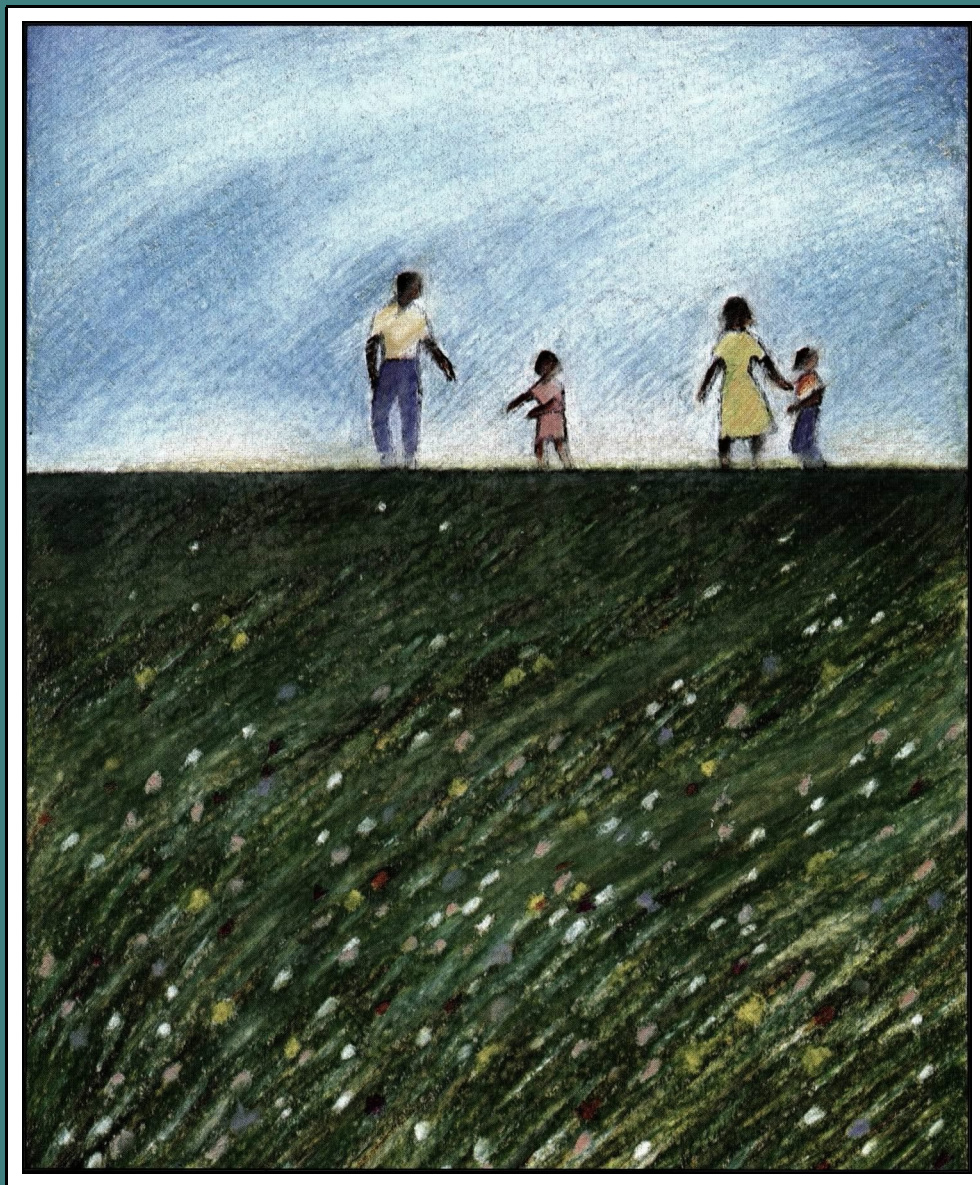


# Taking Time

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SUPPORT FOR PEOPLE WITH CANCER  
AND THE PEOPLE WHO CARE ABOUT THEM



NATIONAL INSTITUTES OF HEALTH  
National Cancer Institute

Look to this day,  
For it is life,  
The very life of life.  
In its brief course lie all  
The realities and verities of existence,  
The bliss of growth,  
The splendor of action,  
The glory of power—

For yesterday is but a dream,  
And tomorrow is only a vision.  
But today, well lived,  
Makes every yesterday a dream  
of happiness  
And every tomorrow a vision of hope.

Look well, therefore, to this day.

*Sanskrit Proverb*

# Taking Time

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## **SUPPORT FOR PEOPLE WITH CANCER AND THE PEOPLE WHO CARE ABOUT THEM**

**T**his book is dedicated to the many people with cancer and their family members whose letters, thoughts, and perceptive comments provided the basis for it. They shared with us their insights into the special problems people with cancer face and the ways in which they have found the courage to cope with them. It could not have been published without exceptional editorial and clerical assistance from several people as well. Our heartfelt thanks go to everyone involved.

Each chapter begins with a brief summary of the main points. You may want to review the summaries first and then read entire chapters as you feel ready.

Note: Today many of us find ourselves far from family ties. A circle of close and loving friends may act as “substitute family” for our blood relatives. If this is true for you, think of these friends when the book refers to family members and think about sharing the book with them.

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service  
National Institutes of Health

# Introduction

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“**A** diagnosis of cancer . . . is a powerful stimulus against procrastinating on warm and kindly or beautiful things . . . a reminder that many of the material things aren’t all that urgent after all . . . Take time to watch the sunset with someone you love; there may not be another as lovely for the two of you.”

These are the thoughts of a woman with cancer who needed to share her feelings with someone who would care and who could understand.

This book is written for those affected by cancer: you, someone in your family or someone very close to you. We wrote this book because, as another person described it, we often feel that “we share a common bond that only victims of cancer know, the feelings of anguish and the loneliness no one else can share.”

We’ve used letters, conversations, books and articles from, with, and by cancer patients, families and friends. The observations of professionals who work with cancer patients as expressed in conferences, seminars, and journals also have been explored. Our main emphasis, though, is on what the people who live with cancer in their own lives and their own homes think, feel, and do to cope with the disease.

No two people with cancer are alike as are no two relatives or friends of people with cancer. Although the material in this book is intended to be helpful, some sections may not apply to certain circumstances; a few might suggest responses that make you feel uncomfortable. Each person has to cope with cancer in an individual way. What follows is intended as a guide: a brief look at how some people with cancer and their loved ones feel and the ways they found to deal with those feelings.

Perhaps, if we explore together our emotions—a side of cancer that neither surgery, drugs, nor radiation can treat—we can help each other dispel some of those feelings.

People with cancer, dear friends, and family members face intense fears, anxieties, and frustrations that are new to many of us, although others have taken the journey we now begin. We travel a road paved with an awesome mingling of hope and despair, courage and fear, humor and anger, and constant uncertainty. Perhaps, sharing the experiences of those who have walked the road before will help us define our own feelings and find our own ways of coping.

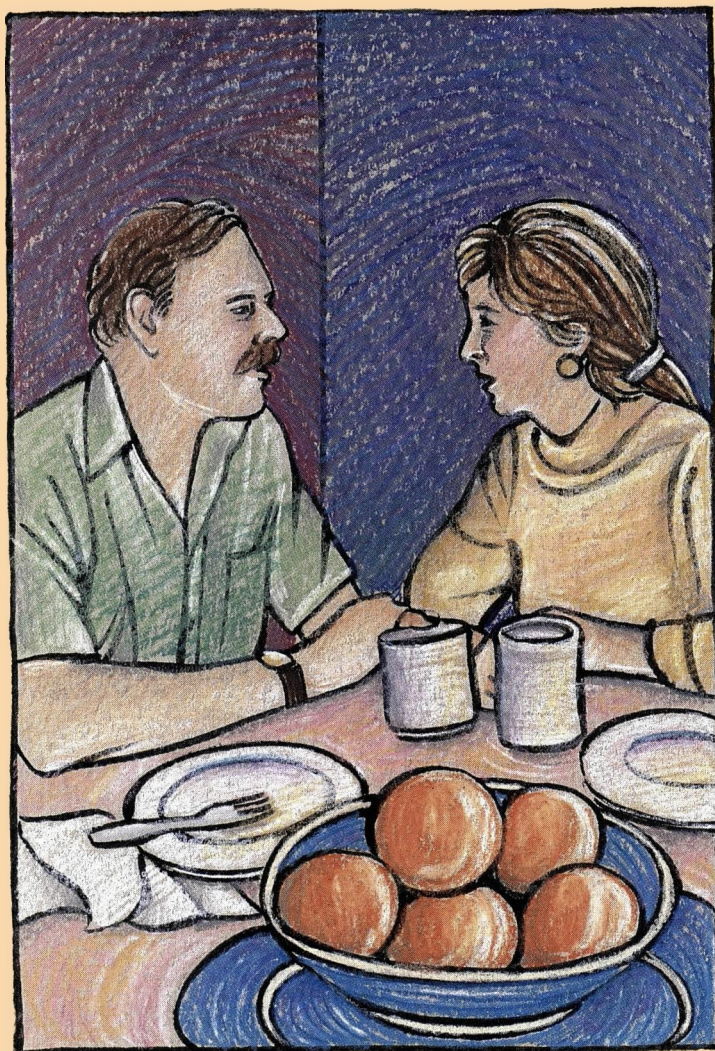
Our bodies and minds are not completely separate. It will help us keep our bodies strong if we also deal successfully with the emotional turmoil of cancer. We shall talk about some of the emotional problems we might face and some possible adjustments. We'll explore learning to express and share our feelings about cancer, dealing with new responsibilities, coping with rejection by others, finding new meaning in our days, and using each day to its fullest measure.

There is another good reason for learning to define and live with our feelings about cancer. They may be with us for a long time. Cancer is undeniably a major illness; it is not necessarily fatal. Over 7 million Americans alive today have a history of cancer. For them cancer has become a chronic condition, somewhat like hypertension, diabetes, or a mild heart condition. As is true for others with chronic conditions, periodic health checkups will be part of their lifelong routine. They will, undeniably, be more sensitive to, and anxious about, minor signs of illness or discomfort. Unlike others with chronic disease, they most likely will not need lifelong medication or special diets to remind them daily that they once were ill. Many will live for years, grow old and die much as they had expected to do before cancer was diagnosed.

It is hard not to think about dying, but it's important to concentrate on living. Remember, a diagnosis is not

a death sentence. Many cancer patients will be treated successfully, and many others will live a long time after the diagnosis before dying with the disease. Indeed, there are sunrises as well as sunsets to be enjoyed. So let us take a look at living–living with cancer and its treatment, but living nonetheless.

# Sharing the Diagnosis



■ Cancer can be unutterably lonely. No one should try to bear it alone.

■ Patient, family, and friends usually learn the diagnosis sooner or later. Most people find it easier for all if everybody can share their feelings instead of hiding them. This frees people to offer each other support.

■ Patients usually agree that hiding the diagnosis from them denies them the right to make important choices about their life and their treatment.

■ Families say patients who try to keep the diagnosis secret rob loved ones of the chance to express that love and to offer help and support.

■ Family members and intimate friends also bear great emotional burdens and should be able to share them openly with each other and the patient.

■ Even children should be told. They sense when something is amiss, and they may imagine a situation worse than it really is.

■ The patient might want to tell the children directly, or it may be easier to have a close friend or loving relative do so.

■ The children's ages and emotional maturity should be a guide in deciding how much to tell. The goal is to let children express their feelings and ask questions about the cancer.

■ By sharing the diagnosis, patient, family, and friends build foundations of mutual understanding and trust.

One question many people ask after diagnosis is, “Should I tell?” Perhaps not. A family member could be too old, too young, or too emotionally fragile to accept the diagnosis, but people are surprisingly resilient. Most find ways to deal with the reality of illness and the possibility of death- even when it involves those they love most. They find the strength to bounce back from situations that seem to cause unbearable grief.

The way in which people differ is in the speed with which they bounce back. The diagnosis of cancer hits most of us with a wave of shock, of fright, of denial. Each person needs a different amount of time to pull himself or herself together and to deal with the reality of cancer. In reading the sections that follow, you should remember that only you really know your emotional timetable. Think about sharing at a time when you are ready to do so.

## Should You Tell?

Usually, family and close friends learn sooner or later that you have cancer. Most people with cancer have found the best choice is to share the diagnosis and to give those closest to them the opportunity to offer their support. They have found it easier, in the long run, to confide their fears and hopes rather than trying to hide them. Of course, you must use the words and timing that you find comfortable to tell family and friends that you have cancer. We will talk more about that in the next chapter.

If you have no family, it is especially true that the road appears less lonely when shared with a few close friends. You might lose one or two. Some people will find it too difficult to talk with you or to be around you, and they will slip away. On the other hand, you may discover hidden strengths and compassion in the least likely of companions.

A woman with cancer wrote, “As for whether or not people should keep their illness a secret, I think they will learn with whom they can talk. Some people make themselves scarce if cancer is mentioned. But, cancer patients soon learn who their trusted friends are.”

Another person said, “I don’t think a cancer patient should keep it to himself. If it isn’t revealed, family and friends are robbed of the opportunity to share the feelings and anxieties that arise from having the disease. At most, life is very short for everyone. Because there are no guarantees, we should make the most of each day.”

On a practical level, trying to hide the diagnosis is usually fruitless. As you move from hope to despair and back again, family and close friends will sense something is deeply troubling you, even before they learn the facts. When you feel ready, try to share your news with them.

As you ponder whether you can share the diagnosis of cancer with others, it might help to remember the following. In telling the people you love that you have cancer, you give them the opportunity to express their feelings, to voice their fears and hopes and to offer their hand in support. Then, each can give and take strength as they are able.

## **When Family Must Decide**

Sometimes family members are the first to learn the diagnosis. If, as a family member, the decision falls to you, should you tell the patient? Some might think not, but most people with cancer disagree. “I think a cancer patient should be told the truth,” one wrote. “Time is so valuable, and there may be things the person would like to accomplish. There are decisions to be made . . .”

All of us have important life choices to make. People with cancer often find these choices become crystal clear when they feel their life span could be cut short.

They might outlive any one of us, but people with cancer have the right to know and decide how they will spend their remaining days. There are exceptions to any generalization, but most people relate that “Mom took the news much better than we thought she would.”

A woman who herself has cancer recalled how things have changed since her mother was diagnosed in 1930. “My relatives never told my mother ‘that she had cancer. Of course, then, they didn’t have the treatment they have available now. Looking back I realize no one fooled her. In not telling her, though, she was deprived of a very valuable outlet for her emotions.’”

Family members also bear great emotional burdens during the period of diagnosis. They, too, need the comfort of sharing their feelings. Yet, it is almost impossible to support the rest of the family if you are hiding the diagnosis from the person with cancer. He or she inevitably learns the truth. The consequences can be deep anger, hurt, or bitterness. The patient might believe that no one is being honest about the diagnosis because the cancer is terminal. On the other hand, while you are trying to “spare the patient,” the person with cancer might be trying to protect family and friends from learning the truth. Then each ends up suffering alone, with thoughts and feelings locked within.

### **Somehow Children Know.**

Even children sense the truth. Some parents who tried to “spare” their children from knowing later voiced regret at not discussing the truth during the course of the disease. Children have amazing capabilities when they understand a situation. However, when their normal world is turned upside down and whispered conversations go on behind closed doors, they often imagine situations that are worse than reality. Young children dwell on “terrible” things they

have done or said that place responsibility for the upheaval in the household on themselves. This is especially true if the child is going through a period of testing parental authority or in some other way is in disagreement with family members. Children, especially young ones, tend to view themselves as the center of the universe and see many situations only in direct relationship to themselves.

The children's ages and emotional maturity should suggest what and how much to disclose. It might help to realize that including the children, among those who know, comforts them by confirming their belief that something is amiss within the family.

A parent with cancer might want to tell the children directly. "I've been sick a lot lately, haven't I? I have a disease called cancer. The doctors are doing everything they can to make me well. I can't spend as much time with you as I wish to; it's going to be hard on all of us, but I still love you very much."

Perhaps this is too painful. A close and loving aunt or uncle or friend might be able to explain things more comfortably. "Your daddy is ill. The doctors are almost sure they can make him well, but sometimes his treatments make him feel sad or grouchy. It's nothing you children have done, but he needs your patience and understanding."

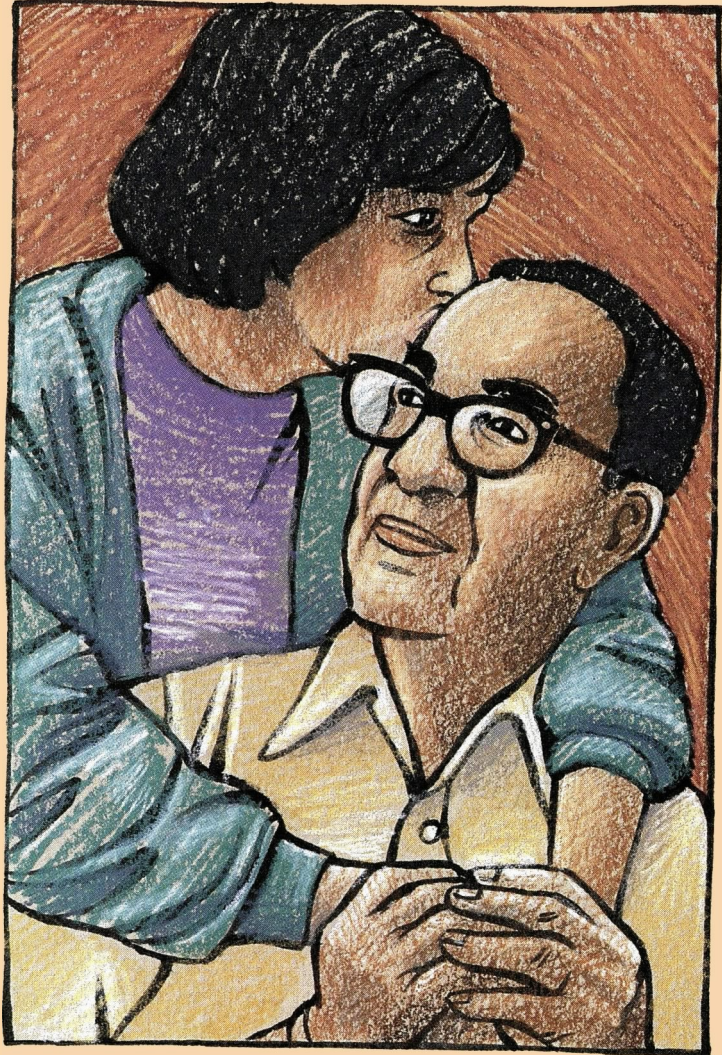
The goal in telling the children that someone in the family has cancer is to give them opportunities to ask questions about the disease and to express their feelings about it. Of course, all of us want to shield our children from pain, but pain they understand is easier for them to cope with than hurts that they imagine. Some adults tell us that they still remember the feelings of rejection they suffered as children of cancer patients. As children they were aware of great disruption within the family, but at the time they were denied knowledge of the cause. They were hurt and confused by what seemed to be lack of attention and unreasonable demands or expectations.

## Sharing Mutual Support

We begin to see that the most compelling reason for sharing the diagnosis with adults and children alike is that cancer can be so terribly lonely. No one need try to bear it alone. At times you will feel totally without ally or solace, regardless of supports. There is no need to increase these moments with poses meant to convince others close to you that you do not need their help. At a time when each of us who is trying to cope with cancer is in need of mutual support, we should not shut each other out. Through sharing we can build foundations of mutual understanding to sustain us through the long period ahead. We can share anxiety and sorrow, but we also can share love and joy and express our appreciation for each other in ways we ordinarily might find difficult or embarrassing.



# Sharing Feelings



■ Some in the family are able to absorb the impact of diagnosis sooner than others. This can create clashing needs as some wish to talk and some need to be private and introspective.

■ Verbal and nonverbal clues help determine when is a good time to discuss the illness and how each will learn to live with it.

■ If family members cannot help each other, other emotional support systems are available in the form of support groups or professional counselors.

■ The person with cancer has the primary right to set the timetable for when he or she is ready to talk. Others can encourage that readiness through their love and continued presence.

■ Talking may include expressing anger, fear, and inner confusion.

■ False cheeriness—the “everything will be all right” routine—denies the person with cancer the opportunity to discuss fears and anxieties.

■ Emphasizing the uniqueness of each person, positive test results, or good response to treatment is true support, both valid and valuable.

■ The person with cancer needs family or friends as a constant in a changing world. “I’m here,” offers great reserves of support.

## Emotional Timetables

Sometimes, the whole family suspects the truth before the diagnosis is made. Someone recognizes the symptoms, or the family doctor seems overly concerned. Nonetheless, hearing those words—tumor . . . cancer . . . leukemia—we are stunned as we never may have been in our lives. It is often impossible to take in the diagnosis immediately. We hear it, but somehow we don't believe it. This is normal. People's minds have a wonderful capacity for absorbing information only as they are ready to accept it.

All of us may not operate on the same emotional timetable. One of the family might feel the need to talk about the cancer before the others come to grips with it. Each of us has to decide when we are ready to talk; none should feel forced to do so.

This sometimes creates clashing needs—some need to talk; others need to be private and introspective or even to shut the whole subject out of their minds for a while. The desire to respect privacy may be pitted against an equal need to get the whole thing out in the open.

In some families everyone becomes overly considerate of everyone else's needs for time to adjust. Instead of meeting anyone's needs, everyone avoids one another, building walls just when they ought to be opening doors to communication.

It is important to let the person who has cancer call the signals for when it's time to talk. But, it is always helpful to look for clues to determine when might be a good time to discuss the cancer and how to live with it.

Signs such as apparently idle conversation, more time than usual spent with other family members, or even unusual nervousness might indicate that a person wants to talk but doesn't know where to begin. Yet, facing cancer together makes it easier. It eliminates the need for pretense when there are so many important matters to address. As you talk, you should

## Consider Your Needs

try to be sensitive to what family members or friends say, how they position their bodies, and whether or not they make eye contact. These clues suggest whether the conversation is serving a purpose or driving someone you care about into hiding.

Some people cannot adjust their feelings and cannot help each other. Not all families can be open and sharing, and during a crisis is a difficult time to adjust family patterns. Nonetheless, the situation may not eliminate the need to air feelings. This is the time to turn to one of several sources outside the family for emotional support. These are described in the chapter “When You Need Assistance.”

When cancer is first diagnosed, some patients can absorb only the most basic information, and even that might need to be repeated. That’s normal. We each have the right to digest information at our own pace and determine when we are ready for more, and when we are ready to talk about what we know or want to know.

If others in the family want to talk about cancer before you are ready, try to postpone the discussion without rejecting the person. “I appreciate your concern but not yet. I can’t talk yet,” for example, suggests that the day will come when you will be ready to talk. Taking care of your own needs, which are great, while trying to recognize the fears and anxieties of those you love is not easy.

The period right after diagnosis is often a time of anger, fear, and inner confusion. You might need to sort out conflicting emotions before you can express them. Or, you might find yourself lashing out, wishing to find a target for anger and frustration. Often it is those closest who bear the brunt of these outbursts. You don’t want to hurt them, but you may be angry that they will live and you might die. Perhaps you assume that they will understand and endure the rage.

Family members have feelings, too. They may lash back, expressing their own anger and hurt at your

outbursts, at the possibility of losing you, at the burden of new responsibilities or at their powerlessness to change the reality of the disease. As you express your own feelings, try to remember that others need the same release.

## The Family Adjusts

The period following diagnosis is a difficult time of adjustment for family members. Each has to deal with individual feelings, while trying to be sensitive to those of the person who has cancer. Being part of the family doesn't mean you can make people talk about their feelings before they are ready, but you need outlets, too. There are ways to encourage openness. Be ready to listen when others are ready to talk, and let your continued presence show your support. But remember, the person with cancer gets to set the timetable.

If the decision is to talk, you may find yourself the target for a lot of anger and frustration. It is easier to *tell* yourself that you are not the cause of this hostility than it is to *accept* this. You know you should respond with patience and compassion, but sometimes you answer anger with anger. Even these exchanges can have value if everyone learns through them to share feelings.

The opposite of anger may be false cheer. In trying to bolster the person with cancer, you may actually cut off his or her attempts to express feelings. Remember that lifting the spirit doesn't mean hiding from the truth. Sensing despondency, some people rush in with assurances that "everything will be all right." But everything is not "all right." If you insist it is, you deny the reality of the patient's world. In response, he or she may withdraw, feeling deserted and left to face an uncertain world alone. Without meaning to, you've abandoned the one you hoped to help and set up patterns that can be difficult to change just when support is so important. Although the cancer may be controlled, the gulf between you may endure.

It may help the one with cancer to know that you share the same fears and anxieties about the

uncertainty of the future. People who honestly share these feelings find they can hold them to the light, better accept that the future may be questionable, and turn more readily to fulfilling the present. This is a very difficult period, but if you can share the difficulties, you will find there are more good days to enjoy together. And you are less likely to be devastated by truly difficult ones.

## **Finding Hope**

There are ways to find hope during periods of despondency or despair. We all need to remember the individuality of each case. We tend to get caught up in statistics and averages, but no two cancers ever behave exactly the same way. Each individual has different genes and an immune system, a distinctive will to live, and an urge to fight. These cannot be measured on charts or graphs. No one can offer any of us “forever,” but there are good prognoses; with an increasing number of cancers, the outlook is good for successful treatment. You can look to promising test results and to treatments that previously have been effective in many people. Even if the future is guarded, there may be another remission, good days, comfortable nights, and shared experiences. These are real beyond any statistics. The enjoyment of life’s gifts constitutes living, not the number of days we are given in which to enjoy them.

There are safeguards against hopelessness even if there is no real cause for hope. You can still provide reassurance of continuing love and comfort. At times, “I’m here” may be the two most supportive words you can say.

## **Listening, Sharing, Being Yourself**

There are different ways in which you can be important as a family member or friend. You can listen to expressions of feeling or act as a sounding board for a discussion of future plans. You can help focus anger or anxiety by helping to explore some of the specific causes, including drug reactions, the job situation, and

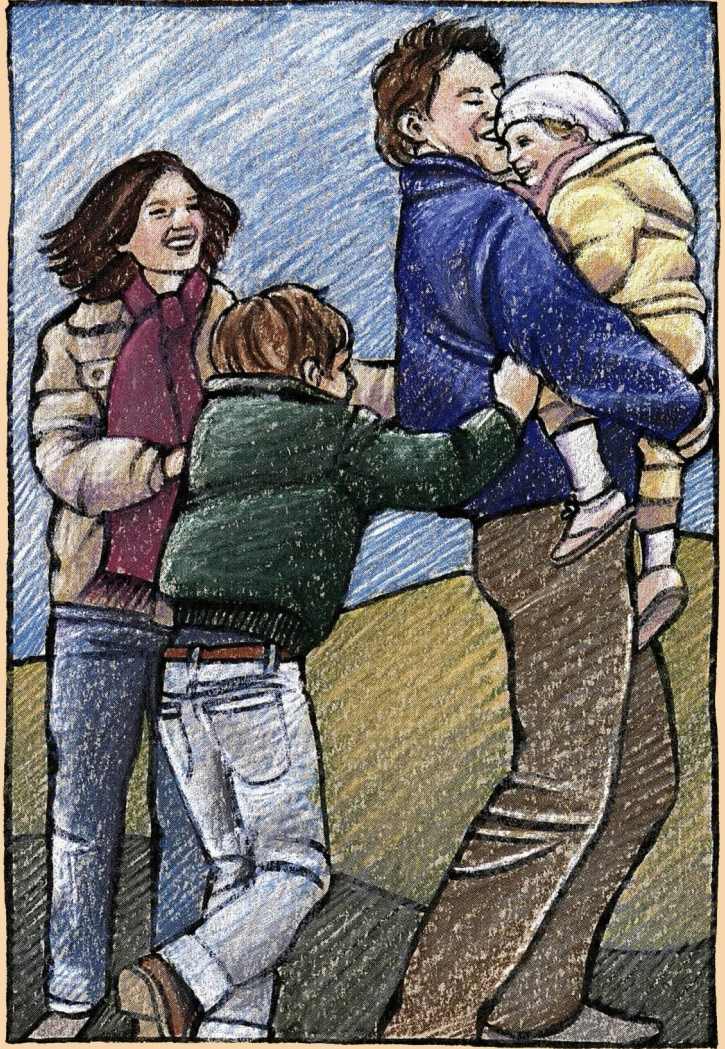
finances. This may be what is needed-someone to listen, to react and absorb the patient's outpourings, not necessarily to "do" anything. It is a difficult role, but it can be immensely rewarding.

There is a more passive but equally difficult role. Some cancer patients view theirs as a private battle to be fought alone with only their physicians as allies, and they prefer to fight their emotional battles alone as well. But they need family and friends for silent support, as respite, shelter, or an island of normalcy. It can be draining to provide "safe harbor" from a day in the clinic or nights of sleepless panic. It can be a struggle to be forced to plan an evening out, to ask friends in, or simply to stand by with wordless support. However, there may be times when this is what is needed most.

Many people think they don't know "how to act" with people with cancer. The best you can offer is to be natural, to be yourself. Let your intuition guide you. Do what you comfortably can do; don't try to be someone you are not. This in itself is comforting. Dealing with cancer entails enough mystifying changes without having to adapt to a new you.



# Coping Within the Family



■ Cancer is a blow to every family it touches. How it is handled is determined to a great extent by how the family has functioned as a unit in the past.

■ Problems within the family can be the most difficult to handle; you cannot go home to escape them.

■ Adjusting to role changes can cause great upheavals in the way family members interact.

■ Performing too many roles at once endangers anyone's emotional well-being and ability to cope. Examine what tasks are necessary and let others slide.

■ Consider hiring professional nurses or homemakers. Financial costs need to be compared with the physical and emotional cost of shouldering the load alone.

■ Children may need special attention. They need comfort, reassurance, affection, guidance, and discipline at times of disruption in their routine.

## Not Everyone Can

**A**lthough cancer has “come out of the closet,” much of what we read in newspapers and magazines is about the disease itself—its probable causes or new methods of treatment. There is little information about how families deal with cancer on a day-to-day basis. This gap reinforces feelings that families coping with cancer are isolated from the rest of the world: that everyone else is managing nicely while you flounder with your feelings, hide from your spouse, and are incapable of talking to the children.

Cancer is a blow to every family it touches. How you handle it is determined to a great extent by how you have functioned as a family in the past. Families who are used to sharing their feelings with each other usually are able to talk about the disease and the changes it brings. Families in which each member solves problems alone or in which one person has played the major role in making decisions might have more difficulty coping.

Problems within the family can be the most difficult to handle simply because you cannot go home to escape them. Some family members deny the reality of cancer or refuse to discuss it.

It is not uncommon to feel deserted or to feel unable to face cancer openly. “My brother-in-law is suffering from cancer,” one man confided. “The entire situation is depressing, and my reaction has been one of running and hiding. I have not visited them for I feel I have nothing to offer.”

A woman with cancer found none of her family could help her. “My two wonderful sons tolerated their dad’s heart surgeries very well, but now I have cancer, and they don’t know how to act. Phone calls and letters expressing sympathy are not what I need. I’ve tried since last November to express my thoughts to my husband, but he shuts out what I’m saying. I know that he’s uncertain about our future, but I can’t seem to get through to him; I’ve learned from other patients that it’s a common concern.”

In these situations individual counseling or cancer patient groups can provide needed support and reinforcement. Moreover, these resources provide an outlet for the frustrations you are facing within the family.

## Changing Roles

Families may have difficulty adjusting to the role changes that are sometimes necessary. One husband found it overwhelming to come home from work, prepare dinner, oversee the children's homework, change bedding and dressings, and still try to provide companionship and emotional support for his children and ill wife.

In addition to roles as wife, mother, and nurse, a woman might have to add a job outside the home for the first time. A spouse who was sharing the load sometimes becomes the sole breadwinner and homemaker. The usual head of the household might now be its most dependent member.

These changes can cause great upheavals in the ways members of the family interact. The usual patterns are gone. Parents might look to children for emotional support at a time when the children themselves need it most. Teenagers might have to take over major household responsibilities. Young children can revert to infantile behavior as a way of dealing with the impact of cancer on the family as a unit and on themselves as individuals. The sheer weight of responsibility can become insurmountable, destroying normal family associations, devouring time needed for rest and recreation, and depriving family members of wholesome opportunities for expressing anxiety and resentment.

## The Health of the Family

Performing too many roles at once can endanger emotional well-being and the ability to cope. Examining what's important can solve the problem. For example, you can relax housekeeping standards or learn to prepare simpler meals. Perhaps the children can take on a few more household chores than they have been handling.

If a simple solution is not enough, consider getting outside help. Licensed practical nurses can help with the patient; county or private agencies might provide trained homemakers. If outreach is an important part of your church, feel free to ask for help with cooking, shopping, transportation, and other homemaking tasks. One family was adopted by the daughter's Scout troop when the girls learned of the extra responsibility she had assumed. Everyone benefited from the relationship.

Let someone who can be objective help you sort out necessary tasks from those that can go undone. The financial cost of professional services needs to be compared with the emotional and physical cost of shouldering the load alone. You also may be able to obtain assistance from hospital, community, or self-help groups or from a clergy member. It is important to remember that the family is still a unit. If the family strength is sapped, the patient suffers, too.

The San Diego chapter of Make Today Count, a mutual support group for patients and families, compiled a "Bill of Rights for the Friends and Relatives of Cancer Patients." Several items address the problems of family burdens:

*The relative of a cancer patient has the right and obligation to take care of his own needs. Even though he may be accused of being selfish, he must do what he has to do to keep his own peace of mind, so that he can better minister to the needs of the patient.*

*Each person will have different needs . . . These needs must be satisfied. The patient will benefit, too, by having a more cheerful person to care for him.*

*The relative may need help from outsiders in caring for the patient. Although the patient may object to this, the relative has the right to assess his own limitations of strength and endurance and to obtain assistance when required.*

*. . . When the relative knows that he is already doing all that can reasonably be expected of anyone in caring for*

*the patient, he can have a clear conscience in maintaining contacts with the rest of the world.*

*If the patient attempts to use his illness as a weapon, the relative has the right to reject that and to do only what can reasonably be expected of him.*

*If the cancer patient's relative responds only to the genuine needs of the moment—both his own needs and those of the patient—the stress associated with the illness can be minimized.*

Increased burdens and shifting responsibilities can occur whether the patient in the household is a spouse, a child, or an elderly parent. Each family member must take care to meet his or her own needs and those of the other healthy members of the family as well as those of the patient.

## Help for the Children

Children might have difficulty coping with cancer in a parent. Mother or Dad may be gone from the house—in a hospital that may be hundreds of miles from home—or home in bed, in obvious discomfort, and perhaps visibly altered in appearance.

In the face of this upheaval, children often are asked also to behave exceptionally well: to “play quietly,” to perform extra tasks or to be understanding of others’ moods beyond the maturity of their years. The children may resent lost attention. Some fear the loss of their parent or begin to imagine their own death. Some children, formerly independent, now become anxious about leaving home and parents. Discipline problems can arise if children attempt to command the attention they feel they are missing.

It may help if a favorite relative or family friend can devote extra time and attention to the children, who do need comfort and reassurance, affection, guidance, and discipline. Trips to the zoo are important, but so is regular help with homework and someone to attend the basketball awards banquet. If your efforts to provide support and security fail, professional counseling for a child, or child and parent together, may be necessary and should not be overlooked.

# When You Need Assistance



■ When cancer develops, many people need to learn to ask for and accept outside help for the first time. These are good ways to begin:

■ Take time to ask medical questions of your doctor, nurse specialists, therapists, and technologists.

■ Make lists of questions. Write or tape-record the answers. Take someone else along as a second listener.

■ Ask your physician to suggest other doctors if you wish a second opinion on your diagnosis before deciding on treatment.

■ Ask your physician about alternative treatments if you have questions about them.

■ Physicians wait for clues from their patients to determine how much to say. Let your doctor know whether you want to know everything at once or in stages.

■ Remember that there is a difference between a physician who does not know that cancer need not be fatal and one who will not promise you a miracle.

■ Trust and rapport between patient and physician are important; you must be able to work together to treat the cancer most effectively.

■ Your physician, hospital, library, the National Cancer Institute or affiliated Cancer Information Service offices, and local chapters of the American Cancer Society are good sources of facts about cancer. Many also can provide the names of local support and service organizations established to help you cope with the emotional stresses of the disease.

■ Emotional assistance takes many forms. Counseling or psychiatric therapy for individuals, for groups of patients, and for families often is available through the hospital or within the community.

■ Many groups have been established by patients and their families to share practical tips and coping skills. One may be right for you.

■ Your minister or rabbi, a sympathetic member of the congregation, or a specially trained pastoral counselor may be able to help you find spiritual support.

Which one of us did not feel that the world had stopped turning when cancer struck us? But somehow each day goes on. During the period of active treatment a pressing number of decisions need to be made, questions must be answered and arrangements handled.

There are medical questions. There might be confusion or disagreement over the diagnosis—what did the doctor say; what do various terms mean; what is the outlook for recovery?

Financial burdens can be crushing. Transportation to and from treatment can seem a major, frustrating obstacle. Where does one get a hospital bed, a night nurse, a person to look after the children?

The stress of handling such responsibilities can be enormous. A new kind of communication and acceptance becomes necessary: asking for and accepting outside help, which is an entirely new role for some. People who were raised to believe that “going it alone” indicated maturity and strength now might have to overcome their distaste for appearing to be in anything less than total control.

Some simply do not know where to turn. You might feel uncomfortable asking for help—even from those agencies that were designed precisely for emergencies such as you now face. So, where do you turn?

## **The Health Care Team**

Physicians or nurses are good sources of answers to medical questions. It’s helpful to write down on a sheet of paper all questions you have about cancer, its treatment, any side effects from it, or any limitations treatment may place on your activities. (Incidentally, there may be surprisingly few limitations other than those caused by changes in physical capability.) Other members of your treatment team, such as physical therapists, nutritionists, or radiation therapists, can explain the “whys” of these aspects of your therapy.

## Asking Important Questions

Writing questions down makes them easier to remember at the next doctor's appointment. It's also helpful to call the office beforehand to alert the receptionist that you will need extra time for your appointment. This time around you can be better prepared to retain the answers. Some people take notes; others bring a tape recorder, or a clear-thinking friend or relative. The point is to depend on something more reliable than your own memory at a time when emotions are likely to overwhelm intellect.

Fear of being thought ignorant or pushy has kept many people from asking their doctors about a most important topic- the alternative treatments they read about in the tabloids or hear about from friends. You may be urged by well-meaning people to try methods that will "spare you any pain or discomfort." Yet they are never available through your cancer specialist. If you are being pressured to abandon the care you are now getting, but haven't discussed it with your doctor because you think you will insult "establishment medicine," you might try this approach. "I keep hearing about the bubblegum treatment for cancer. Can you tell me why it isn't accepted by most American doctors? Why do some people think it works, and why do you believe it won't?"

What you have asked for is information. You haven't attacked the treatment you are getting now or the professionals who are giving it to you. And if you are comfortable with the answers you get, it will help you respond when you are urged to try these methods.

Too many fail to ask the medical questions most important to their physical and emotional well-being through a fear of "taking up the doctor's valuable time." Some say, "I'm sure he told me all this once before." Of course, you want to be a "good" patient or a "cooperative" family member! But it's also true: It's your body. It's your life. It's also true that a well-informed patient

is better able to understand his or her therapy, its possible side effects, or any unusual signs that should be reported to the doctor.

A good approach can be simply to admit that you are asking for a repeat performance. “I’m pretty sure you told me some of this before, but I couldn’t remember anything; I was so shocked. Now, I think I’d feel less anxious if we talked about it.”

Some are ready to hold this conversation sooner than others. Some ask a few questions at a time, absorbing each piece of information before they are ready to go on. Some never ask directly. (If so, someone in the family should speak with the doctor to learn the extent of disease and the outlook for the future.) But sooner or later, in whatever way you find comfortable, it’s important to let the doctor know that you understand you have cancer and want to talk about it.

In an ideal world, physicians all would be patient, understanding and able to sense your every mood. They would know when to bring out all the X-ray films and lab tests and when to draw only the sketchiest picture of your case. They would have unlimited time to wait until *you* were ready to ask questions, and then they would gently help you to phrase them in just the right way.

As a matter of fact, books for cancer specialists—physicians, nurses, therapists—and courses in the health professional schools are beginning to emphasize the importance of recognizing the feelings of the person with cancer. Nonetheless, each person is different, and no textbook can describe your unique needs.

In the real world physicians admit that they wait for clues from you, the person with cancer. *They* need to know what the patient wants to know. Physicians are not mind readers. Whether you like it or not, it is usually up to you to take the first steps toward open communication with your doctor.

## Changing Doctors

Some physicians never have learned to speak comfortably with patients or families who are facing what might be a life-threatening illness. These physicians may appear to be abrupt, aloof and uncaring, although they are not. Nonetheless, if their discomfort creates a barrier, you might be wise to seek referral to someone else. When fighting cancer you have to work as a team. Lack of trust is fair neither to you nor the doctor. It is fair, however, to let the doctor know you wish to see someone else—even to ask him or her for a referral. The physician probably is as aware as you that a relationship based on trust and open communication has not been established.

It is also appropriate to ask your physician to suggest other doctors if you wish a second opinion on the diagnosis before deciding on treatment.

There still might be a physician here or there who believes that all cancer is fatal and that “nothing can be done.” In such a case it is only common sense to ask for referral to a cancer specialist.

Most family physicians practicing now, know that nearly half the patients who get cancer today will live out their lives free of further disease, and others can be provided an extended time of reasonable comfort and activity. While continuing as the personal physician, they usually will refer their patients to cancer specialists—surgeons, radiologists, or medical oncologists—for active treatment. (It’s something like an orchestra conductor calling on the soloists while keeping the whole orchestra playing together.)

You need to be honest with yourself and recognize the difference between a physician who believes all cancer is fatal and one who believes the outlook for a particular case is not good. Refusing to promise complete cure is not the same as forsaking the patient.

A physician who uses all available methods to treat the disease, to minimize its effects, and to keep you comfortable and functioning as long as possible is doing everything he or she can to care for your physical needs. How frustrating it is, then, when you seek to relieve your emotional aches and pains, to be rebuffed

## Information Resources

by the same otherwise excellent specialist. As one man put it, “I found it impossible to discuss the nitty-gritty facts with my doctors and the radiation therapist. I felt that if I told the radiologist how fearful I was, I would be considered childish.” Nonetheless, a decision to change physicians should be based on reality and not on a quest to find a doctor who will promise a cure and guarantee to relieve all your fears.

