone you trust to decide about your medical treatment if you become unable to decide for yourself. You can give the person you choose as little or as much authority as you want. You can allow your agent to decide about all of your health care, or only certain treatments. You may also give your agent instructions that he or she has to follow.
- **What is a “living will”?** A living will is a document that gives specific instructions about health care treatment. It is generally used to state your wishes about life-sustaining treatment under certain conditions. A living will requires that you know in advance all of the decisions that may arise. In contrast, the health care proxy allows you to choose someone you trust to make treatment decisions on your behalf.

If you complete both a living will and a health care proxy form, the living will gives instructions for your health care agent — it will guide his or her decisions. A living will is not as effective as a durable power of attorney because a living will simply states your preferences to your doctor. A durable power of attorney gives legal authority to a person — not a piece of paper — to act in your place and be your advocate.

- **What if I change my mind?** It is easy to cancel your advance health directive or change any of your instructions. Just fill out a new form. In addition, you can require that your directive expire on a given date.
- **Who should get a copy of my *advance health directive*?** Give a copy to the person you have chosen to represent you (who may be called your health care proxy or agent), your doctors, and any other family members or friends you want. You may also give a copy to your lawyer. Keep a copy with your important papers, but not in a bank safety deposit box, so that others can find it if necessary.
- **When should I complete an *advance health directive*?** Appointing someone to be your agent is a very serious decision, and requires some thought and discussion. Complete your health care proxy in advance, not just when you are planning to enter the hospital.

- **Will my doctor or hospital require me to have a durable power of attorney or a “living will”?** Completing an advance health directive is voluntary. No one can require you to do so.
- **What is POLST?** POLST stands for Physician Orders for Life Sustaining Treatment. POLST is a physician order that is recognized and honored in all treatment settings. It is portable, which means that it goes with the patient. It gives directions or orders for a range of medical treatments such as orders for code status; this means whether or not you want to have *cardiopulmonary resuscitation* done (also known as CPR). It also allows for choices about nutrition, *hydration, intubation, mechanical ventilation,* and *antibiotics*. POLST does not replace an advance directive but is intended to supplement it.

You may never become unable to make your own health care decisions, but you can feel reassured and have peace of mind by providing for the possibility.

HOW MUCH TEAMWORK DO YOU WANT?

“When a person is fighting cancer, you do what you have to do.”

—Joel Hernandez,
Rectal Cancer Survivor,
Amarillo, Texas

Some survivors are better able to deal with cancer by leaving most of the information and decision making to their doctor. For these people, having too much knowledge and participating in medical choices is very stressful, and (for them) it may make things more difficult.

Others cope by learning all they can about their cancer and its treatment.

It is okay to be in either group. Only you know the best way for you to cope. Most survivors are somewhere in between the two categories described above. Sometimes, the same person may want different amounts of information at different times during their cancer experience.

It is important to let your loved ones, doctors, and other team members know how much you want to be informed about your cancer, its treatment, and your health outlook (prognosis).

They often look for subtle clues or signals from you. Sometimes they don’t know what to do about keeping you informed. Be open with them. Tell them clearly how much information you want. If your needs change, tell them so.

On the other hand, sometimes loved ones may want to know more about the medical treatment and situation than you do. This can put your doctor in the difficult position of needing to safeguard your privacy while being asked by family members for more information. If you’re concerned, you have the right to say who should know what kinds of information. You need to make sure your doctor understands your preferences about how much can be discussed with loved ones.

You can make it less difficult for them if you discuss these issues and tell your doctor and your loved ones to what extent the doctor has your permission to share information with them.

KEY QUESTIONS TO ASK BEFORE, DURING, AND AFTER TREATMENT

“Knowledgeable, active patients are more likely to do well and less likely to get severely depressed than passive ones. They can become active participants in their care and active partners with their physicians, rather than remaining passive consumers.”

—Harold Glucksburg, M.D.
in Cancer Care, A Personal Guide

NOTE: We don't suggest you ask every question contained in this booklet! Instead, think of these lists as a “menu” from which you make selections at times that are right for you. In addition to asking your doctor, other good sources of information for some questions may be your oncology nurse, *hospital social worker, case manager, patient advocate, or pharmacist.*

Make a list of questions (perhaps in a notebook to keep them together) before seeing the doctor. Leave room under each one to jot down notes during the visit (or ask your partner or a friend to take notes). Don't worry if at first you're uncomfortable asking questions and taking notes during doctor's visits. If you were looking to buy a house or car, you'd jot down notes naturally. So learn to be just as comfortable in the **TEAMWORK** with your doctor.

Your doctors' responses to your questions will be based largely on their training, experience, and judgments regarding your particular situation. Doctors also may be making a judgment as to how much they feel you want to know, how they feel you can deal with it, and their impressions of your ability to understand what is said.

ASKING QUESTIONS: WHO, WHEN, HOW?

“I think if one is informed about the illness, one is better able to deal with it.”

—Carol Friedman
*Wife of Lung Cancer Survivor
San Francisco, California*

Who: Office Staff, Doctor, Nurse, Social Worker. Your doctor is the best source of information for many of your questions. However, if you expect your doctor to meet all your needs, your expectations probably are too high. It is important to understand that doctors can't be expected to meet a patient's every need. Depending upon the question, other good sources of information are the office staff, oncology nurses, social workers, patient advocates, case managers, and pharmacists. If needed, your doctor will be able to refer you to a social worker, psychologist, sex therapist, pastoral counselor, or other professional capable of helping you and your family with your non-medical needs.

When: Timing Can Be Important. Some of your questions will be more important than others. When you have a very important one, you want a response that has been well thought out and not given on the spur of the moment or under time pressure. Asking at the right time may also mean asking at a time that will allow you adequate time to think about the doctor’s response, ask follow-up questions, and make careful decisions about your treatment.

If you need to talk with your doctor for an extended time, either by phone, e-mail, or in person, let the doctor know in advance, if possible. It may also be helpful to give your nurse a list of questions in advance so your doctor can give them adequate attention before talking with you.

“Asking at the right time” also means you shouldn’t delay asking important questions until the doctor visits you in the hospital the day before your surgery, or the day before you begin other treatment. You want to talk with your doctor under the least — not the most — amount of stress, and often you need to “think through” what was said and how it could impact your life. If you become overwhelmed during a visit, ask to set up another appointment in a few days.

You should also find out the best way to contact your doctor (e-mail, phone, etc.) for questions during and after office hours. S/he may need to be contacted differently depending on the time of day and scope of your questions.

Make sure you choose one person to communicate about your concerns. Having many people asking questions over and over again can make it hard to communicate well with your doctor. As transitions or changes happen in your care, sometimes there are special circumstances when you want your family to meet with your doctor to better understand what is happening. In these cases, you may want to ask for a separate appointment for a family meeting to discuss these kinds of care issues.

How: Wording Questions. One thing to remember is: Don’t ask “leading” questions. A leading question is one that is worded in a way that signals the answers you’re hoping for. Without meaning to, you could trigger a response that could be incorrect, misleading, or incomplete. Here are some examples of leading questions and how they can be more worded better:

LEADING QUESTIONS	EFFECTIVE QUESTIONS
Have you done a lot of these operations?	How many of these operations have you done in the past twelve months?
I’m going to be all right, aren’t I?	What do you think my prognosis is?
Is the nursing care in the hospital you use adequate?	What section of the hospital will I be in, and what training have the nurses there had?

**No question is too small to ask.
Every question you have is important.**

Find more communication tips with the free *Cancer Survival Toolbox*[®] *Communicating* program. See the *Resources* section to learn how to order your copy

UNDERSTANDING (AND REMEMBERING!) WHAT THE DOCTOR SAYS

“It is important that, on the average, 50% of what patients are told is forgotten in minutes.”

—*M.E.L. Tonkin, M.D.*

“After he told me, ‘You have cancer,’ I froze. I didn’t hear another word he said.”

—*Judy Truskett,
Lymphoma Survivor.*

There are many reasons why people often don’t understand or remember important parts of talks with their doctors. Just as important, there are many **TEAMWORK** tools you can use to help you with this important part of your cancer experience:

- ❑ **Ask a family member or friend to go with you.** Taking along someone with whom you’re comfortable can make the visit less stressful and can help you remember what the doctor says. The person who goes with you to your visit should be able to do three things: give you emotional support; listen and remember accurately what the doctor says; and think objectively about what is said.
- ❑ **Take notes during the visit.** Take notes (or have a family member or friend take them) carefully enough so that they’ll make sense to you when you get home. Ask the doctor to repeat something if you weren’t able to get it all down on paper.
- ❑ **Try to picture (visualize) what is being explained to you.** Ask your doctor to show you a picture or drawing that will help you understand where your cancer is, how tests will be performed, and how your cancer will be treated. If you can take a copy of the picture or drawing home, it will be easier to explain things to your family.
- ❑ **Ask the doctor to explain in terms familiar to you.** It’s only after you understand what’s being said that you’ll be an effective partner in your treatment and recovery.
- ❑ **Ask how you can learn more.** Your doctor can refer you to a pamphlet, book, videotape, or other resource to help you understand the procedure or treatment that is being explained. Helpful resources can be found on pages 65–66.
- ❑ **Reword your question and/or the doctor’s answer.** If you don’t understand the doctor’s answer, ask the question in a different way, or ask the doctor to explain the answer in a different way.
- ❑ **Verbalize (say) what you heard. Repeat to the doctor what you thought he or she said.** That gives the doctor feedback on what you heard and, if necessary, an opportunity to clear up any communication problems.

- ❑ **Take a small recording device like a tape recorder or cell phone with you.** Ask in advance if your doctor would mind you recording the session, explaining that it will help you better understand and follow the advice given. It also can allow you to be more relaxed when seeing the doctor, since it will free you from note taking. Still, give full attention to the doctor's explanations, asking questions when you need to. Recordings of key doctor visits also can help your family. No matter how well a doctor communicates, it's often difficult for a person to fully understand, recall, and explain to someone else exactly what was said. Playing the recording for family members means they (and you) hear the conversation just as it occurred, without "interpreting" or having to recall what you thought was said. The recording can also help out-of-town family. They can feel more assured when you allow them to hear parts of the recording by phone. In one study, hospital discharge interviews were recorded between 48 patients and their physicians. When later asked if the recording had been helpful, the patient responses were highly favorable: 91% thought the recording helped them to understand what the doctor said, 75% found it helpful to have their loved ones listen to the recording, and 86% believed the recorded interviews improved their health care.

TEAMWORK IN THE HOSPITAL

Sometimes it's hard for patients and loved ones alike to try to talk with the doctor while in the hospital. In some cases, you may not be awake or fully alert during a doctor's normal *rounds*. Further, loved ones often waste countless hours in the hospital room so they can talk with the doctor, not knowing when — or if — the doctor will visit that day. This can cause needless stress for both patient and family.

The following options may improve communication with your doctor while in the hospital:

- ❑ **Notebook.** Keep a notebook and pen in your hospital room so that you or a loved one can take notes and jot down questions as you think of them. Then you will have them ready so you can talk about them during the doctor's visit. Loved ones can also write notes to the doctor in case they cannot be present during his/her visit.
- ❑ **Recording device.** Keep a recording device in the room, and ask the doctor if it is okay to record your conversations so that your loved ones can be kept informed of the details, since they can't always be there. Also, if medication or some other reason prevents you from being fully alert all the time, explain to the doctor that you'd like to be able to replay the conversations later when you're better able to understand them.

- ❑ **Schedule a meeting.** If you or a loved one needs to talk with the doctor about a special or urgent concern, call the doctor's office and schedule a specific time when the doctor can meet with you in the hospital. This can keep you from wasting your time and the doctor's, and can help reduce the stress of waiting. You also can ask your nurse to have the doctor paged if a loved one will only be available at a certain time.
- ❑ **Schedule a phone call.** If the loved one can't meet the doctor at the hospital, ask the doctor to call your loved one at home or work at an agreed upon time. It is best if you select only one family spokesperson to interact with your doctor.
- ❑ **Send an e-mail.** If you or your loved ones need information, find out if you can send your doctor an e-mail with questions or concerns.

TEAMWORK BARRIERS FOR THE DOCTOR AND THE SURVIVOR

Certain barriers, if not recognized or corrected, can hamper or destroy effective communication. Some of them are listed below.

THE DOCTOR	SURVIVOR
Withholding information or giving information in a cold, tactless manner.	Withholding information (not telling your doctor about current medical problems, or that you're not taking your medicine properly, or that you are taking <i>complementary therapies</i> , or about major personal problems that could affect your treatment).
Raising his or her voice.	Raising your voice.
"Talking down" to patients.	Forgetting that doctors deserve your respect — not your worship.
Holding discussions with the patient while standing in the doorway, signaling he or she is really too busy to give you the time you need.	Pretending you understand when you really don't. (Ask for explanations in terms you can understand, since you want to work with your doctor in your treatment and recovery. Keep asking until you understand.)

(Continued on next page)

THE DOCTOR	SURVIVOR
Discussing serious or personal matters with the patient or family in busy hospital halls, busy waiting rooms, etc.	Taking an inordinate amount of the doctor's time (at the expense of other patients) when it's possible for you to schedule a separate period of time for in-depth discussion.
Pressing the patient to make a serious medical decision without adequate knowledge or time to think about it.	Allowing the doctor to discuss sensitive matters in inappropriate places. (Instead, be polite but interrupt and suggest moving to a more private area.)
Using medical terms unfamiliar to patients.	Being reluctant to ask for more time to make a decision that could affect you for the rest of your life. (Ask how much time you can reasonably take for decision-making without reducing the chance that your treatment will be most effective.)
Belittling patients who ask questions that are important to them.	<p>Being embarrassed to ask a question about your body or treatment that's important to you.</p> <p>Being afraid to ask a "dumb" question. (If you are thinking about it, it's not a dumb question.)</p>
Not making available pen and paper in the waiting room and examination room so patients can organize their questions and take notes.	<p>Not making a list of questions prior to seeing the doctor.</p> <p>Not taking notes while talking with the doctor.</p> <p>Not analyzing the doctor's responses to questions and asking follow-up questions.</p>

“It seems to come back to this: You need a physician who will listen patiently to you, answering your questions with candor but compassion, as positively as possible, and taking cues from you as to what you want to know; when, and how.”

*—Natalie Davis Spingarn,
Breast Cancer Survivor*

in Hanging in There: Living Well on Borrowed Time

REMEDIES WHEN TEAMWORK PROBLEMS OCCUR

“The new consumerism need not be regarded as a threat to medicine or as anything alien.

It can be an important source of the doctor’s support and growth,
for what it is actually doing is seeking the best in the physician,
even as the physician seeks to bring out the best in the patient.”

—Norman Cousins, Ph.D.
in *The Healing Heart*

“The doctor and the patient both have a considerable investment in any relationship that has been ongoing for some time, and care should be taken not to escalate simple annoyances or misunderstandings into major problems without discussion with the doctor.

A simple explanation may solve what seemed to be a major crisis.”

—Janet R. Maurer, M.D.
in *How to Talk to Your Doctor*

If you are having problems communicating with your doctor or other health care team members, you can help make things better in several ways:

- ❑ **Be open with your doctor.** Tell your doctor what you feel the communication problem is and ask how you can work together to solve it. It could be that your doctor doesn’t realize there’s a problem. Even some of the best doctors don’t communicate effectively with patients.
- ❑ **Ask yourself if you’re part of the problem.** Faults of others are easy to spot, while our own are not. Ask your doctor or the office nurse how you can improve the communication process.
- ❑ **Put it in writing.** If it’s hard for you to tell your doctor face to face that there’s a communication problem, write out the details, then give it to your doctor, or mail it. Or ask a nurse to give it to the doctor. Be as tactful — yet open — as possible. Try to put yourself in your doctor’s place: how would you react if you received the same written note?
- ❑ **Explain your communication problem to an oncology nurse, social worker, or patient advocate.** They may be able to suggest ways to solve the problem or provide help.
- ❑ **Talk with other cancer patients you know.** See how they’ve handled these kinds of problems with their doctors.
- ❑ **Ask your family doctor to help.** He or she may be able to give you advice or work out a solution with your cancer specialist.
- ❑ **Contact a hospital official.** If a serious communication problem occurs while in the hospital, you may want to ask a hospital administrator to help you.
- ❑ **As a last resort, consider changing doctors.** If you’ve tried all of your other options to improve communication and it’s a major problem to you, consider whether you want

to continue working with the doctor on a long-term basis. Above all, don't feel guilty or hesitant about changing doctors if that is what is right for you.