It’s easier to come to grips with the reality of any crisis if we replace ignorance with information. There is much to learn about each form of cancer, its treatment, the possibility for recovery, and methods of rehabilitation. Well-versed in the facts, you are less likely to fall prey to old wives’ tales, to quacks touting worthless “cures,” or to depressing stories of what happened to “poor old Harry” when he got cancer. Often, the more you know, the less you have to fear.

Local libraries, local divisions of voluntary agencies such as the American Cancer Society, and major cancer research and treatment institutions are sources of information about cancer and its treatment. Depending on the degree of your desire for information and your ability to understand scientific terms, you can get everything from short, concise pamphlets to scientific papers. It’s a good idea to share the fruits of your research with your own doctor. Cancer is a complex set of diseases; the treatment and its side effects may differ slightly for each person.

On a national level, the National Cancer Institute (NCI), which is part of the National Institutes of Health, operates an information office for the public. Its information specialists can answer many general questions about cancer, its diagnosis, and treatment. In addition, the NCI coordinates a network of information offices among the nation’s top cancer research and treatment centers, the Cancer Information Service (CIS). CIS counselors can provide the names of facilities that are most appropriate in terms of

both geography and specialization. They also have written materials and information about local self-help and service organizations for cancer patients and their families.

The NCI specialists also maintain lists of excellent cancer hospitals outside the CIS network that are conducting federally funded research in new methods of cancer treatment. They can suggest not only institutions but also specialists with whom your own physician might wish to consult. However, information staff members cannot offer medical advice or arrange for referral to a specific physician or institution.

## **Emotional Assistance**

It is said that we cope with cancer much as we cope with other problems that confront us. Many do come to terms with the reality of cancer. After initial treatment, they find somehow they are able to continue their normal working and social relationships. Or, as one psychologist put it, they learn to get up in the morning and pour the coffee, even knowing that they have cancer. They find, sometimes to their amazement, that they can laugh at bad jokes, or become totally absorbed in a good movie, or a hard-fought football game.

At other times, strength deserts them. They feel overwhelmed by this new world of uncertainties. Some lose interest in favorite hobbies or activities, viewing them as painful reminders of what will be lost if treatment is unsuccessful. They want to cope, but they need help, some support systems beyond their own. Where does one look for such support?

## **At the Hospital**

It was not very long ago that emotional assistance for the cancer patient or family was impossible to find. Attention to emotional needs is a relatively recent addition to standard cancer treatment. Growing numbers of hospitals routinely include a mental health professional as a member of the cancer treatment

team or offer group counseling programs. This is a hopeful sign; it says, "This diagnosis does not mean imminent death. We have a whole person to treat here, one with a future and a life to live. This person should be able to live as normally as possible. We must provide the emotional tools to get the job done."

Counseling also is now available for health professionals to help them face feelings of frustration and uncertainty in their work. They have recognized the awesome degree of stress that cancer can create in those it touches. You should have no feelings of shame or hesitancy, then, if you feel the need to seek professional help.

Some hospitals consider some form of **group counseling** as part of the standard treatment—as necessary as an exercise class, for example. Programs are organized in a variety of ways. Many begin within days of surgery. Some groups meet only for the length of the hospital stay; others are long-term to enable members to work through problems in the everyday world. Some are composed of people with the same disease site (breast or colon cancer patients); some by type of treatment (in-hospital surgery or outpatient radiation therapy); and some by patient age. Some are just for patients; others include spouses, family, or other special people.

Groups can incorporate music, poetry, or role-playing in attempts to help members explore their feelings. Some are action-oriented with "veteran" patients helping others now facing the same problem. All counseling groups should be run by trained professionals so that the direction of exploration is truly helpful to each participant.

## In the Community

If you want to explore your feelings in **individual therapy**, you will find a growing number of psychologists, psychiatrists, or licensed clinical social workers specializing in counseling people affected by cancer. Many find it helpful to explore feelings—especially those they don't want to accept, such as guilt, resentment,

and intense anger—with a person who, without judging them, will help them understand these feelings and find ways to channel them constructively.

Often the problem is not an individual one. The family is a unit, and each member is affected when any one member is. **Family counseling** can help absorb the shock and deal with the stresses of cancer.

It can be difficult for persons with cancer and their family members to discuss their emotions. Cancer patients themselves have tagged the absence of open communication within their families as a major problem. People are particularly hesitant to express negative feelings when no one is “at fault.” Yet major shifts in responsibilities such as those cancer brings to a family can cause great resentment by those shouldering (or incapable of shouldering) extra burdens. A loss of accustomed responsibility or authority also can cause resentment mingled with anxiety over a loss of power.

Children, especially, find that their usual roles no longer are defined clearly. Parents may not have the emotional energy to provide the usual support, love, and authority. Teenagers can feel torn between expressing independence and a need to remain close to the sick parent.

These problems become less difficult to face if the family can discuss them. Some can do this without outside help. Those who cannot should feel comfortable in seeking professional assistance.

Your physician, a hospital social worker or hospital psychologist are good sources for referrals to psychologists, psychiatrists, or other mental health professionals trained to counsel individuals and families affected by cancer. Many county health departments include psychological services, and neighborhood or community mental health clinics are becoming common in increasing numbers of cities. Community service organizations such as the United Way usually support mental health facilities. County government listings in the telephone book may include an “Information and Referral” listing, one more resource for counseling services.

## Helping Each Other

There are numerous **self-help groups** organized by people like you and designed to help you overcome both the practical problems of cancer and the feelings these changes cause. Some groups are local chapters of national organizations; others are strictly “grass roots.” Some are only for patients; others include family members.

These organizations shun a “pity me” approach. They exist to help you work through your feelings and frustrations. Whether you accept them or change them, you can do so within the framework of a supportive group of people who know your problems firsthand.

Some offer family members an opportunity to share feelings, fears, and anxieties with others bearing similar burdens. Some provide patients a place to express negative feelings that they don’t want to unload on their families. Patients without families can speak openly and release their pent-up emotions without fear of taxing existing friendships.

Some support groups provide skills training and helpful tips for special sets of patients such as those who have had a laryngectomy, ostomy, or mastectomy. Organizations designed to offer emotional support nonetheless can provide opportunities to exchange practical information, such as how to control nausea from chemotherapy or how to talk to an employer about cancer.

A self-help group can give those recovered from cancer an opportunity to aid those who have cancer. With training, some become group counselors or discussion leaders. Many former cancer patients have found that helping others gives a marvelous and oft-needed boost to their own self-esteem. (That can be so important after a long stretch of feeling dependent on and at the mercy of physicians and hospital staff.)

Mutual assistance groups sometimes work with health professionals and the clergy to help them understand the special emotional needs of people with cancer.

## Spiritual Support

**Religion** is a source of strength for some people. Some find new faith in their divine being and new hope from their sacred writings when cancer enters their lives. Others find the ordeal of disease strengthens their faith, or that faith gives them new-found strength. Others never have had strong religious beliefs and feel no urge to turn to religion at such a time.

Members of the clergy in increasing numbers are completing programs to help them minister more effectively to people with cancer and their families.

Individual pastors can provide hope and solace, but they vary, as do physicians and lay people, in their capacity to cope with life-threatening illnesses and the possibility of death. A religious leader untrained in illness counseling may refer you to an associate trained to work with people with cancer. He or she also might introduce you to another member of the congregation who can provide comfort and, perhaps, more time on a regular basis than the leader of a congregation can spare.



# Selves and Self-Images



■ Cancer treatment can extend over weeks or months; side effects may come and go.

■ Side effects can make you feel rotten, even make you think the cancer has returned.

■ The known is less frightening than the unknown. Learn about your cancer, its treatment, and how to treat possible side effects.

■ Fears and anxieties caused by cancer can affect a sexual relationship. Remember: Cancer is not catching. And cancer or other chronic illnesses are rarely the cause for infidelity in a good relationship.

■ Treatment might make you feel uncomfortable about your body and sexually unattractive. Open discussion of these feelings with your mate is very important.

■ Intangible personal qualities make up a great part of your attraction for your mate. These have not changed with treatment.

■ Spouses sometimes hesitate to initiate physical contact. Support, love, and affection do include hugs and caresses. These may lead the partner with cancer to feel more comfortable about sexual intimacy.

■ Physical exercise improves body image and feelings of well-being.

■ Taking on new hobbies and learning new skills can bolster your good feelings about yourself.

■ Reconstructive surgery and well-made prostheses help some people overcome physical disabilities and emotional distress.

■ If you cannot seem to regain good feelings about yourself, do seek professional counseling or therapy.

■ If your relationship is endangered by the stress of cancer, get professional help. You need each other at this time.

## When Treatment Brings You Down

Cancer treatment is nearly always aggressive. Surgery can be disfiguring. Radiation or drug treatment may be prescribed following surgery to ensure that no hidden, microscopic cancer cells are left to travel to other parts of the body. Treatment can extend over weeks or months, and its side effects can include nausea, hair loss, fatigue, cramps, skin burns or weight changes. It is not unusual for the treatment to cause more illness or discomfort than the initial disease. The cancer patient has to contend with emotional reactions to such treatment and side effects.

It is difficult to convince yourself that you are recovering when you feel absolutely rotten. It is hard to be optimistic when you feel worse now than at the time of diagnosis. The schedule of radiation or drug treatments may seem endless. You are convinced that there never was a day when you didn't feel awful; there never will be one when you will feel normal—if only you could remember how normal feels.

Some even interpret these physical reactions to treatment as signs that the cancer is returning. This is rarely the case, although it may be necessary to remind yourself of this fact again and again. Feel comfortable in sharing such anxieties with your doctor.

A return to the hospital setting for outpatient treatment causes anxiety for some. Researchers studied a group of women undergoing radiation therapy following breast cancer surgery. They found that the women felt better psychologically immediately after leaving the hospital after surgery than they did once followup treatment began. It can be unsettling, indeed, to return again and again to the hospital or physician's office, places which may have come to represent the most frightening aspects of cancer.

You can try to plan special activities for the days when you feel well and brace yourself for the days when you feel awful. It's helpful to others and easier for you if you inform people that treatment may cause shifts in moods. You can let them know matter-of-factly that you will have up days and down days.

The known is usually easier to cope with than the unknown. It is important to be familiar with each treatment's side effects and its causes. Not only does knowledge reduce fear, but some side effects can be eliminated (or at least eased) through treatment changes, medication, or changes in diet. There is no need to be more uncomfortable than is absolutely necessary. Written materials with information on what to expect in the way of side effects from treatment usually are available from your physician or treatment center. However, the best way to obtain accurate information about your own situation is through a frank and thorough discussion with the nurse or physician administering treatment.

This brings us back to the problem of busy, unresponsive health professionals. If your physician has been less than helpful, try one of the information resources or special support groups referred to in the previous chapter. Ask one more nurse, one more oncology resident. As one of our "expert patients" wrote, "Look for assistance wherever you have to when you need it. It's a mistake to give up when rebuffed or disregarded by any one individual. There is always a source of comfort somewhere. One has only to look for it." Comfort and, we might add, information.

## **What About Sex?**

The problems and emotional stresses of cancer might follow you into the bedroom. Some couples arrange the financial matters and handle the day-to-day tasks, only to find that sexual problems threaten their relationship. There are a variety of reasons for such problems.

A few people still have the mistaken belief that cancer is contagious. One man complained, "My wife won't kiss me anymore. She thinks cancer is catching." Fact: Cancer is not catching. If your mate believes it is, call your physician. You may feel embarrassed discussing sex, but this is too important a problem to let modesty stand in the way of a solution.

Infidelity, or more likely fear of it, can present a problem. Exploring these fears with your mate is probably the best way to deal with them. If you admit that you are plagued by uncertainty and insecurity, you probably will receive the needed support and affection and can lay your doubts to rest.

Some cancer patients cite disfiguring treatment as a cause of sexual problems. You need to deal not only with discomfort or disability but also with what this change in your body has done to your feelings about yourself. As awkward as it may seem, you need to find ways to communicate those feelings to your partner. An inability to express them may complicate an already difficult period.

## Body Images

Each of us develops over the years an image in our mind about our body. We may not be completely satisfied with that image, but usually we are comfortable with it when with someone we love. This helps us feel sexually attractive to our mate. Disfigurement, hair loss, nausea, radiation burns—even fatigue—can destroy your good feelings about your physical appeal. If you now believe you are unattractive, you might anticipate rejection and avoid physical contact with your partner. It is well to remember that in most cases your partner is more concerned about your well-being than his or her own. The overriding reactions probably begin with, “Will treatment succeed?” “How can I show my love and support?” . . . and, only finally, “What about sex?”

In reality, your partner may be afraid to appear overeager and therefore insensitive. So it may be up to you to show a desire for physical contact and to let it be known whether you are interested in sexual intercourse as well as other expressions of affection—hugging, caressing and kissing.

It might help to keep in mind that it’s not only your body that makes you “sexy.” There are also intangible qualities that your mate finds attractive. A sense of humor, intellect, a certain sweetness or great common

## **Rebuilding Mind and Body**

sense, special talents, loving devotion—each of us knows what makes us special; and it's more than anatomy. If you feel you have lost those special qualities along with a breast or leg or prostate gland, counseling may help you change that perspective.

Time, along with demonstrations of love, understanding and affection by your partner and family should help you work through feelings about your changed body image. In addition, some find that physical activities—sports, dancing classes, exercise, or judo—improve their sense of being in touch with their bodies. A ballet teacher who has had a mastectomy is teaching other women the feeling of grace and balance that comes from dance.

“After I took up yoga,” another woman exclaimed with some surprise, “I achieved a sense of wholeness about my body—even without one breast— that I had never had before.”

People who take on a challenging activity that moves them beyond a disability—skiing for amputees for example—find it can provide a whole new sense of self-worth. “Can you believe, I have more pride in this ragged body than I did when it was all there?” asked a tennis ace, who took up the game after his colostomy.

Poetry, music, painting, furniture building, sewing, and reading provide creative growth of which you can be equally proud. If anything needs strengthening it is our personal self-image. Acquiring new interests and talents can help develop that strength.

## **Physical Restoration**

Reconstructive surgery or cosmetic and functional prostheses (artificial devices) help some people with cancer overcome both physical disabilities and emotional distress from disfiguring surgery. A small but growing body of skilled craftsmen build prostheses for people who have had radical oral and facial surgery. These lifelike pieces enable people to go out in public again with some degree of emotional comfort. For some, they are the difference between silence and the

## What Spouses Can Do

ability to speak. For others, they put eating solid food back into the realm of possibility.

Women who have had a mastectomy can wear a breast form (prosthesis) or have breast reconstruction.

Most insurance companies cover restorative or cosmetic surgery and various prosthetic devices as a necessary part of the rehabilitation process. This is good news, for it is further recognition that cancer patients are entitled to as close to normal a life as possible. No longer are they asked to be grateful and satisfied just to be alive.

Disfigurement or debilitation caused by treatment can affect reactions to a partner with cancer. You expect to see beyond these physical changes to the person within, the one who more than ever needs your love and physical reassurance of that love. Nonetheless, you might find yourself responding negatively, unable to provide that support. You might feel awkward about physical contact because you think your partner is not ready for it and that you will be judged insensitive.

It helps to remember that touching, holding, hugging, and caressing are ways to express the acceptance and caring that is so important to the person with cancer. More than words, they show love and express your belief in the patient's continued desirability as a physical being.

Admittedly it is a difficult time. Beset by treatment reactions, anxiety, self-doubt, or a mistaken notion of what your feelings are, your spouse might withdraw from you. Together, try to prevent a cycle of misunderstanding from developing. As the well partner, try to

## Together as a Couple

feel sure in your love and reach out gently and repeatedly, if necessary, to provide the reassurance that cancer cannot destroy love.

If barriers begin to grow, perhaps a professional counselor can help you work out your reactions toward the patient, the disease or your feelings that too much of the responsibility has been placed upon your shoulders. Make sure you are doing whatever you can to reestablish bonds of closeness and caring.

Essentially, each of us' must deal with heartrending problems in ways that are compatible with our relationship. Facing this battle can strengthen everything that is good in it. Sometimes, it shows us how minor are problems once considered so important. However, cancer also can strain a relationship already stressed by other serious problems.

Sometimes the sexual relationship becomes the barometer of a marriage. In a mature relationship, sex is an expression of love, affection, and respect—not the basis for it. As one woman put it, "If a husband and wife had a good relationship before mutilating surgery, there is little basis for new problems. I contend this is an excuse not to have sexual relations or to seek a new, more exciting partner. The real reasons for problems were there before the surgery, just as the cancer was there before the diagnosis."

Most people find ways to face and overcome the stresses cancer places on their relationship. They find strength in each other, and they work together to establish a new and comfortable routine. Sharing their feelings with each other usually has been their first step toward finding effective solutions.

Sometimes a trained counselor can help you understand ways in which you can begin helping each other. Family therapists or licensed clinical social workers sometimes should be included in the personal cancer

treatment team. Support groups of other couples dealing with cancer can be helpful, even in dealing with intimate problems. The usual personal barriers often fall when you know you have sympathetic and experienced confidants who may be able to offer practical (and tested) guidance. Those who have found ways to maintain or recapture closeness and intimacy throughout this ordeal might be able to help others in a group setting.

# The World Outside



■ Some friends will deal well with your illness and provide gratifying support.

■ Some will be unable to cope with the possibility of death and will disappear from your life.

■ Most will want to help but may be uncomfortable and unsure of how to go about it. Help your friends support you:

■ Ask yourself, "Have friends deserted me or have I withdrawn from them?"

■ Telephone those who don't call you.

■ Ask for simple assistance- to run an errand, prepare a meal, come and visit. These small acts bring friends back into contact and help them feel useful and needed.

■ If you are alone, ask your physician, social worker or pastor to "match" you with another patient. Someone else needs friendships, too.

■ Groups of other cancer patients can offer new friendships, understanding, support, and companionship.

■ When you return to work, coworkers, like others, may shun you, support you or wait for your cues on how to respond.

■ There are laws to protect you against job discrimination.

## When Friends Don't Call

Anyone who has been affected intimately by cancer knows that it can change the pattern of our relationships outside the family as well as those within. Friends react as they do to other difficult situations. Some handle it well; others are unable to maintain any association at all. Casual acquaintances, and even strangers, can cause unintended pain by asking thoughtless questions about visible scars, artificial devices, or other noticeable changes in appearance.

One or two people within your circle may be gratifying in their devotion and in the sensitivity they show toward your needs. One woman said her mother-in-law found one or two close friends with whom she felt truly relaxed. They were not startled when she laughed nor ill at ease when she cried. With others she maintained an outward calm.

"I have three really good friends with whom I can talk about my cancer," explained another. "I have talked about dying with my sister, and she does understand a lot more than I thought a person without cancer could."

Lost friendships are one of the real heartbreaks people with cancer face. Friends do not call for a variety of reasons. They might not know how to respond to a change in your appearance. They might be avoiding you in order to avoid facing the possibility of your death and the eventuality of their own. Their absence does not necessarily mean they no longer care about you. Still, it is little comfort to know that "out there" you have friends if they have so little confidence in their worth as companions that they would rather say nothing than risk saying the wrong thing.

"I see that my friends don't know how to talk to me, and they shy away from me," wrote one person with cancer. "Most people are very ignorant on the subject of cancer."

If you believe discomfort rather than fear is keeping a particular friend from visiting, you might try a phone call to dissolve the barrier. Yet you cannot combat all

## Easing the Way for Others

the reasons why people avoid you; some still believe that cancer is contagious. Certainly, you cannot call them up and say, “Hey, get out of the Dark Ages. It’s not catching!”

Knowing that others are ignorant does little to lessen the hurt and frustration of being needlessly isolated. You only can change the attitudes of others if you are among them. Examine carefully whether friends shun you or whether you have withdrawn from your usual social contacts to protect your own feelings. You can neither enlighten nor draw comfort from an empty room. If possible, the best place to be is out in the world with other people.

Most people fall into a middle group, somewhere between the staunch friends and the “avoiders.” They are groping for an approach to cancer with which they can be comfortable. These people may say things which sound inane, insincere, or hurtful. You have to keep reminding yourself that they are trying their best. If you are open about cancer, they may relax, too.

A perceptive high school student explained, “I guess what I’m trying to say boils down to this. One of these days people may not feel so uneasy around a disabled person. I’m not bitter with people; I’m really quite at ease with them and strive to make them feel at ease with me. They feel afraid of me, and consequently trip over their tongues. I have learned a lot by living in a disabled person’s world and am quite willing to share it. One of these days, I may be given the chance.”

A woman who had had extensive surgery for oral cancer explained how she tried to lessen the discomfort of others without causing discomfort for herself. She focused on her disability rather than its cause.

“I am determined to put people at ease, so when I speak on the telephone, or to someone for the first time, I immediately say, ‘I have a speech defect, so please don’t hesitate to tell me if you don’t understand me.’ I also carry a pencil and paper and offer to write what can’t be understood. I find it much more frustrating

## Helping Friends Help

to have people try to save my feelings by pretending to understand me when they don't."

A man we know startled his fishing buddies, who were paying a group visit to his hospital room. He positively threw open the door to honest communication when he boomed out, "You know, I've learned one hell of a lot about cancer since I became a member of the club."

We can't all be that direct. He had been a straightforward man all his life. But he had let his friends know that he preferred talking about his cancer to pussyfooting around it.

Many times friends are waiting for some clue as to what behavior is appropriate. They might not be sure you want company. They might call to "see how things are going," then add as they hang up the phone, "Let me know if there's anything I can do to help."

These friends are asking for more than a job to do. They are asking for direction, giving you clues that they will not desert you if only they have some guidance on how to proceed. The next time friends or relatives offer assistance, try to look at the offer in that light. If you can think of one specific errand they can run, one chore they can take off your hands, you have done them and yourself a favor.

"Mother hasn't been out since Dad became ill. I think a Saturday afternoon at the shopping center would do wonders for her."

"We'll be at the hospital all day Thursday for chemotherapy. It would be such a help to me if you could whip up a casserole for our dinner."

"I don't feel much like talking these days, but if you'd bring your needlepoint and come sit with me, it would be pleasant to have your company."

Most people are grateful if there is something concrete they can do to show their continuing friendship. If such tasks bring them into your home, it gives them a chance to see that you are still living and functioning—not a funeral waiting to happen. Their next visit

## **Fighting Loneliness**

might be easier, and then they may be able to stop by without a “reason.”

Choosing to help friends in this way is no easy undertaking. When you feel stretched to breaking just keeping your own life going, it is difficult to extend your energies further to make others feel at ease. It can be a new and difficult experience for some, this reaching out, but the rewards can be exhilarating. We all feel better giving than receiving, so it might be easier if you think of your requests for assistance as letting others feel useful, rather than as petitions for help.

Regardless of what you do, your friends might desert you. Circumstances might have left you alone before cancer struck. This is a special, awful loneliness for any human being to endure. There are no easy answers, no pat solutions. The mutual support of other people with cancer might provide some solace and comfort. There probably are others in your community who need your companionship as much as you need theirs. Being housebound need not deprive you of visits from others who would like to share some quiet moments or some deeply felt sorrow with someone who will understand. A physician, social worker, visiting nurse, or member of the clergy should be able to help you contact another cancer patient or shut-in who could use company.

## **On the Job**

For many of us, work forms a cornerstone of life. In addition to income, it provides satisfaction and a chance to interact with peers. Returning to work as soon as you are physically able is one way to return stability to your life. If treatment has made it impossible to return to a former line of work, investigate the availability of rehabilitation and retraining programs within the community to prepare you for another occupation.

You might find on returning to your job that relationships with coworkers have changed. One person

with cancer found his associates had requested separate restroom facilities for him—that old “cancer is catching” myth again!

“If we pretend Jane never had cancer, it will go away” is the approach of many coworkers toward cancer patients when they return to work. This can be demoralizing. Some have found that if you look well and are able to function, people tend to underestimate the seriousness of your condition. They might mumble something like, “Glad you’re back; you look great,” and never ask how you really feel. In turn, you might find you resent their good health and nonchalance as you wonder what happened to the companionship you had looked forward to in returning to work.

The best you can do is assume that your coworkers, like so many others, are unsure of what to say or are trying to protect your feelings—or their own.

Others returning to work might be perfectly delighted with a rather cavalier attitude toward their condition. “Glad you’re back,” might be all you want to hear before plunging into your old routine. If you are being coddled at home, returning to a situation where others do not think of you as sick might be the greatest therapy yet devised.

Some people believe it eases relationships with coworkers if they are quite open about their condition. One young woman described in a speech to other cancer patients why she decided to tell about the cancer.

“Since my bones don’t cooperate, it’s hard for me to appear graceful, but I have a choice in this situation,” she said. “I can either move as though nothing is bothering me (while gritting my teeth and giving my contact lenses a salty bath), or I can move awkwardly in reasonable comfort. I think this is one of the reasons I don’t mind people knowing I have multiple myeloma. I keep having this flash of having died and having someone who just found out about the myeloma saying, ‘So that’s why she kept falling over.’”

If cancer treatment meant leaving your old job, discrimination may be a hurdle to returning to work. Even the person who is completely recovered may find it difficult to obtain employment. The rationale, one hears from indirect sources, is that people who have had cancer take too many sick days, are a poor insurance risk or will make coworkers uncomfortable.

How can you cope? You might begin with this information: Under Federal law (the *Federal Rehabilitation Act of 1973* and the *Americans with Disabilities Act* of 1990), most employers cannot discriminate against handicapped workers, including people with cancer. These laws apply to Federal employers, employers that receive Federal funds, and private companies with 25 or more employees (15 or more employees after mid-1994). The laws protect cancer patients in hiring practices, promotions, transfers, and layoffs. Every state also forbids discrimination based on handicap; however, only some of these state laws protect all people with cancer.

If you apply for a job with a government agency or a firm with government contracts and believe you did not get the job because of your cancer, you can file a complaint under Section 504 of the *Federal Rehabilitation Act of 1973*. You should write directly to the Federal agency involved. If you do not know the name of the agency that provides Federal funds to the employer, contact the Civil Rights Division of the U.S. Department of Justice, Washington, D.C., (202) 514-2151

If you believe you were discriminated against by a private employer because of your cancer, you should file your complaint with the closest regional office of the Equal Employment Opportunities Commission. To obtain the location of your regional EEOC office and find out exactly what to do, call the EEOC Public Information System at (800 USA-EEOC).

To find out more about your legal rights, check with:

- Your local American Cancer Society. Offices have state-specific information about cancer and employment discrimination.

- Your social worker. He or she may know about laws in your state and can also tell you which state agency is in charge of protecting employment rights.

- Your state's Department of Labor or Office of Civil Rights.

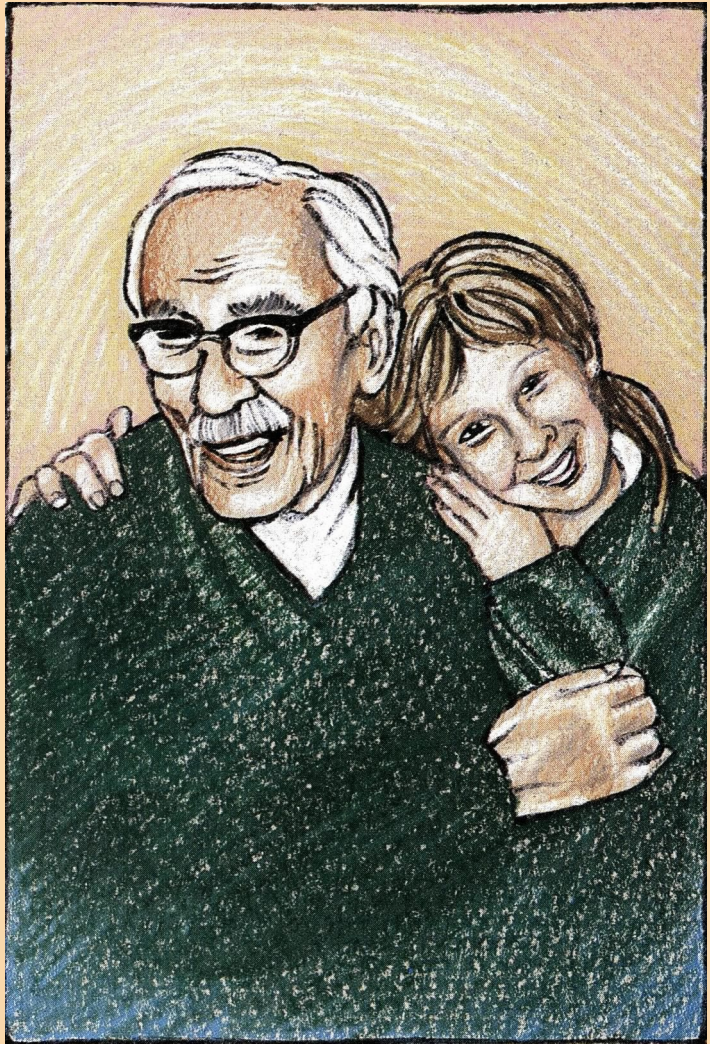
- The National Coalition for Cancer Survivorship. This organization offers information and limited attorney referrals.

- Regional or national offices of the American Civil Liberties Union.

- Your representative or senator. Congressional and senate offices have information about Federal and state laws. If you're not sure who represents your district, call your local library or local chapter of the League of Women Voters.



# Living Each Day



■ Each person must work through, in his or her own way, feelings of possible death, fear, and isolation. Returning to normal routines as much as possible often helps.

■ Give the pleasures and responsibilities of each day the attention they deserve.

■ Responsible pursuits keep life meaningful; recreation keeps it zesty. Fill your life with both.

■ Remember the difference between “doing” and “overdoing.” Rest is important to both physical and emotional strength.

■ It’s harder to bolster one’s will to live if you are alone. Yet many have acted as their own cheering squad and have found ways to lead meaningful lives.

■ Family members must not make an invalid of a person with cancer who is fully capable of physical activity and responsible participation in the family.

■ Family members should not equate physical incapability with mental failing. It is especially important that an ill patient feel a necessary part of the family.

■ Families must guard against “rehearsing” how they will act if the patient dies by excluding him or her from family affairs now.

Whether the outlook for recovery is good or poor, the days go by, one at a time, and patient and family must learn to live each one. It's not always easy. On learning the diagnosis, some decide that death is inevitable, and there is nothing to do but give up and wait. They are not the first to feel that way.

Orville Kelly, a newspaperman, described his initial battle with the specter of death. "I began to isolate myself from the rest of the world. I spent much time in bed, even though I was physically able to walk and drive. I thought about my own impending funeral and it made me very sad."

These feelings continued from his first hospitalization through the first outpatient chemotherapy treatment. On the way home from that treatment, he was haunted by memories of the happy past, when "everything was all right." Then it occurred to Kelly, "I wasn't dead yet. I was able to drive my automobile. Why couldn't I return home to barbecue ribs?"

He did, that very night. He began to talk to his wife and children about his fears and anxieties. And he became so frustrated at the feelings he had kept locked up inside himself that he wrote the newspaper article that led to the founding of Make Today Count, the mutual help organization for cancer patients and their families.

Each person must work through individual feelings of possible death, fear and isolation in his or her own good time. It is hard to overcome these feelings if they are never confronted head on, but it is an ongoing struggle. One day brings feelings of confidence, the next day despair. Many people find it helps considerably if they strive to return, both as individuals and as a family, to their normal lives.

Each day brings pleasures and responsibilities totally outside the realm of cancer. We should try to give each the attention it deserves. These are the threads of the fabric that enfolds our lives. They give it color and meaning.

The days can be more valuable if you can learn

to enjoy common moments as well as memorable occasions. This is true whether you have weeks or years left. It is true, in fact, whether you have a life-threatening disease or not. Physical well-being is closely tied to emotional well-being. The time you take out from attending to cancer strengthens you for the time you must devote to it.

## Staying Involved

When you have cancer, you need responsibilities, diversions, outings, and companionship just as before. As long as you are able, you should go to work, take the kids to the zoo, play cards with friends, go on a trip. Try to remember that responsible pursuits keep life meaningful, and recreation keeps it zesty. You need activities that give you a sense of purpose and those that provide enjoyment.

Some people find cancer is a spur to do the fun, adventurous, or zany things they've always wanted to do but have put off as being not quite responsible. That's a great idea. It helps ward off two overreactions—one is giving up, and the other is trying to cram a life's worth of responsible accomplishment into a very short time.

A young woman with cancer put it this way: "Too often we patients fill up our lives with meaningful activities and neglect the frivolous outlets that keep us sane. And we tend to forget how important our sense of humor is." She quotes Betty Rollin, author of *First You Cry*, as saying that cancer won't bestow a sense of humor on someone who doesn't have it, but a sense of humor can sure get you through the experience.

There is no scientific or medical proof for it, but cancer patients who have "places to go and things to do" seem to live longer—or at least they feel that life still stretches before them. "I'm in my own real estate business, started a year ago, and serve as an officer in eight civic organizations," a woman wrote. "Life has never been fuller, and for a 47-year-old grandmother, I've never felt stronger or better." Seven years earlier, her family had been told she had six months to live.

Others have combined humor with too much interest in life to let go of it. "Mine has been a long battle, but I'm not ready to call it quits yet," one such person declared. "I'm just too busy to schedule my demise, or maybe I just haven't the good sense to lie down and let it happen!" Many have found they cannot retire from living. It's much like employment—every day you show up, you may as well give it your best!

"Doing," it might be pointed out, is not the same as overdoing. Try to recognize your limitations as well as your capabilities. Fatigue can bring on crushing despair, and many people have found that as simple a safeguard as adequate rest fends off depression. Exhaustion weakens our physical and emotional defenses.

Pain also can make a mockery of attempts to function normally. Physicians have learned much about controlling pain, so all pain, especially if it is prolonged, should be discussed with your physician.

"Putting one's house in order" is a desire that strikes many who learn they have cancer. This is not the same as giving up. In fact, everyone needs to review insurance policies, update wills, and clean out the closets and drawers from time to time—and that gives you something constructive to do.

## Going It Alone

It is obvious that many of these remarks have been directed toward the person with cancer who is part of a family. Some live alone, however, and some feel they have no one to "live for." This increases loneliness and can make the will to live seem a bitter irony. They may want to pull the covers over their head and "get it over with." If you have no one else to provide encouragement, you have to act as your own cheering squad. It is hard, but it's not impossible.

An amazing gentleman of 73, who had been treated on and off for 8 years for Hodgkin's disease, described how he coped. "I kept on fighting. This is what you must do. Positive thinking and an active life are two

## Support From the Family

things which will do a great deal to relieve the tension.” In order to stay involved with life and mentally active, he enrolled in the university where he had received his bachelor of arts degree and began work on his master’s degree. “Some people think I’m crazy,” he admits. “Maybe I am, but it is a nice crazy anyway. At least, I have achieved happiness.”

An elderly woman decided to “start a new life, make what’s left of this one count.” She started helping a state school for the retarded, and her home became “a depot for people with used clothing and toys. Now I have branched out to helping with nursing homes. I am so busy and happy; I have no worries.”

Not everyone can go beyond themselves and give to others to this extent. You might not have the physical or emotional strength. It may not be natural to you, and you are still the same person you were. But many find cancer is easier to live with if they choose constructive ways to fill their time—to make part of each day count for what they can put into it.

The desire to “do something” is common among nearly everyone with a family member or dear friend who has cancer. There is nothing you can do to change the course of cancer, so you do everything you can for the person. Sometimes, doing everything is the worst course to follow.

People with cancer still have the same needs and often the same capabilities as they did before. If they are physically able, they need to participate in their normal range of activities and responsibilities—right down to taking out the garbage. Helplessness, or worse, an unnecessary feeling of helplessness, is one of the great woes of the person with cancer. In the words of one:

“I am deeply angry over the way patients (not only cancer patients but any patient with a life-threatening diagnosis) are automatically treated as if we were mentally incompetent. Our relatives have RIGHTS; we have none. This is by a sort of mutual consent, an

unconscious conspiracy which seems to be part of our culture. Let an individual become a patient . . . and he is treated, without any 'competency hearing,' as if he had been found in a court of law to be incompetent. Only the relatives are consulted or empowered to make decisions . . . ”

There is great bitterness in this woman's words, and they can stand as a lesson to all. Although bedridden, a patient probably still is able to discuss treatment options, financial arrangements, and the children's school problems. The rest of the family must make every effort to preserve as much as possible the patient's usual role within the family.

The least you can do is to keep the patient informed of necessary decisions. You can help the seriously ill patient ward off feelings of helplessness or abandonment if you continue to share your activities, goals, and dreams as before.

Few of us who are well know what it is like to be placed in a position of dependency. Cancer attacks one's self concept as a whole person as well as threatening one's life. Feelings of helplessness are real enough when one is flat on one's back. Make every effort not to compound them by ignoring the wishes of the patient, or worse, by trying to make an invalid of a person who is up and around. Pulling one's weight is good exercise.

## How the Family Copes

The needs of the family as a unit are important, too. Maintain normal living patterns within the family as well as possible. This is important for long-range as well as day-to-day coping. Sometimes, when the patient is in active treatment, family life becomes totally disrupted. If that happens, it is harder to resume functioning as a unit during periods of extended remission or permanent control.

“My worst emotional problem,” one patient said, “was finding that my improved health posed inconveniences and threw my family's plans all out of line.”

Understanding such a situation might help prevent it. There are many ways we cope with fear, anxiety and the threat of loss or death. One way is to begin preparing ourselves for an event by thinking about it, without being aware that we are doing so, as if it had already happened. Thus, we “rehearse” life as it will be so that we can assume our new roles more easily when the time comes. People do this throughout their lives, although usually they are unaware of it. For example, teenagers spend increasing amounts of time with friends rather than with family, “rehearsing” for the time when they will go out on their own.

When a family member has cancer, you may be “rehearsing” the future in your own mind. You might begin to “practice” how the family will function if that person dies. Watch for signs that you are excluding the patient and turn the routine back toward normal if you are. Knowing that these things happen, however, try not to feel guilty if you find yourself emotionally out of step with remission or recovery.

# The Years After

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**C**ancer is not something anyone forgets. Anxieties remain as active treatment ceases and the waiting stage begins. A cold or a cramp may be cause for panic. As 6-month or annual checkups approach, you swing between hope and anxiety. As you wait for the mystical 5-year or 10-year point, you might feel more anxious rather than more secure.

These are feelings we all share. No one expects you to forget that you have had cancer or that it might recur. Each must seek individual ways of coping with the underlying insecurity of not knowing the true state of his or her health. The best prescription seems to lie in a combination of one part challenging responsibilities that command a full range of skills, a dose of activities that seek to fill the needs of others, and a generous dash of frivolity and laughter.

You still might have moments when you feel as if you live perched on the edge of a cliff. They will sneak up unbidden. But they will be fewer and farther between if you have filled your mind with thoughts other than cancer.

Cancer might rob you of that blissful ignorance that once led you to believe that tomorrow stretched forever. In exchange, you are granted the vision to see each today as precious, a gift to be used wisely and richly. No one can take that away.



# Resources

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You may want more information for yourself, your family and your doctor. The services explained below will help you obtain what you need.

## **Cancer Information Service (CIS)**

The National Cancer Institute sponsors a toll-free Cancer Information Service to help you. By dialing 1-800-4-CANCER (1-800-422-6237) you will be connected to a Cancer Information Service office, where a trained staff member can answer your questions and listen to your concerns. Persons with TTY equipment, dial 1-800-322-8615. Spanish-speaking CIS staff are also available.

## **PDQ Service**

The National Cancer Institute has developed PDQ, a computerized database designed to give doctors quick and easy access to:

- The latest treatment information for most types of cancer.
- Descriptions of clinical trials that are open for patient entry.
- Names of organizations and physicians involved in cancer care.

To get access to PDQ, a doctor can use an office computer with a telephone hookup and a PDQ access code or the services of a medical library with online searching capability. Cancer Information Service offices (1-800-4-CANCER) provide free PDQ searches and can tell doctors how to get regular access to the database. Patients may ask their doctor to use PDQ or may call 1-800-4-CANCER themselves. Information specialists at this toll-free number use a variety of sources, including PDQ, to answer questions about cancer prevention, diagnosis and treatment.

For additional written resources about cancer, information about particular forms of the disease, its treatment, and possible side effects, and nutritional information and recipe's for the cancer patient, ask the Cancer Information Service to send you information or write:

*Office of Cancer Communications*

National Cancer Institute  
Building 31, Room 10A16  
31 Center Drive, MSC 2580  
Bethesda, MD 20892-2580

**American Cancer Society**

1599 Clifton Road, N.E.  
Atlanta, GA 30329  
1-800-ACS-2345

The American Cancer Society is a voluntary organization with a national office (at the above address) and local units all over the country. It supports research, conducts educational programs, and offers many services to patients and their families. It also provides free booklets on cancer. To obtain information about services and activities in local areas, call the Society's toll-free number, 1-800-ACS-2345, or the number listed under American Cancer Society in the white pages of the telephone book.

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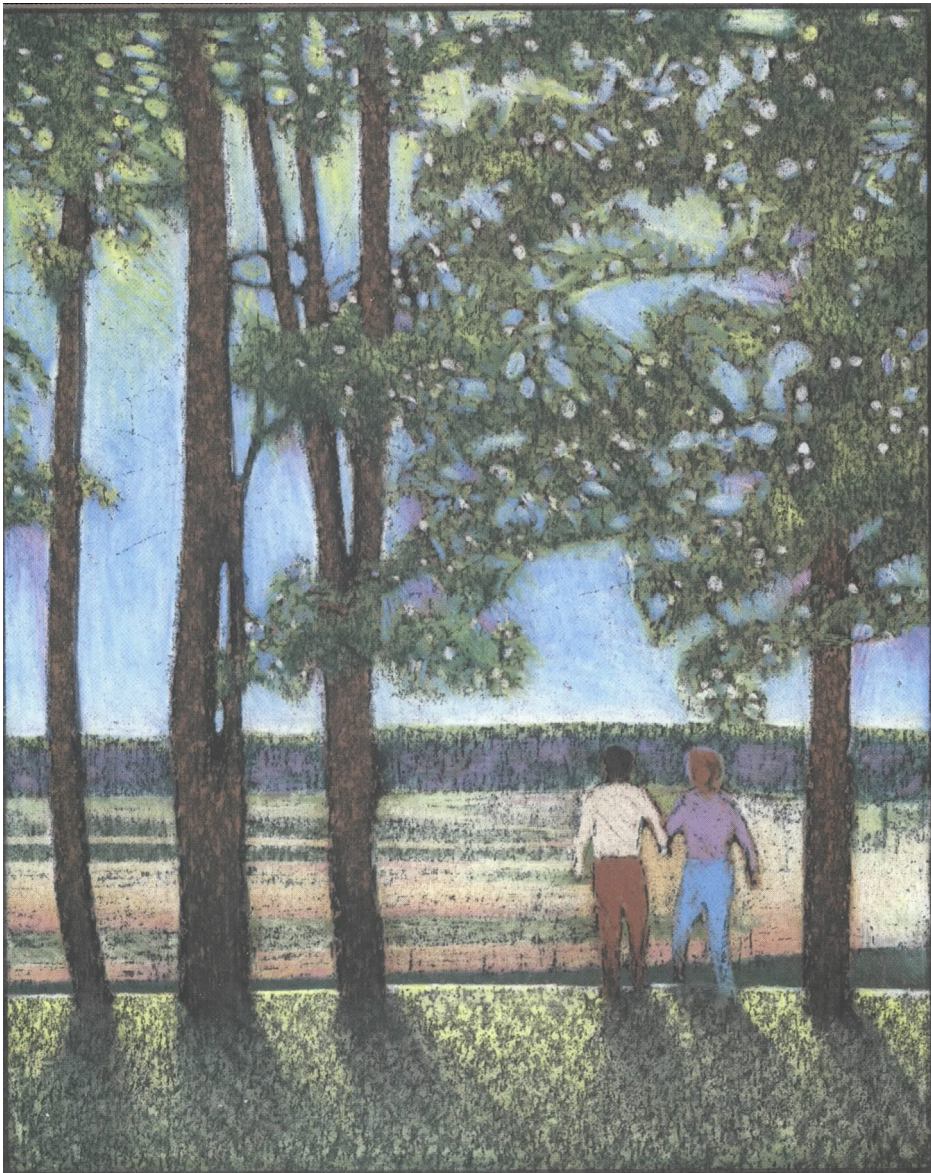


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# When Cancer Recurs

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MEETING THE CHALLENGE



NATIONAL INSTITUTES OF HEALTH  
National Cancer Institute



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# Introduction

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In the back of every cancer patient's mind is the possibility that the disease may return. Yet if it does, most patients think, "How can this be happening to me again?"

The shock is back. The fears are back—of telling your family and friends, of more treatment, and possibly of death. The anger is there, too. You've been told you have cancer again. You may feel that after all you've been through, it should have been enough. And the unanswered question is, "Will the treatment work this time?"

Even though you may feel some of the same things, you felt when you were first diagnosed, now there is a difference. You've been through this before. You've faced cancer and its treatment and the changes that came to your life. You know that medical care and emotional support are available to you. Facing cancer again is difficult, but it's a challenge you can handle.

This booklet is about cancer that has returned—its diagnosis and treatment, suggestions for coping, and where to get help. The glossary at the end of the booklet explains some of the terms that you will read or may hear in talking with your treatment team.

As you read this booklet, remember that there are more than 100 different types of *cancer*.<sup>\*</sup> Each is different, and each person responds to treatment differently. No booklet can cover every situation for every person. For this reason, the information here is general, and some of it may not apply to you. Still, a lot of people have found ways to handle recurring cancer in similar ways, and their experiences may help you.

Many people who have faced the return of cancer will tell you that learning more about your illness and its treatment helps you take part in your care. Having a positive attitude toward treatment may help you control some of your emotional and physical reactions to it. Drawing on your own strengths and support from the people and resources around you can help you meet this challenge again.

Some of those resources are listed at the back of this booklet. Many of them are available from the National Cancer Institute's Cancer Information Service or the American Cancer Society (see p. 36).

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\*Highlighted words are defined in the glossary that begins on p. 30 of this booklet.

# Why Cancer Can Recur

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A cancer *recurrence* is the reappearance of disease that was thought to be cured or inactive (in remission). Cancer may recur after several weeks, several months, a few years, or many years.

Recurrent cancer starts from cancer cells that were not removed or destroyed by your original therapy. You may have had previous treatment that was meant to destroy the original cancer, as well as any cancer cells that may have moved to another part of your body. Sometimes, no matter what treatment is used, a small number of cancer cells survive, and it may take a while for them to grow into tumors that are large enough to be detected.

A cancer recurrence is not the same thing as a new cancer, even if it appears in a new place in your body. A recurrence has the same type of cancer cells as the original *tumor*—no matter where it is found. For example, if you had colon cancer and it recurs in your liver, it is not liver cancer; colon cancer cells have spread to the liver, and the disease is still colon cancer. (The spread of cancer cells to a new part of the body is called *metastasis*.) This point is important because there are different treatments for different types of cancer.

Although it's possible to develop a second, entirely new tumor that is not related to your original cancer, this situation is more unusual than a recurrence.

# Where Cancer Can Recur

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Not every cancer cell that breaks away from a tumor is able to grow elsewhere. Most are stopped by the body's natural defenses or destroyed by treatment. Cancers differ in their ability to recur and in the places where they are likely to show up.

Recurrent cancers are classified by location: local, regional, or distant.

■ Local recurrence means that the cancer has come back in or very close to the same place as the original cancer. For instance, a woman who has had a mastectomy could later have a local recurrence of breast cancer in the area of her surgery. The term "local" also means that there is no sign of cancer in nearby lymph nodes or other tissues.

■ A regional recurrence involves growth of a new tumor in *lymph nodes* or tissues near the original site but with no evidence of cancer at distant places in the body. A person who has had a melanoma removed from an arm, for instance, might have a regional recurrence in the lymph nodes under that arm.

■ In distant recurrence, the original cancer has spread (metastasized) to organs or other tissues far from the site of origin. For example, a man who had prostate cancer could have a recurrence of that cancer in his bones. This man does *not* have bone cancer; he has prostate cancer that has spread to his bones.

# Diagnosing Recurrent Cancer

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Over the past several months or years, you may have had a number of tests and checkups. Most likely, your doctor told you to watch for changes in your body and to report any unusual symptoms. You may have noticed a weight change, bleeding, or pain (these changes don't always mean that you have cancer), or your doctor may have found signs of illness while examining you.

In either case, specific procedures and tests are used to find the exact cause of the problem and decide on the best treatment. These procedures and tests, which you may be familiar with from your original cancer, help your doctor answer these questions:

- Are the signs and symptoms caused by cancer or by some other medical problem?
- If cancer is present, is it a recurrence or is it a new type of cancer?
- Has the cancer spread to more than one place?

Because certain types of cancer tend to recur in certain parts of the body, your doctor is likely to check those places first. Information from physical exams and tests helps the doctor make an accurate diagnosis. If your cancer has recurred, an accurate diagnosis is the first step in determining the best course of treatment and getting the disease under control again.

## Physical Exams

In addition to your routine physical exam, which includes feeling for lumps and swelling, your doctor may need to look inside your colon, stomach, bladder, breathing passages, or other organs for recurrent cancer. Special instruments are used for viewing different parts of the body. The names of most of these instruments end in “scope.” For example, a bronchoscope is used to view the air passages of a lung. In some cases, the doctor may even take a tissue sample (biopsy) through the scope and for viewing under a microscope.

## Laboratory Tests

A number of laboratory tests are used to help diagnose recurrent cancer. For example, blood samples can be tested to check the levels of certain *tumor markers*, such as carcinoembryonic antigen (CEA), that may change when cancer recurs.

Other tests, such as the examination of a stool smear (*fecal occult blood test*), can detect internal bleeding that may be too slight for you to notice. If blood is found, a series of x-rays or another type of test is done to learn if the bleeding is caused by cancer or some other problem.

These are only a few examples of laboratory tests used to diagnose cancer and other health problems. Your doctor will select those that may be helpful in your case.

## Imaging

To learn the location and size of suspected cancer, the doctor can use x-rays, computed tomography (CT) scans, magnetic resonance imaging (MRI), nuclear scanning, or ultrasonography. These tests are often done someplace other than your doctor’s office.

These tests may use radiation, computers, magnets, and other sophisticated equipment. If you have questions about how they’re used, their risks or ben-

efits, or what you should expect during the procedure, be sure to talk with your doctor, nurse, or technician about your concerns. It may be possible for you to see the equipment and how the test will be done in advance. Most CT and MRI equipment requires you to be in a tight space, sometimes for an hour or more. It also may be noisy. If you feel extremely uncomfortable in small spaces, discuss this with your doctor before your test is scheduled. The CT or MRI technician also may have suggestions.

**X-Ray.** Tumors can often be seen with a standard *x-ray*. Other tests use x-rays and a barium solution, dye, or air to give sharp pictures of organs such as the stomach, kidney, and colon that cannot be seen clearly with x-rays alone. An example of this kind of test is the “lower GI series” (barium enema followed by an x-ray of the gastrointestinal tract). Barium is a white, chalky substance that outlines the colon and rectum on the x-ray.

**CT Scan** (also called **CAT scan**, for computed axial tomography). In a *CT scan*, x-rays are taken from many directions and combined into one cross-sectional picture with the aid of a computer. The CT scan gives more detailed pictures than standard x-rays for certain body parts and often is used for tissues such as the liver and brain. In some cases, a special dye is injected into a vein before the scan to improve the details of the pictures.

**MRI.** Instead of x-rays, MRI uses radio waves and a powerful magnet to create detailed pictures of areas inside the body. Like a CT scan, MRI uses a computer to combine many images into a single picture. That picture may include organs, muscles, blood vessels, and other parts of the body that are hard to see with other equipment. For MRI, you’ll be asked to lie very still in a tunnel-like machine. Headphones are often available to help block the machine’s rather loud clicking sounds.

**Nuclear Scan.** *Nuclear scans* often are used to see areas inside the body. A special substance is swallowed or injected into the bloodstream. It contains a small amount of radioactivity, similar to the amount used in a chest x-ray, so it can be seen inside the body. A machine called a scanner then takes pictures of the areas of the body where the substance shows up. In the pictures, a cancer can appear as an area of more or less radioactivity than the tissue around it.

**Ultrasonography.** In *ultrasonography*, a microphone-like device sends sound waves that bounce off internal organs, like the brain or lung. A computer converts the echoes made by the sound waves pictures called sonograms. The pictures are shown on a monitor like a TV screen. Tissues of different densities look different in the picture because they reflect sound waves differently. For example, a sonogram can often show whether a breast lump is a fluid-filled cyst or a recurrent cancer.

## Biopsy

*Biopsy* is the removal of a tissue sample so it can be examined under a microscope to establish a precise-diagnosis. Although an abnormal area of the body may be seen on physical exam or imaging, a biopsy is the only way to tell for sure whether the tissue contains cancer cells.

For some suspected cancers, the doctor uses a needle to withdraw fluid (aspirate) or remove small tissue samples (needle biopsy). A surgical biopsy, done under local or general anesthesia, removes the entire tumor or a piece of it.

# Treatment Methods

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Many of the same factors that affected treatment decisions for your original cancer will be taken into account in planning treatment for recurrent cancer. Some of those factors include the type, size, and location of the cancer, your general health, and other treatments you've had.

Your doctor may recommend surgery, radiation, anticancer drugs (chemotherapy), or a combination of these treatments. For certain cancers, such as those in the breast or reproductive organs, the doctor may suggest hormone therapy. In other cases, biological therapy may be considered. These kinds of treatments are discussed below.

Before you and your doctor agree on a treatment plan, you should understand why one treatment is recommended over others. Talk to your doctor about treatment goals, methods, and side effects. Compare the recommended treatment with other treatments. Do this by looking at the possible benefits, risks, side effects, and impact on the quality of your life.

NOTE: If you're having radiation therapy or chemotherapy, be sure to check with your doctor before taking *any* medicines—even those you can buy without a doctor's prescription for colds or headaches. Some of these products can interfere or interact with your other treatments.

As with other important medical decisions, a second opinion about treatment for recurrent cancer is a good idea. Some insurance companies require a second opinion; others will pay for a second opinion at the patient's request. You can find another doctor to consult by asking your doctor or calling a local medical society, nearby hospital, or medical school. The Cancer Information Center (1-800-4-CANCER)

also can tell you about treatment facilities, including cancer centers and other programs supported by the National Cancer Institute (NCI).

You can take an active part in your treatment by asking questions and expressing your feelings. Questions that patients often ask are included throughout this section. You may want to add your own questions to discuss with your doctor, nurse, social worker, or other member of your health care team. Family members or others close to you may have questions, too.

*Questions to ask about any recommended treatment:*

- What is the goal of this treatment? Is it a cure, or will it shrink the tumor and relieve the symptoms only for a period of time?
- Why do you think this treatment is the best one for me?
- Is this the standard treatment for my type of cancer?
- Are there other treatments? What are they?
- Am I eligible for any clinical trials?  
(See p. 21.)
- Where is the best place to receive treatment?
- What benefits can I expect from the treatment?
- Are there side effects with this treatment? What are they? Are they temporary or permanent?
- How can the side effects be treated or relieved?
- How safe is this treatment? What are the risks?
- How will I know if the treatment is working?
- Will I need to be in the hospital?
- What will happen if I don't have the treatment?
- Will I lose time from work or need help at home?
- What does my family need to know about the treatment? Can they help?

- How long will I be on this treatment?
- How much will the treatment cost?
- How is this treatment similar to or different from my last treatment?

The remainder of this section describes the most common treatments, some of the newer methods now under study, and unconventional treatments that may not be familiar to you.

## Surgery

*Surgery is local treatment* to remove the cancer, and possibly tissue around it and nearby lymph nodes. Surgery often is used to treat cancer when it is first diagnosed, but it is used less often in recurrent cancer. Your doctor may recommend an operation to remove a recurrent cancer if it seems to be limited to a single or few spots on the skin or in the lung, liver, bone, brain, or lymph nodes. Surgery also may be suggested to alleviate symptoms. For many sites of recurrence, other methods such as radiation therapy, chemotherapy, biological therapy, or a combination of these have been shown to be more effective.

When cancer recurs in a weight-bearing bone such as the leg, the growing tumor can cause a fracture. In such a case, the doctor may suggest an operation to support the bone and prevent a break. This procedure can help relieve pain and keep the patient active during the wait for other forms of treatment to take effect and control the cancer.

### *Questions to ask about surgery:*

- What type of anesthetic will be used?
- What side effects should I expect after surgery?
- How can the side effects be treated or relieved?
- How long will I have to restrict my activities after surgery?
- Is the surgery aiming to cure the cancer (curative) or relieve some of my symptoms (palliative)?

## Radiation Therapy

*Radiation therapy* (also called radiotherapy) directs high-energy rays (tens of thousands of times the amount used to produce a chest x-ray) at a cancer site to stop cells from growing and dividing. Sometimes radiation therapy is used before surgery to shrink a cancerous tumor. After surgery, it may be used to stop the growth of any cancer cells that remain in a certain part of the body. In some cases, doctors use both radiation and anticancer drugs, in addition to or in place of surgery, to destroy a cancer and prevent it from returning.

Radiation affects both normal cells and cancer cells. Special equipment aims the radiation directly at tumors or target areas of the body, sparing as much normal tissue as possible. Like surgery, radiation therapy is a local treatment; it affects cells only in the treated area. Tiny marks, called pinpoint tattoos, are made on the body to help the technician direct treatment to the right place every time. Another type of radiation therapy uses implants that contain small amounts of a radioactive substance. This is called *internal radiation therapy*.

Radiation therapy is a commonly used treatment for cancer. The type of cancer, location, stage (extent of disease), previous radiation therapy, and other factors will determine whether this treatment is appropriate for you. Sites that may be treated with radiation include the brain, lung, and bone. When normal cells are affected by radiation therapy, most appear to recover.

Although radiation treatment can cause side effects, most are not serious. For example, fatigue and skin changes, such as redness or dryness, are common. The type of side effects you may experience depends on the part of the body that's being treated and the amount of radiation received. Side effects usually disappear within a few weeks after treatment ends, although some may last longer.

***Radiation Therapy and You***, a booklet available from NCI, answers many questions about the various forms of radiation therapy.

*Questions to ask about radiation therapy:*

- What benefits can I expect from this therapy?
- What type of radiation therapy will I be getting?
- How long do the treatments take? How many will I need? How often?
- Can I schedule treatments at a certain time of day?
- What if I have to miss a treatment?
- What risks are involved?
- What side effects should I expect? What can I do about them? How long do they usually last?
- Who will give me the treatments? Where are they given?
- Will I need a special diet?
- Will my activities be limited?
- Will I miss work or need help at home?

## Chemotherapy

*Chemotherapy* is the use of anticancer drugs to treat cancer. It may consist of a single drug or a combination of drugs. Chemotherapy may be used alone or in combination with radiation therapy, surgery, or biological therapy.

Anticancer drugs may be given by mouth or by injection into a vein or muscle. Because anticancer drugs can reach and destroy cancer cells in nearly every part of the body (called *systemic treatment*), chemotherapy is the primary treatment for many kinds of recurrent cancers that have spread beyond a single site or region.

Chemotherapy can affect any rapidly growing cells in the body—normal as well as cancer cells. The normal cells most likely to be affected are the

blood-producing cells in the bone marrow, cells lining the mouth, digestive tract, reproductive organs, and hair follicles. Again, many normal cells are able to replace themselves.

Every person reacts differently to chemotherapy. Some people have few or no side effects; others say their side effects are less severe than they expected; still others have a more difficult time. Ask your doctor, nurse, or pharmacist about side effects that could occur with the anticancer drugs prescribed for you. They can give you suggestions to help with problems that may occur. Although most side effects gradually go away between treatments or after treatment ends, the fatigue that some patients feel during chemotherapy sometimes lingers for a while.

The NCI booklet ***Chemotherapy and You*** provides more information about this type of cancer treatment.

## Hormone Therapy

*Hormone therapy* (also called endocrine therapy) is the treatment of disease by blocking hormones or changing the way they work. Some cancers use *hormones* in the body to grow. *Hormone therapy* can prevent cancer cells from getting or using the hormones they use. Like chemotherapy, hormone therapy may be given by mouth or by injection and is a systemic treatment. Sometimes surgery is suggested to remove organs that make the hormones. Radiation therapy and chemotherapy can also stop the body from producing the hormones that cancer cells need to grow.

Hormone therapy is often used to treat breast, uterine, and prostate cancers. It is also being studied in the treatment of other cancers, such as melanoma, uterine cancer, and certain leukemias. It can cause a number of side effects, depending on the type of drug or surgical procedure used. Patients may have

nausea, swelling, or weight gain. Breast cancer patients taking the anti-estrogen drug tamoxifen may have some symptoms of menopause.

*Questions to ask about chemotherapy and hormone therapy:*

- What do you expect the drugs to do for me?
- Which drugs will I be getting? How is each one given?
- Where are the treatments given?
- How long do the treatments take? How many will I need?
- What happens if I miss a dose?
- What risks are involved?
- What side effects should I expect? What can I do about them? How long do they usually last?
- Will I need a special diet or other restrictions?
- Can I take other medicines during treatment?
- Can I drink alcoholic beverages during treatment?
- Can my treatment be delayed if I don't feel up to it?
- Will I miss work or need help at home?

## **Biological Therapy**

*Biological therapy* (also called immunotherapy and biotherapy) is a promising new area of cancer treatment. It uses both natural and manufactured substances, called biological response modifiers (BRMs), to boost the body's own immune (defense) system to fight cancer or reduce side effects from treatment. Researchers are studying biological therapies to learn how BRMs work best and against which cancers. BRMs that are being used in cancer treatment include interferons, interleukins, tumor necrosis factor, colony-stimulating factors, monoclonal antibodies, and cancer vaccines.

## Bone Marrow Transplantation

### *Questions to ask about biological therapy:*

- Exactly what kind of therapy will I receive?  
How is it given?
- Has this type of therapy already been shown to work against my type of cancer?
- Will I need to change my diet?
- Will I miss work or need help at home?
- What side effects should I expect? What can be done about them? How long do they usually last?
- Where will I have to go for treatment?
- Who will be the doctor responsible for my care?
- How long will the treatment last?
- Will I have to be in the hospital?
- How much will the treatment cost? Will my insurance pay for it?

Some cancers and cancer treatments can damage or destroy bone marrow, the soft, spongy material found inside bones. In some cases, high doses of chemotherapy or radiation therapy are needed to treat cancer. These treatments can destroy bone marrow, whose main job is to produce blood cells. *Bone marrow transplantation* (BMT) is a procedure that replaces damaged or destroyed marrow with healthy marrow. In BMT, healthy marrow is removed from a bone with a needle. The patient later receives the marrow by injection into a vein. Cells with the potential to re-form all the normal blood cells also circulate in the bloodstream. These are called stem cells. They can be separated from the blood by a machine, stored, and returned to the patient after treatment.

There are three categories of BMT, depending on where the marrow comes from: the patient (autolo-

gous transplantation), an identical twin (syngeneic transplantation), or another person (allogeneic transplantation). Numerous factors determine what type of transplant a patient receives. These include the type of cancer and the availability of a suitable donor. (See NCI's Research Report, ***Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation***, available from the CIS.)

*Questions to ask about bone marrow transplantation:*

- Why is BMT appropriate for me?
- Will the BMT extend my life or improve my quality of life?
- Can my own marrow be used, or will I need someone else's?
- What risks are involved?
- What side effects should I expect? What can I do about them? How long do they usually last?
- Will I need a special diet?
- Will my activities be limited?
- Will I miss work or need help at home?
- Where will I have to go for treatment?
- Who will be the doctor responsible for my care?
- Will I have to be in the hospital?
- How much will the treatment cost? Will my insurance pay for it?

## Supportive Therapy

When you were first treated for cancer, you may have had physical therapy or used the services of a psychological counselor or social worker. You may want to consider seeking those kinds of help again. Two other types of supportive therapy that also could be important to you are nutritional support and pain management.

### ***Nutritional Support***

Nutrition should be considered an important part of your treatment plan. Radiation therapy and chemotherapy destroy normal cells as well as cancer cells. Good nutrition is needed to replenish those normal cells. Studies have shown that patients who eat well may be able to cope better with the cancer and its treatment. Dieting during treatment is not advised because it deprives the body of needed calories and nutrients. It's a good idea to discuss your nutritional plans with your doctor, a dietitian, or both.

Eating well means choosing foods that have the protein, calories, and other nutrients you need to keep your body working normally. If you're having problems eating and digesting because of the treatment or the cancer, you may need nutritional supplements, or you may find it easier to eat several small meals throughout the day rather than large meals at your regular breakfast, lunch, and dinner times.

You can find many suggestions for healthy ways to eat during treatment in the NCI booklet ***Eating Hints for Cancer Patients. Chemotherapy and You*** and ***Radiation Therapy and You***, also available from NCI, discuss specific nutrition problems associated with those treatments.

If eating enough to stay at your normal weight continues to be a problem in spite of your efforts, ask to speak with a dietitian at the hospital where you had your treatment about planning your diet. For severe nutrition problems, special treatments can be given at home or in the hospital.

### ***Pain Management***

Having cancer doesn't always mean having pain. But if pain does occur, there are many ways to relieve or reduce it. Cancer pain almost always can be relieved or controlled. **You have a right to ask those caring for you to help you control your pain as much as possible.**

The best way to manage pain is to treat its cause. When it is clear that a tumor is the direct cause of pain, the pain can sometimes be treated by removing the tumor or decreasing its size. To do this, your doctor may recommend surgery, radiation therapy, or chemotherapy. If removing or shrinking the size of the tumor is not possible, or when the cause of pain is unknown, other pain relief methods are used.

Most pain can be controlled by oral pain medicines. Your doctor may recommend over-the-counter (nonprescription) pain medicines for mild pain, or may give you a prescription pain medicine for moderate to severe pain. Many patients try to avoid using pain medicine because they're afraid of becoming "addicted." This rarely happens in cancer treatment. If you have concerns, talk with your doctor or nurse. Pain is most effectively relieved when pain medication is taken on a regular schedule, and if it's taken when the pain first begins. **Tell your doctor or nurse if the pain medication is not effective.**

When describing pain to your doctor, be as specific as you can. To recommend the best pain treatment for you, your doctor will want to know the following things:

- Where *exactly* is your pain? Does it ever move from one spot to another?
- How does the pain feel (dull, sharp, burning, etc.)?
- How often does it occur?
- How long does it last?
- Does it start at a specific time of day (morning, afternoon, evening)?
- Does anything (lying down, sitting, eating, etc.) seem to relieve the pain or make it worse?

Narcotic pain medications usually have some sedative effects, which disappear after a few days. This type of medication also can cause constipation. Your doctor may prescribe a laxative or stool softener to be taken with your medicine.

Because pain can be worse when you're frightened or worried, you may find some relief by using relaxation exercises or meditation. These activities, which usually involve deep, rhythmic breathing and quiet concentration, can be done almost anywhere.

A number of nonmedical ways to reduce pain have been gaining attention in recent years. Hypnosis and *biofeedback* have been helpful for some people with serious illness. If you want to learn about them, ask your doctor or nurse to refer you to a health professional who is trained to teach these methods. Three booklets on handling pain—***Questions and Answers About Pain Control, Managing Cancer Pain, and Getting Relief From Cancer Pain***—are available from NCI's Cancer Information Service (CIS). ***Questions and Answers About Pain Control*** is also available from the American Cancer Society (ACS). To get copies, call the CIS at 1-800-4-CANCER, the ACS at 1-800-ACS-2345, or contact your local ACS office listed in the telephone directory.

# New Cancer Treatments

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## Clinical Trials

*Clinical trials* are studies of new methods for treating disease that are used under strict scientific conditions. These methods have been tested on animals and have shown promise for treating humans. Doctors test the value of new treatments with the help of cancer patients who take part in these studies.

Patients who take part in clinical trials may be the first to benefit from improved treatment methods. They also can make an important contribution to medical care because the results of the studies may help many people. Patients participate in clinical trials only if they so choose and are free to leave the trial at any time. More information about these studies is available from the Cancer Information Service. NCI's booklet ***Taking Part in Cancer Treatment Studies: What Patients Need to Know***, also provide information.

Right now, cancer clinical trials are studying several new treatments. If proven effective, these treatments could become the standard treatments of the future.

*Questions to ask about clinical trials:*

- What trials are available for my type of cancer?
- What is the purpose of these trials?
- Who is sponsoring the study?
- How are the study data and patient safety being checked?
- Where will the information from the study go?
- What benefits can I expect from the treatment?
- Is there scientific evidence that the treatment can help?

## Unconventional Cancer Treatments

- What are the known or potential risks?
- What are the possible side effects?
- Will I have to get the new treatment from a different doctor?
- Will my insurance cover the costs of treatment?
- Will I have to travel to get the treatment?  
How often?

Unconventional cancer treatments are those that have not been shown to be effective in accepted scientific studies. Some unconventional treatments you may have heard about use various diets, vitamins, and herb mixtures.

Certain clues can help you know whether a new treatment approach is part of a clinical trial or is an unconventional method. One way is to look at how results of the treatment are reported. Findings from clinical trials usually are reported first in medical and scientific journals or at scientific conferences and later may be reported on TV and in newspapers and magazines directed to the general public. Today, a lot of clinical trials information is also available on the Internet. Unconventional methods generally rely on reports by patients, don't discuss scientific data, and keep details of the treatment secret. They often make ambitious claims about results and minimal side effects, especially for advanced cancers. Using unconventional treatments actually may be harmful. They may cause dangerous reactions or may delay or interfere with treatments proven to be effective and thus may reduce a patient's chances for cure or control of cancer. If you're thinking of using an unconventional treatment method, be sure to discuss it with your doctor. Be wary of cure claims from profitable companies that cannot product sound scientific data on the efficacy of their products.

As you think about your treatment options, consider the following list of suggested questions carefully.

*Questions to ask about unconventional treatments:*

- What benefits can I expect from the treatment?
- Is there scientific evidence that the treatment can help?
- How many patients have received this treatment?
- How many patients have had successful results? May I speak with one of them?
- Have other researchers had the same results using the same techniques?
- What are the known or potential risks?
- What are the possible side effects?
- How much will the complete treatment cost?
- Will my insurance cover the costs of treatment?
- Will I have to travel to get the treatment? How often?

# Helping Yourself

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## Gathering Information

You may remember that much of the fear and anxiety that you felt the first time cancer appeared in your life was “fear of the unknown.” You can help yourself again by gathering information, taking part in your treatment as actively as possible, and finding the support you need to deal with your feelings.

Learn as much as you can about what’s happening to you. If you have questions, ask your doctor, nurse, and other members of your treatment team. Your pharmacist is a good person to talk to if you have questions about your medicines. Your nurse can discuss ways to handle the side effects of your treatment. If you don’t understand the answer to a question, ask again.

Some patients hesitate to ask their doctors about their treatment options. They may think that doctors don’t like to have their recommendations questioned. Most doctors, however, believe that the best patient is an informed patient. They understand that coping with treatment is easier when patients understand as much as possible, and they encourage patients to discuss their concerns.

Here are some ideas that other people have found helpful:

- Write down your questions about possible treatments or anything else related to treatment. When you see your doctor, bring the questions with you so you don’t forget something you wanted to ask. (You can bring this booklet, which includes some of those questions and space in the back to write answers.)

## Taking Part in Your Treatment

- Ask a friend or relative to go with you. This can be an emotional time, and you may not be able to focus on what the doctor says. It can be easier for someone else to write down information and help you remember later what was discussed. Or use a tape recorder instead of notes.

- Speak openly with the doctor about your needs, expectations, wishes, and concerns, to get the most useful advice. And don't be embarrassed to ask the doctor to repeat or explain something or spell unfamiliar words.

Taking an active part in your care can help you have a sense of control and well-being. You can be involved in many ways. One is to follow your doctor's recommendations about caring for yourself, such as staying on a special diet.

Another way you can help is to keep your doctor informed. Report honestly how you feel, and if problems arise, describe them as specifically as possible. Don't ever hesitate to report symptoms to your doctor or to ask advice about what to do about them. Although many health-related signs and symptoms may not seem important to you, they could provide valuable information to your doctor. Make sure you know what signs you should look for, and if any of them appears, tell your doctor promptly.

Take care of yourself. Some things you can do to keep up your strength are to:

- *Eat well.* Ask about nutrition recommendations for cancer patients. They can be very different from usual suggestions about healthy eating. (See NCI's booklet ***Eating Hints for Cancer Patients***, available from the CIS.) Learn when your appetite is best and try to eat well at that time.

## Managing Your Emotions

■ *Get extra rest.* Your body will use a lot of extra energy during treatment. Get more sleep at night, and take naps whenever you feel the need.

■ *Adjust activities.* Try to stay active, but don't demand too much of yourself. Ask other people to take over some of your tasks if necessary. If your energy level is low, do the things that are most important to you and cut back on the others. Talk to your doctor if you have questions about doing specific activities.

The diagnosis of cancer, whether for the first time or when it recurs, can threaten anyone's sense of well-being. Some people feel shock and denial when they first find out that cancer has returned. Many had put their experiences with cancer completely behind them, and the new diagnosis hits them as hard as it did the first time—or even harder. Others are not surprised, as if they had been expecting it all along.

Starting cancer treatment again can place demands on your spirit as well as your body. Your attitudes and actions really can make a difference. Remember that you've coped with this situation before. Keeping your treatment goals in mind may help you keep your spirits up during therapy. As you go through treatment, you're bound to feel better about yourself on some days than on others. When a bad day comes along, try to remember that there have been good days, and there will be more. Feeling low today doesn't mean you'll feel that way tomorrow or that you're giving up. At these times, try distracting yourself with a book, a hobby, or plans for a new garden. Many people say it helps to have something to look forward to—even simple things like a drive, a visit from a friend, or a telephone call.

Sometimes, however, you may feel overcome by fear, anxiety, anger, or depression, and you may just want to cry. That's okay, too. These emotions are common ways to cope with a difficult situation like

recurrent cancer. Feel free to express these feelings if they occur. None of these reactions is wrong, and letting them out can help you deal with them.

During your treatment, you may need to rely more on the people closest to you, but this may be difficult at first. You may not want to accept help, and some people may have trouble giving it. Many people don't understand cancer, and some may avoid you because they're afraid of your illness. Others may worry that they'll upset you by saying the wrong thing. You may have to make the first move. Try to be open in talking with others about your illness, your treatment, your needs, and your feelings. Once people know that you can discuss these things, they may be more willing to open up and help. By sharing your feelings, you and your loved ones will be better able to help each other through a difficult time. Another NCI booklet, ***Taking Time***, offers useful advice for cancer patients and their families.

Sometimes it's easier to talk to someone other than your family or your friends. Try talking to your doctor, nurse, social worker, or a member of the clergy with whom you feel comfortable. You may want to consider a counselor trained to help cancer patients deal with their feelings. These counselors understand the special problems that go along with serious illness as well as the various ways of coping that others have found useful. If you think this kind of professional support could help you, ask your doctor or nurse for the name of an appropriate counselor, such as an oncology social worker or psychologist.

Many people also find that hospital-sponsored or other support groups, where they can meet others who have been through similar experiences, are helpful places to express their thoughts and feelings. Your hospital, as well as the Cancer Information Service and American Cancer Society, can help you find local support groups.

## **Employment and Insurance Issues**

Although feeling stressed by the continuing changes in your life is normal, too much stress can harm your health and make you feel like you're losing control. You may not be able to remove all the stress around you, but you can try to limit it. Relaxation techniques help you reduce stress and cope better with your illness. Rhythmic breathing, imagery, and distraction are among the techniques that are easy to learn and use whenever you need them. If you're interested, ask your doctor or nurse to refer you to someone trained to teach these techniques. The local library and bookstore also have useful books on relieving stress.

If you have a job, you may want to return to work as soon as you can. You even may find it possible to continue to work during the time you are receiving treatment. This depends on the kind of treatment you are getting, what side effects you have, and how you feel about working.

Sometimes cancer patients find that they are treated differently on the job because of their medical condition. If this happens to you, be aware of your rights. Your employer may be violating laws that protect you from unfair practices.

Although as many as 1 million cancer patients in the United States experience some form of employment discrimination, this practice is illegal. The Americans with Disabilities Act, which went into effect in 1992, bans discrimination by both private and public employers against qualified workers who have disabilities or histories of disability. The Federal Rehabilitation Act of 1973 states that Federal employers or companies receiving Federal funds cannot discriminate against handicapped workers, including cancer patients. In addition to Federal protection, you may be eligible for protec-

tion under state laws. Find out the legal facts on equal opportunity by contacting your local department of employment services.

You need to understand fully your insurance rights not only as a cancer patient but as an employee of your company. Carefully read your health insurance policy. If you have any questions, contact your state insurance commission or department. This agency determines what types of insurance policies must be offered and when rates may be raised. Social workers and financial counselors in your hospital also may be sources of information.

If you have trouble learning what your rights are, or if you have any questions about employment issues, contact the National Coalition for Cancer Survivorship at (301) 650-8868. It can help you find local agencies that respond to problems cancer survivors face regarding their rights. You can also find practical information about cancer survivor issues in ***Facing Forward: A Guide for Cancer Survivors***, available free from the CIS (1-800-4-CANCER).

If you don't feel able to return to work, you may want to find out about disability options. Social Security offers a disability program for people who qualify. (The toll-free number is 1-800-772-1213.) Your employer also may have disability programs.

# Glossary

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**Biofeedback:** A technique to monitor certain body functions, such as heart rate or blood pressure, to gain some control over them.

**Biological (bye-uh-LOJ-i-kul) therapy:** Treatment that uses the body's immune (defense) system to fight cancer or reduce side effects that some cancer treatments may cause. Also called immunotherapy.

**Biopsy (BYE-op-see):** The removal of a sample of tissue, which is then examined under a microscope to check for cancer cells.

**Bone marrow transplantation (trans-plan-TAY-shun):** A procedure in which doctors replace marrow damaged or destroyed by cancer or treatment with high doses of anticancer drugs or radiation. The replacement marrow may be taken from the patient before treatment (autologous; aw-TAHL-uh-gus) or may be donated from an identical twin (syngeneic; sin-jih-NEE-ik) or by another person (allogeneic; al-uh-jih-NEE-ik).

**Cancer:** A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

**Chemotherapy (kee-mo-THAIR-uh-pee):**  
Treatment with anticancer drugs.

**Clinical trials:** Carefully designed research studies that involve patients and have been approved by an Institutional Review Board. Each study is designed to answer specific scientific questions and to find better ways to prevent or treat cancer or improve care.

**CT (an abbreviation for computed tomography) scan:** A series of detailed pictures of areas inside the body; the pictures are created by a computer linked to an x-ray machine. Also called computed axial tomography (CAT) scan.

**Fecal occult (FEE-kul o-KULT) blood test:** A test to check for hidden blood in stools.

**Gastrointestinal (GAS-tro-in-TES-ti-nul) tract:** The part of the digestive tract where the body processes and uses food and eliminates waste. It includes the esophagus, stomach, liver, small and large intestines, and rectum.

**Hormone therapy:** Treatment that prevents certain cancer cells from getting the hormones they need to grow.

**Hormones:** Chemicals that are produced by glands in the body and circulate in the bloodstream. Hormones control the way certain cells or organs act.

**Institution Review Board (IRB):** A group of scientists, doctors, clergy, and consumers at each health care facility at which a clinical trial takes place. IRBs are designed to protect patients who take part in clinical trials. They must approve the protocols (action plans) for all clinical trials funded by the Federal Government. They check to see that the study is well designed, does not involve undue risks, and includes safeguards for participants.

**Local treatment:** Therapy that can affect cancer cells only in the treated area.

**Lymph (limf) 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.

**Metastasis (meh-TAS-ta-sis):** The spread of cancer from one part of the body to another. Cells that have metastasized are like those in the original (primary) tumor.

**MRI:** An abbreviation for magnetic resonance imaging, a procedure that uses a magnet linked to a computer to create pictures of areas inside the body.

**Nuclear (NOO-klee-ur) scans:** Pictures of the inside of the body taken after material “labeled” with radioactivity is swallowed or injected into the bloodstream.

**Radiation (ray-dee-AY-shun) therapy:** Treatment with high-energy rays to kill cancer cells.

**Recurrence (rih-KUR-unse):** The reappearance of cancer.

**Remission (rih-MISH-un):** The disappearance of the signs and symptoms of cancer. When this happens, the disease is said to be “in remission.” A remission can be temporary or permanent.

**Stage:** The extent of a cancer, especially whether the disease has spread from the original site to other parts of the body. There are different staging systems for different cancers.

**Surgery:** An operation.

**Systemic (sis-TEM-ic) therapy:** Treatment that reaches and affects cells all over the body by traveling through the bloodstream.

**Tumor (TOO-mur):** An abnormal mass of tissue.

**Tumor marker:** A substance in blood or other body fluids that may suggest that a person has cancer.

**Ultrasonography (ul-tra-son-OG-ra-fee):** A test in which sound waves (called ultrasound) are bounced off tissues and the echoes are converted into a picture (sonogram).

**Unconventional cancer treatments:** Approaches that use substances or methods of treating cancer that have not been shown to be effective by accepted scientific methods, such as carefully designed clinical trials.

**X-ray:** High-energy radiation used in low doses to diagnose diseases and in high doses to treat cancer.

# Resources

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## Additional Reading

Information about cancer is available from the sources listed below. You may wish to check for additional information at your local library or bookstore and from support groups in your community.

Cancer patients, their families and friends, and others may find the following booklets useful. They are available by calling 1-800-4-CANCER:

■ ***Advanced Cancer: Living Each Day.*** Contains information intended to help patients facing death from cancer live their remaining days as well as they can.

■ ***Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation*** (Research Report). Describes the purpose, potential side effects, and other issues related to two procedures intended to restore a cancer patient's ability to produce healthy blood cells.

■ ***Chemotherapy and You: A Guide to Self-Help During Treatment.*** Explains chemotherapy and addresses problems and concerns of patients undergoing this treatment.

■ ***Datos sobre el tratamiento de quimioterapia contra el cancer.*** Explains chemotherapy and addresses problems and concerns of patients undergoing this treatment.

■ ***Eating Hints for Cancer Patients.*** Provides information and recipes to help patients meet their needs for good nutrition during treatment.

■ ***El tratamiento de radioterapia: guía para el paciente durante el tratamiento.*** Explains radiation therapy and addresses concerns of patients receiving radiation treatment.

■ ***Facing Forward: A Guide for Cancer Survivors.*** Offers practical ideas to help adults address survivorship issues and get on with their lives after a diagnosis of cancer, including childhood cancer.

■ ***Get Relief From Cancer Pain.*** Discusses clearly and briefly how patients can talk to their doctor or nurse about controlling cancer pain.

■ ***Questions and Answers About Metastatic Cancer.*** Presents information on detection, treatment methods, and areas where cancer often spreads.

■ ***Questions and Answers About Pain Control.*** Discusses pain control through use of both medical and nonmedical methods.

■ ***Radiation Therapy and You: A Guide to Self-Help During Treatment.*** Explains radiation therapy and addresses concerns of patients receiving radiation treatment.

■ ***Taking Time: Support for People With Cancer and the People Who Care About Them.*** Discusses the emotional side of cancer—how to deal with the disease and learn to talk with friends, family members, and others about cancer.

■ ***Taking Part in Cancer Treatment Studies: What Patients Need to Know.*** Explains clinical trials to help patients decide if they want to take part in a trial.

■ ***What You Need To Know About...*** This is a series of booklets. Each provides information about a specific type of cancer, including symptoms, diagnosis, treatment, emotional issues, and questions to ask the doctor.

# Additional Services

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## Telephone Service

### *Cancer Information Service (CIS)*

The Cancer Information Service is NCI's national information and education network. The CIS is the source for the latest, most accurate cancer information for patients, the public, and health professionals. Specially trained staff provide scientific information in understandable language. CIS staff answer questions in English and Spanish and distribute NCI materials.

Toll-free phone number: **1-800-4-CANCER**  
(1-800-422-6237)

TTY: 1-800-332-8615.

## Electronic Services

### *National Cancer Institute Web site*

NCI maintains a Web site, at **<http://rex.nci.nih.gov>** on the World Wide Web, that provides easy access to the most current news and information on cancer. Many of NCI's patient education resources are located on the Web site, including full-text publications and fact sheets for cancer patients and their families.