Sometimes you may need to negotiate with your team. Brush up on your negotiating skills and learn how to get what you need with the free *Cancer Survival Toolbox*[®] *Negotiating and Standing Up for Your Rights* programs. See the *Resources* section for ordering information.

FINDING CANCER INFORMATION ON THE INTERNET

Some information that used to be available only in books, medical journals, and educational pamphlets, is now available by computer. Survivors now can find a lot of medical information about cancer by searching the Internet. A word of caution: There is a great deal of very helpful, reliable, factual information available on the Internet, but there also is a lot of information that is not accurate. It is important to be sure your sources can be trusted.

- ❑ **How do I search for cancer-related information on the Internet?** You can use a search engine to locate websites that are related to a topic you want to learn about. Some of the search engines used most are: www.google.com, www.yahoo.com, and www.bing.com. Define keywords as exactly as you can. For example, if you want to learn about the side effects of drugs to treat breast cancer, “breast cancer” would yield too many files to read, while “chemotherapy and breast cancer and side effects” may give you a more narrow selection. Be a wise consumer. Make sure that the information comes from a reliable source. Discuss the information with your doctor.

- ❑ **Where should I start to search for cancer information on the Internet?** New websites are constantly being created that provide information, resources, and support for people with cancer. You may want to start with the National Cancer Institute at www.cancer.gov or the American Cancer Society at www.cancer.org. The best sources of medical information will come from:
 - Well-known cancer organizations
 - Research centers
 - Hospitals
 - Libraries
 - Government agencies
 - Professional journals

Finding information you can trust is important. Learn about how to find the information you need with the free *Cancer Survival Toolbox*[®] *Finding Information* program. See the *Resources* section for ordering information.

CHOOSING A DOCTOR

“Although some patients argue that they are hesitant or are not qualified to check on a doctor, it seems folly not to make every effort to do so, especially when one considers the money that will be spent for the physician’s expertise and the fact, also, that one’s physical and psychological well-being is going to be entrusted to this person.”

—Paul A. Williams, M.D.
University of Missouri,

in *The American Cancer Society’s Cancer Handbook*

Choosing a doctor is an important decision. Be sure to think about at least these three areas when making your choice:

Training and Background

- How long has the doctor been practicing medicine (treating patients)?
- Is the doctor with a *group practice*, a *health maintenance organization (HMO)*, or in a *solo or individual practice*?
- What special training has the doctor had in treating the type of cancer you have?
- Does the doctor have a medical specialty (for example, *medical oncologist*, *radiation oncologist*, *general surgeon*, etc.)? If so, what is it?
- What is board certification?** A board-certified physician has passed difficult exams in one or more specialties. A physician who passes the exams of a given specialty is called a “diplomat” of that board and is said to be “board certified.” Sometimes there are good reasons why a skilled doctor hasn’t taken the time to become board certified. Yet, if two doctors appear “equal” in other respects, board certification shows that the doctor is viewed by his or her peers as being highly skilled in that area of medicine.
 - **Medical oncologists** can become board certified in medical oncology (a subspecialty of *internal medicine*).
 - **Radiation oncologists** can become board certified in the field of *therapeutic radiology*.
 - **Surgeons** can become certified by the American Board of Surgery in a number of subspecialties. There is no special board certification program for *surgical oncology*.

To find out about a doctor’s education, training, certification, and years in practice, you have several options:

- Ask the doctor directly
- Call the doctor’s office

- Call your local medical society or *osteopathic* medical association
 - Call your state board of medical examiners
 - Look in the **Directory of Medical Specialists**, which you can find in public libraries. A quick way to find out if a doctor is board certified is to call (866) ASK-ABMS or (866) 275-2267 during the normal workweek or look on the Internet at www.abms.org. You will need to know the doctor's full name and city. This is a free service of the American Board of Medical Specialties.
- If the doctor is in a group practice, you may want to ask these questions about the other doctors in the practice, since you may be seeing them from time to time.**

Practice Information

- What hospital(s) does the doctor use?** You may hear this called “having hospital privileges,” which means that the doctor can admit patients to that hospital and provide care to them.
- Which hospital does the doctor prefer? Why?**
- Does the doctor participate in *clinical trials* (tests) of potential new cancer treatments, or does someone in the group practice do so?** Many clinical trials are supervised by the National Cancer Institute, which urges patients to ask about this treatment option. For more on clinical trials, see page 37.
- During the past twelve months, how many patients has the doctor treated with cancers like to yours?** This question is important because usually it's better for you to be treated by a doctor who has a great deal of experience in treating your cancer type. Of course, you should consider how common your cancer is. For some rare cancers, it isn't likely that many doctors have treated more than a few cases during the past year.

Communicating with Your Doctor

- When is the doctor normally in his or her office?** List days and also hours of the day.
- How can you reach the doctor during evenings or on weekends?**
- Will the doctor answer e-mail?**
- Does the doctor mind if you record office visits to help you better understand explanations and instructions?** Sometimes it's helpful to record key discussions with your doctor so you can be certain you understand and remember what was said and follow instructions.

How will this doctor plan to communicate with your other doctors about your medical care and how you want it done? For example, if you have a close relationship with your family doctor, you may want your cancer doctor to keep him or her up to date on your treatment.

How will this doctor plan to communicate with loved ones involved in your care?

BACKGROUND INFORMATION AND STAGING

The Background Information and *Staging* sections of the cancer treatment plan like the one below list some basic information about your health and cancer diagnosis. This information will help you know exactly what type of cancer you have and should be filled out fully. The Staging section of the treatment plan provides more detail about your diagnosis, including any tests that may have been done to help your oncology team learn more about your cancer.

As you review this information with your doctor, keep in mind the following questions about *biopsies, diagnosis,* tests you may need or have had, and your health outlook (*prognosis*).

BACKGROUND INFORMATION		
Symptoms/signs:		
Family history/predisposing conditions:		
Major co-morbid conditions:		
Tobacco use: <input type="checkbox"/> No <input type="checkbox"/> Yes, past <input type="checkbox"/> Yes, current (If current, cessation counseling provided?: <input type="checkbox"/> Yes <input type="checkbox"/> No)		
Cancer type/location:		Diagnosis date: (__/__/__)
Is this a new cancer diagnosis or recurrence?: <input type="checkbox"/> New <input type="checkbox"/> Recurrence (date: __/__/__)		
Surgery: <input type="checkbox"/> None <input type="checkbox"/> Diagnosis only <input type="checkbox"/> Palliative resection <input type="checkbox"/> Curative resection		
Surgical procedure/location/findings:		
Tumor type/histology/grade:		
STAGING		
Study	Date	Findings
T stage: <input type="checkbox"/> T1 <input type="checkbox"/> T2 <input type="checkbox"/> T3 <input type="checkbox"/> T4 <input type="checkbox"/> Not applicable N stage: <input type="checkbox"/> N0 <input type="checkbox"/> N1 <input type="checkbox"/> N2 <input type="checkbox"/> N3 <input type="checkbox"/> Not applicable		
M stage: <input type="checkbox"/> M0 <input type="checkbox"/> M1 <input type="checkbox"/> Not applicable		Tumor markers:
Stage: <input type="checkbox"/> I_ <input type="checkbox"/> II_ <input type="checkbox"/> III_ <input type="checkbox"/> IV_ <input type="checkbox"/> Recurrence		Alternative staging system:
Location(s) of metastasis or recurrence (if applicable):		

BIOPSIES

Here are some questions to ask if your doctor says you need a *biopsy*:

- What type of *biopsy* do you recommend? Please explain it.**
 - Incisional biopsy: part of the tumor is cut out and looked at under a microscope.
 - Excisional biopsy: the tumor is removed totally.
 - Needle biopsy: a needle is used to extract either fluid or tissue for analysis under a microscope. This method is also called “aspiration *biopsy*,” and usually can be done as an *outpatient* with a minimal or local *anesthetic*.
- Who will perform the biopsy (a surgeon, *interventional radiologist*, etc.)?**
- Will the biopsy leave a scar? Where will it be? What will it look like?**
- After the biopsy, if there is a *malignancy*, how much time can I take to make up my mind on what type of treatment to have?**
- If I undergo general *anesthesia*, can you guarantee that you won't go ahead with surgery other than a biopsy, if that's my preference?** While this is often desirable to the patient, sometimes it's not possible. However, ask your doctor to explain when that might be the case.

DIAGNOSIS

Below are some questions you can ask about your cancer *diagnosis*:

- What test or examination indicated I have cancer?** While a doctor, such as a surgeon or internist, may suspect cancer, the actual diagnosis is made by a *pathologist*, a doctor specially trained to examine a tissue or blood specimen under a microscope.
- What type of cancer do I have, and what is its medical name?** For example, if the doctor says “lung cancer,” ask which type of lung cancer. Often there are different treatments for different types of cancer, even though they may occur in the same part of the body.
- Has cancer spread beyond the original site (the place where it started)?**

- If it has spread, where and how far has the cancer spread, and what test or tests identified the extent of the spread?**

- Will additional tests be necessary to determine the likelihood and possible location of any spreading?** Often it is unwise to begin cancer treatment until adequate testing has been performed to determine whether the cancer has spread beyond the original site. If this is the case, a different treatment plan may be recommended.

- What are the risks (both temporary and long-term) in having these tests?**

- Would you please explain these tests? When and where will they be done?**

- What will these tests show or indicate?**

- Would you please show me my medical records (the test reports/surgical notes) pertaining to the tests that have been completed and the operation that was performed?** Much of what your doctor tells you will be based on these records. Many patients are concerned that seeing their records will make them anxious, and they do not want to see them. Other patients feel they can participate more effectively as partners with their doctors by having this information. Due to the technical terms that commonly are used and the fact that often they are subject to interpretation, we suggest you ask your doctor to help you understand these records. Sometimes it takes time to get records from other sources. Work with your doctor's office to figure out a reasonable time for getting the documents.

- What stage is the cancer in? How was this determined?**

- What resources (printed materials, videos, computer resources, hotlines, or organizations) are available to help me learn more about the type of cancer I have and to help me cope with the disease and its treatment?** You may also want to ask a nurse or hospital social worker about available resources. Also, refer to *Resources* starting on page 65.

TESTS

We are now learning that there are many types and subtypes of cancer. Tests have become more and more sensitive to these different types, and care is being more tailored to each person based on the biology of his or her cancer. These questions will help guide your discussion with your doctor about which tests you may need.

General Questions About Your Tests

- How reliable are 1) the tests that were already performed, and 2) the tests planned for the future?** You may want to know the range of accuracy for specific tests. That is, how often are the results correct — every single time the test is done, or less? Should the test be repeated to confirm its accuracy before treatment is begun? A test may be less than 100% accurate due to a number of factors. Doctors often must use their individual judgment when interpreting test results, and sometimes the tests must be repeated.
- Are there any *tumor markers* for the type of cancer I have? Will you use tumor markers to decide if my treatment is working well?**
- What are the tests I need? What do they do? How will the testing impact me?**

Questions about Specific Tests

- Would you please explain the test.**
- What will the test show or indicate?**
- Does my insurance company have to approve this test before it is done?** Some companies will not pay for a test unless you have gotten prior approval.
- When and where will the test be done?**
- How long will I be there for the test? Will I be able to drive myself home after the test?**
- Will the test hurt or be uncomfortable? Can you do anything to prevent or lessen the discomfort?**
- What are the risks (both short and long-term) in taking the tests?**
- Are there any special instructions I should follow before or after the test?** For example, should I stop taking my prescription or over-the-counter medicines prior to the test? Should I refrain from eating or drinking for a certain amount of time before the test?

- What are the most likely complications (problems) that could occur during or after the test? If a complication occurs, what symptoms should I look for and what should I do?
- How long will it be after the test before I can go back to doing my usual activities?
- How can I learn more about this test?

Test Results

- When will I find out the results of the test? Will someone call me at a specific time, or should I arrange to call someone?
- Would you please show me the test results? Although many patients don't care to see test reports, some do. It's best to have your doctor explain what the medical terms mean.

HEALTH OUTLOOK (PROGNOSIS)

“What are my chances, Doctor?”

...may be the most frequently asked question and the one that is most emotionally charged...

Overall statistics...do not really apply to the individual — because each person is a ‘series of one’ and whatever the outcome is, it will be 100 percent for that patient. So statistics can be useful only as generalized guidelines, never as absolute end results...”

—John Lazlo, M.D.,
Former Senior Vice President for Research
American Cancer Society,
in Understanding Cancer

Prognosis is defined as a prediction of what might happen in a specific case of disease. Many patients want to know their odds of beating cancer. It is okay to ask. It is also okay to not ask. The usual way a doctor gives an opinion on your health outlook is in percentages or by past experience. But different people react differently to a disease. Your body, your goals, your will to live, the treatment tailored to you, and other factors are unique to you. Your situation has its own prognosis, which no one can give you precisely. Doctors can tell you the outcome of other patients, but your individual “story” is still being written.

If a doctor tells you that your illness is terminal, ask questions to make sure you understand. It could mean one of three things:

1. The doctor may not know all there is to know about treating every kind of cancer (there are over 100 types). This is not to discredit your doctor. But there may be other specialists who know of a treatment that may help you. (See *Second Opinions* bullet on page 36.)
2. Your doctor may have decided that it is unlikely that additional treatment would help you. He or she may have decided for you that you should not be put through more tests, operations, or other treatment. The doctor may honestly believe that the chances you will improve are very small, perhaps compared to the risks and discomfort they would cause. However, this is a decision that you should be allowed to make, if you so desire. Some patients stop treatment sooner than others, and some doctors stop treatment sooner than others.
3. Your doctor concluded that there is nothing more that he or she can recommend for treatment. Again, you may want to seek other opinions. If you choose, you have the right to explore every option for finding effective medical treatment. It is a personal decision that may be different than what others would do.

COPING WITH A DIAGNOSIS

Once you have worked with your doctor to create your treatment plan, it is important to consider other emotional issues that are common for people with a cancer diagnosis. These issues can affect how you feel and how you cope with your illness.

EMOTIONAL ASPECTS OF CANCER

Cancer is an emotional roller coaster. At first you might not know how to think about your cancer, how to make choices about your treatment, or even how to begin to imagine living with a disease like cancer. As hard as it is to believe, you will adjust to living with, through, and beyond your cancer.

- ❑ **What are the most common emotions that accompany cancer?** Four of the most common emotions that accompany cancer are fear, anxiety, anger, and depression.
- ❑ **How can I manage my fear?** Information is probably the best defense against fear. You need to understand that there are many myths about cancer. For example, it is a myth that cancer is an automatic death sentence. There are more than 12 million cancer survivors alive today, and over 62% have lived for more than five years since their cancer diagnosis.
- ❑ **How can I keep my anxiety under control?** While feelings of anxiety are normal during many parts of the cancer experience, most cancer survivors rank diagnosis of their cancer as the most upsetting and anxious time. A diagnosis of cancer is a shock, and often people first react with denial —“it can’t be true” or “this can’t be happening to me.” You may not know how to think about your situation or how to plan for the future. Remember that over time you will become an expert on your own illness and treatment and that you will gain the coping skills that you need in times of crisis. Eventually, the disbelief and anxiety you feel will give way to adjusting to life after cancer.
- ❑ **How do I express the anger I am feeling about my cancer diagnosis?** Again, anger is a normal response to cancer and the effects that it has on your life. A cancer diagnosis may require you to alter plans and to change dreams. It may interfere with your work life and your relationships. It would be unusual if you didn’t feel some anger. The key is to express your anger in a positive way. Some people find talking to a counselor, a good friend, or a support group helpful. Others join an online chat room. Still other people find it helps to write about their anger or to paint or draw or use some type of creative outlet to lessen it. You need to guard against “misplaced” anger. This occurs when you take your anger out on your family, friends, doctors, or others who are not really the cause of your anger. If you are feeling angry, let others, especially your caregiver, know so they can be aware.

- ❑ **What do I do if I am depressed?** The depression felt by people who have been newly diagnosed with cancer is called reactive depression and it is different from that of people suffering from chronic mental depression. It is a natural way to cope with shock, and it most often is fairly short-term. To lessen your depression, understand first that it is normal. Allow yourself some time to get used to cancer-related losses such as the loss of control you may be feeling, or the loss of a body part or hair or the loss of self-image. Take an active role in your treatment plan and refuse to be helpless. You might also ask your health care team about speaking with a counselor or finding a support group to help you through this difficult time.

The emotional distress that cancer causes can take many forms. Anxiety, anger, depression, and frustration are all quite common. Cancer specialists use the Distress Thermometer to help them measure the emotional impact of cancer on survivors. If you are experiencing emotional distress from your cancer, it is very important to know that help is available, and to go get the help you need. The Distress Thermometer may help you describe the way you are feeling to your health care team.

- ❑ **Will my family also face emotional problems due to my cancer?** A family is a social system, and changes in one part of a system cause change in other parts of that system. Therefore, a diagnosis of cancer for one family member will have significant effects on all other family members. During your diagnosis, your family will face many challenges. The prolonged stress of cancer can have a negative effect on even the strongest and closest family. Communicating openly and expressing feelings within the family are crucial to creating a healing environment and helping one another gain the strength needed to deal with the crisis of cancer.

The emotional distress that cancer causes can take many forms. Anxiety, anger, depression, and frustration are all quite common. Cancer specialists use the Distress Thermometer to help them measure the emotional effects of cancer on survivors. If you are experiencing emotional distress from your cancer, it is very important to know that help is available, and to go get the help you need. The *Distress Thermometer* may help you describe the way you are feeling to your health care team. Learn more about maintaining hope in the free booklet, *You Have the Right to Remain Hopeful*. See the *Resources* section to learn how to order your copy.

MAINTAINING HOPE

“Hope and hopelessness are both choices. Why not choose hope?”

—Greg Anderson

The Cancer Conqueror

- ❑ **What is hope?** Hope is a way of thinking, feeling, and acting. It acts as a protective mechanism and it is essential for managing and adjusting to an illness as serious as cancer. Maintaining hope in the face of cancer is not always easy. At times of crisis you may need extra support and assistance from your family, your friends, and your health care team.
- ❑ **Do people hope the same way?** Many people have never thought much about the role that hope plays in their lives. You may never have thought about how you hope or how you learned to hope. Yet research tells us that people hope very differently and that our personal hope is affected by a number of social factors including the way our family hopes.
- ❑ **What are the different ways to hope?** Families have well-established ways of hoping. Your family hope pattern contains your family values and norms regarding hope, and the ways that you maintain hope. For example, one family might use a religious or spiritual basis for their hope. As a result, statistics and medical facts may not be very important for them because they believe God will decide the outcome. Another family may use information as a basis for their hope. Their approach to hoping leans more toward fact gathering. They read about cancer and its treatment. They seek second, and even third and fourth opinions. For them, information equates with control and hope.
- ❑ **What is the best way to hope?** No one hoping pattern is the best or most useful. What is important is that you recognize how you and your family think about hope and what methods you use to maintain hope. You need to be direct with your family, friends, and health care team about what is not helpful to you with regard to using and maintaining hope. Everyone might not feel as hopeful as you feel. Remember that you have the right to decide for what, when, and how you hope.
- ❑ **Is it best to keep hoping for a cure, no matter what my situation?** Hope related to cancer is broader than just the desire for successful treatment and control of disease. Hope has many dimensions. It changes over time as situations and reality change. For example, when first diagnosed with cancer, you hope for a cure. If you have a type of cancer that cannot be cured, you may have to shift your hope to control — long-term control. Even if hope for long-term control dims, you can find other things to hope for. Perhaps you are hoping to have a family reunion, or hoping to see a child graduate from college, or hoping to welcome the birth of a grandchild. There is always something to hope for, and it is important to choose hope.

Learn more about maintaining hope in the free booklet, *You Have the Right to Remain Hopeful*. See the *Resources* section for ordering information.

TREATMENT OPTIONS

Your treatment options will depend on the type and stage of your cancer and on what is important to you. Before making a decision about which treatment is right for you, discuss the questions below with your doctor. It is important to make sure you understand your treatment options, the possibility of enrolling in a clinical trial, and whether surgery is necessary.

Cancer care planning is a way to help you understand your treatment options and discuss your needs and concerns with your doctor and what is important to you with your doctor. You can work with your doctor to create a treatment plan like the one included in this booklet. This plan will help you if your treatment needs to change, when you transition off of treatment, and when you visit other doctors.

Making decisions can be difficult, but you can learn decision-making skills with the free *Cancer Survival Toolbox*[®] *Making Decisions* program. See the *Resources* section for ordering information.

ASKING ABOUT TREATMENT OPTIONS

NOTE: Also see separate *Clinical Trials* section of questions, which begins on page 37, and the section on *Surgery* that follows this section.

- What treatment options are available considering the type and extent of my cancer, my age, and my lifestyle?** Also, the National Cancer Institute (NCI) Cancer Information Service can provide you with information on treatment options. For details, see the *Resources* section, which begins on page 65.
- Are there any treatments, such as chemotherapy, that can be given in my own home?**
- Are there new treatments that might be good for me to consider?**
- Which treatment option(s) do you recommend? Why?**
- What is the goal of the treatment?** *Possible goals:*
 - Control growth of the tumor
 - Cure or eradicate (destroy) the disease
 - Increase comfort level through palliative care (reduce pain, stimulate appetite, increase energy level)
 - Shrink the tumor so it can be treated by other means
 - Prevent complications such as bleeding, pressure, or blockage of a vital organ

- How familiar is the doctor with treating this cancer?**
- What types of doctors do you foresee being involved in treating me?** The National Cancer Institute recommends that diagnosis and treatment of cancer patients often may best be managed by a multidisciplinary team of doctors. This concept recognizes that effective cancer treatment often is a very complex task that requires not just a single doctor and a single medical specialty, but the team effort of doctors representing several types of medical skills. This team may consist of a medical oncologist, a surgeon, a radiation oncologist, sometimes referred to as a radiation therapist, and oncology nurses, social workers, pharmacists, dietitians, and rehabilitative specialists.
- What role will *complementary and alternative medicines* play in my care?**
- It would be helpful for me to talk with someone who has been treated for this kind of cancer. Can you arrange that for me?**

Questions About Each Treatment Option:

Once you have learned what treatments are available to you, you can use the questions below to learn more about each treatment option.

- Would you please explain what the treatment is?**
- What are the short-term and long-term risks?**
- How long will I be in this treatment (how many weeks or months)?**
- How often will I take the treatment (once a day, once a week, etc.)?**
- What are the skills and training of the staff who will give the treatment?** For example, nurses giving chemotherapy should have had special training to safely give this type of treatment, and to recognize and treat potential problems. Many cancer nurses have OCN — oncology certified nurse — after their names. This means they are specifically trained and have passed a rigorous test in the field of cancer care.
- How and when will you be able to tell if this treatment is working as intended?** This is often a difficult question to answer. For example, in many cases where radiation therapy or chemotherapy is given, follow-up tests can be done in order to see if any cancer cells can be detected. It is a good sign if the tests are negative (there is no evidence of cancer cells), although there is no guarantee that the cancer will never return.
- How can I learn more about this type of treatment?**

Possible Side Effects

- What are the treatment side effects? Will they be:**
 - Short-term (how long will they last?)
 - Long-term (will I need *rehabilitation*?)
 - Late or delayed (what might be a problem in the future?)
- Will the treatment hurt or be uncomfortable?**
- What can be done to prevent or lessen the discomfort?**
- Will *palliative care* start right away? What can I do to prevent or lessen the side effects?** Examples include:
 - Medication (If medication to treat the side effects is available, will it be helpful to take it before the side effects begin?)
 - *Meditation*
 - *Visualization*
 - Prayer
 - Self-hypnosis
 - Nutrition support or changes in eating habits
 - Exercise

NOTE: Many doctors may not have personal experience with some of these and understandably may need to refer you to those trained and experienced in using them.

- Should I have a dental checkup before my cancer treatment begins? Is there any risk in having dental exams during treatments?** A dental exam may find possible sources of infection that might pose serious problems for people taking chemotherapy, and, in some cases, when radiation therapy is given to the head or neck. There also are special dental treatments that help to protect your teeth when you receive cancer treatment.

Possible Infections or Complications During Treatment

- Will the treatment make me prone to infections?** Some chemotherapy drugs suppress bone marrow functions and thus may make you more prone to serious infections.
- During chemotherapy or radiation treatments, what should I do if I have symptoms of possible infection?** Since these treatments can cause the *white blood cell* count to drop and thus increase the risk for infection, be aware of these symptoms:
 - Sore throat
 - Runny nose
 - *Sputum* production

- Diarrhea,
- Burning feeling when urinating
- Muscle aches
- A sore or cut that is red, will not heal, or drains pus
- Fever higher than 100° F

- What should I do about these symptoms?**
- What side effects should I report to you during or after treatment?** For example, temperature higher than 100° F (38° C), nausea, and vomiting?
- What are other possible complications (problems) that could occur during the treatment?** For example, infection, bleeding, *anemia*?
- How will I recognize them, and what should I do?**

Other Possible Treatment Side Effects

- How will this treatment affect any other medical problems I now have or medication I am now taking?**
- How will the treatment affect my ability to work or perform other activities that are necessary or important to me?**
- Will the treatment affect my emotions or sex life? If it will, will it be temporary or permanent?** See the sections in this booklet on *Emotional Aspects of Cancer* on page 29, and *Sexuality* on page 52.
- Will the treatment affect my ability to have children?** See separate section on *Fertility* on page 53.
- Will the treatment cause any temporary or permanent personality change?**
- If I take this treatment, what will my quality of life be like during and after treatment?**
- Will the treatment leave a scar or a permanent skin discoloration?**

Taking Care of Yourself During Treatment

- What will be done to monitor my nutrition and help me maintain good nutrition during treatment? Would vitamin supplements or other nutritional support be helpful?** Nutrition is a very important but often neglected subject. Cancer survivors, in particular, must maintain good nutrition in order to withstand cancer treatment and keep

their immune systems as strong as possible. Often, a registered dietitian or oncology nurse can be very helpful.

- Is there any need to restrict my diet or fluid intake (including alcohol)?**
- What should I do if my appetite decreases or if I have problems swallowing during treatment?**
- Under what conditions should I avoid being in contact with people who have contagious illnesses?** A low white blood cell count increases your risk of infection. You may be told to avoid people with colds, the flu, measles, or chickenpox, or to avoid large crowds of people.
- What other precautions should I take depending upon my blood count levels?**

After Treatment

- After treatment ends, what medical care will I receive to determine whether the cancer recurs or spreads in the future? How often should I be checked for possible recurrence?**

Getting a Second Opinion

- Should I get a second opinion?** Requesting a second opinion does not mean that the initial diagnosis is wrong or that the suggested treatment is not the best. Rather, you have the right to hear about all possible treatment options. Most doctors will not be offended if you chose to get another opinion, and some health insurance plans even require a second opinion. The doctor may not know all there is to know about treating every kind of cancer (there are over 100 types). This is not to discredit your doctor. But there may be other specialists who know of a treatment that may help you.

You may want to seek a second opinion and/or call the Cancer Information Service (CIS) to request a “Physician Data Query” (PDQ), which will give you information on the latest cancer treatment being used for your cancer. Study the PDQ printout you receive with your doctor. The CIS can also provide information on what are called *“comprehensive cancer centers.”* Comprehensive cancer centers are recognized by the National Cancer Institute (NCI) as leaders in research and treatment of cancer. The CIS also can give you information on what are called *“clinical trials”* of potential new cancer treatments. Many clinical trials are supervised by the National Cancer Institute, which urges patients to ask about this treatment option (see below). The CIS can be reached at 1-800-4-CANCER nationwide, during the work week. It is sponsored by the National Cancer Institute.

If you receive a second opinion that is different than your doctor’s opinion, you will have to decide about which opinion you believe is best in your situation. Understanding which opinion is backed by the latest research might help you decide.

**“I’ve taken care of cancer patients for a long time.
I have never taken care of a doctor who didn’t get a second opinion.”**

—*Vincent T. DeVita, Jr., M.D.,
Former Director, National Cancer Institute,
as quoted in **Fighting Cancer** by Annette and Richard Bloch*

CLINICAL TRIALS

- ❑ **What is a *clinical trial*?** A clinical trial is a research study conducted with cancer patients, most often to evaluate a new treatment. Clinical trials help us find out if a promising new treatment is safe and effective for patients. Patients in a clinical trial are among the first to receive new research treatments before they are widely available. You will be given a written consent form that will have important information about risks and benefits of taking part in a trial.
- ❑ **Why are patients interested in clinical trials?** There are many reasons patients take part in clinical trials. They may be hoping the treatment will cure their disease, or extend their life, or contribute to a research effort to help others. Although there is always the chance that a new treatment will be disappointing, the researchers involved in the study have reason to believe that the treatment will be as good as, or better than, current treatments.

A clinical trial may be the only therapy option for patients who have not responded to other treatments or for whom no other treatment exists.

- ❑ **Are there risks involved in taking part in a clinical trial?** Yes, there are risks involved in clinical trials. There may be side effects and other health risks depending on the type of treatment. Before taking part in a clinical trial, your doctor will tell you what side effects you can expect, and, as much as possible, about what is unknown or uncertain about the treatment side effects. It’s important to keep in mind that standard treatments also cause side effects and risks.
- ❑ **Can anyone take part in a clinical trial?** No. Each study only enrolls patients who fit certain criteria or guidelines. It will depend on what research questions the study is trying to answer and whether or not you are a good fit for the study. This will depend upon your type and stage of cancer and your health status.

- What else should I know about clinical trials before I decide to enroll in one?** The National Cancer Institute (NCI), the Federal government's chief agency for cancer research in the United States, suggests you ask the following questions before making a decision about taking part in a clinical trial:
- What is the purpose of the study?
 - What does the study involve?
 - What kinds of tests and treatments are involved and how are they done?
 - What are the other choices and their advantages and disadvantages? Are there standard treatments for my case and how does this study compare with them?
 - Will the study affect my daily life? If so, how?
 - What side effects and risks will I have?
 - How long will the study last?
 - Will I have to be in the hospital? If so, how often and for how long?
 - Will I have any costs? Will any of my treatment be free?
 - If I am harmed as a result of the research, what treatment would I be entitled to?
 - What type of long-term follow-up care is part of the study?
- How can I find out about clinical trials?** First, talk with your doctor and get the opinion of cancer specialists. A treatment system called Physician Data Query (PDQ) is supported by NCI and it can give your doctor the latest information about what clinical trials are being offered around the country for different types and stages of cancer. Or, you can call the Cancer Information Service (CIS) to request a search for yourself at 1-800-4-CANCER (1-800-422-6237). You can get information in both English and Spanish. You also can find clinical trials information on the Internet at: www.clinicaltrials.gov or www.cancer.gov/clinicaltrials or www.cancertrials-help.org.
- Do I have to enroll in a clinical trial if my doctor suggests one?** No. Taking part in a clinical trial is strictly voluntary. Before you begin, you will be asked to sign an *informed consent* document stating that the research, its risks, and its potential benefits have been explained to you and that all of your questions have been answered.
- If I start a clinical trial, do I have to finish it?** No, you are free to leave the study at any time. Leaving a trial will not be held against you by your health care team.

SURGERY

“The most important discussion may be the hardest.

It is the one where you must challenge the need for the surgery. To do this, you must ask why it is necessary and whether there are any non-surgical alternatives. If not, ask whether other surgeons use different procedures to accomplish the same purpose. Ask the surgeon to describe exactly what he will do, so that you understand each step.”

—Lawrence C. Horowitz, M.D.

Taking Charge of Your Medical Fate

Below are some questions that you may want to ask your surgeon:

- Would you please explain the goal for this surgery and why you feel surgery is necessary for me?**
- Are there any non-surgical treatment options? If so, how do the potential benefits and risks of the two (the surgical and the non-surgical) compare?**
- Is there a less invasive way to do this surgery?** For example, a vaginal hysterectomy rather than an abdominal one.
- What will you do during the surgery? Can you show me a diagram or illustration to help me to understand it better?**
- How many of these operations have you performed during the past twelve months?**
This question is important because with many operations — especially more complex ones — you are in better hands with a surgeon who has performed it many times, has become highly proficient at it, and is experienced in dealing with possible complications during the surgery.
- What were the results?**
- How familiar is the surgical team with this type of surgery?** Just as with the surgeon, the hospital surgical team should be highly skilled with this type of surgery. The skill level often comes with performing the surgery many times — not just with your surgeon, but with others as well.
- Will the surgery leave a scar? Where will it be? What will it look like?**
- Will it be possible to have reconstructive or corrective surgery either at the time of the original operation or at a later date if I choose to do so?** For example, with breast cancer:
 - What are my options for timing the reconstructive surgery?
 - What types of reconstruction can be done?
 - What reconstruction techniques are possible with my body type?