### *PDQ*

The National Cancer Institute has developed PDQ (Physician Data Query), a computerized database designed to give health professionals, patients, and the public quick and easy access to:

- the latest treatment information for most types of cancer;
- descriptions of clinical trials that are open for enrollment (including the names and addresses of the doctors and facilities conducting the studies); and

■ the names of organizations and doctors involved in cancer care.

PDQ can be accessed through the National Library of Medicine, licensed vendors, the Information Associates Program (1-800-624-7890), or a medical library with online searching capability. Cancer Information Service offices (1-800-4-CANCER) provide PDQ searches to callers. The PDQ Search Service also conducts PDQ searches for physicians and other health care professionals (1-800-345-3300).

### ***CancerNet™***

You can use e-mail or the Internet to acquire PDQ and other NCI information by computer. CancerNet Mail Service (via e-mail): To obtain a contents list, send e-mail to [cancernet@icic.nci.nih.gov](mailto:cancernet@icic.nci.nih.gov) with the word “help” in the body of the message.

CancerNet Internet Service: To access CancerNet through the Internet, use the World Wide Web at **<http://cancernet.nci.nih.gov/>** and gopher servers at **<gopher://gopher.nih.gov>**.

### ***CancerFax®***

For NCI information by fax, dial 301-402-5874 from the telephone on a fax machine and listen to recorded instructions.

# Notes

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This booklet was written and published by the National Cancer Institute, 31 Center Drive, MSC 2580, Bethesda, MD 20892-2580. NCI, the largest component of the National Institutes of Health, coordinates a national research program on cancer cause and prevention, detection and diagnosis, and treatment. In addition, NCI's mission includes dissemination of information about cancer to patients, the public, and health professionals.



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# Facing Forward

## A GUIDE FOR CANCER SURVIVORS



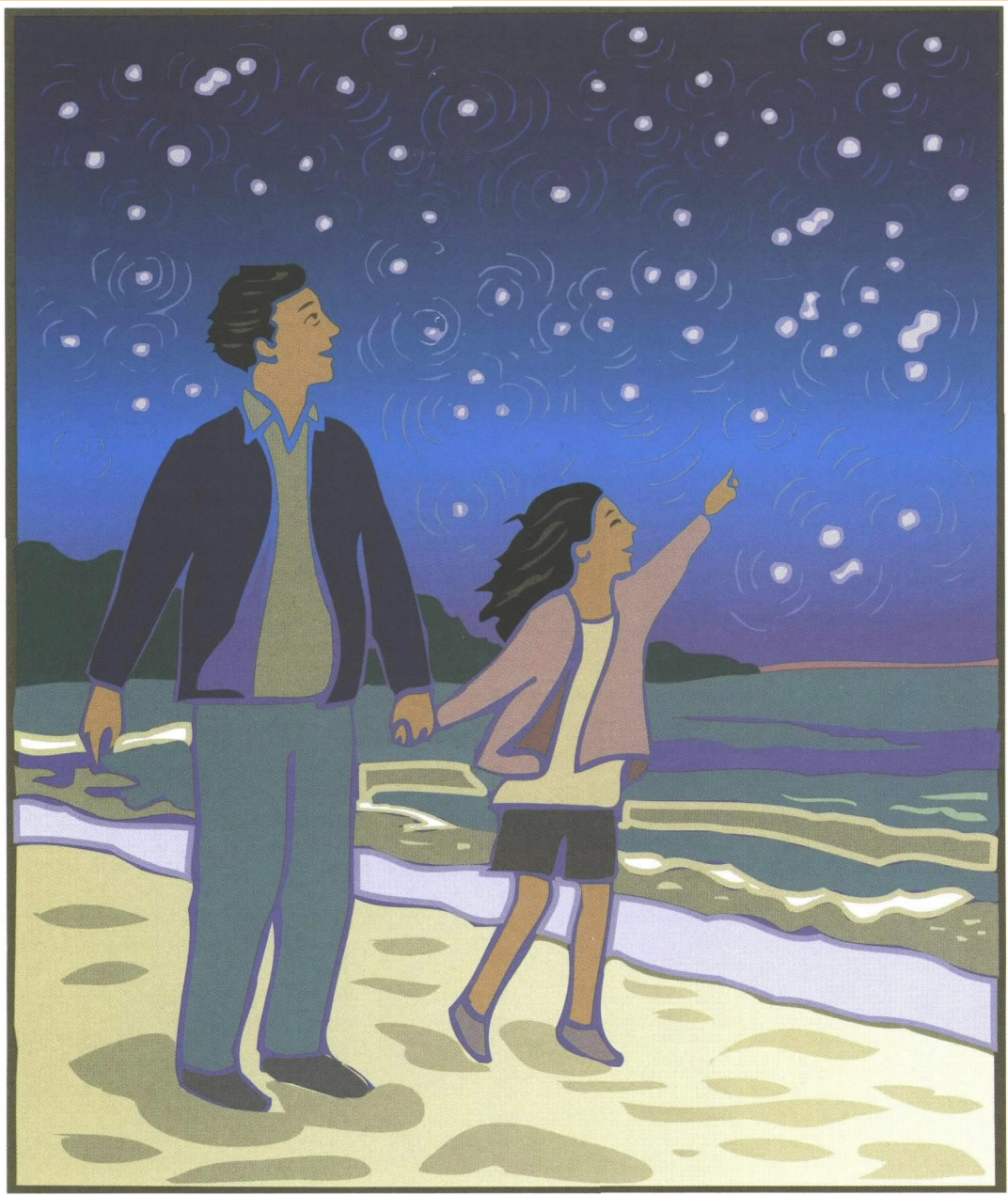
NATIONAL INSTITUTES OF HEALTH • National Cancer Institute

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service  
National Institutes of Health

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About *Facing Forward*



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# About *Facing Forward*

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## Who Should Read *Facing Forward*?

If you are moving on with your life after a diagnosis of cancer, this guide is for you. *Facing Forward*:

- gives you advice on taking care of your health and dealing with the fears and anxieties many people with cancer have,
  - suggests how to get the most from your insurance and outlines your legal employment rights, and
  - gives childhood cancer survivors information about caring for their special needs.
- 

If your cancer treatment is just ending, this guide may prepare you for concerns you have not yet faced. But even if your treatment ended a while ago, and these concerns are not new to you, some of the tips and sources of help may supplement your own experience. Chances are good that you share common concerns with other cancer survivors. Keep in mind, however, that not everyone will have all of the concerns discussed in this guide.

*Facing Forward* is also a guide to share with the people who care about you. They can use this guide to learn more about your challenges and how to support you, and they can turn to it as a resource when they are acting on your behalf. *Facing Forward* can help you

explain to your family and friends how your concerns may affect them and how they can get help.

Each chapter of *Facing Forward* stands alone. If only one issue concerns you right now, that chapter is all you need to read. Or you may prefer to read *Facing Forward* from cover to cover to get the big picture. Contacts, tools, and resources to aid you over the long term round out this guide. A fill-in-the-blank form at the back of the book will help you keep track of the questions you ask your doctors and the answers they give you.

Using what you learn here, you can face your challenges and meet your needs as you—like so many cancer survivors before you—move forward.





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Caring for Your Health



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# Caring for Your Health

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Even after cancer treatment is over, taking good care of your health is important to feel your best and keep your cancer under control. This section outlines the basics of health care for cancer survivors. It also gives key steps to take in managing your health care, getting relief from cancer pain, and coping with cancer-related fatigue.

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## *Six Basics of Health Care for Cancer Survivors*

When your cancer treatment ends, keep these tips in mind for your continuing care.

- **Decide who will provide your cancer followup care.** The doctor who cared for your cancer may be the one you choose for followup care, or you may want another doctor who specializes in long-term cancer followup. Choosing an expert on cancer is key. For your routine health care needs, continue to see your family doctor and medical specialists, but be sure that all your doctors know your cancer history.
- **Ask your doctors about your specific health care needs.** Your type of cancer, the type of treatment you received, and the current state of your health can all create special needs. Be sure you understand what you need to do now. And be sure you know the general health care guidelines for anyone your age.
- **Get regular checkups.** In general, people who have been treated for cancer return to the doctor every 3-4 months at first, and once or twice a year later on. Long-term cancer survivors need a yearly physical exam to check for the return of cancer, a second cancer, and late effects of cancer treatments. Ask your doctor how often you should be rechecked, and keep your appointments.
- **Be alert for possible signs of cancer return and for late effects of treatment.** Ask your doctor what symptoms you should look for and what you should do if they occur.
- **Get tested for other cancers.** Your doctor can tell you how often you should have tests such as those to detect breast cancer, prostate cancer, and colon cancer. When found early, these cancers are more easily treated.
- **Maintain good health habits.** Eating right, getting enough sleep, and being physically active will help you feel better and stay healthy. Talk to your doctor or a nutritionist about ways you can improve your diet.



## **Managing Your Health Care**

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It's up to you to inform your family, friends, and even your health care providers about your health. Keep track of your medical history, and gather as much information as you can about your health care needs.

## **Your Medical Records**

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Decisions about how you are treated in the future may depend on how you have been treated in the past. You need to maintain your own records of that treatment. When your personal records are up to date and accurate, you can make certain that health records given to your insurers or others are correct.

Get copies of your medical records, especially if you are moving or if you have more than one doctor. In most states, you have a legal right to these records, which

you can get from the Medical Records Department at your hospital.

To protect your right to privacy, ask your doctors who has access to your records. When you sign an "Informed Consent" form or a "Release of Information" form, you allow release of your records to a third party. If you don't want this, cross out the pertinent clause or write in new wording that you can accept. If you are unsure what the forms mean, ask to speak to a social worker or someone who can explain them to you.

## **Talking to Others About Your Health**

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Tell those close to you about the results of your checkups. Some of your friends or family may not want to ask how you're doing for fear of seeming nosy or pushy. But they may worry when they don't know what's going on.

## ***Talking with Your Doctors***

### **What to Tell Your Doctors and Nurses**

- Your cancer history. Give all the doctors you see from now on a copy of your cancer medical records.
- Your fears or concerns, especially those that might keep you from following treatment or getting regular checkups. Talking with your health care team may help solve the problem.
- Changes in your lifestyle. Even changes that seem minor could affect your treatment. For example, if you quit smoking, you may need a different dose of some medicines.
- Any symptoms you develop and are concerned about.

How much you want to hear about your cancer. You have a right to hear as much or as little as you wish.

### **What to Ask Your Doctors and Nurses**

#### ***About your con timing care***

- How often should I have a checkup?
- What are the signs of cancer's return? How likely are they to occur?
- What are the signs of long-term effects of my treatments? How likely are they to occur?
- What changes might I see that are not danger signs?
- How do I know if I should be concerned about a problem?
- What if I am anxious about every health problem I have?
- What are my treatment choices for handling chronic pain, the return of cancer, or the long-term effects of therapy?

#### ***About your concerns***

- What is the best way to talk to you about my concerns? (By phone? At a special appointment? At a regular visit scheduled in advance to run longer?)
- Who else can talk with me about special problems (for example, sexual concerns, care instructions, general fitness, foods to eat)?

## Talking with Your Doctors

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When you talk with your doctors, you need to give information as well as get it. Your doctors and nurses need the facts to prescribe the best treatments and to involve you in your own care.

Ask questions-lots of them. No question you have about your care is “dumb.” Many people bring a tape recorder, take notes, or ask a friend along to help them recall what is said. You can also bring a list of questions when you visit your doctor and write down the answers you receive. To get the information you need, try these approaches:

- If don’t understand what your doctor says, ask the doctor to show you a picture from a medical book.
- If you don’t understand the doctor’s answer to your question, ask the question in a different way. Don’t let the conversation move forward until you understand.
- If you think you understand but aren’t sure, repeat the information back to the doctor. The doctor then knows if he or she has explained the information clearly or, if necessary, can explain it again.

## Getting Relief From Cancer Pain

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Chronic pain may develop from your cancer treatment, usually in a part of your body where surgery and radiation have been used together. This combination can lead to scar tissue that can injure the

nerves around the treatment area. Pain can also be caused by cancer that remains and continues to grow in the same place.

Pain does not have to be a normal part of life, and it can be relieved. Free from cancer pain, you can be more active and live a fuller life. You can sleep and eat better, enjoy the company of friends, and continue with your work and hobbies.

Many different medicines and methods are available to control cancer pain. To get pain relief, follow these guidelines.

- Use pain medicine on a regular schedule to prevent the pain before it starts or to keep it from getting worse. Many people think that they should hold off as long as possible between doses. This approach is not the way to control pain. If pain begins, don’t wait for it to get worse before doing something about it. If your pain worsens, it may take longer for your medicine to give you relief.
- Ask your doctor, nurse, or pharmacist to explain your medicines to you. Ask about different doses of medicine, combinations of medicines, changing medicines, and different ways to receive the medicine. Learn how to use pain medicines safely, and mention any concerns you have about addiction. Don’t let fear of being “addicted” to pain medicines keep you in pain.
- Try complementary therapies such as relaxation techniques and distraction to help relieve pain. You might want to try using these methods along with the medicine you

take. See “Practice Relaxation Techniques” on page 13.

- **If you are in pain and your doctor suggests no other options, ask to see a pain specialist, or have your doctor consult with a pain specialist.**

Pain specialists can be oncologists, anesthesiologists, neurologists, neurosurgeons, radiologists, or other doctors, nurses, or pharmacists. If you have trouble locating a pain program or specialist, contact a cancer center, a hospice, or the oncology (cancer) department at your local hospital or medical center.

## **Coping with Cancer-Related Fatigue**

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Feeling tired and lacking energy — fatigue — is very common among cancer survivors, especially those still going through treatment. Fatigue from cancer feels different from the fatigue of everyday life. Survivors describe it as a total lack of energy, feeling worn out, drained, and “wiped out.” Rest does not always relieve it.

### **What Causes Cancer-Related Fatigue?**

Fatigue in people who have completed treatment for cancer and who are considered to be disease-free is a different condition from the fatigue people who are still receiving treatment have. Studies show that some people continue to have fatigue for up to 18 years after bone marrow transplantation. Long-term therapies such as tamoxifen can also cause fatigue.

The exact cause of the fatigue is not always known, but some frequent causes are

- the cancer itself or other disease
- the long-term side effects of cancer treatment — from chemotherapy, radiation, and surgery
- low blood counts
- lack of sleep
- pain, stress, and depression
- poor appetite.

Of course, not everyone feels the same kind of fatigue or for the same length of time. It may last days, weeks, or months. Fatigue may greatly affect the quality of life for a survivor. If you experience fatigue after cancer therapy, seek medical care. Your health care providers will first look for physical causes of the fatigue.

### **Managing Fatigue**

Fatigue does go away gradually as the tumor responds to treatment. In the meantime, some people are able to reduce their fatigue with new medicines to prevent anemia (low red blood cell counts), proper nutrition, vitamin and mineral supplements, anti-depressant and anti-anxiety medications, and counseling. The following suggestions may help you cope with your fatigue.

### **Manage Your Activity Level**

- Tell your doctor about your fatigue and any changes in your energy level over time. Ask how to reduce the fatigue or treat any physical conditions that may be causing the problem.
- Take short walks or exercise moderately, if you can. Many people have more energy after being physically active.

- Be as active as you are able, even if you can't do as much as you'd like. Doing things you enjoy can help you feel better.
- Try activities such as meditation, prayer, yoga, guided imagery, and visualization. (See page 13.)
- Allow time in your day for rest. Short naps or breaks are often more beneficial than one long rest.
- Plan quiet times when you can relax, listen to music, read, or write a letter to a friend.
- Save your energy for what matters most to you.

## **Fuel Your Body Well**

- Eat a balanced diet.
- Drink plenty of fluids.
- Limit the amount of caffeine and alcohol you drink.
- Talk to your doctor or nutritionist about how to improve your eating habits.

## **Get the Help or Support You Need**

- Think about joining a support group. (See page 14.) Sharing your feelings with others can ease the burden of fatigue — and you can learn how others deal with this problem.
- Ask your loved ones to help. Don't feel you have to do it all yourself.
- Ask your nurse or the social worker at your hospital about homemaker

services, home health services, classes, rides to the hospital, and other local services.

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*"I had thought that leaving the hospital after cancer treatment would be the happiest day of my life. When that time came, though, I felt very alone. My nurse said that this is a common response."*

—Jack C.

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*"Just seeing the hospital again when I go for a checkup reminds me of a part of my life I'd rather forget. The sounds and smells of the place almost make me ill. But I'm trying to get over it, because I know how important these checkups are to my health."*

—Janet V.

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*"When I think I see signs that my cancer may be coming back, it's hard to stay calm. My first doctor was not very sympathetic, so I found another doctor who is."*

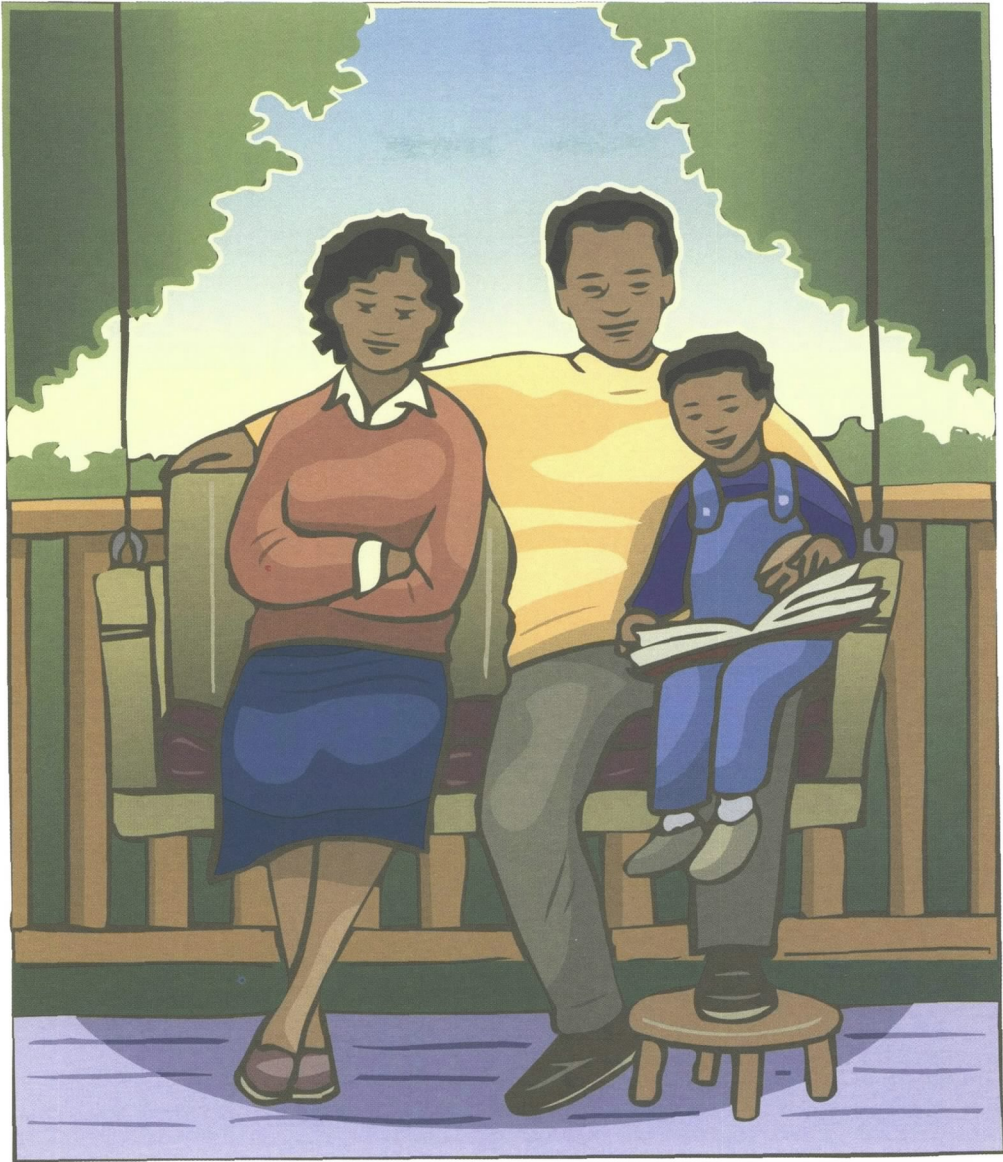
—Louise F.

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*"Much of my cancer treatment took place at home after surgery—for a while my room looked like a hospital. That's over now, but I still see the doctor regularly for checkups and pain control. I guess my cancer is more like a lifelong, chronic disease that I need to manage than something the doctors can 'cure' once and for all."*

—Irene L.

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Taking Care of Your Feelings



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# Taking Care of Your Feelings

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You may have felt anxious, sad, and angry when you were diagnosed with cancer and during your treatment. But even after treatment is over, anxieties and fears can continue. Taking care of these feelings is just as important as — and can be a part of — healing your body.

Common causes of anxiety in cancer survivors include changes in self-image and self-esteem, worries about the future, problems such as medical bills and job issues, and relationships with family, friends, and coworkers. Many survivors worry about whether the cancer will return — especially when they have a new ache or pain, or when they have a medical checkup. As time passes, though, your thoughts about the possibility of cancer returning will be fewer and farther between.

You may wonder what kinds of feelings are “normal.” The truth is, there is no “right” way to feel. The key is to handle your feelings in a way that works for you. Survivors have found many ways to find peace of mind while dealing with ongoing concerns.

This section explains why it’s important to take care of your feelings. It also talks about ways to relieve anxiety and get the support you need.

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## **Dealing with the Stresses of Cancer**

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You can do much to help heal your spirit and give yourself peace of mind. Therapies can include practicing relaxation techniques, participating in a peer support network such as a support group, receiving counseling, and meditating and praying. These activities may also help heal your body.

## **Practice Relaxation Techniques**

Cancer can make you feel as though you’ve lost control over your body. You can regain some of that control by learning how to relax deeply. Feeling your tension ease can be a great relief. Relaxation exercises can help you focus positive thoughts and feelings, defuse disturbing thoughts and feelings, and control your pain.

Relaxation methods include massage, listening to music, exercise, yoga, meditation, self-hypnosis, biofeedback, and

imagery. Be open-minded about trying different methods. It's helpful to keep a written record of what makes you feel better and what doesn't. If a method doesn't work the first time, try it a few more times before you decide it's not the right one for you.

Many methods are easy to learn yourself. For others, you may need the help of health professionals—social workers, physical therapists, psychologists, nurses, or family and friends. Remember to tell your doctor what methods you are using.

To find practitioners who specialize in these therapies and organizations knowledgeable about these techniques:

- Talk to your doctor or nurse.
- Contact the National Institutes of Health's National Center for Complementary and Alternative Medicine by calling toll-free at 1-888-644-6226, or visit the Web site at **<http://nccam.nih.gov>**.
- Call or visit a local cancer treatment center or pain clinic.
- Contact medical regulatory and licensing agencies in your state. These agencies may be able to provide information about a specific practitioner's credentials and background. Many states license practitioners who provide alternative therapies such as acupuncture, chiropractic services, naturopathy, herbal medicine, homeopathy, and massage therapy.
- Contact a professional association or organization. These organizations can provide names of local practitioners and give you information about

how to determine the quality of a specific practitioner's services.

- Visit your local bookstore or library.

## **Consider Joining a Peer Support Network**

Through peer support networks, people share feelings and practical information with one another—the wisdom they've gleaned from personal experiences. Peer support networks take many forms:

- support groups,
- one-on-one support,
- telephone hot lines,
- newsletters,
- Internet exchanges,
- weekend or week-long retreats with small groups, or
- workshops and conferences with larger groups.

One example of a peer-support organization is the American Cancer Society's (ACS) Reach to Recovery Program. This program connects women who recently have had breast cancer surgery with breast cancer survivors. Another example is the Candlelighters Childhood Cancer Foundation, which has local chapters providing opportunities for sharing experiences and information about the needs of children with cancer and their families.

Many survivors find it comforting to talk with someone who knows, first hand, what they are experiencing. Support networks have other benefits as well.

- You may become inspired by the courage of others and become more motivated to fight for your own life.
- Telling your story to the group may help you vent your feelings.
- You may find that others are dealing with their anxieties the same way you are.
- Talking with others can help you decide if you might need professional help.
- Other cancer survivors and families can give you information you may need to make difficult decisions.

### **Seek Professional Counseling**

Professional counseling is guided by a therapist who has been formally trained to help others. Counselors help people explore and change behaviors, thoughts, and relationships. They also help them develop more healthful and rewarding habits.

Survivors can benefit from both professional counseling and peer support. Support groups often encourage members to get professional help, while therapists often suggest peer support groups.

### **Explore Faith and Prayer**

An active spiritual life may help lessen the stress and distress of cancer. For some people, spiritual life takes the form of faith and prayer. For others, it may mean thinking about what's most important and forming new goals.

If prayer or meditation has helped you in the past, it may also comfort you now and help you cope. Although prayer

### ***Should You Join a Support Group?***

If you are unsure whether joining a support group is the right choice for you, ask yourself the following questions. If you answer “yes” to most, you might want to look into the groups in your area. Your doctor, nurse, or hospital social services department can help you locate support groups in your area or online.

- Do you want to learn more about cancer and survivor issues?
- Are you ready to talk about your cancer experience with others?
- Do you want to hear others' feelings about their cancer?
- Do you have helpful advice or hints to share with others?
- Would you like the advice of others who have gone through cancer treatment?
- Would reaching out to support other cancer survivors make you feel good?
- Would you be able to work with people who have different ways of dealing with cancer issues?

## ***Find the Right Therapist for You***

- Ask whether your hospital or treatment center provides counseling services for cancer patients and their families.
- Ask your doctor, nurse, and/or social worker for a referral for outside individual or family counseling. You will want a counselor who has experience dealing with people who have cancer.
- Contact community agencies that provide counseling services.
- Call referral services of professional mental health organizations.
- Contact your local American Cancer Society chapter.

alone has not been shown to cure cancer, it may help you feel less isolated.

Having cancer often makes people feel angry or question their faith. Spiritual counseling may help. If you have a regular place of worship, ask if your clergy are trained to counsel people with cancer. If not, ask hospitals, hospice programs, or your social worker where to find a trained pastoral counselor. This service is often free, or the fee is based on your income.

## **Coping with Body Changes**

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Cancer survivors often have to deal with physical changes. Learning to use an artificial limb or regaining the weight

they lost can be a challenge. They may need help in coping with feelings about their changed bodies. Some of the changes may make them feel uncomfortable with the way they look.

If you have had physical changes, health professionals are available to help you adjust to changes and live life to the fullest, both physically and mentally. For example, a physical therapist can help you use an artificial limb, a counselor can help you learn to have a satisfying sexual relationship with your partner, or a dietitian can help you regain your lost weight.

## **Getting the Help You Need**

Ask your doctor or nurse for a referral to a rehabilitation specialist who can help you adjust to body changes. A rehabilitation specialist can help with the skills you need to live as independently as possible. Such specialists include, for example:

- physical therapists to help women increase their arm strength after a mastectomy
- occupational therapists to help people regain strength and coordination and plan for a return to normal activities
- speech therapists to help people learn new ways to communicate after a laryngectomy
- enterostomal therapist to help people dealing with an ostomy
- social workers or counselors to help deal with feelings and concerns about body changes

You may want to contact a home health aide if you need help moving around, bathing, cooking, or doing household chores.

## *When You Have Trouble Coping*

Emotions such as sadness and anxiety are normal responses to having cancer. But for some people, negative feelings become intense and overwhelming. Overpowering emotions may signal an emotional illness that should be treated by a mental health professional. Problems cancer survivors sometimes have are anxiety disorder, post-traumatic stress disorder, and depression.

- Anxiety disorder. Some people become so worried about their cancer that it consumes their lives. They may not enjoy family and friends as much as they did before getting cancer. Or they may not get the cancer followup care they need. Their cancer pain may also get worse. People who have had other anxiety disorders before the cancer are more likely to be troubled with anxiety about cancer.
- Post-traumatic stress disorder. After highly stressful events such as having cancer and cancer treatment, some people have extreme reactions. They may have persistent nightmares or flashbacks. They may also avoid any reminder of cancer, even if it means they withdraw from loved ones or don't get the followup care they need.
- Depression. Major depression affects about one in four people with cancer. People may have depression if, for 2 weeks or more: they have feelings of guilt, worthlessness, or hopelessness; they think of suicide; and they feel no pleasure. Look at this list of warning signs. Place a check mark next to each statement that is true for you for the past 2 weeks or more.
  - I feel tired, low on energy, or slowed down.
  - I sleep too much or too little.
  - My appetite has changed.
  - I've had a rapid weight gain or loss.
  - I've lost interest and pleasure in sex.
  - I've lost interest and pleasure in my daily activities.
  - I have problems making decisions or thinking clearly.
  - I'm worried about the cancer most of the time.
  - I cry a lot.
  - I have thoughts of suicide or death.
  - I feel sad, hopeless, or guilty most of the time.
  - I've had nightmares or flashbacks for many months.

**If you—or someone you care for—appears to have any of these problems, tell your doctor.** Emotional illnesses can be treated. Your health and quality of life will improve. Treatment may include counseling, support groups, behavior change therapy, relaxation techniques, and medicines.

## Learning from Others

Ask your local cancer support organization, social worker, or doctor's office staff to put you in touch with other survivors. A support group can give you practical tips on how to manage the physical changes, and other members can tell you how they coped emotionally. See pages 14 and 1.5 for more information on support groups.

## Feeling Good about Yourself

Keep in mind what really makes each of us special — a sense of humor, intellect, a certain sweetness or great common sense, special talents, caring for others. Taking on new activities or returning to those you were not able to do during treatment can give you a new sense of self-worth. Participating in physical activities, such as sports, dancing, and yoga, can help you feel good about your body. Taking up new interests, such as painting, playing a musical instrument, or sewing, can help you grow creatively.

Most people find that caring for their appearance and looking their best helps them feel better about themselves. Makeup, clothes, accessories, or new products may help you look and feel as good as possible. Ask your local cancer support organization, your social worker, and other survivors where to find products such as wigs and breast forms.

## Rediscovering Your Sexuality

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Intimacy with your partner can help you feel better about yourself and your relationship. It may take some time, however, to enjoy the same sexual relations

that you had before treatment. A number of obstacles may stand between you and your old relationship.

- You may feel less interest in sex. Your worries about how your body looks and anxiety about your health, family, or finances, or side effects of treatment may be contributing to your lack of interest.
- Your partner may fear that he or she could harm you.
- Your partner may fear catching cancer or being affected by the drugs. You can reassure your partner that there is nothing to fear.

To begin to enjoy one another physically again, you may want to start out with hugging, touching, holding, and cuddling. You and your partner should decide together what gives both of you pleasure by sharing your feelings with one another. There is no one “right” way to express your sexuality.

If talking to each other about sex, cancer, or both, is hard, you may want to speak to a counselor who can help you talk more openly. People who can help include psychiatrists, psychologists, social workers, marriage counselors, sex therapists, and members of the clergy. Talk with your doctor, nurse, social worker, or other counselor who can give you the information and the reassurance you need.

## Getting Further Support

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Family and friends can be great sources of support. But you may need to let them know how they can help you. Although they want to rush to your aid,



family and friends simply may not know what to do. You might have to make the first move. Be specific about what people can do for you. For example, ask someone to take your daughter to soccer practice, make a meal on a certain night, or just spend time with you. It may also help to talk to family and friends about their needs for support.

To obtain the broadest range of help — from counseling to helping to find other services — contact a social worker. Some of the services a social worker can provide are:

- individual or family counseling,
- referrals to home health care,
- rehabilitation services,
- transportation for followup care,
- child care,
- help with financial planning,
- dealing with the health care system, and
- working with insurance companies.

*“In the first 6 months after my cancer treatment, I saw my cancer more as a threat to my life plans for marriage and a career than I did as a threat to my life. I felt the most sadness and worry during the first 3 months, but then I started to get back to normal.”*

— Marcia B.

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*“Having cancer made me look at the red possibility of my own death, something I had never thought much about before. That made me take a hard look at my life and decide what really matters to me. I now see every day as a precious gift.”*

— Vicki W.

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*“I was hurt that very few of my friends really made the effort to ‘be there’ for me. My nurse said that people often want to help but they do not know how—and they may be embarrassed to ask. So I made the first move with some of the people I cared about most. I feel much more in touch now.”*

—Rhonda L.

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*“The hardest thing was learning to adjust to new family roles. My wife went back to work while I was at home, and my teenage daughter had to take care of the house. As I got better, none of us was sure what roles were ‘normal.’ The doctor suggested family therapy, and although I had my doubts, it’s really helped.”*

—Ralph Y.

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## Managing Insurance Issues



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# Managing Insurance Issues

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If you are like most cancer survivors, insurance issues are a major focus. In general, people who had life and health insurance before treatment are able to keep it, although costs and benefits may change. Those who change jobs or apply for new policies, however, often face problems. Knowing what your policy covers — and dealing with the paperwork — are also key concerns.

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## Examining Your Health Insurance Coverage

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### Benefits

Inpatient hospital care, physician services, laboratory and x-ray services, prenatal care, inpatient psychiatric care, outpatient services, and nursing home care should all be covered by your health insurance. Be sure you know your prescription drug coverage policy. It will be important if you will be taking a medicine for a long time. Some HMOs and other plans do not cover well care or monitoring visits to a specialist in long-term cancer followup. If you plan to see such a specialist, check to be sure.

### Financial Protection

Your insurance company should pay at least 80 percent of each covered service. The exception is inpatient psychiatric care, for which you may be required to pay more than 20 percent of expenses. In addition, your insurer should pay at least \$250,000 for catastrophic illness coverage. You should pay no more than 30 percent

of your income toward catastrophic illness expenses.

Ask your insurance agent whether the company can drop you or raise your premiums if you use covered services.

## Making the Most of Your Insurance

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Dealing with the complexities of health insurance can be overwhelming. This section offers some tips that others have found useful to make sure they got the maximum coverage available to them.

### Understand All the Benefits Your Policy Provides—And File for Them

Get copies of your insurance policies and find out exactly what they cover. Your personal files should contain careful records of all your expenses and claims. Keep track of every step of the claims process, including any appeals you file. Confirm in writing anything you agree to on the phone. If you think the person on the phone is wrong, ask to speak with his or her supervisor. Keep each written response with your files.

File claims for all covered costs. Get help in filing a claim if you need it. If friends or family can't assist, ask a social worker for help. Private companies and some community organizations can also help you. (See page 2.5.) If your claim is turned down, file again. Ask your doctor to explain to the company why your care meets the standards for coverage under your policy. If you are turned down again, find out if the company has an appeals process.

### **Keep Your Insurance Needs in Mind If You Change Jobs**

Try to find a new job with good insurance coverage (or make other plans for insurance) before you leave a job that has insurance benefits. Your spouse should also keep this in mind if you are covered under his or her policy. Look at the insurance coverage and other benefits various employers offer. You may be better off taking a new job with a lower salary that has better insurance coverage. Large companies have group insurance plans, which are less likely to exclude employees with a history of illness.

Consider your options when leaving your job. The Federal Comprehensive Omnibus Budget Reconciliation Act (COBRA) allows you to stay in your current company's group plan for — usually — up to 18 months after you leave a job. (See page 28.) Some company group policies allow you to convert to an individual policy when you leave the company or retire. Often, you can obtain coverage for about 1 year under a converted policy. Individual policies, however, may cost a lot more and include a lot less.

### **Work with Your Doctors to Get Maximum Coverage of Clinical Trials Costs**

Many clinical trials (treatment studies) offer some care free of charge. But some insurers will not cover certain costs when a new treatment is under study. Many handle new treatments on a case-by-case basis. You can always ask about whether your plan covers a treatment you will receive, although some people say that this can hurt your chances by “raising a red flag.”

If you are age 65 or older, you are eligible for Medicare, which is health insurance funded by the Federal Government. Medicare covers the patient care costs of clinical trials.

To increase your chances of getting coverage for clinical trial treatments, take these steps.

- Ask your doctor about other patients in the trial. Have their insurers paid for their care? Have some treatments or tests always been a problem?
- Make your request for hospital precertification as soon as you can. Ask the hospital to set a target date for your treatment or test so you can give the insurer a deadline for making its coverage decision.
- Talk to your doctor about the paperwork he or she submits to your insurer. Often, the way the doctor describes a treatment can help or hurt your chances of coverage. Have your doctor and the hospital send information to the insurer showing that the medical community accepts your treatment/test, that it is safe, and that it has benefits.

- Be sure you know what's in your policy. Check to see if "experimental treatment" is excluded.
- Tell your study coordinator if you are a veteran or have health insurance through TRICARE (which covers eligible active and retired members of the military and their families or survivors). Under agreements with the NCI, the Department of Veterans Affairs (VA) or TRICARE will likely cover your costs if you take part in the studies NCI sponsors.
- Local office on aging (if you are an older adult)
- City or county social services agencies
- Nonprofit consumer credit counseling services in your area. If you cannot find one in the phone book, the National Foundation for Credit Counseling (301-589-5600; <http://www.nfcc.org>) can direct you to a service in your area.
- Labor unions
- Community service organizations
- Religious organizations
- Social and fraternal organizations
- Pharmaceutical companies that offer free drugs to indigent patients
- Your local Congressional Representative's office
- Local public assistance office

To learn more, order a copy of *Taking Part in Clinical Trials: What Patients Need to Know*, by calling 1-800-422-6237 or go to <http://cancertrials.nci.nih.gov>.

### **Find Other Ways to Reduce Your Out-of-Pocket Costs**

Take all the Federal income tax deductions for health care costs that the law allows, such as gas mileage for trips to and from the doctor's office or hospital, out-of-pocket costs for prescription drugs and equipment, and meals during lengthy medical visits. A tax consultant can help you decide what to claim and what receipts and other papers you will need as support. Think about filing an insurance complaint if you receive unfair treatment. (See page 30.)

For help in paying medical costs not covered by insurance, look to organizations, the Government, and your local hospital. Here are some suggestions.

#### **Organizations**

- Local cancer support organizations, which may refer you to local sources of aid

#### **U.S. Government**

- Aid to Families With Dependent Children (AFDC) and Food Stamps Programs. Look for the numbers under the Local Government, Social Services section of your telephone book.
- The Children's Health Insurance Program. This agency provides health insurance to low-income children who do not qualify for Medicaid and have no other health insurance. Call 1-877-543-7669 or visit their Web site at <http://www.insurekidsnow.gov>.

- Medicare/Medicaid Information. Call your local Social Security office (or visit the Web sites: **<http://www.medicare.gov>** and **<http://www.hcfa.gov/medicaid/mcaicnsm.htm>**) to get an explanation of the medical costs covered. NOTE: If you are under age 65, Medicare coverage does not begin until 2 years from the date you are declared disabled.
- Social Security Administration. Call 1-800-772-1213 or visit SSA's Web site at **<http://www.ssa.gov>** for general information on Social Security benefits that you may be eligible to receive.
- The Department of Veterans Affairs. To request information about medical benefits for veterans and their dependents, call 1-800-827-1000 or visit the VA Web site at **<http://www.va.gov/benefits.htm>**.
- The Cancer Information Service. Call 1-800-422-6237 to request information about drug companies that assist cancer patients with low incomes.
- The Internal Revenue Service (IRS). You may have tax-deductible medical expenses. To find out what the IRS allows, call your local IRS office (the number is in the phone book) or visit their Web site at **<http://www.irs.ustreas.gov>**.

### ***Your Hospital***

To find out about setting up monthly payment plans for hospital bills, contact your:

- hospital patient advocate,
- hospital financial aid counselor,

- hospital social worker, or
- patient representative in the hospital business office.

## **Getting Health Insurance After Cancer Treatment**

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When you look into a new health insurance plan, make sure that the coverage it provides suits your health care needs. Try these three approaches to get health insurance.

### **Investigate group policies.**

- Join your current company plan.
- Request group insurance through a professional, fraternal, membership, or political organization to which you belong.

### **Explore alternatives.**

- Get coverage as a dependent under your spouse's insurance plan.
- Join a health maintenance organization (HMO).
- Get coverage through an independent broker.
- Get insurance during open enrollment periods. Many states require all the health insurers they license to allow anyone — including people with “pre-existing conditions,” such as cancer survivors — to buy a policy at certain times of the year. Ask your state health insurance office if your state has this policy. Many companies have waiting periods for costs related to preexisting conditions. Other benefit limits may also apply.



### **Look to the Government for help.**

- Use Medicare. It covers most people age 65 or older and those who are permanently disabled.
- Use Medicaid or other state or local benefits. Coverage and eligibility criteria differ from state to state. Check with your local office.
- Join a state-run “high risk” health insurance pool for people who cannot get conventional coverage. (See page 26.) Under this type of plan, health

insurance is available to all, no matter what their health history. These plans have some drawbacks: (1) your policy may cost more; (2) your benefits may be less; and (3) you may face a waiting period during which you cannot receive benefits for costs related to your cancer or any other conditions you had before joining this pool.

- Remember: every state has free health insurance counseling. (See the resources section on page 29.)

## ***Health Insurance: Your Legal Rights***

<b>The Law</b>	<b>How It Protects You</b>
Federal law “Employee Retirement Income Security Act of 1974” ( <b>ERISA</b> )	Your employer cannot fire you to prevent you from getting your health insurance benefits.
<p>The Consolidated Omnibus Budget Reconciliation Act (<b>COBRA</b>)</p> <p><i>Applies to employers with 20 or more employees</i></p>	<p>Your employer must allow employees who quit, are let go, or whose hours are reduced, to pay their own premiums for the company’s group plan and keep their insurance coverage.</p> <p>This protection lasts 18 months for employees (up to 29 months if they lose their jobs due to disability and are eligible for Social Security disability benefits at the time they leave the job) and 36 months for their dependents.</p> <p>If you leave a company and take a new job, you can continue coverage by the former company for up to 18 months if the new company’s coverage is limited or excludes a preexisting condition such as cancer.</p>
The Health Insurance Portability and Accountability Act of 1996 ( <b>HIPAA</b> )	<p>Your employer cannot exclude you from group coverage because of past or present medical problems (preexisting conditions), including having a known genetic risk for a disease you do not have.</p> <p>You also cannot be charged higher premiums based on your medical history or genetic information.</p> <p>One limit: HIPAA does not apply to individual health insurance policies. For more information, contact the Health Care Financing Administration at 1-800-318-2596 or visit online at <b><a href="http://www.hcfa.gov">http://www.hcfa.gov</a></b>.</p>

Many States also have laws similar to COBRA and HIPAA. In addition, 35 States now have laws that specifically address health insurer discrimination based on genetic information. Your State insurance office (see page 29 to learn how to contact this office) can tell you what your State’s laws cover. Page 51 explains how to enforce your rights.