- What techniques fit with my lifestyle?
- Will the general surgeon work closely with the plastic surgeon? Most surgeons suggest a consultation with a qualified plastic surgeon before the breast surgery is performed.

UNPROVEN METHODS

“Optimistic pessimism’ is probably the best approach when the odds don’t look good.

Hope for the best, but prepare for the worst.”

—Grace Powers Monaco, J.D.

Founder, The Candlelighters Childhood Cancer Foundation

Some people who are offered little hope through standard medical treatment turn to unproven methods of curing cancer. The term “unproven” means that these methods haven’t been scientifically proven by medical research. There have been many unproven methods hailed as cancer cures. Your public library or bookstore will have some books covering details of some of these methods. If you consider an unproven method, it will be tempting to accept everything you read as truth because you want to be cured. But just as when using proven medical treatment, remember that, as a consumer, you have the right to try to question or consider any unproven method. Some unproven methods, while not effective in treating cancer, aren’t harmful. In fact, they may have some benefit in terms of giving you a sense of control or a better outlook. Some of these methods include *complementary and alternative medicines*.

Other unproven methods may actually be dangerous.

There’s a distinction between unproven methods that claim to cure cancer and certain programs intended to improve your quality of life. Some dietary plans can improve your body’s ability to cope with cancer treatment. Some other programs, such as imagery, self-hypnosis, and biofeedback may also help improve your quality of life. However, none of these techniques has been proven to cure cancer. In the case of so-called “revolutionary” nutritional approaches, ask a registered dietitian to give you an opinion on their soundness.

If you are considering an unproven method, you may want to ask the following questions:

- The key question for any treatment — either a proven one or an unproven one — is the same. Has this method been shown through unbiased research to be of possible benefit for the condition you have?**
- What is the treatment supposed to do?**

- Has the method been reviewed in respected medical journals? If so, what did the reviews say? If the method hasn't been reviewed in any recognized medical journal, why not?**

- What are the background and training of the person who “discovered” or is promoting this treatment?** Many unproven methods are offered by doctors with unrecognized degrees such as:
 - N.D. [Doctor of Naturopathy]
 - Ph.N. [Philosopher of Naturopathy]
 - DABBA [Diplomate of the American Board of Bio-Analysts]
 - Ms.D. [Doctor of Metaphysics]

- Does it sound too good to be true?**

- Will the person giving the treatment be willing to work as a partner with my medical doctor?**

- Does my doctor believe this method could be harmful?**

COST AND INSURANCE ISSUES

Knowing your insurance plan and the costs of medication may be helpful in choosing which treatment options are best for you. Sometimes you may need to work with your insurance company to make sure certain treatments are covered (paid for) under your plan. Chemotherapy can be costly, but there are many resources that provide financial aid. See the Resources section for a list of helpful organizations that can help you find resources like co-pay assistance programs or financial counselors.

NOTE: The *Glossary of Insurance Terms* beginning on page 76 may be useful as you read this section.

Find out about available financial assistance with the free *Cancer Survival Toolbox*[®] *Finding Ways to Pay for Care* program. Understand your insurance plan by reading the free booklet, *What Cancer Survivors Need to Know About Health Insurance*. See the Resources section for ordering information.

COSTS/INSURANCE COVERAGE

Many people have questions about how their health insurance works and how to find out if your cancer care needs will be paid for:

- How much of the costs of my care will be covered by my health insurance or by Medicare or Medicaid?**
- Will I have to bill the insurance company, or will someone do it for me?**
- If my insurance company refuses to pay my claim (bill for services), how can you help me convince the company that my medical treatment is covered by my policy?** In most cases, the best way to get an insurance company to reconsider your claim is for your doctor to provide a letter and medical data on why your treatment is appropriate. You can obtain a copy of *What Cancer Survivors Need to Know About Health Insurance*, a publication of the National Coalition for Cancer Survivorship. (See Resources section on page 65.)
- If I am unable to pay for chemotherapy, can you help me enroll in a patient assistance (indigent patient) program?** Some drug companies provide free chemotherapy drugs to physicians who are treating patients who are unable to pay for the drugs.
- I'm not sure if I have enough insurance coverage or financial resources for this treatment at the present time. Can I work out a payment plan with you?** Some patients are more comfortable asking this question to the doctor's office manager, although many doctors are accustomed to seeing these financial concerns arise.

MANAGED CARE

Over half of Americans who have insurance are members of *Managed Care plans*, which include *health maintenance organizations (HMOs)*, *preferred provider organizations (PPOs)*, and *point-of-service plans (POSs)*.

- ❑ **What is *managed care*?** Managed care is an approach to health care that takes the cost of services into account. Its goal is to provide high-quality health care at a *reasonable* cost. Managed care plans provide services (treatment) to their members (patients) through a network of doctors, hospitals, laboratories, and pharmacies that are selected by the plan and under contract to work with the plan. There are many types of managed care (see the *Glossary of Insurance Terms* starting on page 76).
- ❑ **What is a “*gatekeeper*” and how can such a mechanism affect my care?** Managed care is centered around the primary care physician, usually your family doctor or *internist* or *pediatrician*. This doctor provides most of your routine care, and controls your access to other doctors (specialists). Therefore, the primary care doctor is referred to as a “gatekeeper” for your care.
- ❑ **What is a *case manager*, and do I need one?** A case manager is a person hired by your local insurance plan or hospital to monitor your ongoing care. It is often in the best interest of a cancer survivor to ask for a case manager to oversee their care. This ensures that there will be a person familiar with your case and care. Ask the case manager for his or her direct phone number, pager number (if they have one), and, if needed, a cell number to call outside of normal business hours.
- ❑ **What kinds of problems do survivors have with managed care?** Sometimes the plan or your primary care doctor declines to refer you to a specialist because they decide the specialist’s care is not medically necessary. Or, the plan refuses to pay for a certain test or treatment, especially if they consider it to be experimental or unproven. Sometimes the doctor you’re used to seeing is not under contract to the managed care plan, and his or her services are not paid for by your plan.
- ❑ **What should I do if I have trouble getting my care paid for by my managed care plan?** To be most satisfied with your managed care plan, you will need to take an active role in working with the plan. You should make sure you are getting all of the benefits you are entitled to under your plan. To make sure your claims are paid fairly:
 - Send in your medical claims promptly.
 - Keep copies of all paperwork.
 - Make sure that you follow the insurance company’s rules, such as whether you must call a toll-free number before you go to the hospital.
 - *Appeal* (ask the company to reconsider) every time the company does not pay a health claim that is covered by the policy or does not pay as much as you think it should. You do not have to take “no” for an answer. *Always:*

- Send the claim back with a letter explaining why the treatment was necessary and why your doctor's charges were reasonable. Keep a copy of the letter for your records.
- If the company rejects your claim again, ask that a doctor, instead of a clerk, look at your claim. Send it back with a letter that says, "I would like to request a review of this denial of coverage by the peer review physicians."
- If you call your insurance company, always get the name of the person you speak with and keep notes of what he or she tells you.
- If the company still rejects your claim and you believe they are wrong, get the help of a state or federal agency, social worker, cancer support group, or an attorney.
- Don't give up.

TREATMENT PLAN

Once you have discussed treatment options with your doctor, it is important to understand what medicines, or chemotherapy, will be used. For each medicine, you should understand what it is, how to take it, what the side effects are, and how side effects will be managed. The Treatment Plan part of your Cancer Care Plan will allow you to see the roadmap for your treatment.

TREATMENT PLAN				TREATMENT SUMMARY	
<i>White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy</i>					
Height:	in/cm	Pre-treatment weight:	lb/kg	Post-treatment weight:	lb/kg
Pre-treatment BSA:	Treatment on clinical trial: <input type="checkbox"/> Yes <input type="checkbox"/> No				
Name of chemotherapy regimen:					
Chemotherapy start date: (__/__/__)			Chemotherapy end date: (__/__/__)		
Chemotherapy intent: <input type="checkbox"/> Curative, adjuvant or neoadjuvant <input type="checkbox"/> Disease or symptom control					
ECOG performance status at start of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4			ECOG performance status at end of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4		
Chemotherapy Drug Name	Route	Dose mg/m ²	Schedule	Dose reduction	# cycles administered
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
Major side effects of this regimen: <input type="checkbox"/> Hair loss <input type="checkbox"/> Nausea/Vomiting <input type="checkbox"/> Neuropathy <input type="checkbox"/> Low blood count <input type="checkbox"/> Fatigue <input type="checkbox"/> Menopause symptoms <input type="checkbox"/> Cardiac <input type="checkbox"/> Other					

© 2011 American Society of Clinical Oncology. All rights reserved.

Use the following questions to guide your conversation about your treatment plan.

MEDICATIONS

NOTE: In addition to your doctor, your oncology nurse or pharmacist are good sources of information on the questions below.

- What is the medicine supposed to do?
- How and when will I know if it is working?
- How often and at what times should it be taken?
- Does it matter whether I take it before or after a meal?
- Are there certain liquids or foods this medicine should not be taken with?

- Should I take all of the medicine, or stop when I feel better?
- What if I forget to take the medicine?
- Are refills approved for this prescription? For what reasons should I get it refilled?
- Will this medicine create problems with the other prescription or over-the-counter medicine (or vitamins, herbs, or minerals) I'm already taking?
- Are there any special instructions?
- Can I take the generic drug version of this prescription and expect to get the same results?
- Can I take my chemotherapy medicine orally? Is it the same as other types of chemotherapy?
- Is there any printed material about this drug that I can read?
- If I have trouble swallowing the pill, can it be chewed or crushed? If it cannot be chewed or crushed, does it come in another form such as a liquid or patch?
- Is there someone to help me set up a system ensure that I take my medications on time and according to directions ?

PAIN RELIEF

**“I am not so much afraid of dying of cancer
as I am afraid of suffering in pain.”**

*—Debra Thaler-DeMers,
Cancer Survivor and Oncology Nurse*

**“Pain is whatever the experiencing person says it is,
existing whenever the experiencing person says it does.”**

*—Margo McCaffrey, R.N., M.S.,
Consultant in the nursing care of patients with pain*

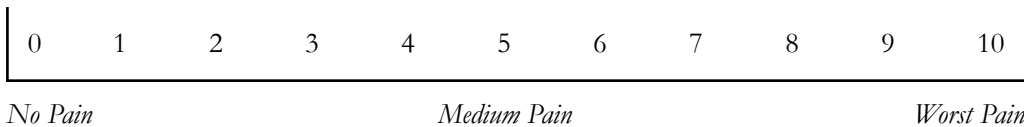
Pain may be caused by the cancer itself, by the treatment, or by the side effects of the treatment. Most pain experts agree that 90-95% of all cancer-related pain CAN be successfully treated. Patients and health care professionals can work as a team to manage pain and discomfort.

Many patients have questions about managing pain, such as those below:

- ❑ **I've heard that pain is a part of cancer. Should I just try to learn to live with it?** Living with pain decreases your overall quality of life. It may make you depressed or less active. You may have trouble sleeping or working or spending time with family and friends. You may wrongly equate your pain with advancing cancer and begin to feel hopeless. Because you need all of your energy to get through your cancer treatments, you should seek out ways to reduce or relieve your cancer pain.
- ❑ **Will I experience pain during the course of my treatment?** Many cancer survivors will go through treatment without ever having pain. Others may have pain that is related to the tumor itself, surgery to remove the tumor, or from the tumor's effect on another part of the body, such as a bone or pressure on a nerve.

Describing Pain

- ❑ **What will the doctor or my health team need to know about my pain?** They will need to know where your pain is, how much pain you feel, and what your pain feels like. They also will want to know what helps the pain and, if you are already being treated for the pain, how well the treatment is working.
- ❑ **Isn't pain hard to describe to someone else?** Yes, pain is hard to describe, but you are the only one who can tell how much pain you are in, and you are the only one who can best help your doctor or nurse understand your need for pain control. You can describe your pain in many ways. You can use a number scale from 0 to 10, with 10 meaning the worst pain (see pain level scale below).



You also can use words to describe your pain (for example, mild, moderate, or severe, or the worst pain you have ever felt). Try to think of words to describe the pain you are feeling. Is it a tingling, a stabbing pain, an ache, or a throb? Write down the words that describe your pain so you will remember to use them when you see your doctor.

Pain Medicines

- ❑ **What types of medicine are available to relieve my pain?** The type of pain reliever prescribed depends on the type and cause of pain. Your doctor will determine which medication is likely to best work to control your pain. Pain that changes during the day may respond best to oral pain relievers. Constant pain responds well to pain medicines that are given in a steady dose, such as a slow-release tablet or a skin patch that lasts up to three days. For chronic pain, medications need to be taken at regular time intervals, both day and night.

- ❑ **Are there any risks in taking the medicine you are prescribing?** You should not take any over-the-counter medicines, herbs, or health supplements without telling your physician. Some medicines interact with each other or with non-prescription medications or herbs. If you have more than one doctor who prescribes medicine for you, each doctor should be aware of all the medications, herbs, or supplements that you are taking. It is important that your physician know if you plan to consume alcohol, including beer or wine, while taking any medicines prescribed for you. Alcohol interacts with many medications. Your physician will advise you whether it is safe to drive or operate machinery when taking your medication.
- ❑ **What are the side effects of these medicines and can you lessen or control the side effects?** Some of the common side effects of pain medication are drowsiness, nausea, vomiting, and constipation. Your doctor, nurse, or pharmacist can advise you of the side effects for the medications prescribed for you and ways to reduce or control these side effects.
- ❑ **Are there things I can do to relieve my pain without taking medicine?** Pain is most often treated with medicine, but other treatments may be added to your treatment plan if needed. Sometimes *radiation therapy* is used for pain control. Treatment may include procedures such as *nerve blocks* or surgery. Other types of treatment include rest, hot or cold packs, massage, *guided imagery*, *acupressure*, *cutaneous stimulation* (such as a *TENS* unit) or techniques such as *biofeedback*, relaxation therapy, music therapy, or hypnosis. Your doctor and nurse will recommend the pain control plan that works best for your pain. If it is not successful, insist on trying other ways to control your pain.

Getting the Best Relief from Pain

- ❑ **The doctor said to take my pain medicine whether I had pain or not. Why shouldn't I save them to use in case the pain gets worse later?** This is a mistake that many patients make. The main goal of pain relief is to get the pain under control and prevent it from coming back. This can best be done by taking your pain medicine as it is scheduled whether you have pain at that moment or not. Taking your medicine as prescribed allows each dose to become effective before the previous dose wears off. Taking pain medicine on a regular basis leads to better pain control. In fact, you may use a lower total dosage of medication than you would if you only took medicine when the pain comes back and is more severe.
- ❑ **If I take too much pain medicine, won't I become used to it?** Your body may get used to a certain medication. This is called *tolerance*. If you develop tolerance to a medicine, the amount of medication can be changed or other medicines can be added. There are many different pain medicines and other techniques to choose from, so don't put off using your medications to relieve your pain. If you do find that your pain medicines aren't working as well as they did before, be sure to tell your doctor or nurse.

- ❑ **If I use pain medicine regularly for a long period of time, won't I become addicted to it?** Many patients, family members, and health care professionals have needless fears of addiction related to taking pain medication. Studies show, however, that getting addicted to pain medicine is very rare. Taking medications for pain due to a disease is not the same as abuse of drugs.

- ❑ **What are the side effects of these medications and can you minimize or control the side effects?** Some of the common side effects of pain medication are drowsiness, nausea, vomiting, and constipation. Your physician, nurse, or pharmacist can advise you of the specific side effects for the medications prescribed and ways to minimize or control these side effects.

If Pain Remains a Problem

- ❑ **What if my pain is not controlled by the medication you have prescribed?** It is important to keep your doctor advised of changes in your level of pain. The dosage of the medicine you are taking may need to be increased if your body develops a tolerance to the medication. Your physician also may change the type of medicine or the way you take it in to control your pain better.

- ❑ **Do you have special training in pain management?** Pain management is a subspecialty of medicine that uses a multidisciplinary approach to the management of pain. Physicians who work in *hospice* care, *anesthesiologists*, surgeons, and internists may choose to specialize in the treatment of patients with pain. If your doctor is not a specialist in pain management, ask for a referral to a pain management clinic or to a pain management specialist.

A BILL OF RIGHTS FOR PEOPLE WITH CANCER PAIN
1. I have the right to have my pain believed by health professionals, family, friends, and others around me.
2. I have the right to have my pain controlled, no matter what its cause or how severe it may be.
3. I have the right to be treated with respect at all times. When I need medication for pain, I should not be treated like a drug abuser.
4. I have the right to have pain resulting from treatments and procedures prevented or at least minimized.

Developed by Cancer Care, Inc., in cooperation with the Iowa and Wisconsin Cancer Pain Initiatives to encourage patients, their loved ones, and caregivers to learn the facts about pain and its treatment.

CANCER FATIGUE

“For some patients, treating fatigue may be as important as treating the disease.”

—*Russell Portenoy, M.D.,
Department of Pain Medicine,
New York's Beth Israel Hospital*

- ❑ **What is cancer fatigue?** Cancer fatigue has long been a catchall term for everything from mild tiredness to complete exhaustion. Cancer patients often describe the experience as a total lack of energy or feeling “bone tired.” This type of fatigue is not only physical; it also can affect social, psychological, and spiritual functioning.
- ❑ **What causes cancer fatigue?** There are many causes of cancer fatigue. The disease itself is often responsible, and any of the three standard treatments for cancer — surgery, chemotherapy, or radiation — may cause fatigue. Emotional fatigue also can occur, because the stress of living with a cancer diagnosis can lead to feelings of despair, depression, helplessness, and futility. Cancer pain and physical discomfort can cause fatigue. Your age, general fitness, and lifestyle also affect how you experience cancer fatigue.
- ❑ **What are the effects of cancer fatigue?** The effects of cancer fatigue vary from person to person. Some people become totally exhausted, while others experience short bouts of fatigue or only feel fatigued every now and then. For some patients, fatigue is only a mild bother, but for others, it is hard to get out of bed or walk up a flight of stairs. Fatigue may also cause shortness of breath, depress appetite, and affect thought processes; it may affect a person's ability to work or make it necessary to shorten work hours.

Being aware of some of the possible side effects of cancer fatigue can help the patient and loved ones cope. Family roles may change depending on a person's ability to parent, handle chores, drive, or be intimate with a partner. Cancer fatigue can affect a person's ability to concentrate, think clearly, retain information, and make decisions. These problems in turn can lead to depression and anxiety, which can increase physical and emotional fatigue in a seemingly never-ending cycle. Talking with health care providers and loved ones can lessen feelings of frustration, reduced self-esteem, and aloneness due to cancer fatigue. Communicating about your fatigue also can decrease the likelihood that fatigue will interfere with treatment or the outcome of care.

- ❑ **How long can cancer fatigue last?** People experience fatigue in different ways and for different lengths of time. Fatigue can last for days, weeks, or months. Some people seem to experience “post-cancer fatigue.” This term describes the lack of energy or complete exhaustion that can persist to varying degrees for years.

- ❑ **Do low blood counts affect fatigue?** Generally the answer is yes, but this is a discussion to have with your doctor. Low blood counts can reduce your ability to continue treatment or have it be very effective. Working together with your health care team, you may find that you can benefit from products designed to treat and increase low blood counts.
- ❑ **How likely is it that I will get cancer fatigue?** A national survey released in 1997 found cancer fatigue to be “the most common side effect of cancer and its treatment.” Earlier studies and surveys report that “78–96% of patients receiving chemotherapy experience fatigue.” Patients receiving radiation therapy often experience fatigue that worsens as treatment continues, regardless of treatment site.
- ❑ **If it is so common, should I even mention it to my doctor?** Yes! The effects of cancer fatigue on quality of life are now being recognized and researched. It is important to discuss your fatigue with your health care team so that your fatigue and its effects can be minimized when possible.
- ❑ **Fatigue is so personal. How do I describe it to my doctor?** Fatigue is difficult to measure, but because it can affect your life from hour to hour, day to day, and week to week, it is important to recognize it and accurately describe it. Pay attention to your fatigue and write notes about when you feel more or less fatigued. Convey this information to your doctor and nurse; try using a scale from one to ten to describe your level of fatigue to your doctor. Note when your energy levels are highest and lowest, and prioritize activities. In this way you can work together to find the treatment plan that will work best for you.
- ❑ **What can I or my doctor do to improve this condition?** There are several things that you can do on your own and with your doctor. For example:
 - Ask your health care team about vitamin and mineral supplements, prescription drugs, and exercise and nutrition that may help.
 - Try varying your eating and sleeping patterns.
 - Ask to be referred to a mental health specialist, physical therapist, and/or nutritionist who works with cancer patients.
 - Join a support group; you may learn ways to manage your fatigue from other group members.
 - Try to find interests or activities that are nourishing, such as meditation or relaxation techniques.
 - Educate yourself about the subject of cancer fatigue and the research being done so that you will feel more in control.

SEXUALITY

Many types of cancer treatment (such as surgery and chemotherapy) can affect sexual functioning. Added factors include fear, cancer fatigue, depression, and poor communication. Also, it's not uncommon for patients to experience partial or total lack of interest in sex while in treatment or for some time afterward. People often are embarrassed to talk about sex. They are hesitant to bring up the topic with their doctor or health care team, or even with their sexual partner. As a result, questions go unanswered and relationships suffer. It's important to understand that a number of medical and psychological treatments are available to help you continue a satisfying sex life after cancer. The following are some questions you may want to discuss with your doctor, nurse, or social worker:

- Do I need to refrain from sexual intercourse for a certain length of time? If so, when can I be sexually active again?**
- Will my cancer and/or treatment affect my sexual functioning? What changes should I expect? Will these changes last only a short time or will they be permanent?**
- Can you recommend a sex therapist whom I might see if I need some counseling or help during my cancer treatment?**
- Have you found that health insurance usually covers sex therapy that is related to cancer? Will you help me obtain coverage if it is part of my policy (such as writing a letter in support of sex therapy)?**

With time and information you can often resolve sexual problems caused by your cancer or its treatment. There are excellent written resources, and you may find a support group helpful.

If you have an *ostomy* (a *colostomy* or *ileostomy*) you should ask for a referral to an *enterostomal* therapist (a nurse who specializes in helping people adjust to ostomies). However, you will need professional help from your cancer care team to get medical treatment for a sexual problem. Your oncologist may refer you to a medical specialist (like a *gynecologist* or *urologist*) to assess and treat any physical dysfunctioning related to your cancer. If you choose to see a sex therapist, be certain you find someone who is certified in sex therapy. Ask your doctor, oncology nurse, or social worker to provide you with a list of specialists. Be sure to check your health care policy in advance to see if sex therapy is covered so that you can plan accordingly.

FERTILITY

Cancer and its treatment may affect fertility and fetal development. Both radiation and chemotherapy can cause the fetus to be injured or malformed. Another concern is the risk of permanent *sterility* if the testes or ovaries receive direct radiation. If you have concerns about the effect of cancer treatment on your fertility, you should discuss the following with your doctor and health care team.

- Will the treatment affect my ability to have children?
- Is there another treatment that might preserve my ability to have children without reducing my chance of long-term survival?
- What is the risk of *congenital abnormality* (birth defects) in any children conceived after my treatment ends?
- Will you refer me to a fertility specialist to discuss my options before starting my treatment?
- Will preserving my fertility delay my treatment?

For Women:

- Is there anything you can do to protect my ovaries from exposure to radiation (for example, *surgical relocation*)?
- Will you do a pregnancy test before starting treatment to make certain I am not pregnant now? If I am pregnant, how will this affect my treatment?
- Is it possible to harvest eggs, fertilize them, and store them as embryos before starting treatment?
- Can I still conceive a child when I am getting cancer treatment? Should my partner and I use birth control measures during treatment? What kind would you recommend or advise against? Why?
- What are the risks to me and to my child should I become pregnant during treatment for my cancer?
- Will the treatment induce menopause? Will the menopause last only a short while or will it be permanent? Would you recommend hormone replacement therapy in light of my cancer diagnosis?
- Should my partner and I use birth control measures after treatment is over? For how long? Why?

- If I am able to conceive a child after my cancer treatment is over, will there be any risk to my health?
- Once my cancer treatment is over, how long would I have to wait before trying to get pregnant?

For Men:

- Is there anything you can do to protect my testicles from exposure to radiation?
- Is it possible to bank my sperm before starting treatment?
- Will you help me get insurance reimbursement for sperm banking? (Some health insurance policies will pay for sperm banking when treatment may result in infertility.)
- While I am in treatment, will I still produce sperm? Is it necessary for me to use condoms during sexual activity?

MAKING THE TRANSITION OFF OF ACTIVE TREATMENT: YOUR TREATMENT SUMMARY AND FOLLOW-UP SURVIVORSHIP CARE PLAN

Before your treatment ends it is important to discuss with your doctor what to expect when you make this transition, which may include how to cope with the change and uncertainty. When you talk about the end of treatment, a Treatment Summary will be helpful to better understand what treatment you received, and a Follow-Up Survivorship Care Plan will help you and your health care team coordinate your care moving forward. If you and other members of your medical team know what treatment you had, any issues with that treatment, and new issues to monitor in the future, you will be better prepared to deal with your new health care needs.

LIVING BEYOND CANCER

Find out more about post-treatment survivorship with the free *Cancer Survival Toolbox*[®] *Living Beyond Cancer* program. See the *Resources* section for ordering information.

You may want to ask your doctors these questions:

- What happens when my treatment ends?** After you receive your last dose of chemotherapy or your last radiation treatment, you will probably feel both grateful to be finished with your treatments, yet anxious and uncertain about your future. If all signs of the cancer are gone, you are said to be *in remission*. While you are no longer *sick* with cancer, you may not feel totally *well*, either.
- Will I ever get back to normal?** After cancer treatment, you may long to *get back to normal*, to put your cancer behind you, to get on with living. Yet, cancer permanently changes you in many ways. A “new normal” must evolve so that you can move forward, and this will take time. It will not happen overnight, and will happen in different ways for different people. Some of this change will include living with uncertainty and with fear of *recurrence* (return of cancer), and learning how to evaluate your health and feel comfortable with your body again.
- How can I live with such uncertainty?** Resuming life-oriented thought processes after living with an acute fear of death is a difficult transition. You may have trouble making long-range plans, and this may be a problem for you for months, or even years. You will find it easier to move forward if you take the experiences and the skills and strengths you have gained and use them in your “new normal” life.

- ❑ **Sometimes I feel guilty that I have survived my cancer while others I know did not. Is this normal?** This is called “*survivor guilt*.” Although it is an often-mentioned emotion of long-term cancer survivors, it is not helpful to dwell on these feelings. Some people search for meaning and purpose in their survival, and they make a renewed commitment to life. Others decide to give something back to the cancer community or to others with cancer. You may find your “survivor guilt” is reduced by helping others.

- ❑ **How often should I see my doctor and which doctor should I use?** While completing your treatment is a milestone to celebrate, it also marks a new beginning in how to best care for yourself after treatment. The reality is that while you might be cancer-free, you are not free of cancer. Once you have had cancer your treatment becomes a part of your medical history that will affect how you manage your health care going forward. Simply put, a diagnosis of cancer changes your health care needs for the rest of your life.

When you complete treatment, request a formal consultation with your doctor and ask him/her for a Cancer Care Summary (a summary of your diagnosis and treatment) and a Survivorship Care Plan (a plan for follow-up care after primary cancer treatment). Your Survivorship Care Plan should outline how often you need to follow-up with your cancer doctor and when you should consult another type of doctor to meet your health care needs.

- ❑ **How much should I know about my cancer history and what information should my Survivorship Care Plan include?** Your Cancer Care Summary and Survivorship Care Plan should include, but are not limited to:
 - Your cancer diagnosis (the specific type of cancer)
 - The date(s) of your cancer diagnosis
 - Details of all the cancer treatments you received (including the type and date of all surgeries, the names and dosages of all drugs, the sites and total amount of radiation therapy, the date and type of transplant)
 - The names and addresses of all of your cancer doctors
 - Any complications you had as a result of your cancer treatment
 - Any *palliative care* or symptom management that you received (such as pain or nausea medicine, emotional support, nutritional supplements)
 - The places where you received treatment
 - The dates when all treatments were completed
 - Specific information about the timing and type of recommended follow-up (for example, screening tests for recurrences and/or *secondary cancers*, follow-up visits with your oncologist, etc.)
 - Recommendations about preventative practices and how to maintain health and well-being (for example, nutrition, exercise, and emotional support)
 - Information on employment rights as a cancer survivor and access to health insurance (see question on employment rights below)
 - Available of emotional support services in the local community

During the consultation ask your doctor and/or nurse to explain the Cancer Care Summary and Survivorship Care Plan to you. It is important that you understand it. You should keep

it in a safe place where you store other important personal papers and give copies to all other doctors who examine you in the months and years to come.

❑ How closely should I monitor my health after I have completed cancer treatment?

You will need to be aware of possible problems or effects that may result from certain types of cancer treatments. These effects may be:

- *Chronic* or *long-term* in that they begin during treatment and continue long afterward. For example, you may have numbness and tingling in your fingers and toes that will almost, but not always, get better over time; you may have a higher risk for infection if you have had your spleen removed; or you may continue to feel tired even though you are no longer in treatment.
- *Delayed* or *late* in that they happen months to years after treatment, and may be a result of having had a specific cancer or certain types of treatment for that cancer. For example, you may become infertile; you may be at risk for heart or lung disease; or you might develop other cancers.

❑ How can I prevent possible problems after my treatment for cancer? Ask your doctor and cancer nurse for ways to help you recover from the treatment, regain your health, and prevent further problems. Depending upon your type of cancer and treatments, your age, culture, and general health, what would they suggest you do in relation to:

- Diet and vitamins
- Alcohol use
- Rest and exercise
- Smoking and other tobacco products
- Sun protection
- Immunizations
- Medical check-ups and special tests

❑ What should I know about my rights as a cancer survivor? After treatment some survivors experience employment discrimination. However, federal laws exist to protect cancer survivors from unfair practices such as firing or a denial of benefits after a cancer diagnosis. Learn about your employment rights as a cancer survivor. NCCS offers a free booklet titled *Working It Out: Your Employment Rights As A Cancer Survivor*. You can order or download it from www.canceradvocacy.org.


Also, many communities have organizations that offer counseling and guidance on employment related issues. Access to adequate and affordable health insurance can also be a hurdle for cancer survivors. Since state laws set and enforce many of the rules related to health insurance, you should seek out and get to know local organizations that can counsel and guide you on health insurance issues. NCCS offers a free booklet for survivors titled, *What Cancer Survivors Need to Know About Health Insurance*, which you can order or download from www.canceradvocacy.org. Many communities also have organizations that offer help in navigating the field of health insurance.

- ❑ **I just finished my cancer treatment — why don't I feel happy?** The emotional stress that cancer causes can take many forms: anxiety, anger, depression, frustration, and grief are all very common. In fact, researchers have found that 1/3 of people with cancer experience anxiety and depression serious enough to require professional help. It is normal to feel some level of emotional stress even after you finish your cancer treatment. Don't be afraid or embarrassed to seek help.

YOUR TREATMENT SUMMARY

A Treatment Summary lists key information about your treatment so it is easy for you and other health care team members to understand what treatment(s) you had and if there are any lasting issues that need to be managed. The Treatment Summary template on the next page can be copied or torn out of this book and taken to your doctor. There also are online tools to make it easier for fill out your Treatment Summary. *Journey Forward*, available at www.JourneyForward.org, is free online software you can download to your computer and take with you to your health care team as you complete treatment. Your doctor can help you fill it out so you can have a record of your cancer treatment. Keep several copies for yourself and to give to other doctors you may see. Below is a sample of a treatment summary using *Journey Forward*.

SAMPLE
 Jane Doe
 DOB: 9/10/1963
 3 of 11



Cancer Survivorship Care Plan

Treatment Plan & Summary		
Patient's height	157.5 cm	
	Pre-treatment	Post-treatment
Patient's weight	50.8 kg	54.4 kg
Patient's BSA	1.49 m ²	1.54 m ²
Patient's BMI	20.5	22.0
Date last menstrual period	6/2/2008	
Comments		Dose reduction due to sepsis.