## Getting Life Insurance After Cancer Treatment

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Insurance companies will look at your medical history closely before giving you life insurance. These four suggestions may help you get the insurance you need.

- **Contact large life insurance companies first.** Many larger companies carefully grade insurance risks by type and stage of cancer. Depending on your diagnosis, you may be able to get a policy.
- **Get prices from several companies.** Policy costs can vary a great deal among companies.
- **Request group insurance** through a professional, fraternal, membership, or political organization to which you belong.
- **Consider a policy that has limited benefits** (a “graded” policy) if you cannot get full death benefits. If the insured person dies of a preexisting condition, such as cancer, within the first few years of a graded policy, only the premiums plus part of the face value are paid out. If the insured person dies after the specified waiting period, the company usually will pay the full face amount of the policy.

## *Your State Has Free Health Insurance Counseling*

As a cancer survivor, you may need information and new skills to handle insurance matters. Every state (plus Puerto Rico, the Virgin Islands, and the District of Columbia) has a health insurance information and counseling service that can help.

The service gives you free information and help on Medicare, Medicaid, Medigap, long-term care, and other health insurance benefits. These offices will give you printed information, help with choosing health insurance coverage, and even help you understand your bills, insurance claims, and forms. To find the number for your state’s health insurance counseling office, call the Medicare hotline at 1-800-MEDICARE (1-800-633-4227) or visit the Medicare Web site at <http://medicare.gov>.

## ***Where To File an Insurance Complaint***

<b>If Your Insurer Is—</b>	<b>File a Complaint With—</b>
A private company <i>(for example, Blue Cross, Prudential)</i>	Your State department of insurance
A licensed health care service plan <i>(for example, an HMO)</i>	Your State department of corporations, division of health care service plans
A Federal qualified HMO	U.S. Department of Health and Human Services, Division of Compliance
A private employer or union self- insurance or self-financed plan	U.S. Department of Labor, Pension and Welfare Benefits Administration, Division of Technical Assistance and Inquiries
Medicaid <i>(sometimes called other names; for example, in California it's MediCal)</i>	Your State department of social services
Medicare Supplemental Security Income Social Security Benefits	U.S. Social Security Administration
Veterans Benefits	Department of Veterans Affairs
TRICARE	Health Care Finance Administration

Look for the telephone numbers of state agencies in the phone book. Ask the State Insurance Counseling Offices or your State insurance office how to contact Federal agencies.

*“When I tried to get life insurance after cancer, several companies refused to accept me at all. I have coverage now, but the policy has an ‘exclusion’ for cancer, and it pays nothing if cancer is the cause of death. I’m still looking for a policy without this clause.”*

—Burt W.

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*“When my health insurance company canceled my individual policy after my cancer treatment, I started checking in to other options. My best bet turned out to be joining my new company’s group policy, even though employees have to pay all their own premiums. The benefits are pretty good, and they accepted me despite the cancer history.”*

—Jean T.

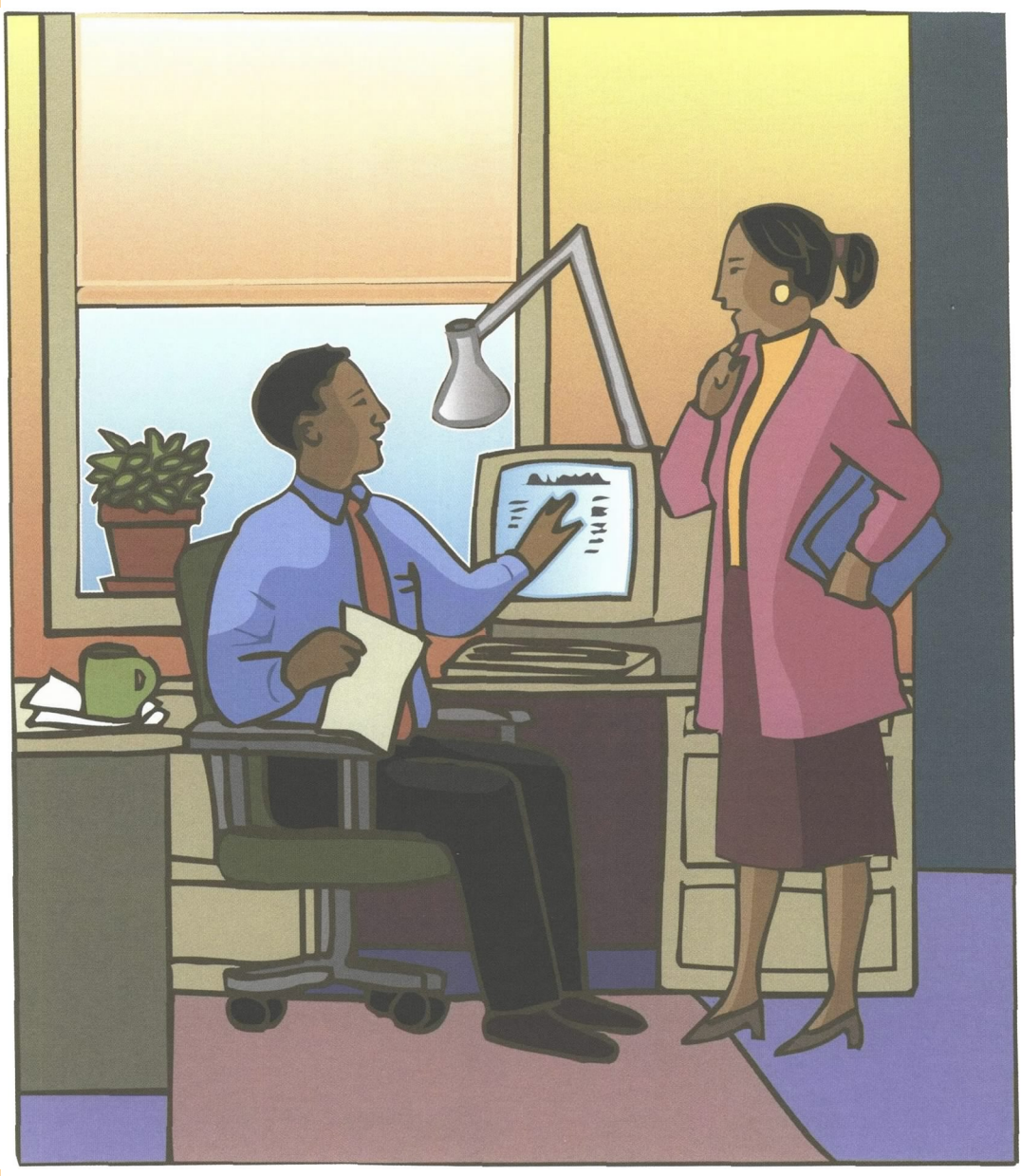
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*“My health insurance after cancer treatment worked pretty much like my car insurance: after I had an accident, my rates went up.”*

—Barbara K.

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Earning a Living



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# Earning a Living

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Most cancer survivors who are physically able to work do go back to their jobs. Returning to work can help cancer survivors feel they are getting back to the life they had before being diagnosed with cancer.

Some survivors are treated unfairly when they return. Employers and employees may have doubts about cancer survivors' ability to work.

Your employment rights are protected by Federal and State laws. This section offers ideas to help ease your return to work. It talks about how to deal with coworkers, handle job problems, and change jobs after cancer treatment. It also outlines your job-related legal rights as a cancer survivor.

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## Returning to Work

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When your coworkers hear about your illness, many will want to help, but they won't know how. Cancer may frighten some people who do not know much about it. You can deal with their concerns.

### Keep up Contacts During Your Treatment and Recovery

People at work will worry about you. If they find out about your treatment and progress, they will be less anxious and scared. Talk to them on the phone or send e-mail. When you are able, have lunch with friends or stop in for an office party. Your return to work will be easier for you and others if you stay in touch.

### Plan What You'll Say About Your Cancer

There is no "right" way to deal with others about your illness, but you do

need to think about what you'll say when you're back on the job. Some cancer survivors don't want to focus on their cancer or be linked with the disease in people's minds. Others are very open about it, speaking frankly with the boss or other workers to air concerns, correct wrong ideas, and decide how to work together. The best approach is the one that feels right to you.

### *Cancer Survivors as Employees*

- Research shows that cancer survivors are as productive on the job as other workers and that they are not absent from work more often.
- Most adult survivors of childhood cancers have normal job satisfaction and reach the same educational levels as people with no cancer history.

## ***Handling Job Problems***

### **Decide what you want to do about an employment problem.**

- Do you still want to work there?
- Are you willing to take action to correct a problem?
- Would you rather look for a new job?

### **Educate your employer.**

- Give management the facts about cancer survivors on the job (See page 35).
- Have your doctor explain how, if at all, your cancer may affect your work or your schedule.

### **Ask your employer to adjust to your needs.**

- Start by talking informally to your supervisor, the personnel office, employee assistance program, shop steward, or union representative.
- Ask for a specific change that would make it easier for you to keep your job (for example, flex-time, working at home, special equipment at the office).
- Document your requests and the outcome for your records.

### **Get help working with your employer if you need it. Ask—**

- your doctor or nurse
- your company's doctors and nurses
- medical social workers
- State rehabilitation workers
- staff and volunteers at your local cancer support organization
- advocacy groups for disabled workers
- your family and friends

### **Talk about your legal rights with the groups that enforce anti-discrimination laws.**

- State commissions on discrimination
- State affirmative action offices
- U.S. Department of Health and Human Services, Office for Civil Rights in your region
- US. Department of Labor, Office of Federal Contract Compliance programs in your region

### **Talk to a lawyer who has experience in solving job discrimination problems.**

- Ask your local bar association or cancer support group how to find a qualified lawyer. The National Coalition for Cancer Survivorship may also be able to refer you (See Resources section, page 50).
- Discuss any formal process your workplace may have for settling disputes.
- Think about filing a discrimination complaint under State or Federal law.

## **Get Help if You Need It**

If a coworker's feelings about cancer are making it hard for you to do your job, try first to resolve the problem face-to-face with that person. It can be hard to correct another's wrong ideas without being defensive. But a direct approach may help things change for the better.

When such efforts don't work, you may want to get help. Your manager, shop steward, company medical department, employee assistance counselor, or personnel office may be able to change coworkers' ideas, procedures, or the way your job fits in with others to lessen problems. It is a good idea to have a possible solution in mind when you point out a problem.

Most survivors don't want to make formal complaints. When hurtful remarks or actions get you down, talking to a friend or counselor may help you deal with it. But if coworker attitudes get in the way of doing your job, it is a problem that management needs to address.

## **Changing Jobs After Cancer Treatment**

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When you look for a new job after cancer treatment, be aware of the concerns that your cancer may raise. Keep these three tips in mind as you prepare for the job search:

### **Don't Discriminate Against Yourself**

Instead, take an honest look at your current skills, then apply for jobs you know you can do. You don't need to try to do more — or settle for less — than you are able to handle.

### **Set up Your Resume by Skills or Achievement**

Don't arrange it by job and dates worked. This way, you don't highlight gaps caused by cancer treatment or recovery. You have no legal obligation to talk about your cancer history unless your past health has a direct impact on the job you seek. So, you don't need to bring up your cancer if no one asks.

### **Consider Working with a Job Counselor**

Use state and local rehabilitation programs if you need them. Under Federal law, States must assess your return-to-work potential, counsel you, and provide placement help. Some States also offer transportation and special equipment.

You can find your State rehabilitation office by looking in the phone book under Rehabilitation Services or Vocational Rehabilitation Services or under state departments such as Labor, Human Resources, Public Welfare, Human Services, or Education.

## Knowing Your Legal Rights

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Employee rights laws — on both the Federal and State levels — protect cancer survivors. These laws prohibit job discrimination and guarantee the right to medical leave.

Keep in mind that if you do plan to file a legal complaint under one of these laws, you must meet the proper deadlines. Most complaints to Federal and State agencies must be made within 180 days of a problem, but periods can be shorter. For instance, if you are a Federal employee filing under the Federal Rehabilitation Act (see below), you have only 30 days to state your complaint.

### **The Americans with Disabilities Act (ADA)**

The ADA bans discrimination by both private and public employers against qualified workers who have disabilities or histories of disability. Although cancer survivors may not feel “disabled,” they may be legally protected under this umbrella term. The ADA covers private employers with 15 or more workers. Under this law, employers

- must make a “reasonable accommodation” to allow you to do your job if it does not cause the employer “undue hardship.” Simple changes employers are required to make include
  - making facilities accessible (for example, having desks, aisles, and restrooms that accommodate a wheelchair).
  - allowing you to work a flexible schedule to adjust for time spent getting treatment or followup care.

— changing the way a job works (for example, letting you work part-time or share a job).

- cannot require you to take pre-employment exams designed to screen out people with disabilities, such as a history of cancer.
- cannot ask you medical questions until after they make you a job offer and, at that point, can ask only questions that relate specifically to the job.
- cannot ask you for the results of a genetic test or treat you differently because of your genetic history.
- cannot treat you differently from other workers. A disability must not affect pay, promotions, insurance and pension benefits, vacation time, job training, or continued employment.
- cannot punish you for filing a discrimination complaint.
- cannot discriminate against your family members because of the relationship. For example, your spouse’s employer cannot treat your spouse differently because the employer assumes he or she will take leave time to care for you.

For more information about the ADA, go to **<http://www.usdoj.gov>**.

Complaints filed under this law are handled by the local offices of the Equal Employment Opportunities Commission (EEOC). The EEOC suggests filing promptly. Time limits apply. You can find the EEOC office nearest you at 1-800-669-4000 or on the Internet at **<http://www.eeoc.gov>**.



## **The Family and Medical Leave Act of 1993**

This law requires employers with 50 or more employees to provide unpaid leave to employees with a serious illness or family members who need time to care for a seriously ill child, spouse, parent, or healthy newborn or newly adopted child. The Family and Medical Leave Act—

- allows up to 12 weeks of unpaid leave during any 12-month period.

- requires employers to continue providing health insurance and other benefits during the leave period.

- requires employers to give employees the same job, or an equivalent job, when they return from leave.

- allows employees to reduce their work schedule or work on-and-off when it is medically necessary.

Employees must make every effort not to disrupt the work schedule, and employers may verify a medical need. To qualify for leave under this law, an employee must have worked at least 2.5 hours per week for 1 year. Companies may deny unpaid leave to their highest paid workers. To enforce your Family and Medical Leave Act rights, you must file a lawsuit against your employer within 2 years of the problem.

For more information, visit the U.S. Department of Labor Web site at <http://www.dol.gov> and use the search function, or go directly to <http://www.dol.gov/dol/esa/public/regs/compliance/whd/1421.htm> or to <http://www.dol.gov/dol/esa/public/regs/compliance/whd/whdfs28.htm>.

## Federal Rehabilitation Act

This law protects cancer survivors who work for the Federal Government from discrimination in hiring practices, promotions, transfers, and layoffs. Federal employees file complaints with the agency that employs them. Those who work for companies that receive money from Federal agencies file complaints with the funding agency.

For more information, visit the US Department of Labor Web site at <http://www.dol.gov> and use the search function, or go directly to <http://www.dol.gov/dol/esa/public/regs/compliance/ofccp/fs503.htm>.

## State Laws

Most States also have laws that forbid job discrimination against people with disabilities. Many have rules similar to those of the ADA. In some States, though, these laws cover only people who have physical handicaps.

To enforce your rights under State law, you must file a complaint with your State enforcement agency. To find out about the laws in your State, or to locate your State enforcement agency, contact the EEOC at 1-800-669-4000. You can also check in your local telephone book under "State Government."

*"After I had my colostomy, my employer asked me to quit my job because the cancer upset my fellow workers. He said I might receive a demotion or transfer if I didn't agree. Except for my wife, that job was my whole world. So rather than quit, I chose to fight for it."*

—Jon H.

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*"My boss denies that my treatment last year for cancer was the reason I did not advance to a higher grade in my job. He said he just didn't feel I was ready for the added pressure and duties at this time. I do not know what to believe, but I'm looking into my legal rights."*

—Betty C.

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*"When I went back to work, my boss told me that the firm had some concerns about me. Her boss had asked how she planned to get the job done, since she could no longer count on my staying healthy. But she had done some research on cancer survivors. It showed that, in general, we perform as well as people who have not had cancer. Her facts helped correct management's myths."*

—Roy P.

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## Facing Forward as a Childhood Cancer Survivor



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# Facing Forward as a Childhood Cancer Survivor

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More and more survivors of childhood cancer are growing into adulthood. Researchers are studying the long-term effects of cancer and cancer treatment on these survivors. They are finding out that these survivors have special needs in the areas of health care, emotional support, and job and insurance assistance.

This section touches on a few of those concerns. For more information on childhood cancer survivors, contact the Candlelighters Childhood Cancer Foundation at 1-800-366-2223 (<http://www.candlelighters.org>).

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## Caring for Your Health

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When you switch from pediatric to adult medical care, continue to get yearly checkups. Throughout your life, you should seek out doctors who have experience in followup and treatment of long-term survivors of childhood cancers. Call your local cancer center or a children's hospital to find specialists in childhood cancer survivors.

Most childhood cancer survivors say that having yearly checkups makes them feel better about their good health. Followup specialists will check you for any late effects of cancer and the treatment. They also can give you the information you need to recognize and deal with any late effects. Late effects may include heart disease, thyroid disease, cataracts, kidney disease, osteoporosis, and other cancers. Such effects can occur many years later — even 20 years or longer after your treatment.

## Having Children

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Although radiation therapy and chemotherapy can affect both men's and women's fertility, most survivors of childhood cancers are able to have children. Studies have shown that cancer survivors are not at increased risk of having children who have congenital defects.

Young women who are treated with radiation and chemotherapy may experience early menopause. A woman who has survived cancer and who wants children may need to consider pregnancy at a younger age than someone who did not receive cancer therapy. Young men who have received radiation and/or treatment with certain medications may want have their sperm tested. Discuss any fertility questions you have with your long-term care doctor.

## **Taking Care of Your Feelings**

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Survivors of childhood cancers often face different stresses and emotional concerns than older survivors. Some may have a sense of loss for teenage years or a childhood spent in cancer treatment. Others worry that cancer may shatter their dreams for the future. The effects of cancer on their social life often can be greater for younger survivors.

The issues that seem most important also may change over time. For instance, at 18, you may focus on cancer's effects on how you look, and at 25, your concerns may turn to your feelings about making an emotional commitment. If friends or loved ones develop cancer, you may recall old feelings or have flashbacks about treatment.

Most childhood cancer survivors go on to have satisfying lives. Although late effects of treatment have caused social or learning problems in some survivors, teachers and counselors can help you deal with any problems. Although you may worry more about cancer-related illness, you also are likely to feel more positive about life than your peers.

In dealing with your unique feelings and stresses, keep these tips in mind.

- Insist that your needs as a cancer survivor be taken seriously by your health care providers and your loved ones. Your concerns as a younger person deserve the same attention as the issues older adults are facing.

- If you want to join a cancer survivors' group, look for one made up of other young people. You may find you have more in common with people your own age who can share ideas about coping with problems unique to you.
- Work with your family as you move from living at home to living on your own. Your cancer may make it even harder for your parents to accept your independence. You may still need their help in some ways, too. If you cannot resolve problems, think about family counseling.

## **Getting Insurance Benefits**

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Use the ideas on page 26 to find your own insurance coverage before you must go off your parents' policy. Many plans no longer cover children when they reach age 18 or when they leave college. For ideas on how to increase your chances of finding life insurance, use the ideas listed on page 29. Adult survivors of childhood cancers sometimes have more problems getting life insurance than they do in getting health insurance.

## Earning a Living

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If you are a cancer survivor in your 20s, you may find getting a job somewhat harder than it is for your peers who have not had cancer. Because you had cancer as a child, you may have no job history. But as you get older, most of these problems will likely lessen.

Studies show that survivors of childhood cancers who are age 30 and older achieve about the same economic levels as people who have never had cancer. Some exceptions are military service, police work, and firefighting, in which fewer survivors appear to get jobs. Overall studies show that most childhood cancer survivors achieve their work goals. About 8 out of 10 who have jobs report feeling good about them.



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# Resources



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# Resources

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## National Cancer Institute (NCI)

The NCI leads the Nation's fight against cancer by supporting and conducting research into the prevention, detection, treatment, and causes of cancer. The NCI has cancer information available in print and online. The following resources are available to patients, families, and health professionals.

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### Cancer Information Service (CIS)

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English or Spanish or on TTY equipment.

**Toll-free:** 1-800-4-CANCER  
(1-800-422-6237)

**TTY** (for deaf and hard-of-hearing callers): 1-800-332-8615

### CancerNet

Contains a variety of cancer information and links to other cancer information sites at <http://cancernet.nci.nih.gov>.

### National Cancer Institute Online

Contains cancer and cancer research information for patients and health professionals at <http://www.cancer.gov>.

### Office of Cancer Survivorship, NCI

Contains information on research in cancer survivorship at <http://dcccps.nci.nih.gov/ocs/>.

### Other Cancer Organizations

Below are some organizations that offer support and information to cancer survivors and their families. For more information or a larger list of organizations, call the NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

#### American Cancer Society (ACS)

The ACS is a voluntary organization that offers a variety of services to patients and their families. The ACS also supports research, provides printed materials, and conducts educational programs. Staff can accept calls and distribute publications in Spanish. A local ACS unit may be listed in the white pages of your telephone directory under "American Cancer Society."

American Cancer Society

1599 Clifton Road, NE

Atlanta, GA 30329-4251

Telephone: 404-320-3333 or 1-800-ACS-2345 (1-800-227-2345)

Web site: <http://www.cancer.org>

### **Cancer Care, Inc.**

Cancer Care provides free, professional assistance to people with any type of cancer, at any stage of illness — and to their families. This organization offers education, one-on-one counseling, specialized support groups, financial assistance for nonmedical expenses, home visits by trained volunteers, and referrals to community services. A section of the Cancer Care Web site and some publications are available in Spanish, and staff can respond to calls and e-mails in Spanish.

Cancer Care, Inc.  
275 Seventh Avenue  
New York, NY 10001  
Telephone: 212-302-2400 or 1-800-813-4673  
Web site: <http://www.cancercare.org>  
E-mail: [info@cancercare.org](mailto:info@cancercare.org)

### **National Coalition for Cancer Survivorship (NCCS)**

NCCS is a network of groups and individuals that offer support to cancer survivors and their loved ones. It provides information and resources on cancer support, advocacy, and quality-of-life issues. A section of the NCCS Web site and a limited selection of publications are available in Spanish.

National Coalition for Cancer Survivorship  
1010 Wayne Avenue, Suite 707  
Silver Spring, MD 20910-5600  
Telephone: 1-877-NCCS-YES (1-877-622-793 7)  
Web site: <http://www.cansearch.org>  
E-mail: [info@cansearch.org](mailto:info@cansearch.org)

### **Candlelighters Childhood Cancer Foundation (CCCCF)**

The CCCC is a nonprofit organization that provides information, peer support, and advocacy through publications, an information clearinghouse, and a network of local support groups. A financial aid list is available that lists organizations to which eligible families may apply for assistance.

Candlelighters Childhood Cancer Foundation  
3910 Warner Street  
Kensington, MD 20895  
Telephone: 301-962-3520 or  
1-800-366-CCCCF (1-800-366-2223)  
Web site:  
<http://www.candlelighters.org>

## **Groups to Help You Enforce Your Legal Rights**

### **Pension and Welfare Benefits Administration**

Your rights under the COBRA, ERISA, and HIPAA legislation (see page 28) are enforced by the Pension and Welfare Benefits Administration of the U.S. Department of Labor. The Web site below contains a link to the 15 regional offices.

Pension and Welfare Benefits  
Administration  
Division of Technical Assistance and  
Inquiries  
U.S. Department of Labor  
200 Constitution Avenue, NW,  
Room N-5619  
Washington, DC 20210  
Telephone: 202-219-8776  
Web site: <http://www.dol.gov/dol/pwba/public/contacts/main.htm>

### **Medical Information Bureau (MIB)**

To verify the accuracy of information on file about your health, contact the MIB and ask for a form to request disclosure of any information in your file. (You may be on file with MIB and not know it. The MIB keeps files on nearly 15 million Americans for the insurance companies it represents.) When you request it, the MIB will send your file to your doctor, and he or she can check whether it is correct. This step is important because the information in your file may affect insurance company decisions.

Medical Information Bureau  
P.O. Box 105, Essex Station  
Boston, MA 02112  
Telephone: 617-426-3660  
Web site: <http://www.mib.com>

### **State Health Insurance Counsel Offices**

Call the Medicare hotline at 1-800-MEDICARE (633-4227) for the telephone number of the state office you want to contact or go to <http://www.medicare.gov/contacts/related/ships.asp>. For the phone numbers of the offices, click on “Helpful Phone Numbers” on the right side of the screen.

### **Job Accommodation Network (JAN)**

JAN is a source of information about job accommodations and the employability of people with disabilities. JAN also provides information about the Americans with Disabilities Act (ADA). The JAN Web site contains more than 250 links to help you find the information you need.

Job Accommodation Network  
West Virginia University  
P.O. Box 6080  
Morgantown, WV 26506-6080  
Telephone: 1-800-526-7234 (voice and  
TTY available)  
Web site: <http://janweb.wvu.edu>

## ***Keeping Track of Your Followup Care — A Form You Can Use***

Use this form to keep a record of the questions you want to ask your doctor about your cancer care and the answers you receive. Make copies of this form before you use it.

<b>Date</b>	<b>Reason for Visit</b>	<b>Your Questions</b>	<b>Doctor's Answers</b>	<b>When to Check Back</b>

The National Cancer Act, passed by Congress in 1971, made cancer research a national priority. Since that time, the National Cancer Institute (NCI), the lead Federal agency for cancer research, has collaborated with top researchers and facilities across the country to conduct innovative research leading to progress in cancer prevention, detection, diagnosis, and treatment. These efforts have resulted in a decrease in the overall cancer death rate, and have helped improve and extend the lives of millions of Americans.

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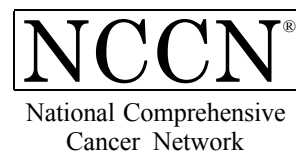
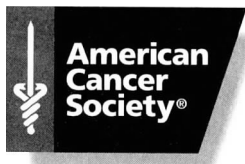
Printed April 2001

# Prostate Cancer

## Treatment Guidelines for Patients

Version II

January 2001





# Prostate Cancer

## Treatment Guidelines for Patients

**Version II**

**January 2001**

The mutual goal of the National Comprehensive Cancer Network<sup>®</sup> (NCCN<sup>®</sup>) and the American Cancer Society (ACS) partnership is to provide patients and the general public with state-of-the-art cancer treatment information in understandable language. This information, based on the NCCN's Clinical Practice Guidelines, is intended to assist you in the dialogue with your physician. These guidelines do not replace the expertise and clinical judgment of your physician. Each patient's situation must be evaluated individually. It is important to discuss the guidelines and all information regarding treatment options with your physician. To ensure that you have the most up-to-date version of the guidelines, consult the web sites of the ACS ([www.cancer.org](http://www.cancer.org)) or NCCN ([www.nccn.org](http://www.nccn.org)). You may also call the NCCN at 1-888-909-NCCN or the ACS at 1-800-ACS-2345 for the most recent information.

NCCN Clinical Practice Guidelines were developed by a diverse panel of experts. The guidelines are a statement of consensus of its authors regarding the scientific evidence and their views of currently accepted approaches to treatment. The NCCN guidelines are updated as new significant data become available. The Patient Information version will be updated accordingly and will be available on-line through the NCCN and the ACS web sites. To ensure you have the most recent version, you may contact the ACS or the NCCN.

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NATIONAL COMPREHENSIVE CANCER NETWORK  
MEMBER INSTITUTIONS

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CITY OF HOPE NATIONAL MEDICAL CENTER

DANA-FARBER CANCER INSTITUTE

FOX CHASE CANCER CENTER

FRED HUTCHINSON CANCER RESEARCH CENTER

H. LEE MOFFITT CANCER CENTER & RESEARCH INSTITUTE  
AT THE UNIVERSITY OF SOUTH FLORIDA

HUNTSMAN CANCER INSTITUTE AT THE UNIVERSITY OF UTAH

ARTHUR G. JAMES CANCER HOSPITAL AND  
RICHARD J. SOLOVE RESEARCH INSTITUTE AT THE OHIO STATE UNIVERSITY

JOHNS HOPKINS ONCOLOGY CENTER

MEMORIAL SLOAN-KETTERING CANCER CENTER

ROBERT H. LURIE COMPREHENSIVE CANCER CENTER  
OF NORTHWESTERN UNIVERSITY

ROSWELL PARK CANCER INSTITUTE

STANFORD HOSPITAL AND CLINICS

ST. JUDE CHILDREN'S RESEARCH HOSPITAL

UCSF COMPREHENSIVE CANCER CENTER

UNIVERSITY OF TEXAS M. D. ANDERSON CANCER CENTER

UNIVERSITY OF ALABAMA AT BIRMINGHAM  
COMPREHENSIVE CANCER CENTER

UNIVERSITY OF MICHIGAN COMPREHENSIVE CANCER CENTER

UNMC/EPPLEY CANCER CENTER  
AT THE UNIVERSITY OF NEBRASKA MEDICAL CENTER

**W**ith this report, patients have their first access to information on the way prostate cancer is treated at the nation's leading cancer centers. Originally devised for cancer specialists by the National Comprehensive Cancer Network (NCCN), these treatment guidelines have now been translated for the lay public by the American Cancer Society (ACS).

Since 1995, doctors have looked to the NCCN for advice on treating cancer. The NCCN Clinical Practice Guidelines were developed by a diverse panel of experts from 18 of the nation's leading cancer centers.

For more than 85 years, the public has relied on the ACS for information about cancer. The Society's books and brochures provide comprehensive, current, and understandable information to hundreds of thousands of patients, their families, and friends. This collaboration between the NCCN and ACS provides an authoritative and understandable source of cancer treatment information for the layperson.

These patient guidelines will help you better understand your cancer treatment and your doctor's counsel. We urge you to discuss them with your physician and ask the following questions:

- How do my age, general health, and other medical conditions affect my treatment choices?
- What are the T, N, and M stages (see pages 14-15) of my cancer and how do they influence 'my treatment options'?
- How does the Gleason score of my cancer and my blood prostate-specific antigen

(PSA) level predict my outlook for survival and 'affect treatment options'?

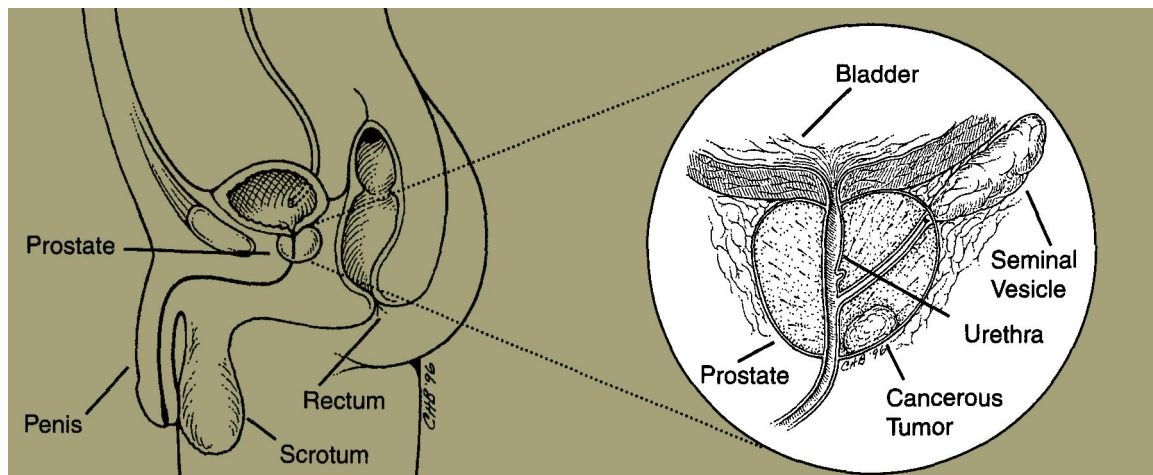
- What are the likely side effects of each proposed therapy and how will they affect my quality of life?
- What can be done to help manage the side effects of treatment?

## ***Making Decisions About Prostate Cancer Treatment***

Prostate cancer is the most common cancer (excluding skin cancer) of American men. The ACS estimates that about 198,000 new cases of prostate cancer will be diagnosed in the United States and 31,500 men will die of this disease during 2001.

Most prostate cancers develop in older men and grow very slowly. But some prostate cancers can grow quickly and spread to other parts of the body, causing symptoms and, sometimes, death. Treating men with such cancers can help them to live longer and can prevent or relieve symptoms. One reason why prostate cancer is so confusing to both doctors and patients is that it is sometimes difficult to distinguish men who will benefit from treatment from others in whom the side effects of treatment will outweigh the benefits;

Although prostate cancer is a very serious disease, it is one that a multidisciplinary team of health-care professionals can treat. But not all men with prostate cancer should receive the same treatment, and, in some cases, no treatment may be the best option.



**Fig 1. Location of the Prostate Gland**

This report can help you and your physician decide which choices best meet your medical and personal needs. On the following pages you'll find flow charts that doctors call "algorithms," "decision trees," or "clinical pathways." The charts show how you and your doctor can arrive at the choices you need to make about your treatment.

To reach an informed decision you need to understand some of the medical terms your doctor uses. You may feel you're on familiar ground already, or perhaps you need to refer to the various sections listed on the front-page index. Not only will you find background information on prostate cancer, but also explanations of cancer stage, work-up, and treatment. We've also provided a glossary of medical terms.

## ***Inside and Around the Prostate***

The prostate is about the size of a walnut and, when the man is standing, is located in front of the rectum, behind the base of the penis, and

under the bladder. It is a *gland* found only in men and produces some of the seminal fluid, which protects and nourishes sperm cells. The prostate surrounds the upper part of the urethra, the tube that carries urine and semen out of the penis.

Prostate cancer develops from cells of the prostate gland. Prostate cancer may spread directly to tissues and organs near the prostate gland. Eventually, the cancer, cells can spread to other parts of the body.

Nerves located next to the prostate gland take part in causing an erection of the penis. Treatments that remove or damage these nerves can cause erectile dysfunction, also known as impotence.

Lymph is a clear fluid that contains tissue waste products and immune system cells. Lymphatic vessels carry this fluid to lymph nodes (small, bean-shaped collections of immune system cells important in fighting infections). Most lymphatic vessels of the prostate lead to pelvic lymph nodes. Cancer cells may, enter lymph vessels and spread out along these vessels to reach lymph nodes, where they can continue to grow. If prostate

cancer cells have multiplied in the pelvic lymph nodes, they are more likely to have spread to other organs of the body as well. This spread is called metastasis.

## ***Early Detection and Work-Up (Evaluation) of Prostate Cancer***

### **APPROACH TO PROSTATE CANCER EARLY DETECTION AND EVALUATION OF ABNORMAL TEST RESULTS**

Many uncertainties persist regarding the early detection and treatment of prostate cancer. Cancers found by digital rectal examination (DRE) and/or prostate-specific antigen (PSA) testing are, on average, smaller and have spread less than cancers discovered because of symptoms they cause. But prostate cancer is unlike many other cancers in that it often grows very slowly.

For men with cancer that is proven not to have spread beyond the prostate gland, the five-year relative survival rate is near 100%, whether or not they are treated. On the other hand, before early detection tests were widely used, most men with prostate cancer were diagnosed with advanced disease, and most died within a few years of the diagnosis.

Although early diagnosis and treatment of prostate cancer can help some men to live longer, it may have no impact on the life span of other men. For a man with a life expectancy of less than 10 years, there is no need to make an early diagnosis of prostate cancer. And, prostate cancer treatments can affect a man's quality of life. A man's life expectancy is esti-

mated by considering his age and any serious medical problems he may have. Making such estimates does not mean that doctors can predict exactly how long patients will live. But, they can make educated guesses that help in deciding who will benefit from testing.

Since prostate cancer testing became relatively common (about 1990) the prostate cancer death rate has dropped. But it has not been conclusively proven that this is a direct result of early detection. Studies are underway to try to prove that early detection in large groups of men will lower their prostate cancer death rates, but results will not be available for several years. Until then, the decision as to whether or not a man should be tested should be left, up to the individual and his health care provider.

Recommendations of the ACS and the NCCN for early detection of prostate cancer include the PSA blood test and the DRE. The NCCN recommends that a DRE be done annually and a PSA blood test be offered initially, beginning at age 50 years, to men who have at least a 10-year life expectancy, and to younger men who are at high risk. Depending on the results of the initial PSA, the NCCN guideline indicates that some men only require a PSA test every two years. The ACS recommends offering both the PSA blood test and DRE annually to these men. Both the ACS and NCCN agree that information should be given to patients regarding potential risks and benefits of early detection and treatment. Men who choose to have early detection testing should begin at age 50 years. However, men in high-risk groups, such as those with a strong family history (for example, a father or brother diagnosed at a young age) or African Americans should begin testing at 45 years of age.

Some other scientific and medical organizations do not believe that tests for early detection of prostate cancer can lower the number of men dying of this disease. For this reason, these organizations do not recommend that health care providers routinely offer tests for early detection of prostate cancer to their patients.

The ACS, the American Urological Association, and the NCCN believe that the majority of available evidence, though not conclusive, supports the view that prostate cancer early detection can save lives. These organizations recommend that providers offer men the option of prostate cancer early detection and discuss the potential benefits, side effects, and uncertainties regarding early prostate cancer detection and treatment, prior to testing.

## **PROSTATE-SPECIFIC ANTIGEN (PSA) BLOOD TEST**

The ACS and the NCCN recommend that this blood test be offered initially to men 50 and older with a life expectancy of at least 10 years. The ACS recommends offering this test annually. The NCCN guideline recommends this interval if the initial PSA result is between 2 and 4, and every 2 years if the PSA value is less than 2. Men with high prostate cancer risk should begin testing at 45 years of age. This test is used to detect cancers at an early stage, before they cause any symptoms.

Certain measures are recommended to make PSA testing as accurate as possible. Because ejaculation can cause a temporary increase in blood PSA levels, NCCN guidelines recommend abstaining from sexual activity for two days before testing. This helps avoid

unnecessary worry and extra tests that might be done, because doctors cannot tell whether a slight PSA increase was caused by ejaculation or might be due to a prostate cancer. The PSA test should not be done if a man has an acute urinary tract infection or prostatitis because these can elevate levels as well.

Several medications and herbal preparations may lower PSA levels. In some cases, a man may have an early prostate cancer, but these products lower the PSA level enough to produce a normal test result. The outcome is that the cancer remains undetected. For this reason, NCCN guidelines emphasize that doctors should ask men having the PSA test about any of the following: finasteride (Proscar<sup>®</sup> or Propecia<sup>®</sup>), androgen-receptor blockers, saw palmetto (an herb used by some men to treat benign prostate enlargement), and PC-SPES (an herbal mixture that contains saw palmetto).

PSA blood test results are reported as nanograms per milliliter or ng/ml. Results under 4 ng/ml are usually considered normal. Results over 10 ng/ml are high, and values between 4 and 10 are considered borderline. The higher the PSA level the more likely the presence of prostate cancer.

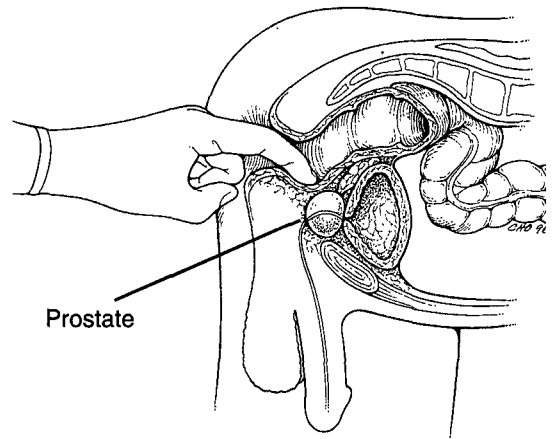
PSA levels estimate how likely a man is to have prostate cancer, but the test does not provide a definite answer. Conditions such as *benign prostatic hyperplasia* (noncancerous prostate enlargement) and prostatitis (inflammation of the prostate) can cause a borderline or high test result. On the other hand, some men with prostate cancer have negative, or borderline PSA results. About 25% of men with cancer will have a low PSA. This is why neither the ACS nor the NCCN recommends doing a PSA test without including the DRE

as well. Since doctors started using this test, the number of prostate cancers found at an early, curable stage has increased. Since most men have normal test results, they can be reassured that they are unlikely to have prostate cancer, especially if their DRE result is also negative.

*Percent free-PSA* indicates how much PSA circulates alone or unbound in the blood and, how much is bound together with other blood proteins. For PSA results in the borderline range, a low percent free-PSA means that a prostate cancer is more likely to be present and suggests the need for a biopsy. The exact number used to separate low from high results may vary slightly depending on the testing methods used by each laboratory. The laboratory doing the testing or the manufacturer of the test kit will provide this information to your doctor.

The PSA *velocity* is the increase in PSA level occurring over a period of time. The measurement of PSA velocity should be made on three specimens taken over at least an 18-month period. The PSA velocity will not be available until the third PSA blood test is done. A PSA velocity over 0.75 ng/ml per year is considered high. Even when the total PSA level is normal, a high PSA velocity suggests that a cancer may be present and that a biopsy should be done.

Although the PSA test is used mainly for early detection, it has value in other situations. In men known to have prostate cancer (based on their biopsy result), the PSA test can help predict *prognosis* (outlook for survival). Men with very high PSA results are more likely to have cancer that has spread beyond the prostate and are less likely to be cured or have long survival. PSA levels can be used together with clinical examination results and the



**Fig. 2 Digital Rectal Exam**

tumor's Gleason score (See pages 10–11) to help decide which tests are needed for further evaluation. The PSA test is also used to monitor the effectiveness of treatments. After surgery, radiation, or hormonal treatment, rising PSA levels can provide an early sign that the cancer is coming back or continuing to grow.

## **DIGITAL RECTAL EXAM (DRE)**

The NCCN recommends that men who are 50 or older (as well as younger men with high prostate cancer risk) have a DRE. The ACS recommends that the DRE be offered. During this examination, a doctor inserts a gloved, lubricated finger into the patient's rectum to feel for any, irregular or abnormally firm area that might be a cancer. The prostate gland is located next to the rectum, and most prostate cancers begin in the part of the gland that can be reached by a rectal exam.

This exam is also used once a man is known to have prostate cancer, in order to help predict whether the cancer has spread beyond his prostate gland.

## HISTORY AND PHYSICAL EXAM

When your doctor “takes a history,” he or she will ask you a series of questions about your symptoms and risk factors. Some prostate cancers may be found because of symptoms such as slowing or weakening of the urinary stream or the need to urinate more often. These symptoms can also be caused by benign diseases of the prostate such as nodular *hyperplasia* (also known as benign prostatic hyperplasia or BPH). Symptoms of advanced prostate cancer may include blood in the urine, swollen lymph nodes in the groin area, impotence (difficulty having an erection), and pain in the pelvis, spine, hips, or ribs. These symptoms may also be due to other diseases, and do not always mean that a man has prostate cancer. Most early prostate cancers cause no symptoms and are found by early detection. This is why testing with the PSA blood test and DRE should be considered by some men.

A physical exam for men suspected of having prostate cancer will include a digital rectal exam of the prostate (see section on early detection). A general physical exam is also important in helping to detect or evaluate any other medical problems.

## TRANSRECTAL ULTRASOUND (TRUS) AND BIOPSY

Transrectal ultrasound (TRUS) uses sound waves to create an image of the prostate on a video screen. Sound waves are released from a small probe placed in the rectum. The same probe detects the echoes that bounce back from the prostate tissue and a computer translates the pattern of echoes into a picture. This procedure is used to guide the biopsy needle

into exactly the right area of the prostate. Placing the TRUS probe into the rectum may be temporarily uncomfortable, but the procedure itself is essentially painless. It usually takes about 10–20 minutes.

If the possibility of prostate cancer has been raised by certain symptoms (such as blood in the urine, difficult urination, or pelvic pain) or the results of early detection tests, the doctor will take a *biopsy* to decide whether the disease is present. A core needle biopsy is the main method used to diagnose prostate cancer. Under transrectal ultrasound guidance, the doctor places a narrow needle through the wall of the rectum into the abnormal or suspicious area of the prostate gland. The needle removes a cylinder of tissue, usually about 1/2 inch long and 1/16 inch across, which is sent to the laboratory and examined under a microscope to see if cancer is present. The procedure is usually done in the doctor’s office and takes less than half an hour.

Though the procedure sounds painful, it typically causes little discomfort because a special instrument called a biopsy gun inserts and removes the needle in a fraction of a second. Several biopsy samples are taken from different areas of the prostate. Usually six to eighteen cores are removed (from upper, mid, and lower areas of the left and right sides) to get a representative sample of the gland and tell how much of the gland is affected by the cancer.

If a cancer is found in the prostate biopsy sample, it will be graded in order to estimate how aggressive it is likely to be. Grading is done by examining the tissue sample taken during the prostate biopsy. Prostate cancers are graded according to how closely they look like normal prostate tissue when viewed under a microscope. The most commonly used prostate

cancer grading system is called the Gleason system. This system assigns a Gleason primary and secondary grade, each ranging from 1 through 5 based on how closely the arrangement of the cancer cells mimics the way normal prostate cells form glands. If the cancer cell clusters resemble the small, regular, evenly spaced glands of normal prostate tissue, a *Gleason grade* of 1 is assigned. If the cancer lacks these features and its cells seem to spread haphazardly through the prostate, it is a grade 5 tumor. Grades 2 through 4 have intermediate features. Because prostate cancers often have areas with different grades, primary and secondary grades are assigned to the two areas that make up most of the cancer. The Gleason primary and secondary grades are summed (e.g., 3+2=5) to yield the *Gleason score* (range 2–10). The higher the score, the more likely that the cancer will grow and spread rapidly, and the worse the patient's prognosis.

If you have questions about pathology results or any other aspect of the diagnostic process, do not hesitate to ask your doctor. You can obtain a pathology review by having microscope slides containing thin slices of your tissue specimen sent to a consulting pathologist at an NCCN center or other laboratory recommended by your doctor.

## LYMPH NODE BIOPSY

This procedure may be done to find out if cancer has spread from the prostate to nearby lymph nodes. If cancer cells are found in the lymph node biopsy specimen, surgery is usually not attempted and other treatment options are

considered. There are several options for doing lymph node biopsies.

Lymph nodes may be removed by the surgeon through an incision in the lower part of the abdomen. This is often done in the same operation as the planned radical prostatectomy. The nodes are sometimes tested in the lab while you are under anesthesia to decide whether the surgeon should continue the radical prostatectomy.

A specially trained radiologist may take a sample of cells from a lymph node by using a technique called *fine-needle aspiration* (FNA). In this procedure, the doctor uses the computed tomography (CT) scan image to guide a long, thin needle into the lymph nodes. The syringe attached to the needle is used to take a small tissue sample from one of the lymph nodes.

## BLOOD TESTS

A complete blood count (CBC) determines whether the patient's blood has the correct number of various cell types. Abnormal test results may suggest spread of cancer to the bone marrow, where blood cells form. Doctors repeat this test regularly in patients treated with chemotherapy, because these drugs temporarily affect the blood-forming cells of the bone marrow.

Spread of prostate cancer to the bones may cause certain chemical abnormalities in the blood. To detect these changes, physicians perform blood chemical tests for substances such as *alkaline phosphatase*. Some of the drugs used in hormonal therapy can interfere with liver function. Changes in liver function can also be detected by blood tests.

## COMPUTED TOMOGRAPHY

Commonly referred to as a CT or CAT scan, this test uses a rotating x-ray beam to create a series of pictures of the body from many angles. A computer combines the information from these pictures, producing a detailed cross-sectional image. The CT scan may reveal abnormally enlarged pelvic lymph nodes. Enlarged lymph nodes could be a sign of a spreading cancer, or could mean that the immune system is fighting an infection. Spread to other internal organs, such as the liver can also be detected: by a CT scan. ACT scan is usually not done for staging purposes in early stage disease prior to surgery.

## MAGNETIC RESONANCE IMAGING (MRI)

MRI is like a CT scan except that magnetic fields are used instead of x-rays to create detailed cross-sectional pictures of selected areas of your body. These pictures can show abnormal nodules in lymph nodes or internal organs that suggest cancer may have spread from the prostate. An MRI scan is usually not done for staging purposes in early stage disease prior to surgery.

## RADIONUCLIDE BONE SCAN

This procedure helps show whether the cancer has spread from the prostate gland to bones. The patient receives an injection of radioactive material. The amount of radioactivity involved is low in comparison to the much higher doses used in radiation therapy, and this low level of radiation does not cause any side effects. The radioactive substance is attracted to diseased bone cells throughout the entire skeleton.

Areas of diseased bone will be seen on the bone scan image. These areas may suggest metastatic cancer is present, but arthritis or other bone diseases could also cause the same pattern. Once again, a bone scan is not routinely ordered unless there are signs of aggressive disease such as a markedly elevated PSA level, a high Gleason score, or a large tumor.

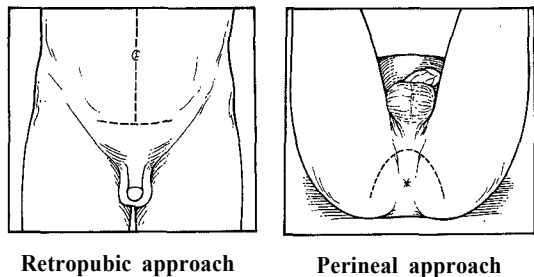
## PROTASCINT SCAN

Like the bone scan, the protascint scan uses low level radioactive material to find cancer that has spread beyond the prostate. The radioactive material used for the bone scan collects in areas of damaged bone that may be caused by prostate cancer, other cancers, or benign conditions. The radioactive material for the protascint scan is attached to a monoclonal antibody, a type of antibody manufactured in the laboratory to recognize and stick to a particular substance. In this case, the antibody specifically recognizes prostate-specific membrane antigen (PSMA), a substance found only in normal and cancerous prostate cells. The advantage of this test is that it detects spread of prostate cancer to bone as well as lymph nodes and other organs, and that it can distinguish prostate cancer from other cancers and benign disorders.

## *Types of Treatments for Prostate Cancer*

### RADICAL PROSTATECTOMY

This operation removes the entire prostate gland plus some tissue around it and is used most often if the cancer is thought not to have spread outside of the gland. The patient is either under



**Fig 3. Radical Prostatectomy**

general anesthesia (asleep and totally unconscious) or under spinal or epidural anesthesia (the same type of anesthesia often given to women during childbirth to numb the lower half of the body) with sedation during the surgery.

There are two main types of *radical prostatectomy*: radical retropubic prostatectomy and radical perineal prostatectomy. In the retropubic operation, the surgeon makes a skin incision in the lower abdomen. The surgeon can remove lymph nodes during this operation through the same incision. A nerve-sparing radical retropubic prostatectomy is a modification of this operation; During this procedure, the surgeon carefully feels the small bundles of nerves on either side of the prostate gland. If it appears that the cancer has not spread to these nerves, the surgeon will not remove them. Because these are the nerves that are needed for erections, leaving them intact lowers (but does not eliminate) the risk of impotence (not being able to have an erection) following surgery.

The radical perineal prostatectomy removes the prostate through an incision in the skin between the scrotum and anus. Nerve-sparing operations are more difficult by this approach and lymph nodes cannot be removed through this incision. If lymph node examination is needed for men having a radical perineal prostatectomy, the surgeon can remove some

lymph nodes through a very small skin incision in the abdomen or by using a laparoscope. A laparoscope is a long slender tube through which a surgeon can view and remove lymph nodes near the prostate gland.

These operations are followed by an average hospital stay of three days and average time away from work of three to five weeks. A catheter, is usually inserted through the penis and into the bladder after surgery while the patient is still asleep. The catheter is kept in place for 10 to 21 days to help patients to urinate easily during healing.

## **RADIATION THERAPY**

Radiation therapy uses high-energy rays (such as x-rays) and particles (such as electrons or protons) to kill cancer cells. Radiation is sometimes used to treat prostate cancer that is still confined to the prostate gland, or has spread to nearby tissue. If the disease is more advanced, radiation may be used to reduce the size of the tumor. The two main types of radiation therapy are external beam radiation and brachytherapy (internal radiation).

**External beam radiation:** External beam radiation is focused from a source outside the body on the area affected by the cancer. It is much like getting a diagnostic x-ray, but for a longer time. Before treatments start, imaging studies are done to find the location of the cancer. The radiation team will then make some ink marks on the patient's skin that they will use later as a guide for focusing the radiation in the right area. Patients are usually treated five days per week in an outpatient center over a period of seven or eight weeks, with each treatment lasting a few minutes.

## Prostate Cancer Stages

A prostate cancer's stage indicates how far it has spread within the prostate, to nearby tissues, and to other organs. The stage of a cancer is one of the most important factors in selecting treatment options, as well as the most significant (but not the only) factor in predicting prognosis.

A staging system is a standardized way in which the cancer care team describes the extent to which a cancer has spread. The most commonly used system in the United States is called the TNM System of the American Joint Committee on Cancer (AJCC). The TNM System describes the extent of the primary tumor (T), the absence or presence of metastasis to nearby lymph nodes (N), and the absence or presence of distant metastasis (M).

### T STAGES

There are actually two types of T classifications for prostate cancer. The *clinical stage* is based on digital rectal exam (DRE), needle biopsy, and transrectal ultrasound findings. The *pathologic stage* is based on surgical removal and examination of the entire prostate gland, both seminal vesicles (two small sacs next to the prostate that store semen) and, in some cases, nearby lymph nodes. The clinical stage is used in making treatment decisions, such as whether a patient might benefit from

surgical removal of the prostate. However, the clinical stage may underestimate the extent of cancer spread, and the pathologic stage determined after surgery is more accurate in predicting the patient's outlook for survival. Men who do not have a radical prostatectomy do not have a pathologic T stage determined. There are four categories for describing the prostate cancer's T stage.

- **T1** refers to a tumor that is not felt during a digital rectal exam. But, cancer cells are found in a prostate biopsy or prostatectomy specimen. T1 prostate cancers can be further subclassified as T1a, T1b, and T1c. T1a and T1b describe prostate cancers found incidentally (by "accident") during TURP (*transurethral resection of the prostate*), a surgical procedure done to relieve symptoms of benign prostate enlargement. This operation is usually done because the enlarged prostate gland presses on the urethra and makes it difficult for a man to urinate. When prostate tissue is removed and checked under the microscope, cancer may be found, even though the doctor who removed the tissue did not expect cancer to be present. T1a indicates that less than 5% of the tissue removed is cancer and more than 95% is benign. If more than 5% is cancer, it is classified as T1b. T1c cancers are also found only by biopsy, but in these cases a core needle biopsy is done because the PSA blood test result suggested that a cancer might be present.

- **T2** means that a doctor can feel the prostate cancer by DRE and that the cancer is felt to remain within the prostate gland. This category is subclassified into T2a or T2b. T2a means that the tumor involves only the right or left side of the prostate, but not both sides. If both the left and right sides are involved, it is a T2b cancer.
- **T3** cancers have spread to the connective tissue next to the prostate and/or to the seminal vesicles (two small sacs next to the prostate that store semen), but do not involve any other organs. This group is divided into T3a and T3b. In T3a, the cancer extends outside the prostate, but has not spread to the seminal vesicles. With T3b, the cancer has spread to the seminal vesicles.
- **T4** means that the cancer has spread to tissues next to the prostate (other than

the seminal vesicles), such as the bladder's external sphincter (muscles that help control urination), the rectum, and/or the wall of the pelvis.

## **N STAGES**

N0 means that the cancer has not spread to any lymph nodes. N1 indicates spread to one or more regional lymph nodes in the pelvis. Nx means that tests to detect lymph node spread have not been done.

## **M STAGES**

M0 means that the cancer has not metastasized beyond the regional nodes. M1 means metastases are present in distant (outside of the pelvis) lymph nodes, in bones or other distant organs such as lungs, liver, or brain. Mx means that tests to detect distant spread have not been done.

There is a new form of external beam radiation that appears promising in increasing the success rate and reducing side effects. *Three-dimensional conformal therapy* uses sophisticated computers to precisely map the location of the cancer within the prostate. The patient is fitted with a plastic mold resembling a body cast to keep him still so that the radiation can be more accurately aimed. Radiation beams are then aimed from several directions. Short-term results suggest that by aiming the radiation more accurately, it is possible to reduce radiation damage to tissues near the prostate and improve effectiveness by increasing the radiation dose to the cancer.

**Internal radiation therapy (brachytherapy):** Internal radiation therapy uses small radioactive pellets (each about the size of a grain of rice) that are directly implanted (permanently or temporarily) into the prostate. Imaging tests such as transrectal ultrasound, CT scans, or MRI are used to accurately guide placement of the radioactive material into the cancer. The radioactive materials (isotopes, such as iodine 125 or palladium 103) are placed inside thin needles, which are inserted through the skin of the perineum (area between the scrotum and anus) into the prostate. The permanent pellets, which are sometimes called “seeds,” give off radiation for weeks or months. Because they are so small, their presence causes little discomfort and they are simply left in place after their radioactive material is used up. Alternatively, needles containing more radioactive material can be placed for less than a day. This approach is called high-dose rate brachytherapy. For about a week following insertion of the needles, patients may have some pain in the perineal

area and may have red-brown discoloration of their urine.

## HORMONE THERAPY

This treatment is often used for patients whose prostate cancer has spread beyond the prostate or has recurred after treatment. The goal of hormone therapy is to lower levels of the male *hormones*, androgens. The main androgen is called *testosterone*. *Androgens* are produced mainly in the testicles and cause prostate cancer cells to grow. Lowering androgen levels can make prostate cancers shrink or grow more slowly. But, hormone therapy does not cure the cancer. There are several methods used for hormone therapy.

Some Prostate cancers do not respond to hormone therapy, and are called androgen independent cancers. Some prostate cancers respond to hormonal therapy for a few years before becoming androgen independent. Less often, prostate cancers may be androgen independent at the time they are diagnosed.

**Orchiectomy:** This operation removes the testicles. Although it is a surgical treatment, orchiectomy is considered hormonal therapy because it works by removing the main source of male hormones. By lowering androgen levels, orchiectomy is able to shrink or slow the growth of most prostate cancers.

**Luteinizing hormone-releasing hormone (LHRH) analogs:** These drugs can decrease the amount of testosterone produced by a man’s testicles, as effectively as surgical removal of the testicles. LHRH analogs (also called LHRH agonists) are injected either monthly or every three months. The two

LHRH analogs currently available in the United States are leuprolide (Lupron<sup>®</sup>) and goserelin (Zoladex<sup>®</sup>).

**Anti-androgens:** Even after orchiectomy or during treatment with *LHRH analogs*, a small amount of androgen is still produced by the adrenal glands. Anti-androgens block the body's ability to use androgens. Drugs of this type, such as flutamide (Eulexin<sup>®</sup>), bicalutamide (Casodex<sup>®</sup>), and nilutamide (Nilandron<sup>®</sup>), are taken as pills, once or three times a day. Anti-androgens are often used in combination with orchiectomy or LHRH analogs. This combination is called total androgen blockade.

**Other hormonal drugs:** Megestrol acetate (Megace<sup>®</sup>) and medroxyprogesterone (Depo-Provera<sup>®</sup>) are sometimes used if “first-line” hormonal treatments lose effectiveness. Ketoconazole (Nizoral<sup>®</sup>), initially used for treating fungal infections and later found to also work as an anti-androgen, is another drug for “second line” hormonal therapy.

## CHEMOTHERAPY

Chemotherapy is an option for patients whose prostate cancer has spread outside of the prostate gland and for whom hormone therapy has failed. It is not expected to destroy all of the cancer cells, but it may slow tumor growth and reduce pain.

Chemotherapy uses anticancer drugs that are injected into a vein, injected into a muscle, or taken by mouth. These drugs kill cancer cells, but they also damage some normal cells. The doctor must maintain a delicate balance of chemotherapy doses, making them strong enough to kill the cancer cells but not strong enough to destroy many healthy cells.

Some of the chemotherapy drugs used in treating prostate cancer that has returned or continued to grow and spread after treatment with hormonal therapy include doxorubicin (Adriamycin), estramustine, etoposide, mitoxantrone, vinblastine, and paclitaxel. Two or more drugs are often given together to reduce the likelihood of the cancer cells becoming resistant to chemotherapy. Small cell carcinoma is a rare type of prostate cancer that is more likely to respond to chemotherapy than to hormonal therapy. Small cell carcinoma develops more often in the lungs than in the prostate. Since small cell lung cancer often responds to chemotherapy with cisplatin and etoposide, these drugs are recommended for treating small cell cancers that develop in the prostate.

## EXPECTANT THERAPY (WATCHFUL WAITING OR DEFERRED THERAPY)

One strategy for some patients with prostate cancer may be to “watch and wait” with no immediate active treatment. The cancer is regularly and carefully observed and monitored. This approach may be recommended if a prostate cancer is not causing any symptoms, especially if it is very small and contained to one area of the prostate, expected to grow very slowly, or if the patient is elderly, frail, or has other serious health problems. Because prostate cancer often grows very slowly, many older men who have the disease never need any treatment. Some men may make the judgment that the side effects of more aggressive treatments outweigh the benefits they hope to achieve. In these instances, the man may opt for watchful waiting.

## TREATMENT OF PAIN AND OTHER SYMPTOMS

Most of this document discusses ways to remove or destroy prostate cancer cells or to slow their growth. But it is important to realize that maintaining your quality of life is an important goal. Don't hesitate to discuss your symptoms or any other quality-of-life concerns with your cancer care team. Bisphosphonates are a group of medications that can slow the bone damage caused by spread of prostate cancer within bones. These drugs can relieve pain caused by bone metastases and may slow growth of these metastases. There are other effective and safe ways to treat pain, most other symptoms of prostate cancer, and most of the side effects caused by prostate cancer treatments. When properly prescribed, medications can effectively relieve pain without risk of addiction, dependence, or becoming too drowsy to continue most of your usual activities. Enduring unnecessary pain has no benefit whatsoever. Pain medication does not interfere with anticancer treatments. In fact, getting effective pain relief can help some patients to be more active and may, indirectly, help them live longer.

## ALTERNATIVE OR COMPLEMENTARY THERAPIES

If you are considering any unproven alternative or complementary treatments, it is best to discuss this openly with your cancer care team and request information from the American Cancer Society or the National Cancer Institute. Some unproven treatments can interfere with standard medical treatments or may cause serious side effects.

## Side Effects of Prostate Cancer Treatments

### INCONTINENCE

Incontinence is the inability to control the urine stream resulting in leakage or dribbling of urine. Incontinence is divided into three types: stress incontinence, overflow incontinence, and urge incontinence. Stress incontinence causes urine leakage when coughing, laughing, sneezing, or exercising. It is usually caused by problems with the bladder sphincter (the muscular valve that keeps urine in the bladder). Prostate cancer treatments may damage the muscles that form this valve or the nerves that keep the muscle working. Stress incontinence is the most common type of incontinence after prostate surgery. Men with overflow incontinence take a long time to urinate and have a dribbling stream with little force. Overflow incontinence is usually due to blockage or narrowing of the bladder outlet, by cancer or scar tissue, thus poor emptying of the bladder occurs. Men with urge incontinence often have a sudden need to go to the bathroom (*urinary urgency*) to pass urine. This problem occurs when the bladder becomes oversensitive to stretching by urine accumulation.

Treatment of incontinence depends on its type, cause, and severity. Some men feel embarrassed about discussing this issue, but it is important to remember that this is a common medical problem, and that there are many treatments to improve this condition.

### IMPOTENCE

Impotence, also known as erectile dysfunction, is an inability to get an erection of the penis.

The nerves that allow men to get erections may be damaged or removed by radical prostatectomy. Radiation therapy can also cause damage to these nerves. For men who are impotent, several solutions are available. Prostheses (penile implants) can restore the ability to have erections. Prostaglandin E1 is a substance naturally produced in the body that can produce erections. This medication can be injected almost painlessly into the base of the penis five to ten minutes before intercourse, or introduced into the urethra as a suppository. Vacuum devices can create an erection. These mechanical pumps are placed around the entire penis before intercourse. Sildenafil citrate (Viagra®) is a drug that can promote erections by increasing blood flow to the penis.

### **SIDE EFFECTS OF PROSTATE SURGERY**

The main side effects of radical prostatectomy are incontinence and impotence. Normal bladder control usually returns within several weeks or months after radical prostatectomy. Passing a small amount of urine when coughing, laughing, sneezing, or exercising may persist permanently after prostatectomy in up to 35% of men. Some patients (between 2% and 5%) have more serious stress incontinence, which may be permanent. During the first three to twelve months after radical prostatectomy, most men will have erectile dysfunction, and will need to use medications or other treatments if they wish to have an erection. The effect of this operation on a man's ability to achieve an erection is related to the patient's age and whether nerve-sparing surgery was done.

Nearly all men who have a radical prostatectomy should expect some permanent decrease in their ability to have an erection, but younger men may expect to retain more of their ability. After standard radical prostatectomy, between 65% and 90% of men will become impotent, depending on their age. If surgery does not remove the nerves on either side of the prostate, the impotence rate drops to between 25% and 30% for men under 60. But, impotence occurs in 70% to 80% of men over 70, even if nerves on both sides are not removed.

### **SIDE EFFECTS OF RADIATION THERAPY**

Side effects of external beam radiation may include diarrhea, and colitis (irritated intestines). Occasionally, normal bowel function does not return after treatment is stopped. Both during and after treatment, other side effects may include frequent urination, urge incontinence (feeling like you have to urinate all the time), burning sensation while urinating, and blood in the urine. Radiation therapy may also cause a feeling of fatigue which may persist until a month or two after treatment stops. About 40% to 60% of men who receive external beam radiation develop some degree of impotence (inability to get an erection). Impotence usually does not occur right after radiation therapy but gradually develops over one or more years.

Brachytherapy may also result in impotence, urinary incontinence, and bowel problems. Significant rectal problems (burning, pain, and diarrhea) may occur in up to 5% of patients and are difficult to treat once they develop.

## SIDE EFFECTS OF HORMONAL THERAPY

After orchiectomy, about 90% of men have reduced or absent *libido* (sexual desire) and impotence. Some men have *hot flashes* (sudden rushes of body heat) after surgery but these may go away with time.

Side effects of LHRH analogs are the same as with an orchiectomy, and include reduced or absent sexual desire, impotence, and hot flashes. Some men also have breast tenderness, and growth of breast tissue. These side effects occur about as commonly as after orchiectomy.

Side effects of antiandrogens in patients already treated by orchiectomy or with LHRH agonists are usually not serious or common, but may include nausea, diarrhea, and tiredness. These medications (LHRH analogs and antiandrogens) may also have long-term effects (liver disease, bone loss) with use.

## SIDE EFFECTS OF CHEMOTHERAPY

The side effects of chemotherapy depend on the type of drugs, the amount taken, and the length of treatment. Temporary side effects might include nausea and vomiting, loss of appetite, loss of hair, and mouth sores. Because chemotherapy can damage the blood-producing cells of the bone marrow, patients may have low blood cell counts. This can result in an increased chance of infection (due to a shortage of white blood cells); excessive bleeding or bruising after minor cuts or injuries (due to a shortage of blood platelets); and fatigue (due to low red blood cell counts). Most side effects disappear once treatment is stopped. There are remedies for many of the temporary side effects of chemotherapy. For example, antiemetic drugs can be given to prevent or reduce nausea and vomiting.

## *Treatment and Follow-Up of Prostate Cancer by Stage*

The stage of a cancer is one of the most important factors in selecting treatment options. The following section discusses treatment guidelines based on their AJCC (TNM) stage (see pages 14–15).

### APPROACH TO CONSIDERING TREATMENT OPTIONS

Experts in prostate cancer treatment recommend that men consider treatment options in the context of their age and general health, goals for treatment, and views regarding side effects. Older men and those with other serious health problems often find it useful to think of prostate cancer as a chronic disease, one which will probably not kill them but may cause symptoms they will wish to avoid. In this view; the goal is to relieve symptoms and avoid or minimize side effects of treatment. This view might lead some men to choose watchful waiting or hormonal therapy. Radiation therapy is another good option for some patients. It provides a 5-year survival rate equal to radical prostatectomy.

On the other hand, men in their 40s or 50s will also want to know about 10-year and 20-year, survival rates. Postponing or relieving symptoms may not be their main goal. Instead, many younger, healthy men are more interested in a cure or at least in surviving beyond 10-20 years. Views regarding side effects are another very important factor. Some men cannot imagine living with side effects such as incontinence or

impotence. Other men are less concerned about these and more concerned about survival.

These difficult decisions are even harder for men who try to make them alone. Many men find that speaking with other men who have faced or are currently facing the same issues is useful. The American Cancer Society's Man-to-Man program and similar programs sponsored by cancer centers and other patient organizations provide a forum for men to meet and discuss these issues and cancers. For more information, call the ACS toll-free at 800-ACS-2345 or visit our web site at [www.cancer.org](http://www.cancer.org).

## ***Other Things to Consider During and After Treatment***

During and after treatment for your prostate cancer you may be able to hasten your recovery and improve your quality of life by taking an active role. Learn about the benefits and disadvantages of each of your treatment options, and ask questions of your cancer care team if there is anything you do not understand. Learn about and look out for side effects of treatment, and report these promptly to members of your cancer care team so they can take steps to minimize them and shorten their duration.

Remember that your body is as unique as your personality and your fingerprints. Although understanding your cancer's stage and learning about the effectiveness of your treatment options can help predict what health problems you may face, no one can say precisely how you will respond to cancer or its treatment.

You may have special strengths such as a history of excellent nutrition and physical

activity, a strong family support system, or a deep faith, and these strengths may make a difference in how you respond to cancer. There are also experienced professionals in mental health services, social work services, and pastoral services who may assist you in coping with your illness.

You can also help in your own recovery from cancer by making healthy lifestyle choices. If you use tobacco, stop now. Quitting will improve your overall health and the full return of the sense of smell may help you enjoy a healthy diet during recovery. If you use alcohol, limit how much you drink. Have no more than 1 or 2 drinks per day. Good nutrition can help you get better after treatment. Eat a nutritious and balanced diet, with plenty of fruits, vegetables, and whole grain foods.

If you are in treatment for cancer, be aware of the battle that is going on in your body. Radiation therapy and chemotherapy add to the fatigue caused by the disease itself. Give your body all the rest it needs so that you will feel better as time goes on. Exercise once you feel rested enough. Ask your cancer care team whether your cancer or its treatments might limit your exercise program or other activities.

It is important that your concentration on tests and treatments and the physical aspects of recovery does not prevent you from considering your emotional, psychological, and spiritual health as well.

Concerns about sexuality are often very worrisome to a man with prostate cancer: It is important to remember that some treatments for prostate cancer can negatively impact sexual interest and/or response. Partner issues are also important because these issues have an impact on the partner, as well as the patient. Partners

are usually concerned about how to express their love physically and emotionally during and after treatment.

Suggestions that may help a man cope with these changes in his body include seeking the support of others, preferably before surgery; involving his partner as soon as possible after surgery; and openly communicating feelings, needs, and wants.

A cancer diagnosis and its treatment is a major life challenge, with an impact on you and everyone who cares for you. Before you get to the point where you feel overwhelmed, consider attending a meeting of a local support group. If you need individual assistance in other ways, contact your hospital's social service department or the ACS for help in contacting counselors or other services.

## *ABOUT CLINICAL TRIALS*

**W**hen studying promising new or experimental treatments, researchers want to know:

- Does this new type of treatment work better than other treatments already available?
- What side effects does the treatment cause?
- Do the benefits outweigh the risks, including side effects?
- Which patients will the treatment most likely help?

During your treatment for prostate cancer, your doctor may suggest that you take part in a clinical trial of a new treatment. You should know that scientists only conduct clinical trials when they have reason to believe that the treatment under study may

indeed be superior to other treatments. No one will receive a placebo (sugar pill) if a treatment is already available. During testing of a new drug that the Food and Drug Administration has not yet approved, some people will receive the standard treatment while others will get the experimental drug. A computer randomly assigns participants to each group.

Whether the experimental treatment will work better than the standard treatment must be proved. The new therapy may have some side effects which your doctor will discuss with you before you enter the trial.

There are three phases of clinical trials in which treatments are studied before they are eligible for approval by the Food and Drug Administration. The purpose of a Phase I study is to find the best way to give a new treatment, and how much of it can be given safely. Physicians watch

patients carefully for any side effects. While treatments tested in a Phase I study have been well tested in laboratory and animal studies, the side effects in patients are not completely predictable.

Phase II trials determine the effectiveness of a research treatment after safety has been evaluated in a Phase I trial. Doctors closely observe patients for an anti-cancer effect by carefully measuring cancer sites present at the beginning of the trial. In addition to monitoring patients for response, any side effects are carefully recorded and assessed.

Phase III trials require a large number of patients, sometimes thousands. A “control group” of patients may receive standard (the most accepted) treatment while another group, randomly assigned, may receive the treatment or drug under study. In this way researchers can compare the two to find out whether the new treatment is more beneficial to survival and quality of life. Doctors carefully monitor all patients in Phase III trials for side effects. The trial is discontinued if the side effects are too severe.

Taking part in any clinical trial is completely voluntary. Your doctors and nurses will explain the study to you in detail and will give you a form to read and sign. This informed consent document states that you understand the potential risks and want to participate. Even after you sign the form and the trial begins, you may leave the study at any time, for any reason. Participating in a clinical trial is an appropriate option for men at any stage of prostate cancer. Taking part in the study does not prevent you from getting other medical care you may need. But you should check with your health insurance company to find out how they will cover the costs of your taking part in a clinical trial.

Participating in a clinical trial may help you directly, and it may help other men with prostate cancer in the future. For these reasons, members of the NCCN and the ACS are committed to conducting clinical trials.



# ***Work-Up (Evaluation) and Treatment Guidelines***

## ***'Decision Trees'***

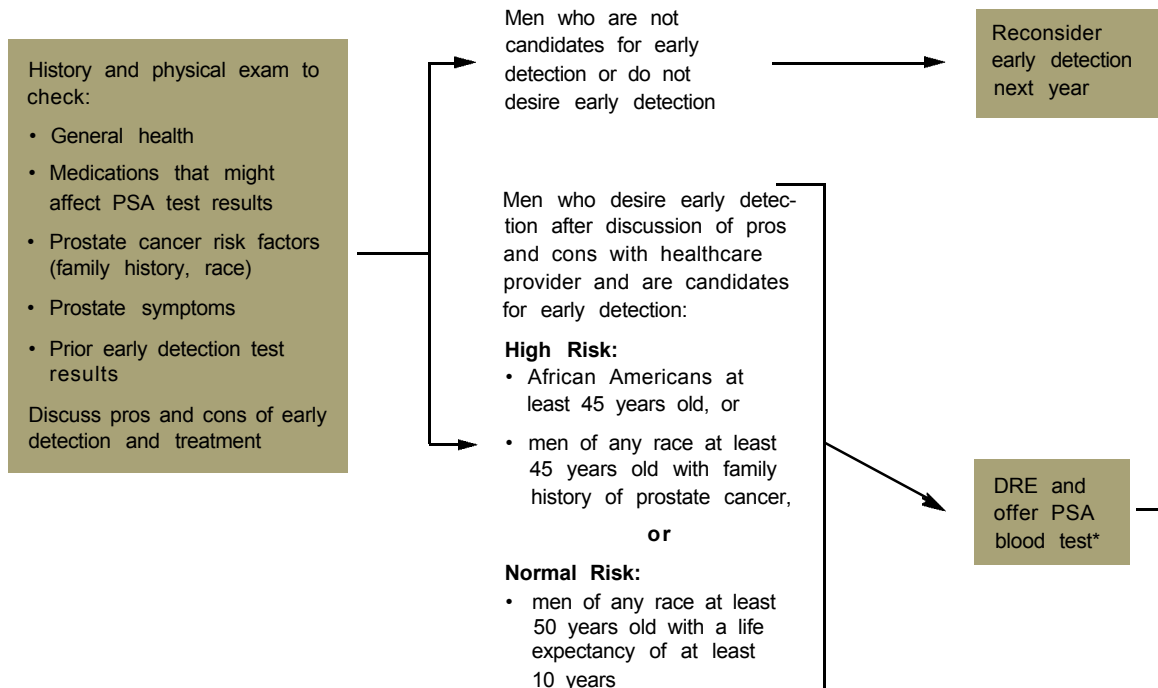
The ‘decision trees’, or algorithms, on the following pages represent different stages of prostate cancer. Each one shows you step-by-step how you and your doctor can arrive at the choices you need to make about your treatment.

Keep in mind, this information is not meant to be used without the expertise of your own physician who is familiar with your situation, medical history, and personal preferences.

Participating in a clinical trial is an appropriate option for men at any stage of prostate cancer. Taking part in the study does not prevent you from getting other medical care you may need.

The NCCN guidelines are updated as new significant data become available. To ensure you have the most recent version, consult the web sites of the ACS ([www.cancer.org](http://www.cancer.org)) or NCCN ([www.nccn.org](http://www.nccn.org)). You may also call the NCCN at 1-888-909-NCCN or the ACS at 1-800-ACS-2345 for the most recent information on these guidelines or on cancer in general.

## BEFORE EARLY DETECTION



*\*NCCN recommends doing a DRE and offering the PSA blood test. ACS recommends offering both tests.*

*Keep in mind, this information is not meant to be used without the expertise of your own physician who is familiar with your situation, medical history, and personal preferences.*

*Participating in a clinical trial is an appropriate option for men at any stage of prostate cancer.*

*Taking part in the study does not prevent you from getting other medical care you may need.*

*The order in which therapy options are listed does not imply a hierarchy*

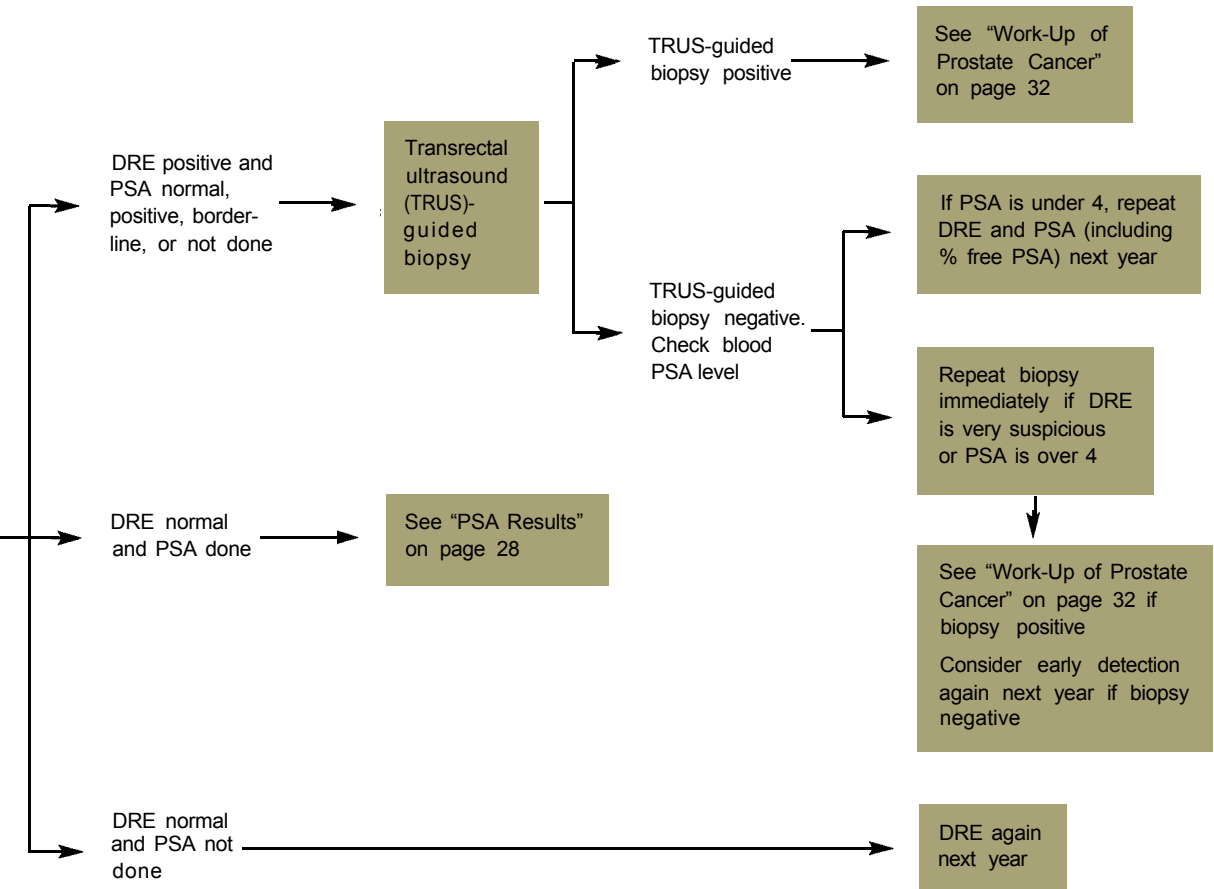
## DECISION TREE FOR PROSTATE CANCER EARLY DETECTION

The decision each man makes about prostate cancer is a complex and important one. Factors to consider include his age and life expectancy, family history (prostate cancer in close relatives), race, prostate symptoms, prior early detection

test results, and personal views about prostate cancer treatments and their likely side effects. Life expectancy is an estimate based on each man's age and any serious health problems.

If early detection test results are negative or if the tests are not done, the man and his doctors should discuss testing once again the next year.

# Decision Tree for Prostate Cancer Early Detection

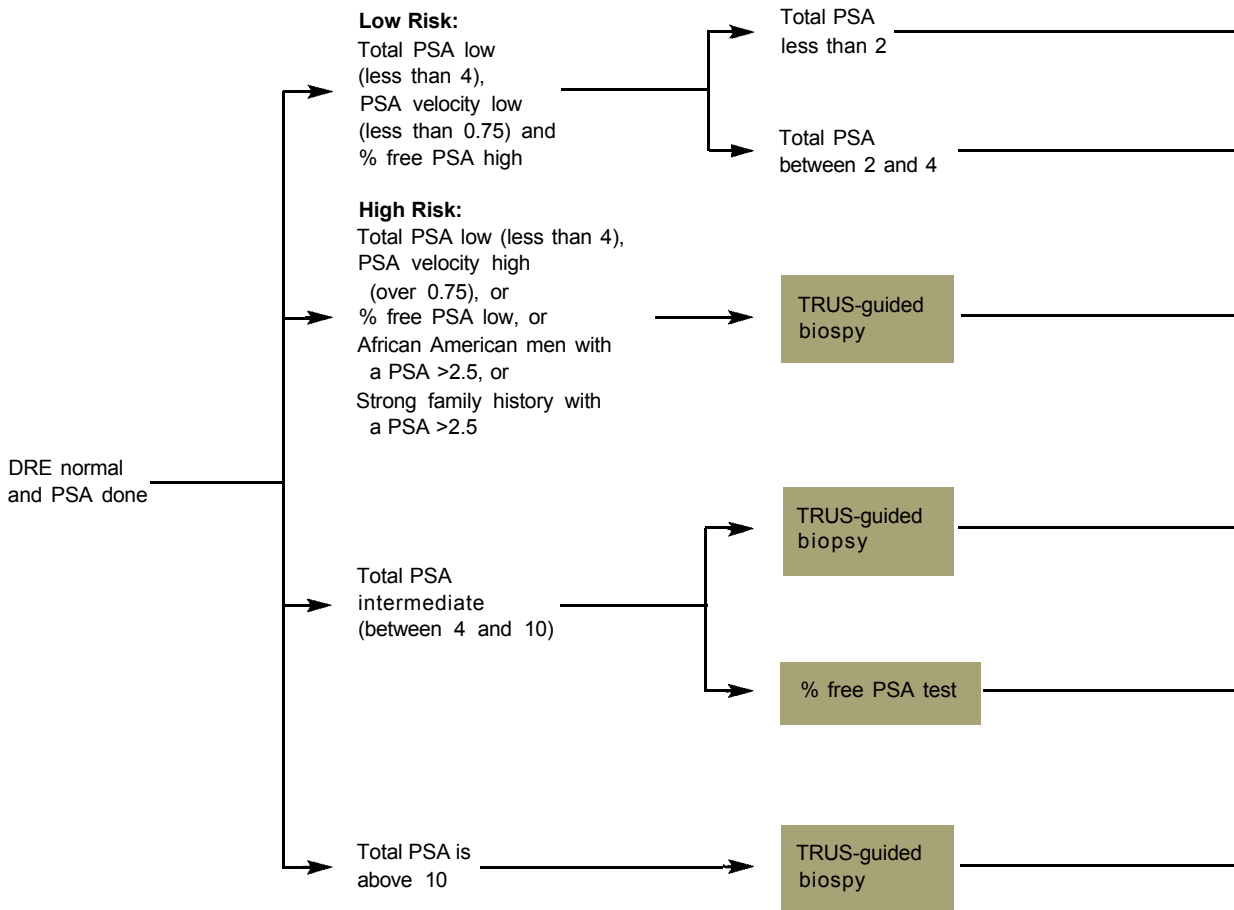


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If the DRE reveals a suspicious nodule, it should be evaluated by a TRUS-guided biopsy. It is important to realize that a negative (no cancer found) biopsy does not ensure that a man does not have prostate cancer. Especially

if the cancer is small, it may be missed by the biopsy needle. If the biopsy is negative and the prostate lump feels very suspicious, or if a man's PSA level is over 4, an immediate repeat biopsy is recommended.