Regimen	TAC Docetaxel (Taxotere) 75 mg/m ² iv d1 Doxorubicin (Adriamycin) 50 mg/m ² iv d1 Cyclophosphamide (Cytoxan) 500 mg/m ² iv d1 Q3w x 6 cycles Filgrastim (Neupogen) support	
	# cycles	% dose reduction
Chemotherapy agents		
Docetaxel	6	25% in cycle 6
Doxorubicin	6	
Cyclophosphamide	6	25% in cycle 6
Filgrastim support		

Anthracycline administered	Doxorubicin, 430 mg (279 mg/m ²)
Treatment on clinical trial	No
Chemotherapy treatment period	6/14/2008 - 10/20/2008
Possible side effects of regimen	Anemia, Fatigue, Hair loss, Infertility, Low blood count, Menopause symptoms, Nausea/vomiting, Neuropathy, Sores in mouth
Reconstruction	Planned: Yes
Radiation therapy	Planned: Yes, completed: 12/20/2008, dose:
Growth factor given	Yes
Grade 3 or higher toxicities	Anemia, Dehydration, Mucositis, Neutropenia, Sepsis, Thrombocytopenia
Hospitalization for toxicities	Yes
Neurotoxicity impairing activities	No
Early termination of treatment	NA—treatment completed

v1.0.96
Printed 10/29/2008

www.JourneyForward.org

YOUR TREATMENT SUMMARY TEMPLATE


Below is the paper-based template from the American Society of Clinical Oncology (ASCO). You can tear this out to take with you to your health care team.

Insert Practice Name/Info Here:					
<i>The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.</i>					
Patient name:			Patient ID:		
Medical oncology provider name:			PCP:		
Patient DOB: (__/__/__)		Age:		Patient phone:	
Support contact name:					
Support contact relationship:			Support contact phone:		
BACKGROUND INFORMATION					
Symptoms/signs:					
Family history/predisposing conditions:					
Major co-morbid conditions:					
Tobacco use: <input type="checkbox"/> No <input type="checkbox"/> Yes, past <input type="checkbox"/> Yes, current (If current, cessation counseling provided?: <input type="checkbox"/> Yes <input type="checkbox"/> No)					
Cancer type/location:				Diagnosis date: (__/__/__)	
Is this a new cancer diagnosis or recurrence?: <input type="checkbox"/> New <input type="checkbox"/> Recurrence (date: __/__/__)					
Surgery: <input type="checkbox"/> None <input type="checkbox"/> Diagnosis only <input type="checkbox"/> Palliative resection <input type="checkbox"/> Curative resection					
Surgical procedure/location/findings:					
Tumor type/histology/grade:					
STAGING					
Study	Date	Findings			
T stage: <input type="checkbox"/> T1 <input type="checkbox"/> T2 <input type="checkbox"/> T3 <input type="checkbox"/> T4 <input type="checkbox"/> Not applicable N stage: <input type="checkbox"/> N0 <input type="checkbox"/> N1 <input type="checkbox"/> N2 <input type="checkbox"/> N3 <input type="checkbox"/> Not applicable					
M stage: <input type="checkbox"/> M0 <input type="checkbox"/> M1 <input type="checkbox"/> Not applicable			Tumor markers:		
Stage: <input type="checkbox"/> I_ <input type="checkbox"/> II_ <input type="checkbox"/> III_ <input type="checkbox"/> IV_ <input type="checkbox"/> Recurrence			Alternative staging system:		
Location(s) of metastasis or recurrence (if applicable):					
TREATMENT PLAN			TREATMENT SUMMARY		
<i>White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy</i>					
Height: in/cm		Pre-treatment weight: lb/kg		Post-treatment weight: lb/kg	
Pre-treatment BSA:		Treatment on clinical trial: <input type="checkbox"/> Yes <input type="checkbox"/> No			
Name of chemotherapy regimen:					
Chemotherapy start date: (__/__/__)			Chemotherapy end date: (__/__/__)		
Chemotherapy intent: <input type="checkbox"/> Curative, adjuvant or neoadjuvant <input type="checkbox"/> Disease or symptom control					
ECOG performance status at start of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4			ECOG performance status at end of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4		
Chemotherapy Drug Name	Route	Dose mg/m2	Schedule	Dose reduction	# cycles administered
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
Major side effects of this regimen: <input type="checkbox"/> Hair loss <input type="checkbox"/> Nausea/Vomiting <input type="checkbox"/> Neuropathy <input type="checkbox"/> Low blood count <input type="checkbox"/> Fatigue <input type="checkbox"/> Menopause symptoms <input type="checkbox"/> Cardiac <input type="checkbox"/> Other					

YOUR FOLLOW-UP SURVIVORSHIP CARE PLAN TEMPLATE

Like the Cancer Treatment Plan, the Follow-Up Survivorship Care Plan provides a roadmap for your post-treatment care. Some treatments may cause long-term effects, or they may cause late effects that might show up months or years after treatment. Having a Follow-Up Survivorship Care Plan will help make sure you get the right screening and that you are monitored to find any problems early. You can use the Follow-Up Survivorship Care Plan in this booklet, or you can use an online tool to make it easier. *Journey Forward*, available at www.JourneyForward.org, is free online software you can download to your computer, fill out, and take with you to your health care team as you complete treatment. Your doctor can work with you to fill it out so you can have a guide for coordinating your follow-up care. Below is an example of a Survivorship Care Plan using *Journey Forward*.

SAMPLE



Jane Doe
DOB: 9/10/1963
4 of 11

Biologic therapy	Planned: No, Prescribed: No
------------------	-----------------------------

Follow-Up Care

Test	Frequency	Provider to contact
Medical history/physical exam: Yrs 1-3	Every 3 months	Dr. Vorgis
Medical history/physical exam: Yrs 4,5	Every 6 months	
Post-treatment mammography	Every year	
MRI	Every 3 years	
Bone densitometry	Every 3 years	
Pelvic examination	Every year	
Genetic counseling referral	Recommended	Dr. Smithey
Breast self-examination	Every month	

Preventive care recommendations	Bone health, Cholesterol monitoring/management, Diet, Exercise, Mental health, Weight management
---------------------------------	--

ASCO Surveillance Guidelines

Medical history and physical (H&P) examination
Visit your doctor every three to six months for the first three years after the first treatment, every six to 12 months for years four and five, and every year thereafter.

Post-treatment mammography
Schedule a mammogram one year after your first mammogram that led to diagnosis, but no earlier than six months after radiation therapy. Obtain a mammogram every six to 12 months thereafter.

Breast self-examination
Perform a breast self-examination every month. This procedure is not a substitute for a mammogram.

Pelvic examination
Continue to visit a gynecologist regularly. If you use tamoxifen, you have a greater risk for developing endometrial cancer (cancer of the lining of the uterus). Women taking tamoxifen should report any vaginal bleeding to their doctor.

v1.0.96
Printed 10/29/2008

www.JourneyForward.org

YOUR FOLLOW-UP SURVIVORSHIP CARE PLAN TEMPLATE

Below is the paper-based template from the American Society of Clinical Oncology (ASCO). You can tear this out to take with you to your health care team.

<p>Insert Practice Name/Info Here:</p> <p><i>The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.</i></p>		
FOLLOW-UP AND SURVIVORSHIP CARE		
Follow up care	When/How Often?	Coordinating Provider
Medical oncology visits		
Lab tests		
Imaging		
<p>Potential late effects of treatment(s):</p>		
<p>Call your doctor if you have any of these signs and symptoms:</p>		
<p>Needs or concerns:</p> <p><input type="checkbox"/> Prevention and wellness: _____</p> <p>_____</p> <p><input type="checkbox"/> Genetic risk: _____</p> <p>_____</p> <p><input type="checkbox"/> Emotional or mental health: _____</p> <p>_____</p> <p><input type="checkbox"/> Personal relationships: _____</p> <p>_____</p> <p><input type="checkbox"/> Fertility: _____</p> <p>_____</p> <p><input type="checkbox"/> Financial advice or assistance: _____</p> <p>_____</p> <p><input type="checkbox"/> Other: _____</p> <p>_____</p>	<p>Referrals provided:</p> <p><input type="checkbox"/> Dietician</p> <p><input type="checkbox"/> Smoking cessation counselor</p> <p><input type="checkbox"/> Physical therapist or exercise specialist</p> <p><input type="checkbox"/> Genetic counselor</p> <p><input type="checkbox"/> Psychiatrist</p> <p><input type="checkbox"/> Psychologist</p> <p><input type="checkbox"/> Social worker</p> <p><input type="checkbox"/> Fertility specialist or endocrinologist</p> <p><input type="checkbox"/> Other: _____</p>	
COMMENTS		

© 2011 American Society of Clinical Oncology. All rights reserved.

Important caution: This is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

WHEN TREATMENT OPTIONS ARE LIMITED

Many cancer survivors live with a diagnosis of cancer for many years; others, unfortunately, never achieve a lessening of their cancer. These situations may become life-threatening, and as people live through the advanced stages of cancer there are many tasks that need to be completed to prepare for the best care one can have at the end of life.

- What are your preferences with regard to medical care at end-of-life? Have you completed an advance health directive (see pages 9–10)? Have you completed a will and made other legal decisions?**
- Do you want to die at home? In a hospital? Somewhere else? Is your family in agreement about your death taking place at home if that is your choice?**
- Is there a *hospice* program nearby that can help you and your family during your final months and weeks of life? Have you asked your doctor to refer you to such a program?**
- Have you made decisions about funeral arrangements? If you will die at home, how will your death be pronounced? Who will notify the funeral home?**
- How will you and your family know when death is near?**
- If you have pain, how will it be controlled?** These are very hard questions to face, and not easy subjects to discuss with loved ones or with your health care team. But, you want the time that remains in your life to be as complete as it can be and sharing the facts of your dying with those who love and support you can be a source of great comfort and healing. If possible, use this time to say all of the important things you want to say to others, and do things in which you find pleasure and peace. If you can't talk about certain issues, do the best that you can do. Perhaps writing to loved ones will allow you to express your feelings when you can't talk about them directly.

Hospice professionals and clergy are available to help you with these issues and to help you and your family deal with your impending loss and sadness.

Learn about end of life issues with the free *Cancer Survival Toolbox® Dying Well — The Final Stage of Survivorship* program. See the *Resources* section for ordering information.

LIVING WITH LOSS

Losses are a part of life and a part of cancer. Some of these losses, like hair loss and loss of fertility, are physical, but there are emotional losses as well. For example, you may have to learn to live with some limitations, or you may have to alter some goals and hopes to fit your current reality.

Every loss requires a grief response or some type of mourning, but American society is uncomfortable with grief. If you sense this discomfort, you might try to hide your feelings and emotions. But grief must be expressed in some way, and it may be transformed into other emotional experiences such as anger, guilt, or helplessness.

- ❑ **How long does a grief reaction last?** A person's grief is very individual. Some people may be able to deal with hair loss in a fairly short time. Another person may grieve for that lost hair until it begins to grow again. Some losses, however, are more disfiguring or disabling. You may need to adjust to an altered body image and that may take longer to deal with the grief that accompanies such physical losses. Sometimes others — friends, family members, even your health care team — may not understand the personal meaning of your loss. The result may be that you end up feeling guilty. Well-meaning family and friends may make you feel guilty for being sad or depressed. They may point out how lucky you are to be alive. This can compound your grief.

- ❑ **How can I “work through” my grief?** Grief has been studied a great deal, and four “tasks” have been identified for coming to terms with your grief. These tasks are:
 - Accept the reality of the loss
 - Experience the pain of the grief
 - Adjust to your changed environment
 - Emotionally relocate the loss in your life and move on

- ❑ **Are there other ways I can get through my reaction to loss?** First of all, be gentle with yourself. It's very hard to adjust to cancer, its treatment, and all of the emotional factors that accompany cancer. Give yourself time to heal. Speak about your feelings — don't hide your grief.

- ❑ **Are there groups or professionals who can help me adjust to my losses?** You can attend a group meeting or talk with a professional counselor. One of the major values of peer support groups is that you find out you are not alone with your problems, that your fears and concerns are shared by others, and that your reactions are normal for your situation. If you are not comfortable sharing these kinds of feelings with such a group, you may find talking with a counselor or with a member of the clergy helpful. If you don't know exactly who to talk with, ask your doctor for a referral to an *oncology social worker* who will be skilled in dealing with loss and grief.

RESOURCES

The following is a list of resources that were mentioned in this booklet. These resources are offered free by the National Coalition for Cancer Survivorship and can be ordered by calling 877-NCCS-YES (877-622-7937) or visiting www.canceradvocacy.org.

Cancer Survival Toolbox®, developed by NCCS in collaboration with the Oncology Nursing Society, Association of Oncology Social Work, and National Association of Social Workers. Available free of charge at 877-TOOLS-4-U (877-866-5748) in English and Spanish. Chinese transcript also available. May be downloaded from www.cancersurvivaltoolbox.org.

Journey Forward: Survivorship Care Plan Builder. Developed in collaboration with UCLA Cancer Survivorship Center, WellPoint, and Genentech. Available free of charge at www.journeyforward.org.

Self-Advocacy: A Cancer Survivor's Handbook. Published by the National Coalition for Cancer Survivorship (2003).

What Cancer Survivors Need to Know About Health Insurance, by Kimberly Calder, M.P.S., and Karen Pollitz, M.P.P. Published by the National Coalition for Cancer Survivorship. Fifth Edition (2003), 34pp. Available in English and Spanish.

Working it Out: Your Employment Rights As a Cancer Survivor, by Barbara Hoffman, JD. Published by the National Coalition for Cancer Survivorship (2003), 22pp. Available in English and Spanish.

You Have the Right to Be Hopeful, by Elizabeth J. Clark, Ph.D. Published by the National Coalition for Cancer Survivorship. Third Edition (2003), 24 pp. Available in English and Spanish.

ADVOCACY AND EDUCATIONAL RESOURCES

The American public is becoming increasingly sophisticated about health care and is demanding to become involved.

—*Sheldon Greenfield, M.D.,
Professor of Medicine
UCLA School of Medicine*

The following is a brief list of cancer organizations that you may find useful. Many of these groups offer resources and can refer you to other organizations. For a larger list of resources, visit www.canceradvocacy.org or call 877-NCCS-YES (622-7937).

National Coalition for Cancer Survivorship

<http://www.canceradvocacy.org>
877-NCCS-YES (877-622-7937)

American Cancer Society

<http://www.cancer.org>
800-ACS-2345 (800-227-2345)

American Childhood Cancer Organization

<http://www.candlelighters.org>
800-366-2223

Cancer Care, Inc.

<http://www.cancercare.org>
800-813-HOPE (4673)

Cancer Legal Resource Center

<http://www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm>
866-THE-CLRC (843-2572)

The Children's Cause for Cancer Advocacy

<http://www.childrenscause.org>
301-562-2765

Fertile Hope

<http://www.fertilehope.org>
888-994-HOPE

Lance Armstrong Foundation

<http://www.livestrong.org>
866-235-7205

**National Cancer Institute (NCI)
Cancer Information Service**

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

National Childhood Cancer Foundation

<http://www.curesearch.org>
800-458-6223

National Organization for Rare Diseases (NORD)

<http://www.rarediseases.org>
800-999-6673

Patient Advocate Foundation

<http://www.patientadvocate.org>
800-532-5274

The Ulman Cancer Fund for Young Adults

<http://www.ulmanfund.org>
800-393-FUND (3863)

The Cancer Support Community

<http://www.cancersupportcommunity.org>
888-793-WELL (793-9355)

GLOSSARY OF CANCER WORDS

Acupressure: The application of pressure or localized massage to specific sites on the body to control symptoms such as pain or nausea. It is a type of *complementary and alternative medicine*.

Acupuncture: The technique of inserting thin needles through the skin at specific points on the body to control pain and other symptoms. It is a type of *complementary and alternative medicine*.

Acute: A sudden onset of symptoms or disease.

Adenocarcinoma: Cancer that develops in glandular tissue, such as the prostate.

Adherence: The degree to which a patient's behavior is consistent with an agreed-upon mode of treatment.

Adjuvant Chemotherapy: One or more anti-cancer drugs used in combination with surgery or radiation therapy as a part of the treatment of cancer. Adjuvant usually means "in addition to" initial treatment.

Advance Health Directive: Tells your doctor what kind of care you would like to have if you become unable to make medical decisions.

Agent: A medicine, vitamin, mineral, or food supplement that may be used to prevent or treat cancer.

Allogeneic Bone Marrow Transplant: A bone marrow transplant using bone marrow from someone who is healthy.

Analgesic: Any drug that relieves pain. Aspirin and acetaminophen are mild analgesics.

Anemia: A condition in which the number of red blood cells is below normal.

Anesthesia: A temporary loss of feeling and loss of awareness in all or part of the body caused by special drugs or other substances called anesthetics.

General Anesthesia: Temporary loss of feeling and a complete loss of awareness that feels like a very deep sleep. General anesthesia keeps patients from feeling pain during surgery or other procedures.

Regional Anesthesia: Temporary loss of feeling or awareness in a part of the body, such as an arm or a leg. The patient

stays awake but has no feeling in the part of the body treated with the anesthetic.

Local Anesthesia: Temporary loss of feeling in one small area of the body. The patient stays awake but has no feeling in the area of the body treated with the anesthetic.

Anesthesiologist: A doctor who specializes in giving drugs or other agents to prevent or relieve pain during surgery or other procedures being done in the hospital.

Antibody: A substance formed by the body to help defend it against infection.

Antigen: Any substance that causes the body to produce natural antibodies.

Aspiration: The process of removing fluid or tissue, or both, from a specific area.

Assisted Living Facility: A facility providing a living arrangement in which people with special needs, especially older people with disabilities, reside in a facility that provides help with everyday tasks such as bathing, dressing, and taking medication.

Assisted Reproductive Technologies: Procedures used to treat female infertility. The most commonly used assisted reproductive technologies are:

IVF: In Vitro Fertilization

GIFT: Gamete Intra-Fallopian Tube Transfer

ZIFT: Zygote Intra-Fallopian Tube Transfer

Autologous Bone Marrow Transplant: The replacement or recycling of the patient's bone marrow through the process of high-dose chemotherapy and surgery.

Basal Cell Carcinoma: The most common type of skin cancer.

Benign: A swelling or growth that is not cancerous, does not spread from one part of the body to another, and is usually not life-threatening.

Biofeedback: A method of learning to control certain body functions such as heartbeat, blood pressure, and muscle tension with the help of a special machine. This method can help control pain.

Biological Therapy: Treatment to boost or restore the ability of the immune system to fight cancer, infections, and other diseases. Also used to lessen certain side effects that may be caused by some cancer treatments. Also called biological response modifier therapy, biotherapy, BRM therapy, and immunotherapy.

Biopsy: The removal of cells or tissues for examination by a *pathologist*. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue to see if the cells are normal or not. A biopsy is a common way of finding out if a person has cancer and, if so, what type it is. The most common biopsy types include:

Excisional Biopsy: An entire lump or suspicious area is removed.

Incisional Biopsy: Only a sample of tissue is removed.

Needle Biopsy: A sample of tissue or fluid is removed with a needle. When a wide needle is used, the procedure is called a core biopsy. When a thin needle is used, the procedure is called a fine-needle aspiration biopsy.

Blood Cells: Cells that make up the blood. They are produced in bone marrow and consist of (1) red cells (which bring oxygen to tissues and take carbon dioxide from them), (2) white blood cells (which fight invading germs, infections and allergy-causing agents), and (3) platelets (which are responsible for clotting).

Blood Counts: The number value assigned to the major types of blood cells. Blood counts indicate the number of blood cells (red cells, white cells, and platelets) circulating in your bloodstream.

Bone Marrow: The soft, spongy center of the bone. Bone marrow can be thought of as a “factory” that produces blood.

Bone Marrow Transplantation: A procedure in which doctors replace marrow destroyed by treatment with high doses of anticancer drugs or radiation. The replacement marrow may be taken from the patient before treatment or may be donated by another person. When the patient’s own marrow is used, the procedure is called autologous bone marrow transplantation. When someone else’s marrow is used, the procedure is called allogeneic.

Brachytherapy: Radiation treatment in which radioactive pellets are inserted; also called seed implantation.

BRCA 1 & 2: The principal genes that indicate an inherited susceptibility to breast and ovarian cancers.

BSA: Body Surface Area. A measurement used to determine the correct dose of a drug for each person.

Cancer: A general term for more than 100 diseases characterized by abnormal and uncontrolled growth of cells. The resulting mass, or tumor, can invade and destroy surrounding normal tissues.

Cancer Fatigue: A certain type of fatigue associated with the cancer experience that has physical, social, and psychological effects.

Cancer Stage: The extent or severity of cancer, based on factors such as tumor location, tumor size, number of tumors, and extent of cancer spread. The TNM (Tumor, Node, Metastasis) system is one of the most widely used ways of describing tumors. See also *staging*.

Carcinogen: A substance or agent that is known to cause cancer.

Carcinoma: A kind of cancer that starts in the lining of organs.

Cardiac: Having to do with the heart.

Cardiopulmonary Resuscitation (CPR): A combination of rescue breathing and chest compressions delivered to a person thought to be in cardiac arrest. When cardiac arrest occurs, the heart stops pumping blood. CPR can keep a small amount of blood flow to the heart and brain to “buy time” until normal heart function is restored.

Chemo Brain: Thinking and memory problems that can occur after cancer treatment.

Chemoprevention: Use of drugs to prevent cancer development or growth.

Chemotherapy: Treatment with anti-cancer medicines.

Chemotherapeutic Agent: A drug used to treat cancer.

Clinical Trial: Test on human subjects of existing, new, or experimental treatments.

Colony-Stimulating Factors: Substances that stimulate the production of blood cells. Treatment with colony-stimulating factors (CSF) can help the blood-forming tissue recover from the effects of chemotherapy and radiation therapy. These include granulocyte colony-stimulating factors (G-CSF) and granulocyte-macrophage colony-stimulating factors (GM-CSF).

Combination Chemotherapy: The use of more than one drug during cancer treatment.

Co-morbid Condition: A person having more than one health condition or disease (for example, cancer and high blood pressure) is said to have co-morbid conditions. The diseases often are not related to each other.

Complementary and Alternative Medicine (CAM): Forms of treatment that are used in addition to (complementary) or instead of (alternative) standard treatments. These practices generally are not considered standard medical approaches. Standard treatments go through a long and careful research process to prove they are safe and effective, but less is known about most types of CAM. CAM may include dietary supplements, very high dose vitamins, herbal preparations, special teas, *acupuncture*, *acupresure*, massage therapy, magnet therapy, spiritual healing, and meditation.

Comprehensive Cancer Center: A comprehensive cancer center is an institution that has been selected by the National Cancer Institute (NCI) as a center of excellence for cancer care and research. According to the NCI, there's no difference in the quality of care provided by NCI-designated "cancer centers" versus NCI-designated "comprehensive cancer centers." NCI uses the term "comprehensive" to mean that an institution offers the latest care and services that strongly emphasize research along with a prevention, care, and educational activities that serve the community.

Computer Tomography: Computer-generated cross-sectional images of a portion of the body. Also called CT scan or CAT scan.

Congenital : A condition or trait present at birth. It may be the result of genetic or non-genetic factors.

Critical Access Hospital: A small facility that gives limited outpatient and inpatient hospital services to people in rural areas.

Curative Care: Health care practices that treat patients with the intent of curing them, not just reducing their pain or stress.

Custodial Care: Nonskilled, personal care, such as help with activities of daily living like bathing, dressing, eating, getting in or out of a bed or chair, moving around, and using the bathroom. It may also include care that most people do themselves, like using eye drops.

Diagnosis: The process of identifying a disease, such as cancer, from its signs and symptoms.

Dietitian: A health professional with special training in nutrition who can help with food choices. Also called nutritionist.

Durable Power of Attorney: A legal document that lets you appoint someone to make health decisions for you if you become unable to do so for yourself.

Edema: The swelling or accumulation of fluid in a part of the body.

Endocrinologist: A doctor who specializes in diagnosing and treating hormone disorders.

Enterostomal Therapist: A health professional trained in the care of persons with stomas, such as a *colostomy* or *urostomy*.

Excision: Surgical removal.

Fatigue: Extreme tiredness and inability to function due lack of energy. Fatigue may be acute or chronic. Cumulative fatigue refers to fatigue that increases over the course of cancer treatment.

Fecal Occult Blood Test: A test to check for hidden blood in stool. (Fecal refers to stool; occult means hidden.)

Fertility Specialist: An obstetrician/gynecologist (OB/GYN) who specializes in medically assisting people wishing to have children and treatment of infertility.

General Surgeon: A physician who specializes in the treatment of injury, deformity, and disease using surgical procedures.

Gene Therapy: Treatment that alters genes (the basic units of heredity found in all cells in the body). In early studies of gene therapy for cancer, researchers are trying to improve the body's natural ability to fight the disease or to make the tumor more sensitive to other kinds of therapy.

Genetic Counseling: A communication process between a specially trained health professional and a person concerned about the genetic risk of disease. The person's family and personal medical history may be discussed, and counseling may lead to genetic testing.

Genetic Testing: Tests that are used as a health care tool to detect gene variants associated with a specific disease or condition, as well as for non-clinical uses such as paternity testing and forensics.

Granulocyte: A type of immune cell that has granules (small particles) with enzymes that are released during infections, allergic reactions, and asthma. A granulocyte is a type of white blood cell. Neutrophils, eosinophils, and basophils are granulocytes.

Guided Imagery: Any of various techniques (such as a series of verbal suggestions) used to guide another person or oneself in imagining sensations and especially in *visualizing* an image in the mind to bring about a desired physical response (such as a reduction in stress, anxiety, or pain).

Gynecologic Oncologist: A doctor who specializes in treating cancers of the female reproductive organs.

Gynecologist: A doctor who specializes in treating diseases of the female reproductive organs.

Health Care Proxy: A person you appoint as your agent to make health care decisions for you if you become unable to do so for yourself.

Hematologist: A doctor who specializes in the problems of blood and bone marrow.

Histology: The study of tissues and cells under a microscope.

Home Health Agency: An organization that provides health care in the home. To be certified for payment by Medicare, a home health agency must provide skilled nursing services and at least one additional type of therapy, usually physical or occupational therapy.

Hormonal Therapy: Treatment that adds, blocks, or removes hormones. Also called endocrine therapy, hormone therapy, and hormone treatment.

Hospice: Care for the terminally ill and supportive services for patients and their families.

Hydration: In medicine, the process of giving fluids needed by the body.

Hyperalimentation: Giving a highly nutritious solution through a vein instead of by mouth.

Imaging: In medicine, a process that makes pictures of areas inside the body. Imaging uses methods such as x-rays (high-energy radiation), ultrasound (high-energy sound waves), and radio waves.

Immune System: The complex group of cells and organs that defends the body against infection and disease.

Immunotherapy: Use of the immune system or the products of the immune system to control, damage, or destroy malignant cells. See *biological therapy*.

Immunosuppression: Weakening of the immune system making a person less able to fight infection and disease.

Impotence: Being unable to have an erection.

Infertility: Sterile or barren.

Informed Consent: The legal standard that states that a patient must know certain risks and benefits regarding therapy before agreeing to take it.

Inpatient: A patient who stays overnight in a health care facility to receive treatment or other health care.

Interferon: A type of biological response modifier (a substance that can improve the body's natural response to disease). It stimulates the growth of certain disease-fighting blood cells in the immune system.

Internist: A doctor who works with adult patients to prevent, diagnose, and treat diseases without using surgery.

Interventional Radiology: The use of *imaging* to assist in performing surgical or other medical procedures.

Intubation: The passage of a tube into an organ or body structure; commonly used to refer to the passage of a tube down the windpipe for artificial respiration.

Late Effects: Side effects of cancer treatment that become apparent after your treatment has ended. Cancer survivors might experience late effects of cancer treatment a few months after treatment is completed or years later.

Living Will: A document that provides specific instructions about your health care treatment.

Leukemia: Cancer of the blood. White blood cells may be produced in excessive amounts and are unable to work properly.

Leukopenia: A low number of white blood cells.

Long-Term Care Hospital or Facility: *Acute* care hospitals that provide treatment for patients who stay, on average, more than 25 days. Most patients are transferred from an intensive or critical care unit. Services provided include comprehensive *rehabilitation* and pain management.

Long-Term Effects: Known or expected problems that may occur in persons who have received certain treatments.

Lump: A thickness under the skin that can be felt by the fingers, either by the person who has it or by a doctor. A lump can be a sign of cancer, but most lumps are not cancer.

Lumpectomy: Surgical removal of the cancerous portion of the breast and a small amount of surrounding tissue. Four to

six weeks of radiation often follow.

Lymphatic System: Spaces and vessels between body tissues and organs through which lymph, a clear fluid, circulates; the lymphatic system removes bacteria and other materials from tissues. Metastasizing cancer cells often appear in lymph nodes.

Lymphedema: A swelling of the arms and legs caused by surgery, radiation or inherited abnormalities.

Lymph Nodes: Small, bean-shaped organs located along the channels of the lymphatic system. Bacteria or cancer cells that enter the lymphatic system may be found in the nodes. Also called lymph glands.

Lymphocytes: White blood cells that kill viruses and defend against the invasion of foreign substances.

Lymphoma: A type of cancer that starts in a lymph node.

Magnetic Resonance Imaging (MRI): A method of creating images of the body using a magnetic field and radio waves instead of x-rays. Although the images are similar to those of CT scans, they can be taken in all three directions rather than just in cross-sections.

Malignant Tumor: A tumor that is cancerous.

Mammography (Mammogram): A low-dose x-ray of the breast to detect abnormalities.

Mastectomy: An operation to remove a person's breast.

Medical Examiner: A doctor officially authorized by a government unit to determine causes of deaths, especially those that did not occur under natural circumstances; also called a coroner.

Medical Oncologist: A doctor who specializes in diagnosing and treating cancer using *chemotherapy*, *hormonal therapy*, *biological therapy*, and *targeted therapy*. A medical oncologist often is the main health care provider for someone who has cancer. A medical oncologist also gives supportive care and may coordinate treatment given by other specialists.

Meditation: A mind-body practice in *complementary and alternative medicine (CAM)*. There are many types of meditation. In meditation, a person learns to focus attention. Some forms of meditation instruct the person to become mindful of thoughts, feelings, and sensations and to observe them in a nonjudgmental way. This practice is believed to result in a state of greater calmness, physical relaxation, and psychological (mental/emotional) balance. Practicing

meditation can change how a person relates to the flow of emotions and thoughts.

Menopause: The time of life when a woman's ovaries stop producing hormones and menstrual periods stop. Natural menopause usually occurs around age 50. A woman is said to be in menopause when she hasn't had a period for 12 months in a row.

Metastasis: The spread of cancer cells from the original tumor through the bloodstream and lymphatic system to another part of the body. Metastasis also is the word used for a secondary tumor caused by this movement of cancer cells.

Monoclonal Antibodies: Substances that can locate and bind to cancer cells wherever they are in the body. They can be used alone, or they can be used as a treatment to deliver drugs, toxins, or radioactive material directly to the tumor cells, or to help make a diagnosis.

Myelosuppression: A decrease in the production of red blood cells, platelets, and some white blood cells by the bone marrow.

Needle Aspiration: Technique of removing cells by suction through a needle.

Neoadjuvant: Treatment given as a first step to shrink a tumor before the main treatment, which is usually surgery, is given. Examples of neoadjuvant therapy include chemotherapy, radiation therapy, and hormone therapy.

Nerve Block: A procedure in which medicine is injected directly into or around a nerve or into the spine to block pain.

Neuropathy: A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet. It may be a side effect of anticancer drugs. Also called peripheral neuropathy.

Neutropenia: A decreased number of neutrophils, a type of white blood cells.

Nutritionist: See *dietitian*.

Occupational Therapist: A health professional trained to help people who are ill or disabled learn to manage their daily activities.

Oncogenes: Genes that, when mutated (altered or damaged), can advance the growth of cancer. When normal, these genes play a role in regulating the growth of cells.

Oncologist: A doctor who specializes in diagnosing and treating cancer.

Oncology: The study and treatment of cancer.

Oncology Social Worker: A social worker who assists patients, families, and loved ones facing a possible or actual cancer diagnosis. Assistance may include help in managing stress and symptoms, care planning, case management, helping patients and families find and secure needed services, providing cancer education, and acting as the patient's and family's advocate.