## RESULTS



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*The order in which therapy options are listed does not imply a hierarchy.*

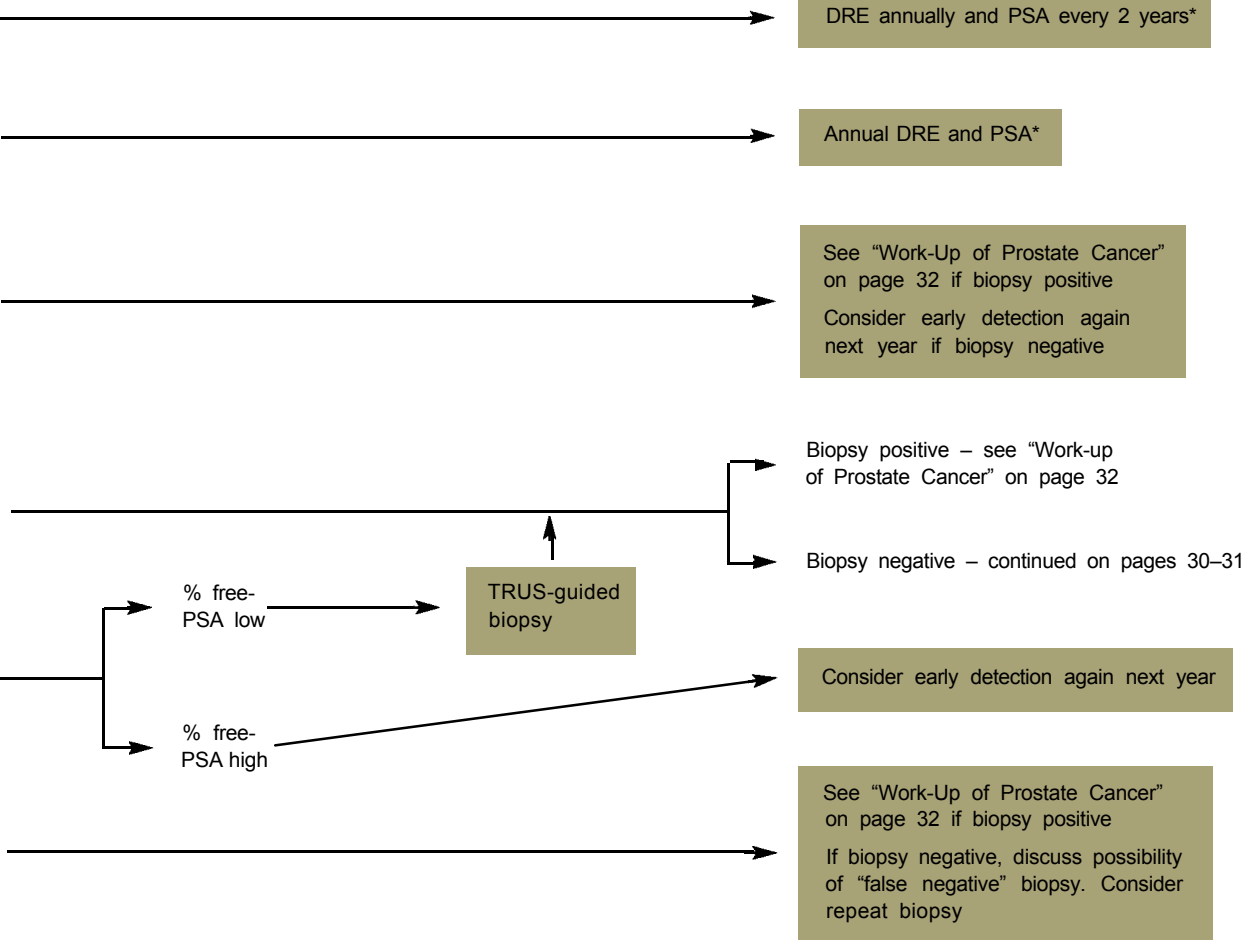
## DECISION TREE FOR PSA RESULTS

If the total PSA level is above 10, a biopsy is recommended. If the biopsy is negative, the

possibility of a “false-negative result” (the needle missed the cancer and sampled benign tissue instead) should be discussed and a repeat biopsy should be considered.

# Decision Tree for PSA Results

## FOLLOW-UP

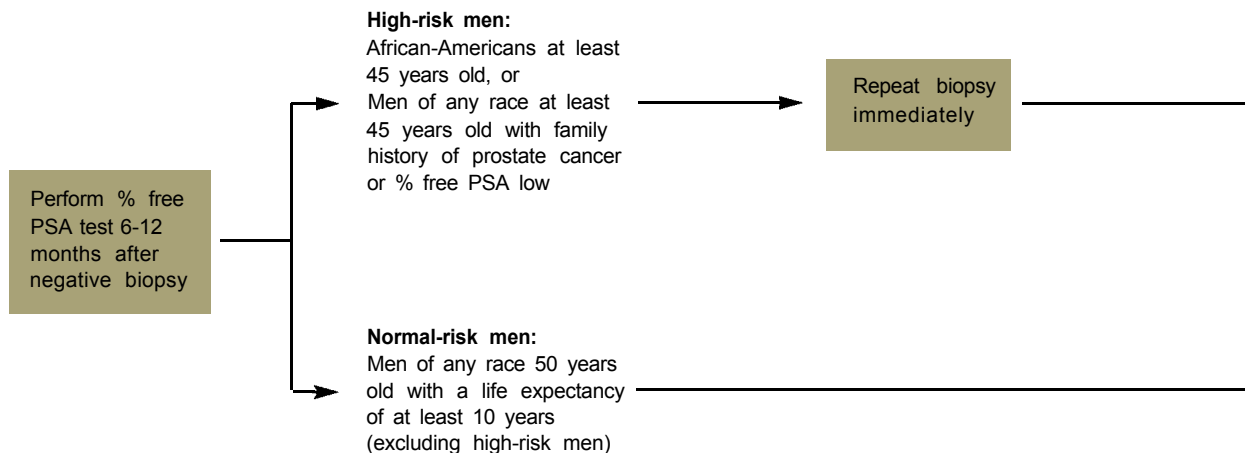


*\*The ACS recommends offering DRE and PSA annually.*

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If the total PSA level is less than 10, evaluation depends on two other types of PSA tests: the PSA velocity and the % free PSA test. The decision pathway above illustrates

how the results of these tests influence whether or not a biopsy should be done and, if that biopsy is negative, whether it should be repeated. The decision to have a repeat biopsy



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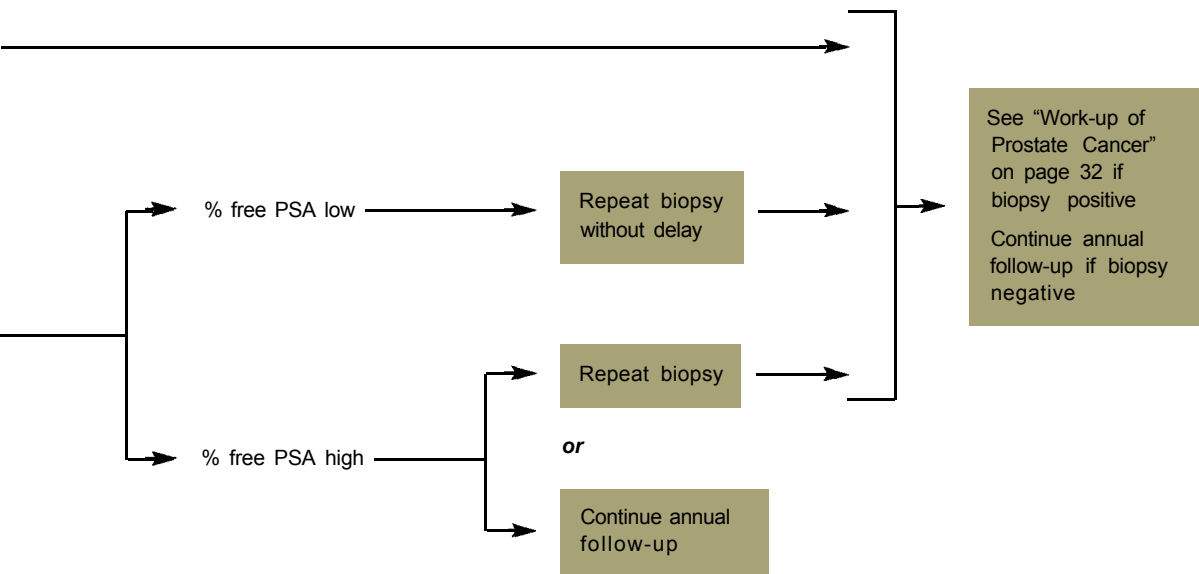
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will be influenced by the % free PSA test as well as by racial and family risk factors. Of course, if the biopsy is positive, turn directly to

page 32 for discussion of additional tests that will be recommended.

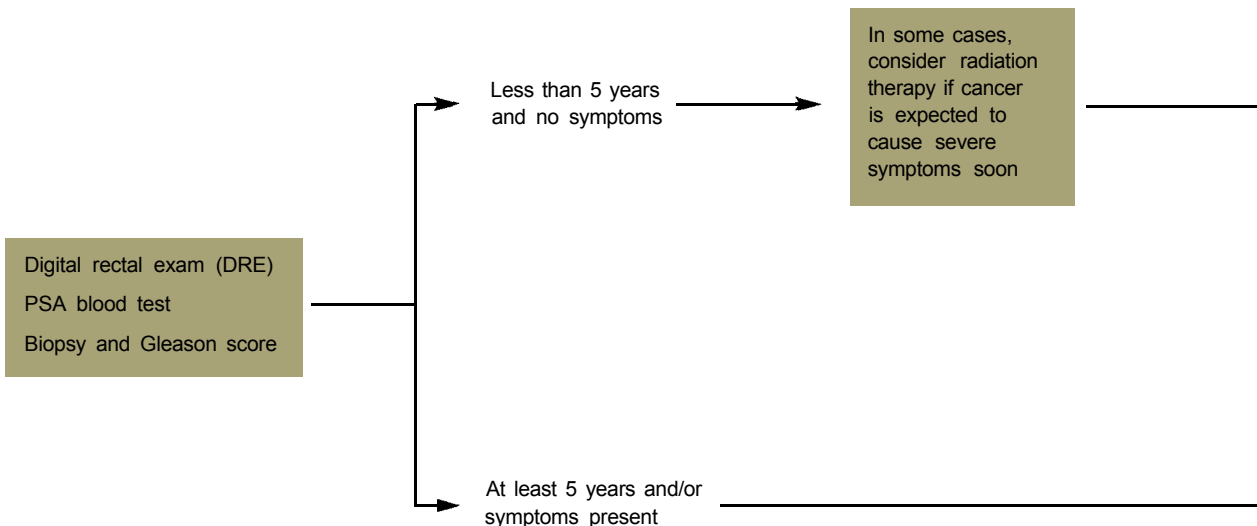
## Decision Tree for PSA Results (continued)



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**INITIAL WORK-UP**

**LIFE EXPECTANCY  
AND SYMPTOMS**



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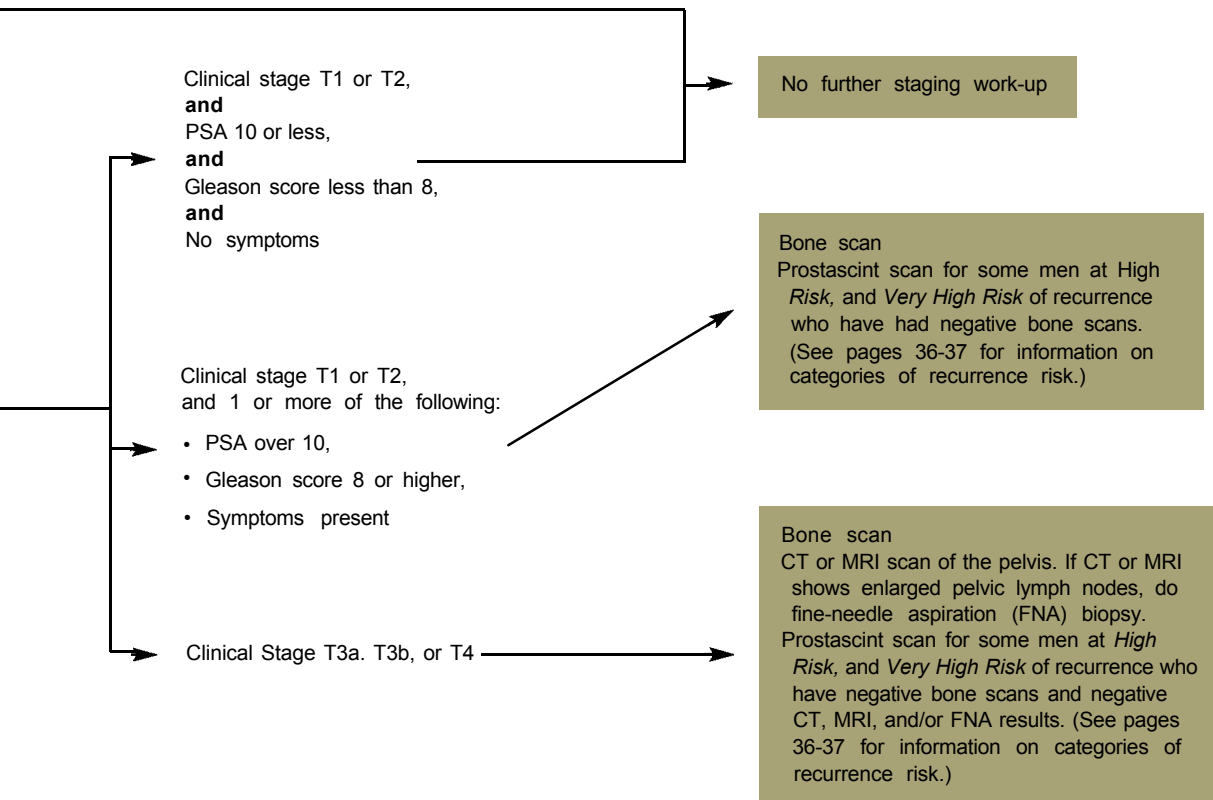
**PROSTATE CANCER WORK-UP  
(EVALUATION)**

The NCCN guidelines for prostate cancer work-up begin with consideration of the patient's life expectancy and symptoms. This

reflects the view that prostate cancer is often a chronic disease, and that men without symptoms may not benefit from immediate treatment, especially if they are in otherwise poor health. In some instances, if the life expectancy is relatively long (3-4 years) and the cancer is

# Decision Tree for Prostate Cancer Work-Up

## STAGING WORK-UP



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very aggressive (Gleason Score 9-10 and PSA is very high), radiation may be given to prevent symptoms likely to result from advance of the cancer. If preliminary tests and examinations suggest the cancer is probably confined within

the prostate (DRE is normal or reveals only a small mass, the blood PSA level is less than 10, and the cancer has a low Gleason score), no further work-up is needed. On the other hand, if the T stage, PSA level, or Gleason

score is higher, suggesting a greater likelihood of further spread, additional tests such as bone scans, CT scans, or MRI are recommended.

If CT or MRI scans show abnormally large pelvic lymph nodes, a fine-needle aspiration biopsy will be done to confirm that the enlarge-

ment is due to spread of cancer (indicating N1 disease) rather than to an infection or some other benign condition.

Bone scan images that show features typical of metastatic prostate cancer are considered evidence of distant spread (M1 disease). If the

## NOTES

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## Decision Tree for Prostate Cancer Work-Up (continued)

bone scan is suggestive but not typical, a bone biopsy may be done to confirm that the bone abnormality is due to cancer spread rather than an infection.

If a man is considered very likely to have spread to lymph nodes and/or bones (based on clinical T stage, PSA result, and Gleason score)

but other test results for cancer spread (such as CT, MRI, FNA, bone scan) were negative, a prostascint scan may be recommended. If the prostascint scan detects spread to lymph nodes or bones, the cancer is classified as N1 or M1 respectively.

### NOTES

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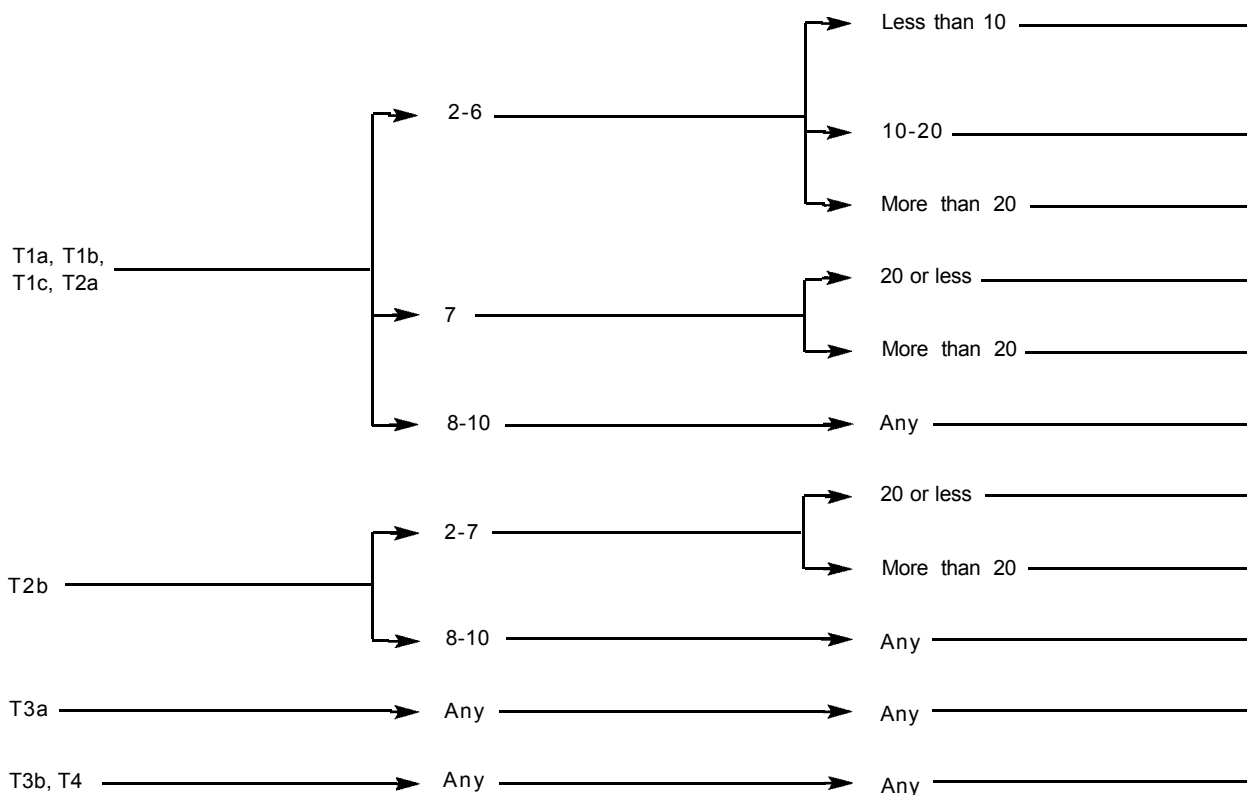
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## CLINICAL STAGE

## GLEASON SCORE

## BLOOD PSA LEVEL



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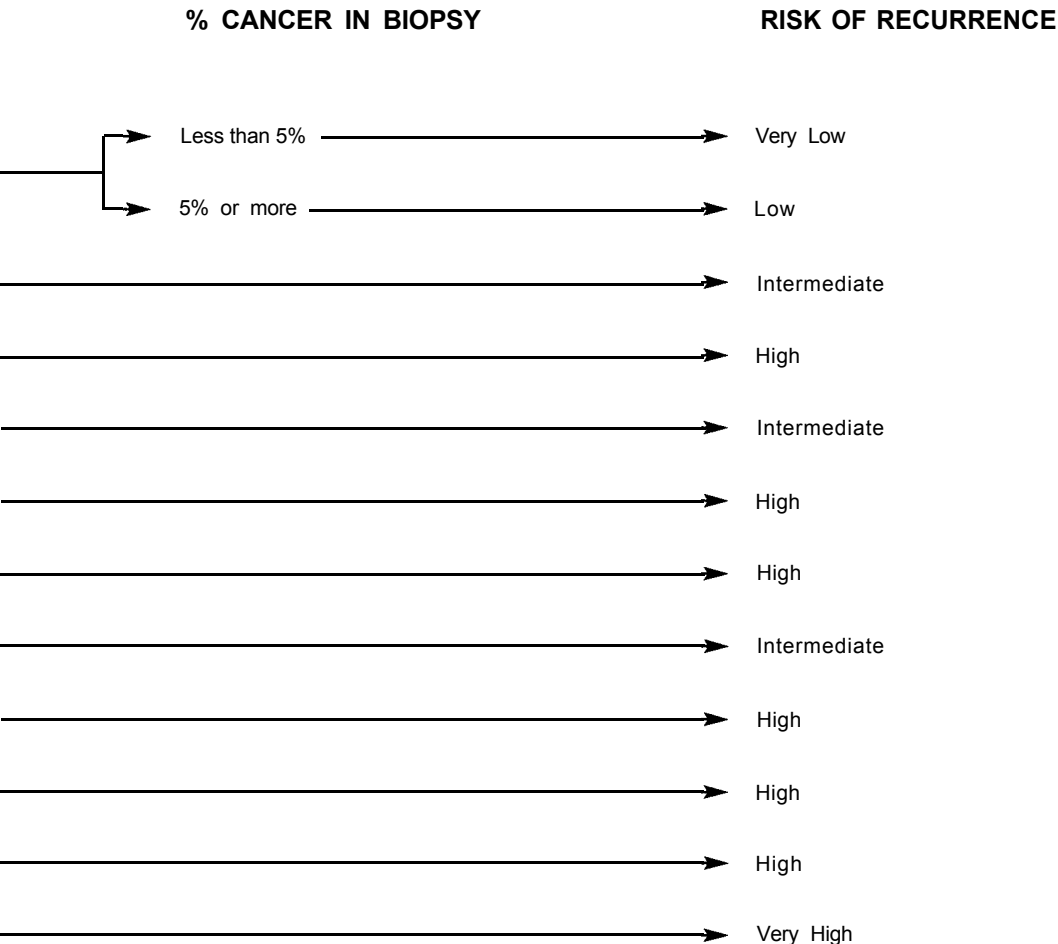
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## ESTIMATION OF RECURRENCE RISK

Because prostate cancers differ so greatly in their potential for spread and in their impact on a man's life, no single treatment is right for all men with this disease. After completing the

work-up (see pages 32-33), estimating the likelihood that a prostate cancer would recur (come back) after local treatment is the next step. Three factors are considered in estimating recurrence risk. Two of these are based on examination of the biopsy sample under a

# Decision Tree for Estimation of Recurrence Risk



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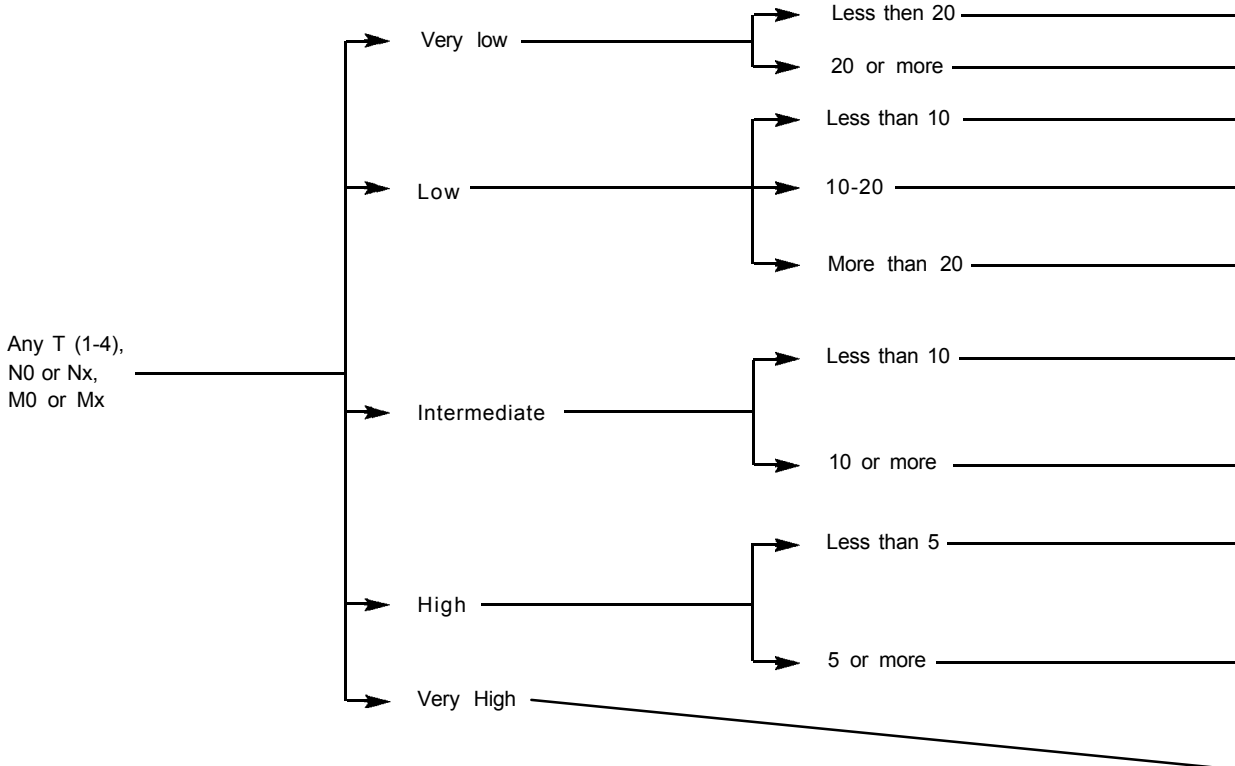
microscope – the Gleason score and the percent of the biopsy sample affected, by cancer. Cancers with high Gleason scores and with cancer involving more of the biopsy sample are more likely to have spread beyond the prostate and are therefore more likely to recur

after local treatment. The third factor used in estimating recurrence risk is the serum PSA level, with higher levels indicating greater risk. Based on these factors, a man's recurrence risk can be estimated as very low, low, intermediate, high, or very high.

STAGE

RECURRENCE RISK

LIFE EXPECTANCY  
(YEARS)



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## INITIAL TREATMENT FOR NON-METASTATIC PROSTATE CANCER

Most newly diagnosed prostate cancers appear to be localized to the prostate gland and nearby tissues. Localized means there is no evidence the cancer has spread to lymph nodes, bones, or internal organs. In considering such cases,

doctors are careful to use terms such as “no evidence that cancer has spread...” because imaging tests to detect such spread will still be negative even after a few cells have metastasized. The treatment options for men in this situation include observation, radical prostatectomy, external beam radiation therapy, and internal radiation therapy. These therapies are

# Initial Treatment For Non-Metastatic Prostate Cancer

## INITIAL THERAPY

Observation (careful follow-up exams)  
 Radical prostatectomy or  
 Radiation (external beam or internal)  
 Observation  
 Observation,  
 Radical prostatectomy, or  
 Radiation (external beam)  
 Radical prostatectomy or  
 Radiation (external beam or internal)  
 Observation,  
 Radiation (external beam with or  
 without internal radiation), or  
 Radical prostatectomy  
 Radiation (external beam with or  
 without internal radiation) or  
 Radical prostatectomy  
 Observation or  
 Hormone therapy  
 Hormone therapy plus radiation  
 (external beam),  
 Radiation (selected patients – see  
 pages 40–41), or  
 Radical prostatectomy (selected  
 patients – see page 41)  
 Hormone therapy or  
 Hormone therapy plus radiation  
 (external beam)

## ADJUVANT (ADDITIONAL) THERAPY

Observation  
 (careful follow-up exams)  
**or**  
 Consider radiation therapy  
 for men who had radical  
 prostatectomy with cancer  
 remaining after surgery  
**or**  
 Consider hormone therapy  
 for men who had radical  
 prostatectomy with spread  
 of cancer to lymph nodes

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discussed in detail on pages 12, 13, and 16. Whether or not each of these options are appropriate for a man with prostate cancer depends on his recurrence risk (see pages 36-37) and his life expectancy (based on his age and illnesses other than prostate cancer).

Cancers with very low or low recurrence risk probably have not yet spread beyond the

prostate and are potentially curable by radical prostatectomy or radiation therapy. Some with intermediate risk are localized within the prostate. Others with intermediate risk may have metastasized and are no longer curable. Routine testing cannot determine which men with intermediate recurrence risk have curable cancers. However, potentially curative treatment

is neither necessary nor desirable for some men with localized prostate cancer. The general approach for men in this group is that more definitive treatments (such as radical prostatectomy or radiation) may be considered for men with an otherwise longer life expectancy. Men with shorter life expectancy (who are older and/or have other serious medical conditions) are less likely to benefit from definitive surgical treatment, and may choose no immediate treatment or treatments such as radiation therapy.

For example, observation is recommended for men with very low recurrence risk and life expectancy less than 20 years, because their cancers are not likely to grow and spread fast enough to significantly reduce their lifespan. If

they develop symptoms later on, treatments can still be given to relieve them. Men with very low recurrence risk and a life expectancy of at least 20 years are expected to live longer if they undergo prostatectomy or radiation therapy, so the guidelines recommend these treatments.

Cancers with high and very high recurrence risk are assumed to have spread too far to be curable. Men with these cancers, regardless of their life expectancy, are unlikely to benefit from local therapy alone because their cancers have probably spread to lymph nodes and/or distant sites. For this reason, NCCN guidelines recommend hormone therapy, alone or together with radiation therapy for most men. The decision tree indicates that radiation therapy

## NOTES

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# Initial Treatment For Non-Metastatic Prostate Cancer (continued)

alone is an option for “selected patients” with high recurrence risk and life expectancy of five or more years. The selection criteria are having a Gleason score less than 7, a PSA level less than 10, and a T3a cancer that has not spread too extensively within the prostate gland. Another group of “selected patients” may consider radical prostatectomy. This group includes men with a T3a cancer that has not spread too extensively beyond the prostate gland into surrounding tissues.

This decision tree illustrates how the remaining combinations of recurrence risk and life expectancy influence initial treatment options. After the initial treatment (prostatectomy, radiation therapy, hormone therapy, or radia-

tion and hormone therapy) careful follow-up exams at regular intervals are recommended. Usually no additional treatment is needed if results of these exams remain normal. The notable exception involves men in whom prostatectomy was done, but did not completely remove the cancer. In such cases, the guideline suggests considering radiation therapy as an adjuvant (additional) treatment. However, adjuvant radiation therapy may not be necessary in all such cases, and not all doctors agree on which patients would be helped by adjuvant radiation therapy. Hormone therapy may also be an option for men who had a radical prostatectomy with cancer that has spread to lymph nodes.

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## STAGE

Any T, N1,  
M0 or Mx

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Any T, Any N, M1

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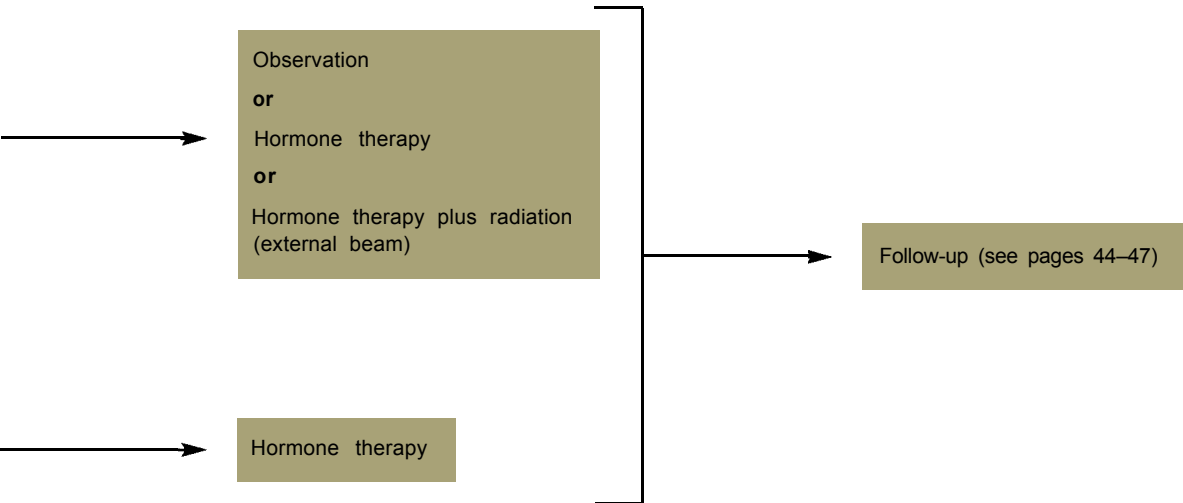
### INITIAL TREATMENT FOR METASTATIC PROSTATE CANCER

Prostate cancers that have metastasized to lymph nodes, bones, or internal organs are generally not considered curable. The options for men with metastases of prostate cancer limited to

pelvic lymph nodes (any T, N1, M0 or Mx) are observation (with treatment remaining as an option if symptoms develop later on), hormone therapy alone, or hormone therapy plus radiation therapy. Hormone therapy is the usual initial treatment for men with prostate cancer that has spread more widely (any T, any N, M1).

# Initial Treatment for Metastatic Prostate Cancer

## TREATMENT



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**LIFE EXPECTANCY, STAGE,  
AND INITIAL TREATMENT**

**FOLLOW-UP**

Observation (close follow-up but  
no initial active treatment)  
Life expectancy less than 10 years



Clinical evaluation, including discussion  
of any new symptoms every 6–12 months

Observation  
Life expectancy at least 10 years



PSA blood test and digital rectal exam  
every 6 months;  
Repeat prostate biopsy within 1 year, then  
repeat biopsy periodically (exact timing  
depends on medical details of each case).

Radical prostatectomy  
N0 or Nx, M0 or Mx (no known  
spread to lymph nodes, bones,  
or internal organs)



PSA blood test every 6 months  
for 5 years, then yearly.  
Digital rectal exam yearly.

Prostate radiotherapy  
N0 or Nx, M0 or Mx



Hormone therapy  
T3b or T4 (spread to seminal vesicles,  
bladder, or rectum), or N1 and/or M1  
(spread to lymph nodes, bones,  
and/or internal organs)



Physical exam (including digital rectal  
exam) every 3 months;  
PSA blood test every 3 months;  
Chemical tests of blood to check for liver  
problems in men taking antiandrogens.

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**FOLLOW-UP AFTER INITIAL PROSTATE  
CANCER TREATMENT**

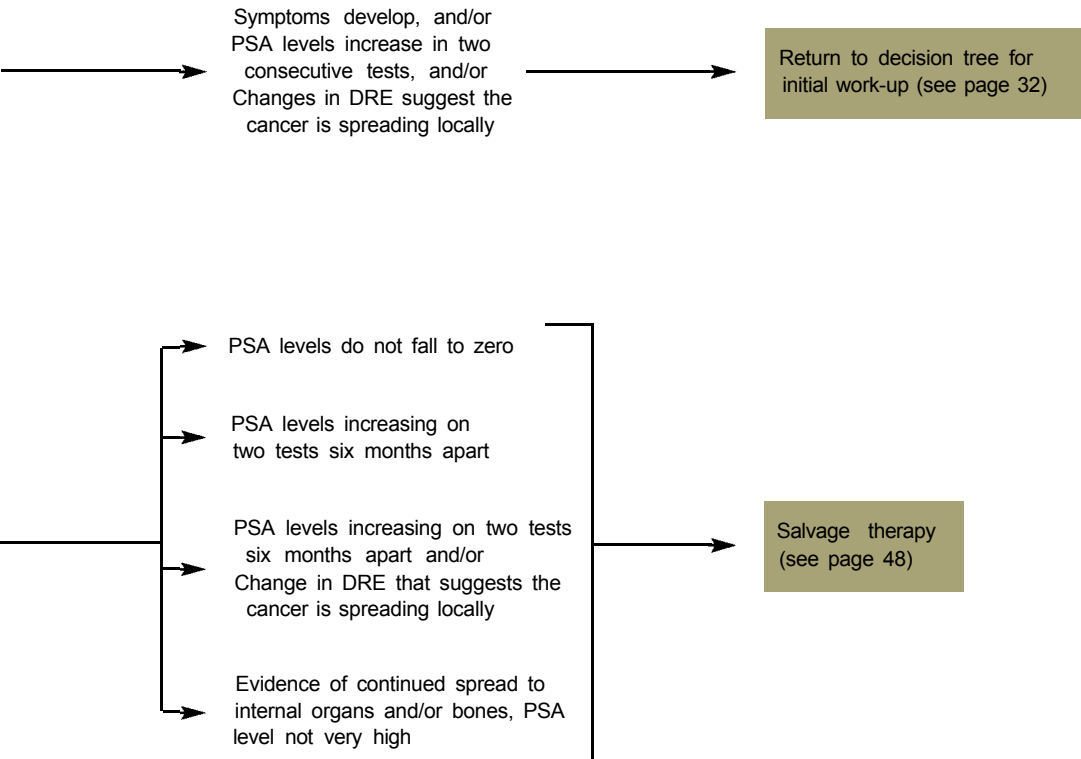
Recommendations for follow-up are based on each man's initial treatment and his life

expectancy. Based on these factors, the PSA blood test and digital rectal exam are done at intervals ranging from three to twelve months. In addition, men with a life expectancy of at least ten years who initially undergo close

# Decision Tree for Follow-Up After Initial Prostate Cancer Treatment

## ABNORMAL FOLLOW-UP RESULTS

(If results are normal, continue follow-up according to schedule)



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observation but no active treatment may have follow-up biopsies at intervals that depend on their individual medical circumstances. The reasoning behind these guidelines is that tests are recommended only when their results will

influence treatment choices in a way that will help the patient to live longer or with fewer symptoms.

If a man under observation without active treatment develops DRE findings that suggest

his cancer is spreading, or has two rising PSA results in a row, or has onset of new symptoms, the guidelines recommend that he reconsider his decision about treatment by returning to the decision tree for “Initial Work-Up” on page 32.

If the PSA level does not fall to zero after radical prostatectomy, it is likely that the

operation did not remove all cancer from the patient’s body. Cancer may remain locally or in distant sites. In either case, further treatment is based on the decision tree for “Salvage Work-Up and Treatment for Prostate Cancer that Returns or Continues Growing After Initial Therapy” on page 48.

## NOTES

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## Decision Tree for Follow-Up After Initial Prostate Cancer Treatment (continued)

Likewise, two rising PSA results in a row in patients treated with radical prostatectomy or radiation therapy suggest the patient has not been cured. Options for these men are also discussed on page 48.

For men initially treated with hormone therapy, a changing DRE that suggests local spread or two rising PSA results in a row should prompt consideration of salvage therapy options on page 48.