Oral Chemotherapy: Cancer medicine taken by mouth to treat cancer, rather than injected into the body. Chemotherapy taken by mouth is as strong as other forms and works just as well.

Osteopathic Medicine: A form of medical practice that includes all of the benefits of modern medicine, (such as prescription drugs, surgery, and the use of medical technology). In addition, rather than just treating a specific disease, osteopathic medicine views the patient as a whole person and strives to improve wellness through health promotion and disease prevention.

Ostomy: An operation to create an opening (a *stoma*) from an area inside the body to the outside. Examples include:

Colostomy: An opening into the colon from the outside of the body. A colostomy provides a new path for waste material to leave the body after part of the colon has been removed.

Ileostomy: An opening into the ileum, part of the small intestine, from the outside of the body. An ileostomy provides a new path for waste material to leave the body after part of the intestine has been removed.

Urostomy: An operation to create an opening from inside the body to the outside, making a new way to pass urine.

Outpatient: A patient who visits a health care facility for diagnosis or treatment without spending the night. Sometimes called a day patient.

Palliative Care/Palliative Treatment: Therapy aimed at relieving symptoms, not aimed at cure.

Pastoral Counselor: A person who is trained to give spiritual and mental health advice.

Patient Advocate: A person who helps a patient work with others who have an effect on the patient's health, including doctors, insurance companies, employers, case managers, and lawyers. A patient advocate helps resolve issues about health care, medical bills, and job discrimination related to a patient's medical condition. Cancer advocacy groups try to raise public awareness about important cancer issues, such as the need for

cancer support services, education, and research. Such groups work to bring about change that will help cancer patients and their families.

Pathologist: Doctor who specializes in analyzing tissues, then communicating the diagnosis to the treating physician.

Pediatrician: A doctor who specializes in the care of children and adolescents.

Peripheral Stem Cell Support: A method of replacing blood-forming cells destroyed by cancer treatment. Certain cells (stem cells) in the blood that are similar to those in bone marrow are removed from the patient's blood before treatment. The cells are given back to the patient after treatment.

Performance Status: A measure of how well a patient is able to perform ordinary tasks and carry out daily activities.

Petechiae: Tiny areas of bleeding under the skin, usually due to a low platelet count.

Pharmacist: A person licensed to prepare and dispense (give out) prescription drugs and who has been taught how they work, how to use them, and their side effects.

Physical Therapist: A health professional who teaches exercises and physical activities that help condition muscles and restore strength and movement.

Platelet (Plt): Cells in the blood that are responsible for clotting.

Predisposed (or Predisposing Factor): Having an unusually high risk of a developing a disease. For example, "predisposed to developing cancer."

Primary Tumor: The original tumor

Prognosis: A prediction of what might happen in a specific case of disease.

Progression or Progressive Disease: Cancer that is growing, spreading, or getting worse.

Prostate-Specific Antigen (PSA): A protein produced by the prostate. Levels of PSA usually rise in men with prostate cancer. The PSA test, which measures the levels in blood serum, is used to detect prostate cancer and to monitor the results of treatment.

Protocol: A treatment plan.

Psychiatrist: A medical doctor who specializes in preventing, diagnosing, and treating mental, emotional, and behavioral disorders.

Psychologist: A specialist who can talk with patients and their families about emotional and personal matters, and can help them make decisions.

Psychosocial: The psychological, social, and spiritual aspects of human activity, such as the care of people with a disease.

Radiation Oncologist: Doctor who specializes in using radiation to treat cancer.

Radiation Therapy: X-ray treatment that damages or kills cells. The dose is recorded as Grays (Gy) or as Centigrays (Cgy).

Radiologist: A doctor who specializes in creating and interpreting pictures of areas inside the body. The pictures are produced with x-rays, sound waves, or other types of energy.

Recurrence: The return of cancer cells and signs of cancer after remission.

Red Blood Cells (erythrocytes): Cells in the blood that bring oxygen to tissues and take carbon dioxide from them.

Regression: Growing smaller or disappearing. Used to describe shrinkage or disappearance of a cancer.

Rehabilitation: In medicine, a process to restore mental and/or physical abilities lost to injury or disease, in order to function in a normal or near-normal way.

Rehabilitation Hospital or Rehabilitation Center: A facility providing therapy and training for *rehabilitation*. The center may offer occupational therapy, physical therapy, vocational training, and special training such as speech therapy.

Rehabilitation Specialist: A health care professional who helps people recover from an illness or injury and return to daily life. Examples of rehabilitation specialists are *physical therapists* and *occupational therapists*.

Relapse: Same as recurrence.

Remission: The disappearance of cancer symptoms; having no evidence of cancer. When this happens to a person, he or she is said to be “in remission.”

Response: An improvement related to treatment. Response rate is the percentage of patients whose cancer shrinks or disappears after treatment.

Complete Response: All signs of cancer disappear in response to treatment. This does not always mean the cancer has been cured. Also called complete remission.

Partial Response: A decrease in the size of a tumor, or in the extent of cancer in the body, in response to treatment. Also called partial remission.

Rounds: The act of seeing patients in the hospital or another *inpatient* setting.

Route of Administration: The way in which a drug is given, for example, by mouth or by injection.

Sarcoma: This is a type of cancer that starts in a bone, nerve, muscle, or blood vessel (as opposed to an organ like the liver or lung).

Second Opinion: Examination of a patient and/or patient’s records by another doctor to get an additional treatment recommendation.

Secondary Cancer: Cancer that has spread to a part of the body other than the site of the primary (original) cancer. Secondary cancer, also called *metastasis*, is usually made up of the same type of cells as the original tumor. However, a second primary cancer is one that is located in a part of the body other than the site of the original cancer and has a different cell type.

Segmental Mastectomy (Lumpectomy): Removal of the lump and a small amount of surrounding breast tissue.

Sex Therapist: A psychiatrist, marriage and family therapist, psychologist, or clinical social worker who is specially trained to use talk therapy to assist individuals and couples experiencing sexual dysfunction (problems).

Side Effects: Problems that occur when treatment affects healthy cells. Common side effects of cancer treatment are fatigue, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.

Skilled Nursing Facility: An establishment that houses chronically ill, usually elderly patients, and provides long-term nursing care, *rehabilitation*, and other services under the supervision of a physician. Also called *long-term care facility*, nursing home.

Skin Patch: A bandage-like patch that releases medication through the skin and produces a steady dose of medicine into the blood stream.

Social Worker: A professional trained to talk with people and their families about emotional or physical needs, and to find them support services.

Sperm Banking: Freezing sperm before cancer treatment for use in the future. This procedure can allow men to father children after loss of fertility.

Sputum: Mucus and other matter brought up from the lungs by coughing. Sputum cytology is the examination under a microscope of cells found in sputum. The test checks for abnormal cells, such as lung cancer cells.

Staging: Performing exams and tests to learn the extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of the body. It is important to know the stage of the disease in order to plan the best treatment.

Stem Cell Transplant: See peripheral stem cell.

Sterile/Sterility: See infertile.

Stoma: A surgically created opening from an area inside the body to the outside.

Supportive Services or Support Services: Nonmedical services a person with cancer or his or her family might need. Supportive services may include child care, transportation, financial aid, support groups, homemaker services, and other services.

Surgical Oncologist: A doctor who specializes in cancer surgery.

Surgical Relocation (Ovaries): An operation to protect ovaries from damage by moving one or both ovaries away from an area of the pelvis that will receive radiation therapy.

Survivor (as in “cancer survivor”): Anyone who has received a cancer diagnosis, whether treatment is being received or has been completed.

Survivor Guilt: Some people who have had cancer may experience feelings of guilt for having survived the disease while others did not.

Systemic: Throughout the body.

Targeted Therapy: A type of treatment that uses drugs or other substances to identify and attack specific cancer cells. Targeted therapy may have fewer side effects than other types of cancer treatments.

TENS Unit: A machine that uses low-frequency electrical stimulation for relief of pain. “TENS” stands for “transcutaneous electrical nerve stimulation.”

Therapeutic Radiology: The use of radiation to reduce or cure disease.

Thrombocytopenia: An abnormally low number of platelets (thrombocytes). If the platelet numbers are too low, bleeding could occur.

Tissue: A group of cells.

Tolerance: Drug tolerance occurs when a person's reaction to a drug decreases so that larger doses are needed to achieve the same effect.

Toxicity: The extent to which something is poisonous or harmful.

Toxin: A poison made by certain bacteria, plants, or animals, including insects.

Transdermal: Through the skin.

Tumor: Cells that group together and keep growing and crowding out normal cells. A tumor can be benign (not cancer) or malignant (cancer).

Tumor Grade: A system used to classify cancer cells in terms of how abnormal they look under a microscope and how quickly the tumor is likely to grow and spread. Grading systems are different for each type of cancer. Tumor grade is not the same as *cancer stage*.

Tumor Markers: Substances found in abnormal amounts in the blood, in other body fluids, or in tumor tissue of some patients with certain types of cancer.

Ultrasound: Diagnostic imaging technique using sound waves to create an echo pattern that reveals the structure of organs and tissues.

Urologic Oncologist: A doctor who specializes in treating cancers of the urinary system.

Urologist: A doctor who specializes in diseases of the urinary organs in females and the urinary and sex organs in males.

Ventilation: The process through which oxygen and carbon dioxide are exchanged between the lungs and the air; also refers to the use of a machine to carry out this process in someone who cannot breathe on his or her own.

Visualization: A mind-body practice where mental images are used to focus energy on relaxation or healing. In visualization, a person focuses on a particular scene or situation with an intent to relieve stress or receive healing. Some *complementary and alternative medicine* practitioners use visualization with cancer patients to attempt to relieve symptoms, or as an addition to cancer treatment.

White Blood Cells: General term for a variety of cells responsible for fighting invading germs, infection, and allergy-causing agents. Specific white blood cells include granulocytes and lymphocytes.

SPECIAL GLOSSARY ON INSURANCE TERMS

Appeal: A second level of review by a managed care company of a patient's complaint if the plan was unable to address acceptably the complaint in the first review.

Capitation: The fixed fee paid to a primary care doctor for the care of each member of the insurance plan who selects that doctor as his or her primary care provider. The fee is paid regardless of services actually provided. *It is important to know whether you are in a capitated health insurance arrangement with your primary care doctor. In capitation, the doctor must absorb the costs that exceed the capitated amount. If you are in a capitated health plan, ask your doctor if this will have any impact on the type of care he or she can provide. Will it affect the number or type of diagnostic exams ordered? Will it affect any decision about hospitalization?*

Case Manager: A person hired by your insurance company or hospital to evaluate your ongoing care.

Claim: In health insurance, an itemized statement of services and costs from a health care provider or facility submitted either by the provider or the patient to an insurance company for payment.

Co-payment: A cost-sharing requirement in which the patient pays a certain charge for a health care service, such as \$15 for each office visit.

Deductible: The amount of money that a patient must pay each year before the insurance plan pays for eligible benefits.

Denial: When the insurance company will not pay for medical care that will be or has been provided.

Donut Hole: The Medicare Part D coverage gap — or the Donut Hole — is the difference of the initial coverage limit and the catastrophic coverage threshold. After a Medicare beneficiary surpasses the prescription drug coverage limit, the beneficiary is financially responsible for the entire cost of prescription drugs until the expense reaches the catastrophic coverage threshold.

Exclusive Provider Organization (EPO): The insured person must select providers from a limited list. Going to a provider not on this list may cost the insured from 20% to 100% of the costs incurred.

Fee for Services: This is the traditional method of insurance in which the providers (doctors and hospitals) are paid after they provide services.

Gatekeeper: The role played by the primary care doctor in managed care plans to control how patients use other services in the plan.

Group Practice: An association of health care professionals who share premises and other resources.

Health Care Alliances (HCAs): Prepaid health care plans that provide treatment of acute and chronic conditions; also promotes preventive care and wellness programs. HCAs may require all care be provided by a limited group of providers. The patient generally must pay the cost of services secured outside the HCA without prior approval.

Health Maintenance Organizations (HMOs): Prepaid health care plans that provide treatment of acute and chronic conditions; also promotes preventive care and wellness programs. HMOs may require all care be provided by a limited group of providers. The survivor generally must pay the cost of services secured outside the HMO without prior approval.

HMO Staff Model: Uses single hospital and employs salaried doctors who do not work outside the HMO.

HMO Independent Practitioner Associations (IPAs): Uses larger number of hospitals and doctors.

Hospitalist: A physician who specializes in the delivery of comprehensive medical care to hospitalized patients.

Individual or Solo Practice: Medical practice by a single physician. Also called a solo practitioner.

Integrated Delivery System: Hospitals, doctors and providers who work together to provide most appropriate, cost effective, quality care.

Managed Care: Managed care is a type of health care delivery and health care insurance that aims to provide a more systematic health care at a reasonable cost. It does this by setting prices to be paid to care providers for their services and to vendors who provide supplies and equipment. Managed care plans control which doctors and treatments enrolled members can use.

Medicaid Managed Care: States obtain a waiver (permission) under the Social Security Act to enroll Medicaid recipients in a managed care plan. The states administer these plans or contract with private insurers to manage the plan. *The quality of Medicaid managed care plans varies from state to state.*

Medicare Part A (Hospital Insurance): Covers inpatient care in hospitals (includes critical access hospitals, inpatient rehabilitation facilities, and long-term care hospitals) and covers skilled nursing facility (not custodial or long-term care), hospice, and home health care services.

Medicare Part B (Medical Insurance): Covers doctor services and outpatient care and some preventive services to help maintain a person's health and to keep certain illnesses from getting worse. Part B usually covers 80% of the Medicare-approved amount for covered services.

Medicare Part C (Medicare Advantage): A way to get Medicare benefits through private companies approved by and under contract with Medicare. Part C includes Part A, Part B, and usually other benefits Medicare doesn't cover. Most plans also provide prescription drug coverage.

Medicare Part D (Prescription Drug Coverage): Covers the cost of prescription drugs and is run by private companies approved by Medicare. Each plan can vary in cost and drugs covered.

Network of Health Care Providers: Doctors, hospitals, labs, and other health care workers who contract with managed care companies to provide care of the customer (patient).

Ombudsman: An official of government or an organization (such as a health plan or hospital) whose role is to help resolve disputes between consumers (including patients) or employees and the organization.

Out-of-pocket: The portion of payment that the patient is required to pay. This includes co-payment, monthly premium, and deductibles.

Point of Service: A health benefit system with some features of both PPO and HMO. A POS plan allows patients to choose to go to non-network provider for lesser reimbursement benefit. *The amount of patient co-payment may be 20% to 100% of costs. Survivors should check the terms of their policy to find out the specific amount of reimbursement for non-network providers.*

Preferred Provider Organization (PPO): A network based indemnity plan (see fee for service) that lowers participants' deductibles and copayments if they choose to use contracted preferred providers. Generally there is a system of utilization review by a third party.

Premium: The fee paid, usually monthly, by a person to an insurance company or managed care plan in order to receive health care services that will be paid for by the health plan.

Primary Care Physician/Provider (PCP): A board-certified or board-eligible family practice, general practice, internist, pediatrician or gynecologist chosen by each insured person when she or he joins a managed care delivery system. All services provided are done so by, or with the approval of, the PCP. *Also referred to as the "gatekeeper" to the managed care delivery system.*

Prior review (or prior authorization): When the primary care doctor must obtain authorization (approval) for emergency care, hospital admissions, surgical procedures, referral to specialists, and certain medical tests and procedures. In some cases, a second opinion is required before surgery will be approved.

Retrospective Review: Utilization review to determine appropriateness of care after the care has been provided. *Reimbursement may be denied following a retrospective review. The decision of the insurer may be appealed by the doctor, the insured, or by other care providers.*

Tiered Pharmacy: Pharmacy co-payment benefit levels that cover different types of prescription drugs. In a three-tiered system, the co-payment for generic drugs is usually the lowest; the second level includes preferred medications on the formulary list; and brand-name drugs typically have the highest co-payment at tier three.

Traditional Indemnity Plan: Insurance plan that pays doctors and providers retrospectively for the amount they bill after services have been provided. There is no restriction in choice of provider. Also called indemnity plan or fee for service.



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

The power of survivorship. The promise of quality care.

NATIONAL COALITION FOR CANCER SURVIVORSHIP
1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
877.NCCS.YES
www.canceradvocacy.org