### NOTES

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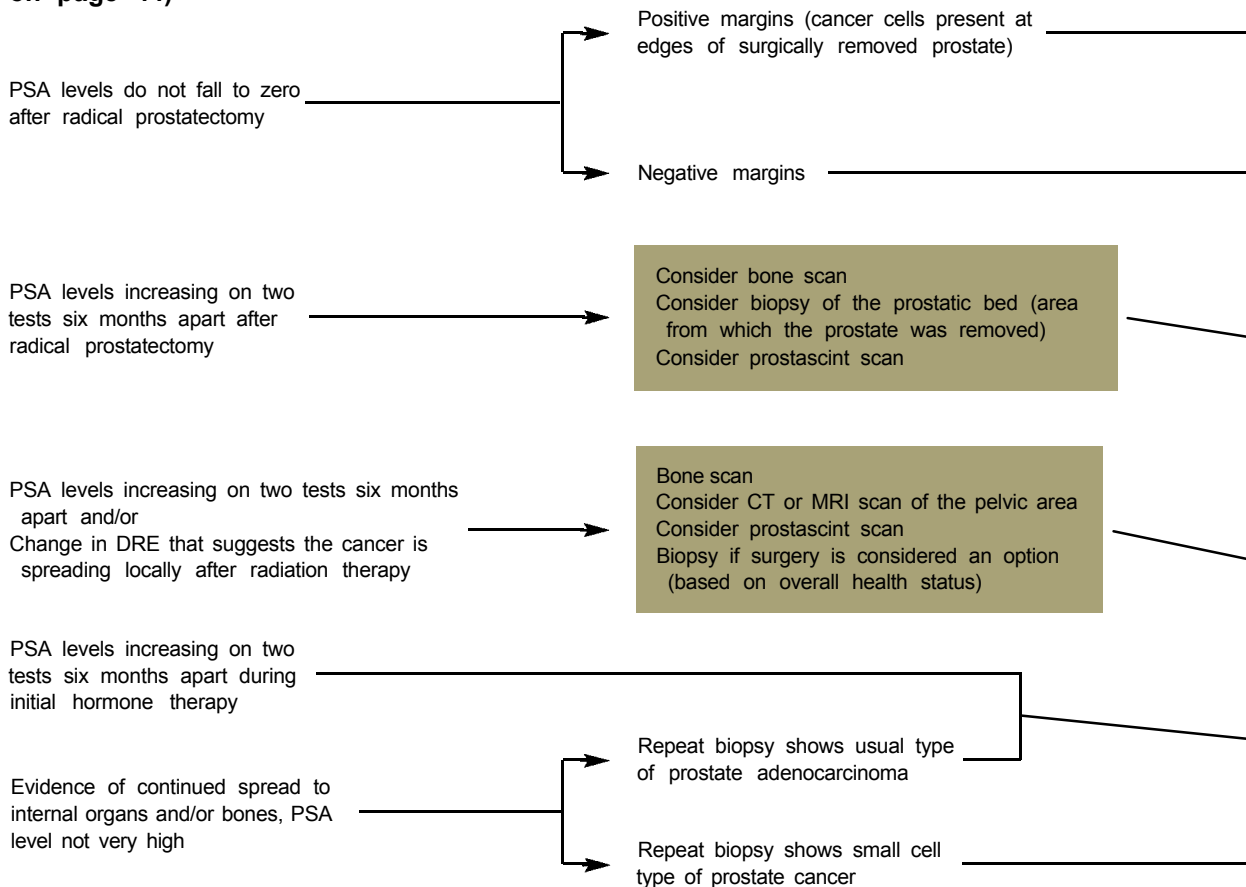
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## ABNORMAL FOLLOW-UP, RESULTS (if results are normal, continue follow-up according to the schedule on page 44)



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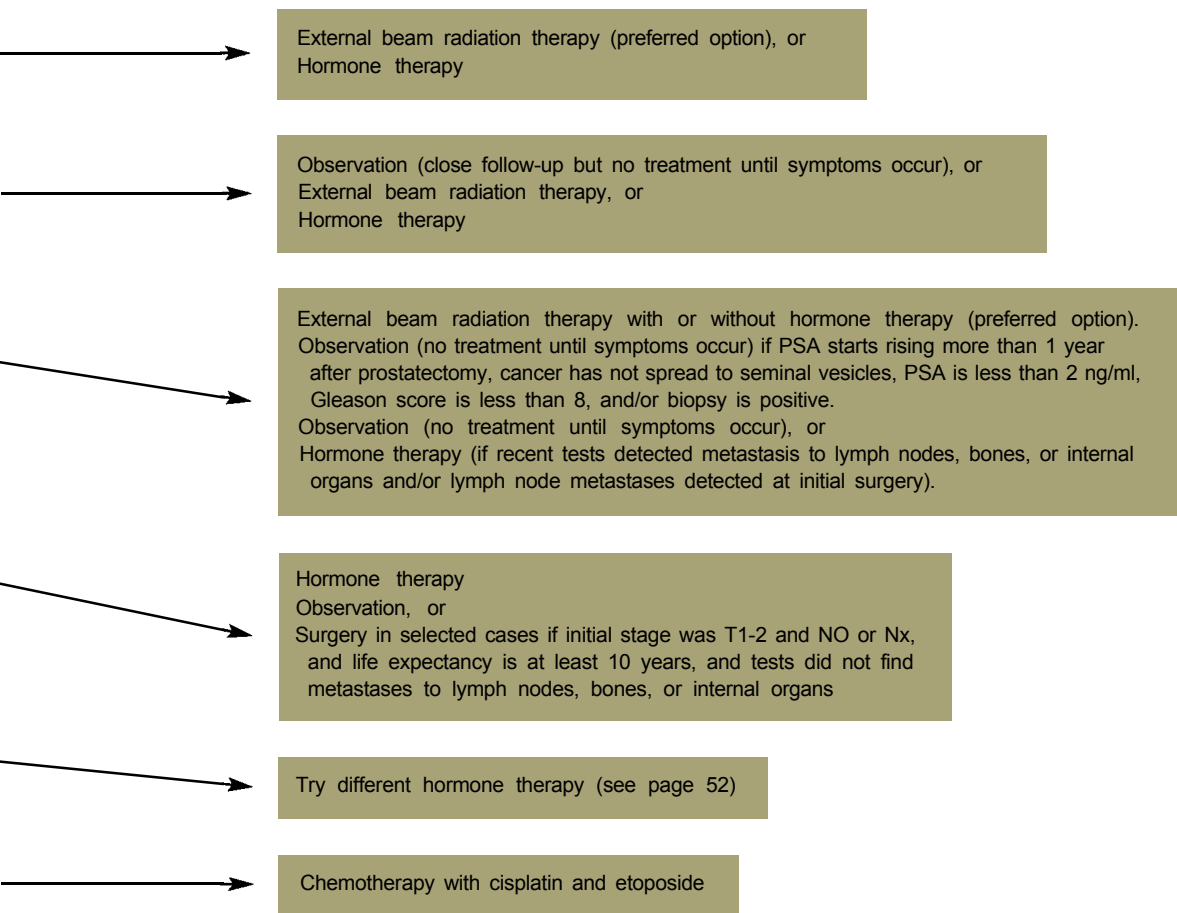
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## SALVAGE WORK-UP AND TREATMENT FOR PROSTATE CANCER THAT RETURNS OR CONTINUES GROWING AFTER INITIAL THERAPY

Salvage work-up refers to additional tests done when the usual follow-up tests suggest that the cancer has come back or continued to spread. Choices of tests, as well as options for salvage

# Decision Tree for Work-Up and Treatment of Prostate Cancer That Returns After Initial Treatment

## SALVAGE THERAPY



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therapy to treat the recurrent or persistent cancer, depend on the patient's stage and initial treatment.

If PSA levels do not fall to zero after radical prostatectomy, further treatment decisions are influenced by whether or not microscopic

examination of the prostate after surgery found cancer cells at the edge of the gland. In that case, some cancer cells may still remain in the prostatic bed (the area where the prostate used to be), and external beam radiation therapy to that area is recommended. If no cancer cells were found at the edge of the gland, cancer cells may still remain in the patient's body, and are producing the PSA that is detected by the blood tests. However, the cells may not be in the prostatic bed. If the cells have spread to distant areas of the body, external beam radia-

tion will not be curative. This treatment is still considered as an option, however. If the PSA level at first fell to zero, but then rose on two tests in a row, the salvage work-up may include a bone scan, a biopsy of the prostatic bed, and a prostascint scan. Depending on clinical details such as when the PSA began to rise, how high the levels rose, and the cancer's Gleason score, external beam radiation therapy, observation, or hormone therapy may be chosen.

If PSA levels rise in two consecutive tests after radiation therapy or the DRE findings

## NOTES

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## Decision Tree for Work-Up and Treatment of Prostate Cancer That Returns After Initial Treatment (continued)

suggest local spread of the cancer, salvage work-up will start with a bone scan and may also include pelvic CT or MRI scans and a prostascint scan. A biopsy will be done if surgery is considered an option. In selected cases depending on the man's life expectancy, and the stage and Gleason score of his cancer, surgery may be considered. Hormone therapy and observation (until symptoms develop) are the remaining options.

Men on hormone therapy whose PSA levels increase twice in a row may have a good

response to other types of hormone therapy, as outlined in the decision tree for "Treatment for Prostate Cancer that Returns or Continues to Grow after Initial Hormone Therapy." On rare occasions, a repeat biopsy will show that the cancer has changed from the usual type (adenocarcinoma) to a form called small cell carcinoma. Small cell carcinomas of the prostate do not usually respond to hormone treatment, but do sometimes respond to chemotherapy with cisplatin and etoposide.

### NOTES

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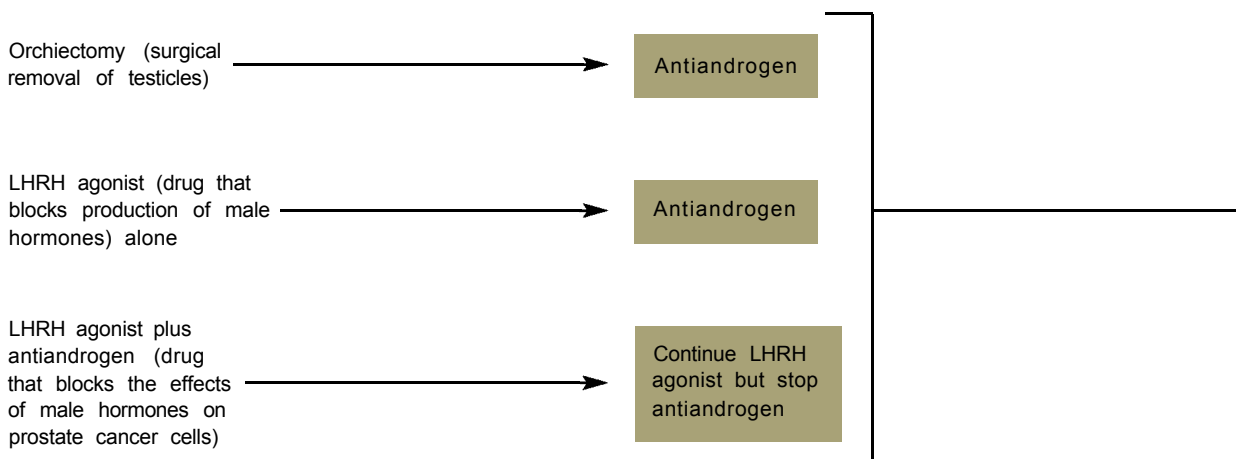
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## INITIAL HORMONE THERAPY

## SECOND HORMONE THERAPY



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## TREATMENT FOR PROSTATE CANCER THAT RETURNS OR CONTINUES GROWING AFTER INITIAL HORMONE THERAPY

As discussed in the section on types of treatments for prostate cancer, men have several options for hormonal therapy. If one hormonal therapy, such as orchiectomy or an LHRH agonist, is initially effective but the cancer starts to grow again later on, other hormonal therapies such as antiandrogens may be effective. If the initial combination of an LHRH agonist and antiandrogen is no longer effective, the former is continued but the latter is stopped.

If the cancer eventually becomes androgen independent, meaning that it can continue to grow despite the second hormonal therapy, several options remain. These include supportive care, other hormone therapies (such as ketoconazole or megestrol), chemotherapy, combinations of hormone therapy and chemotherapy, local external beam radiation therapy intended to slow growth of cancer deposits that are causing symptoms, and systemic radiation therapy (injection of radioactive medications that reach prostate cancer cells throughout the body). Selection from among

# Decision Tree for Treatment of Prostate Cancer That Returns or Continues Growing After Initial Hormone Therapy

## OPTIONS FOR ANDROGEN-INDEPENDENT PROSTATE CANCERS (Second hormone therapy is no longer effective)



Supportive care (treatment that doesn't affect cancer growth but can help to relieve symptoms)

or

Other hormone therapies (ketoconazole or megestrol)

or

Combinations of hormone therapy and chemotherapy drugs such as ketoconazole and doxorubicin, or estramustine and vinblastine, or estramustine and etoposide, or mitoxantrone and prednisone, or estramustine and paclitaxel

or

Systemic radiation therapy (injection of radioactive medications such as samarium or strontium)

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these options may be influenced by initial treatments. For example, radiation may influence the side effects caused by chemotherapy later on, and some men treated initially with radiation therapy may not be able to tolerate certain types and doses of chemotherapy. For this reason, discussing options for treating recurrent cancer before initial therapy is started is often useful. Supportive care includes treatments such as pain medications that don't affect cancer growth but are given to relieve symptoms. It is important to remember, especially in this situation, that the goal of prostate

cancer treatment is to make the patient feel as well as possible. Removing or destroying all of the cancer cells is one option to accomplish that goal. But, even when that approach is no longer an option, patients still have other options for relieving symptoms. There is no reason to endure pain or other symptoms when options are available. Some patients incorrectly assume that symptoms of advanced prostate cancer cannot be effectively treated. By not discussing their symptoms with their cancer care team, they miss out on opportunities to maintain their quality of life as much as possible.

**Adjuvant therapy**

Treatment used in addition to the main treatment. It usually refers to hormonal therapy, chemotherapy, or radiation added after surgery to increase the chances of curing the disease or keeping it in check.

**Alkaline phosphatase**

An enzyme made by cells in the bones and liver. Levels of alkaline phosphatase in the blood often go up in men whose prostate cancer has spread to the bones or liver.

**Androgen**

Any male sex hormone. The major androgen is testosterone.

**Antiandrogens**

Drugs that block the body's ability to use androgens. Several drugs of this type are currently available: flutamide (Eulexin<sup>®</sup>), bicalutamide (Casodex<sup>®</sup>), and nilutamide (Nilandron<sup>®</sup>), which are taken as pills, once or three times a day. Anti-androgens are usually used in combination with orchiectomy or LHRH analogs.

**Atypical**

Not usual; abnormal. Often refers to the appearance of cancerous or pre-cancerous cells.

**Benign prostatic hyperplasia (BPH)**

Non-cancerous enlargement of the prostate that may cause problems with urination such as trouble starting and stopping the flow.

**Biopsy**

Under ultrasound guidance, the doctor places a narrow needle through the wall of the rectum into the abnormal or suspicious area of the prostate gland. The

needle removes a cylinder of tissue, usually about 1/2-inch long and 1/16-inch across, which is sent to the laboratory and examined under a microscope to see if cancer is present.

**Brachytherapy**

Internal radiation treatment given by placing radioactive material directly into the tumor or close to it. Also called interstitial radiation therapy or seed implantation.

**Catheter (urinary)**

A thin, flexible tube through which fluids enter or leave the body; e.g., a tube to drain urine.

**Chemotherapy**

Treatment with drugs to destroy cancer cells.

**Combination hormone therapy**

Complete blockage of androgen production that may include castration (orchiectomy) or LHRH analogs, plus the use of anti androgens; also called total hormonal ablation, total androgen blockade, or total androgen ablation.

**Differentiation**

The normal process through which cells mature so they can carry out the jobs they were meant to do. Cancer cells are less differentiated than normal cells. Grading is done to evaluate and report the degree of a cancer's differentiation.

**Digital rectal examination (DRE)**

The doctor inserts a gloved finger into the rectum to feel for anything not normal. Some tumors of the rectum and prostate gland can be felt during a DRE.

## **Early detection**

Early detection means that the disease is found at an early stage, before it has grown large or spread to other sites. Many forms of cancer can reach an advanced stage without causing symptoms. Mammography can help to find breast cancer early, and the PSA blood test can help find early prostate cancer.

## **Ejaculate**

To release semen during orgasm; as a noun: semen.

## **External beam radiation**

Radiation is focused from a source outside the body on the area affected by the cancer. It is much like getting a diagnostic x-ray, but for a longer time.

## **Fine-needle aspiration**

In this procedure, a thin needle is used to draw up (aspirate) samples for examination under a microscope. Fine-needle aspiration, also called FNA, is sometimes used to determine if prostate cancer has spread to lymph nodes inside the pelvis.

## **Gland**

A group of cells that produce and release substances used nearby or in another part of the body.

## **Gleason grade**

The most often used prostate cancer grading system is called the Gleason system. This system assigns a Gleason grade ranging from 1 through 5 based on how much the arrangement of the cancer cells looks like the way normal prostate cells are arranged in the prostate gland. Because prostate cancers often have areas with different grades, a grade is assigned to the two areas that make up most of the cancer. These two grades are added together to give a Gleason score between 2 and 10.

## **Gleason score**

A method of classifying prostate cancer cells on a scale of 2 to 10. The higher the Gleason score (also called Gleason sum), the faster the cancer is likely to grow and the more likely it is to spread beyond the prostate.

## **Hormone**

A chemical substance released into the body by the endocrine glands such as the thyroid, adrenals, testes, or ovaries. The substance travels through the bloodstream and sets in motion various body functions. Testosterone and estrogen are examples of male and female hormones.

## **Hormone therapy**

Treatment with hormones, drugs to interfere with hormone production or hormone action, or the surgical removal of hormone-producing glands. Hormone therapy may kill cancer cells or slow their growth.

## **Hot flash**

Sudden rush of body heat causing reddening and sweating; a common side effect of some types of hormone therapy.

## **Hyperplasia**

Too much growth of cells or tissue in a specific area, such as the lining of the prostate.

## **Laparoscope**

A long, slender tube inserted into the abdomen through a very small incision. The laparoscope allows the surgeon to view lymph nodes near the prostate and remove these pelvic lymph nodes using special surgical instruments operated through the laparoscope.

## **Laparoscopic lymphadenectomy**

Removal of lymph nodes with a laparoscope.

## **LHRH**

Stands for luteinizing hormone-releasing hormone, a hormone produced by the hypothalamus, a tiny gland in the brain.

## **LHRH analogs**

Synthetically made hormones, chemically similar to LHRH. They block the production of the male hormone testosterone and are sometimes used to treat prostate cancer.

## **Libido**

Sex drive.

## **Luteinizing hormone (LH)**

Pituitary hormone that stimulates the testicles to produce testosterone.

## **Metastasis**

The spread of cancer cells to distant areas of the body by way of the lymph system or bloodstream.

## **Orchiectomy**

Surgery to remove the testicles; castration.

## **Palliative treatment**

Therapy that relieves symptoms, such as pain or blockage of urine flow, but is not expected to cure the cancer. Its main purpose is to improve the patient's quality of life. For instance, radiation therapy may be used to relieve pain from bone metastases is considered as palliative treatment. In other patients, radiation of the prostate gland will be given with the intention of curing the cancer-this is not palliative treatment.

## **Percent free-PSA**

Indicates how much PSA circulates alone or unbound in the blood and how much is bound together with other blood proteins. For total PSA results in the borderline range, a low percent free-PSA (25% or less) means that a prostate cancer is more likely to be present and suggests the need for a biopsy.

## **Prognosis**

A prediction of the course of disease; the outlook for the cure of the patient.

## **Prostate-specific antigen (PSA)**

A protein made by the prostate gland. Levels of PSA in the blood often go up in men with prostate cancer. The PSA test is used to help find prostate cancer as well as to monitor the results of treatment.

## **Prostatitis**

Inflammation of the prostate. Prostatitis is not cancer.

## **PSAV (PSA velocity)**

Measures how quickly the PSA level rises over a period of time. This has been suggested as a way to improve the accuracy of PSA testing. A higher PSAV indicates greater likelihood of cancer being present.

## **Radical prostatectomy**

Surgery to remove the entire prostate gland, the seminal vesicles, and nearby tissue.

## **Salvage therapy**

Treatment given to patients whose cancer has recurred. Choice of salvage therapy depends on the location of the recurrent cancer (local recurrence or distant recurrence) and the type of treatment already given. For instance, if initial treatment was prostatectomy, salvage therapy may involve radiation therapy.

## **Salvage work-up (evaluation)**

Examinations and tests done after cancer has recurred to help in choosing additional treatments.

## **Sequential hormone therapy**

A strategy for hormonal therapy in which the patient's response to one treatment is used to determine whether other treatments are needed. For example, if a patient is receiving an LHRH

agonist and his PSA levels begin to rise, an antiandrogen drug may be added.

### **Supportive care**

Measures taken to relieve symptoms and improve quality of life, but not expected to destroy the cancer. Pain medication is an example of supportive care.

### **Testicles**

The male reproductive glands found in the scrotum. The testes (or testicles) produce sperm and the male hormone testosterone.

### **Testosterone**

The main male hormone, made primarily in the testes. It stimulates blood flow, growth of certain tissues, and the secondary sexual characteristics. In men with prostate cancer, it can also encourage growth of the tumor.

### **Three-dimensional conformal therapy**

This treatment uses sophisticated computers to very precisely map the location of the cancer within the prostate. The patient is fitted with a plastic mold resembling a body cast to keep him still so that the radiation can be more accurately aimed. Radiation beams are then aimed from several directions.

### **Transurethral resection of the prostate (TURP)**

This operation removes part of the prostate gland that surrounds the urethra (the tube through which urine exits the bladder). This operation can be used to relieve symptoms caused by a tumor before other treatments begin. But it is not expected to cure this disease or remove all of the cancer. It is used even more often to relieve symptoms of non-cancerous prostate enlargement.

### **Urinary urgency**

Feeling that you need to urinate right away.

### **Watchful waiting**

Instead of active treatment for prostate cancer, the doctor may suggest close monitoring. This may be a reasonable choice for older men with small tumors that might grow very slowly. If the situation changes, active treatment can be started.

For a more comprehensive glossary, you may access the ACS web site at [www.cancer.org](http://www.cancer.org)

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## NOTES

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## NOTES

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The *Prostate Cancer Treatment Guidelines for Patients* were developed by a diverse group of experts and were based on the NCCN clinical practice guidelines. These patient guidelines were translated, reviewed, and published with help from the following individuals:

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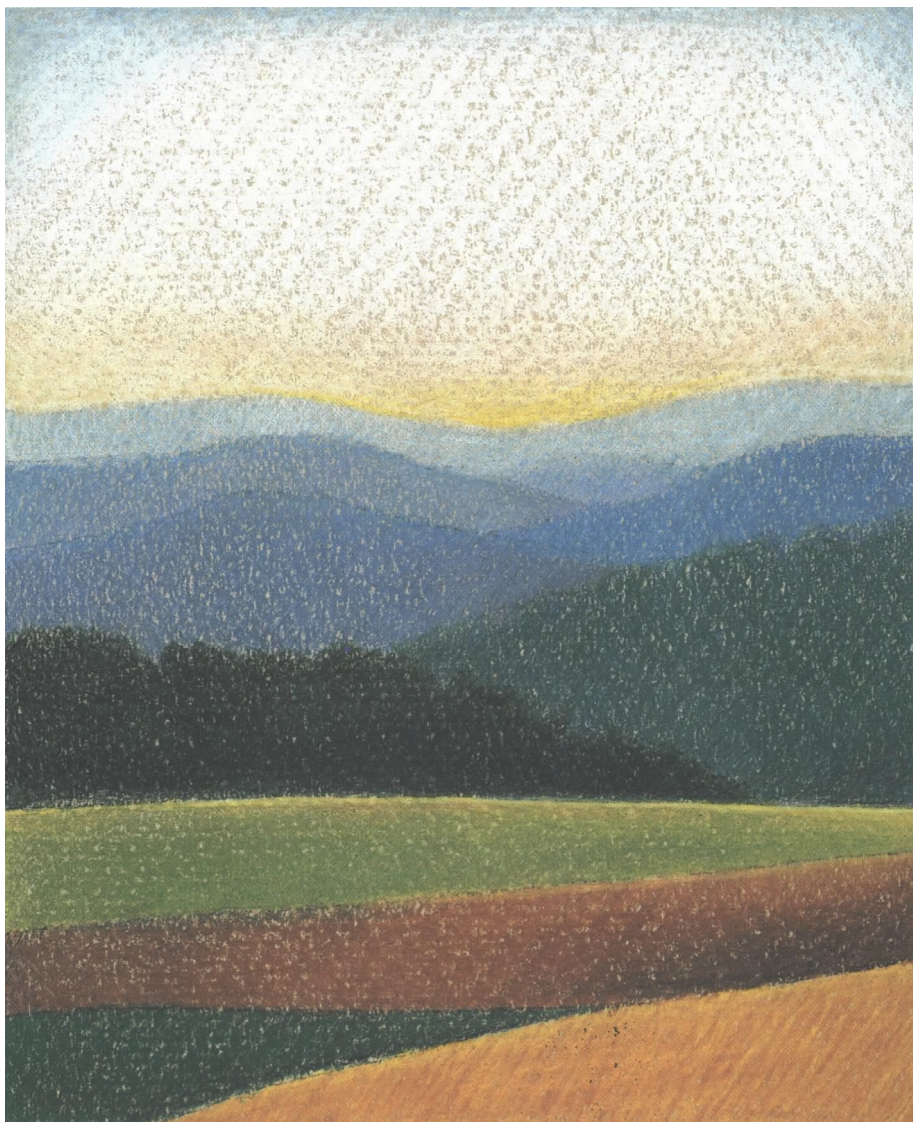


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[www.nccn.org](http://www.nccn.org)

# Chemotherapy and You

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**A GUIDE TO SELF-HELP  
DURING CANCER TREATMENT**



**NATIONAL INSTITUTES OF HEALTH  
National Cancer Institute**



# Chemotherapy and You

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## **A GUIDE TO SELF-HELP DURING CANCER TREATMENT**



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Public Health Service  
National Institutes of Health

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# *About This Booklet*

This booklet is for patients who are receiving chemotherapy for cancer. It describes what to expect during chemotherapy and what you can do to take care of yourself during and after treatment. What can you do? Eat the right foods to build up your strength. Stay away from people who have colds or the flu. Get the rest you need and pace yourself. Talk about your feelings to deal with any sadness, anger, or fear you may have. Work as a team with your health care providers. Knowing how to help yourself can make you feel more in control. These are just a few of the ways that you can help yourself and begin to feel in control again.

This booklet is designed to help you become an informed partner in your care, but it is only a guide. Self-help can never take the place of professional health care. Ask your doctor and nurse any questions you may have about chemotherapy. Also don't hesitate to tell them about any side effects you may have. They want and need to know.

The table of contents identifies all the topics discussed in *Chemotherapy and You*. A glossary at the back of this booklet explains many terms you may hear during chemotherapy. Many of the words defined in the glossary are printed in bold the first time they are used in the text.

# *Understanding Chemotherapy*

## *What Is Chemotherapy?*

**Chemotherapy** is the treatment of cancer with drugs that can destroy cancer cells. These drugs often are called “anticancer” drugs.

## *How Does Chemotherapy Work?*

Normal cells grow and die in a controlled way. When cancer occurs, cells in the body that are not normal keep dividing and forming more cells without control. Anticancer drugs destroy cancer cells ‘by stopping them from growing or multiplying. Healthy cells can also be harmed, especially those that divide quickly. Harm to healthy cells is what causes side effects. These cells usually repair themselves after chemotherapy.

Because some drugs work better together than alone, often two or more drugs are given at the same time. This is called **combination chemotherapy**.

Other types of drugs may be used to treat your cancer. These may include certain drugs that can block the effect of your body’s **hormones**. Or doctors may use **biological therapy**, which is treatment with substances that boost the body’s own immune system against cancer. Your body usually makes these substances in small amounts to fight cancer and other diseases. These substances can be made in the laboratory and given to patients to destroy cancer cells or change the way the body reacts to a tumor. They may also help the body repair or make new cells destroyed by chemotherapy.

## *What Can Chemotherapy Do?*

Depending on the type of cancer and how advanced it is, chemotherapy can be used for different goals:

- **To cure the cancer.** Cancer is considered cured when the patient remains free of evidence of cancer cells.
- **To control the cancer.** This is done by keeping the cancer from spreading; slowing the cancer's growth; and killing cancer cells that may have spread to other parts of the body from the original tumor.
- **To relieve symptoms that the cancer may cause.** Relieving symptoms such as pain can help patients live more comfortably.

## *Is Chemotherapy Used With Other Treatments?*

Sometimes chemotherapy is the only treatment a patient receives. More often, however, chemotherapy is used in addition to surgery, **radiation therapy**, and/or biological therapy to:

- Shrink a tumor before surgery or radiation therapy. This is called neo-adjuvant therapy.
- Help destroy any cancer cells that may remain after surgery and/or radiation therapy. This is called adjuvant chemotherapy.
- Make radiation therapy and biological therapy work better.
- Help destroy cancer if it recurs or has spread to other parts of the body from the original tumor.

## *Which Drugs Are Given?*

Some chemotherapy drugs are used for many different types of cancer, while others might be used for just one or two types of cancer. Your doctor recommends a treatment plan based on:

- What kind of cancer you have.
- What part of the body the cancer is found.
- The effect of cancer on your normal body functions.
- Your general health.



### *What About Clinical Trials?*

Clinical trials, also called cancer treatment studies or research studies, test new treatments in people with cancer. Clinical trials test many types of treatments such as new drugs, new approaches to surgery or radiation therapy, new combinations of treatments, or new methods such as gene therapy. The goal of this research is to find better ways to treat cancer and help cancer patients. There are different types of clinical trials, called Phase I, Phase II, and Phase III trials. Each is one of the final stages of a long and careful cancer research process. If your doctor does not suggest you take part in a clinical trial, you may want to ask about clinical trials as a treatment choice for you.

### *Possible benefits of clinical trials include:*

- Clinical trials offer high-quality cancer care.
- If a new treatment approach is proven to work and you are taking it, you may be among the first to benefit.
- By looking at the pros and cons of clinical trials and other treatment choices, you are taking an active role in a decision that affects your life.
- You have the chance to help others and improve cancer treatment.

### *Possible drawbacks:*

- New treatments under study are not always better than, or even as good as, standard treatment.
- Even if a new treatment has benefits, it may not work for you.
- In a study, if you are randomly assigned to have standard treatment instead of the new treatment being tested, it may not be as effective as the new approach.
- Health insurance and managed care providers do not always cover all patient care costs in a study.

Before deciding to join a clinical trial you will want to ask important questions such as: What are the possible short- and long-term risks, side effects, and benefits to me? How could the study affect my daily life? Will I have to pay for any treatment, tests, or other charges?

The National Cancer Institute's (NCI) booklet *Taking Part in Clinical Trials: What Cancer Patients Need to Know* lists questions you may want to ask your doctor and helps answers many of the questions you may have about clinical trials. It also informs you about your rights and protections. For example, you are free to leave a study at any time. You may order the booklet by calling NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237). You can also look on the Internet at <http://cancertrials.nih.gov>.

# Questions To Ask Your Doctor

## About Chemotherapy

- Why do I need chemotherapy?
- What are the benefits of chemotherapy?
- What are the risks of chemotherapy?
- Are there any other possible treatment methods for my type of cancer?
- What is the standard care for my type of cancer?
- Are there any clinical trials for my type of cancer?

## About Your Treatment

- How many treatments will I be given?
- What drug or drugs will I be taking?
- How will the drugs be given?
- Where will I get my treatment?
- How long will each treatment last?

## About Side Effects

- What are the possible side effects of the chemotherapy?  
When are side effects likely to occur?
- What side effects are more likely to be related to my type of cancer?
- Are there any side effects that I should report right away?
- What can I do to relieve the side effects?

## About Contacting Medical Staff

- How do I contact a health professional after hours, and when should I call?

## Hints for Talking with Your Doctor

These tips might help you keep track of the information you learn during visits with your doctor:

- Bring a friend or family member to sit with you while you talk with your doctor. This person can help you understand what your doctor says during your visit and help refresh your memory afterward.
- Ask your doctor for printed information that is available on your cancer and treatment.
- You, or the person who goes with you, may want to take notes during your appointment.
- Ask your doctor to slow down when you need more time to write.
- You may want to ask if you can use a tape recorder during your visit. Take notes from the tape after the visit is finished. That way, you can review your conversation later as many times as you wish.

# *What Can I Expect During Chemotherapy?*

Some people with cancer want to know every detail about their condition and their treatment. Others prefer only general information. The choice of how much information to seek is yours, but there are questions that every person getting chemotherapy should ask.

This list is just a start. Always feel free to ask your doctor, nurse, and pharmacist as many questions as you want. If you do not understand their answers, keep asking until you do. Remember, there is no such thing as a “stupid” question, especially about cancer or your treatment. To make sure you get all the answers you want, you may find it helpful to draw up a list of questions before each doctor’s appointment. Some people keep a “running list” and jot down each new question as it occurs to them.

## *Where Will I Get Chemotherapy?*

Chemotherapy can be given in many different places: at home, a doctor’s office, a clinic, a hospital’s outpatient department, or as an “inpatient” in a hospital. The choice of where you get chemotherapy depends on which drug or drugs you are getting, your insurance, and sometimes your own and your doctor’s wishes. Most patients receive their treatment as an “outpatient” and are not hospitalized. Sometimes, a patient starting chemotherapy may need to stay at the hospital for a short time so that the medicine’s effects can be watched closely and any needed changes can be made.

## *How Often and For How Long Will I Get Chemotherapy?*

How often and how long you get chemotherapy depends on:

- The kind of cancer you have.
- The goals of the treatment.
- The drugs that are used.
- How your body responds to them.

You may get treatment every day, every week, or every month. Chemotherapy is often given in cycles that include treatment periods alternated with rest periods. Rest periods give your body a chance to build healthy new cells and regain its strength. Ask your health care provider to tell you how long and how often you may expect to get treatment.

Sticking with your treatment schedule is very important for the drugs to work right. Schedules may need to be changed for holidays and other reasons. If you miss a treatment session or skip a dose of the drug, contact your doctor.

Sometimes, your doctor may need to delay a treatment based on the results of certain blood tests. (See the sections on Fatigue, Infection, and Anemia.) Your doctor will let you know what to do during this time and when to start your treatment again.

## *How Is Chemotherapy Given?*

Chemotherapy can be given in several different ways: intravenously (through a vein), by mouth, through an injection (shot), or applied on the skin.

### **■ By vein (intravenous, or IV, treatment)**

Chemotherapy is most often given intravenously (IV), through a vein. Usually a thin needle is inserted into a vein on the hand or lower arm at the beginning of each treatment session and is removed at the end of the session. If you feel a coolness, burning,

or other unusual sensation in the area of the needle stick when the IV is started, tell your doctor or nurse. Also report any pain, burning, skin redness, swelling, or discomfort that occurs during or after an IV treatment.

Chemotherapy can also be delivered by IV through catheters, ports, and pumps.

**Catheters.** A catheter is a soft, thin, flexible tube that is placed in a large vein in the body and remains there as long as it is needed. Patients who need to have many IV treatments often have a catheter, so a needle does not have to be used each time. Drugs can be given and blood samples can be drawn through this catheter. Sometimes the catheter is attached to a **port** — a small round plastic or metal disc placed under the skin. The port can be used for as long as it is needed. A pump, which is used to control how fast the drug goes into a catheter or port, is sometimes used. There are two types of pumps. An external pump remains outside the body. Most are portable; they allow a person to move around while the pump is being used. An internal pump is placed inside the body during surgery, usually right under the skin. Pumps contain a small storage area for the drug and allow people to go about their normal activities. Catheters, ports, and pumps cause no pain if they are properly placed and cared for, although a person is aware they are there.

Catheters are usually placed in a large vein, most commonly to your chest, called a **central venous catheter**. A peripherally inserted central catheter (PICC) is inserted into a vein in the arm. Catheters can also be placed in an artery or other locations in your body, such as:

- **Intrathecal (IT) catheter.** Delivers drugs into the spinal fluid.
- **Intracavitary (IC) catheter.** Placed in the abdomen, pelvis, or chest.



### ■ **By mouth (orally).**

The drug is given in pill, capsule, or liquid form. You swallow the drug, just as you do many other medicines.

### ■ **By injection.**

A needle and syringe are used to give the drug in one of several ways:

- **Intramuscularly, or IM.** (Into a muscle)
- **Subcutaneously, or SQ or SC.** (Under the skin)
- **Intralesionally, or IL.** (Directly into a cancerous area in the skin)

### ■ **Topically.**

The drug is applied on the surface of the skin.

## *How Will I Feel During Chemotherapy?*

Most people receiving chemotherapy find that they tire easily, but many feel well enough to continue to lead active lives. Each person and treatment is different, so it is not always possible to tell exactly how you will react. Your general state of health, the type and extent of cancer you have, and the kind of drugs you are receiving can all affect how well you feel.

You may want to have someone available to drive you to and from treatment if, for example, you are taking medicine for nausea or vomiting that could make you tired. You may also feel especially tired from the chemotherapy as early as one day after a treatment and for several days. It may help to schedule your treatment when you can take off the day of and the day after your treatment. If you have young children, you may want to schedule the treatment when you have someone to help at home the day of and at least the day after your treatment. Ask your doctor when your greatest fatigue or other side effects are likely to occur.

Most people can continue working while receiving chemotherapy. However, you may need to change your work schedule for a while if your chemotherapy makes you feel very tired or have other side effects. Talk with your employer about your needs and wishes. You may be able to agree on a part-time schedule, find an area for a short nap during the day, or perhaps you can do some of your work at home.

Under Federal and state laws, some employers may be required to let you work a flexible schedule to meet your treatment needs. To find out about your on-the-job protections, check with a social worker, or your congressional or state representative. NCI's publication *Facing Forward: A Guide for Cancer Survivors* also has information on work-related concerns.

## *Can I Take Other Medicines While I Am Getting Chemotherapy?*

Some medicines may interfere or react with the effects of your chemotherapy. Give your doctor a list of all the medicines you take before you start treatment. Include:

- the name of each drug
- the dosage
- the reason you take it
- how often you take it

Remember to tell your doctor about all over-the-counter remedies, including vitamins, laxatives, medicines for allergies, indigestion, and colds, aspirin, ibuprofen, or other pain relievers, and any mineral or herbal supplements. Your doctor can tell you if you should stop taking any of these remedies before you start chemotherapy. After your treatments begin, be sure to check with your doctor before taking any new medicines or stopping the ones you are already taking.

## *How Will I Know If My Chemotherapy Is Working?*

Your doctor and nurse will use several ways to see how well your treatments are working. You may have physical exams and tests often. Always feel free to ask your doctor about the test results and what they show about your progress.

Tests and exams can tell a lot about how chemotherapy is working; however, side effects tell very little. Sometimes people think that if they have no side effects, the drugs are not working, or, if they do have side effects, the drugs are working well. But side effects vary so much from person to person, and from drug to drug, that side effects are not a sign of whether the treatment is working or not.

## Questions To Ask About Side Effects

- What are the short-term side effects that may occur?
- What are the long-term side effects that may occur?
- How serious are the side effects likely to be?
- How long will the side effects last?
- What can I do to relieve or lessen the side effects?
- When should I call the doctor or nurse about side effects?
- What can I do to feel better emotionally while trying to cope with the side effects?

# *Coping With Side Effects*

## *What Causes Side Effects?*

Because cancer cells may grow and divide more rapidly than normal cells, many anticancer drugs are made to kill growing cells. But certain normal, healthy cells also multiply quickly, and chemotherapy can affect these cells, too. This damage to normal cells causes side effects. The fast-growing, normal cells most likely to be affected are blood cells forming in the **bone marrow** and cells in the digestive tract (mouth, stomach, intestines, esophagus), reproductive system (sexual organs), and hair follicles. Some anticancer drugs may affect cells of vital organs, such as the heart, kidney, bladder, lungs, and nervous system.

You may have none of these side effects or just a few. The kinds of side effects you have and how severe they are, depend on the type and dose of chemotherapy you get and how your body reacts. Before starting chemotherapy, your doctor will discuss the side effects that you are most likely to get with the drugs you will be receiving. Before starting the treatment, you will be asked to sign a consent form. You should be given all the facts about treatment including the drugs you will be given and their side effects before you sign the consent form.

## *How Long Do Side Effects Last?*

Normal cells usually recover when chemotherapy is over, so most side effects gradually go away after treatment ends, and the healthy cells have a chance to grow normally. The time it takes to get over side effects depends on many things, including your overall health and the kind of chemotherapy you have been taking.

Most people have no serious long-term problems from chemotherapy. However, on some occasions, chemotherapy can cause permanent changes or damage to the heart, lungs, nerves, kidneys, reproductive or other organs. And certain types of chemotherapy may have delayed effects, such as a second cancer,



that show up many years later. Ask your doctor about the chances of any serious, long-term effects that can result from the treatment you are receiving (but remember to balance your concerns with the immediate threat of your cancer).

Great progress has been made in preventing and treating some of chemotherapy's common as well as rare serious side effects. Many new drugs and treatment methods destroy cancer more effectively while doing less harm to the body's healthy cells.

The side effects of chemotherapy can be unpleasant, but they must be measured against the treatment's ability to destroy cancer. Medicines can help prevent some side effects such as nausea. Sometimes people receiving chemotherapy become discouraged about the length of time their treatment is taking or the side effects they are having. If that happens to you, talk to your doctor or nurse. They may be able to suggest ways to make side effects easier to deal with or reduce them.

Below you will find suggestions for dealing with some of the more common side effects of chemotherapy.

## *Fatigue*

Fatigue, feeling tired and lacking energy, is the most common symptom reported by cancer patients. The exact cause is not always known. It can be due to your disease, chemotherapy, radiation, surgery, low blood counts, lack of sleep, pain, stress, poor appetite, along with many other factors.

Fatigue from cancer feels different from fatigue of everyday life. Fatigue caused by chemotherapy can appear suddenly. Patients with cancer have described it as a total lack of energy and have used words such as worn out, drained, and wiped out to describe their fatigue. And rest does not always relieve it. Not everyone feels the same kind of fatigue. You may not feel tired while someone else does or your fatigue may not last as long as someone else's does. It can last days, weeks, or months. But severe fatigue does go away gradually as the tumor responds to treatment.

## How can I cope with fatigue?

- Plan your day so that you have time to rest.
- Take short naps or breaks, rather than one long rest period.
- Save your energy for the most important things.
- Try easier or shorter versions of activities you enjoy.
- Take short walks or do light exercise if possible. You may find this helps with fatigue.
- Talk to your health care provider about ways to save your energy and treat your fatigue.
- Try activities such as meditation, prayer, yoga, guided imagery, visualization, etc. (See the section “Complementary Therapies.”) You may find that these help with fatigue.
- Eat as well as you can and drink plenty of fluids. Eat small amounts at a time, if that is helpful.
- Join a support group. Sharing your feelings with others can ease the burden of fatigue. You can learn how others deal with their fatigue. Your health care provider can put you in touch with a support group in your area.
- Limit the amount of caffeine and alcohol you drink.
- Allow others to do some things for you that you usually do.
- Keep a diary of how you feel each day. This will help you plan your daily activities.
- Report any changes in energy level to your doctor or nurse.

## *Nausea and Vomiting*

Many patients fear that they will have nausea and vomiting while receiving chemotherapy. But new drugs have made these side effects far less common and, when they do occur, much less severe. These powerful **antiemetic** or antinausea drugs can prevent or lessen nausea and vomiting in most patients. Different drugs work for different people, and you may need more than one drug to get relief. Do not give up. Continue to work with your doctor and nurse to find the drug or drugs that work best for you. Also, be sure to tell your doctor or nurse if you are very nauseated or have vomited for more than a day, or if your vomiting is so bad that you cannot keep liquids down.

### **What can I do if I have nausea and vomiting?**

- Drink liquids at least an hour before or after mealtime, instead of with your meals. Drink frequently and drink small amounts.
- Eat and drink slowly.
- Eat small meals throughout the day, instead of one, two, or three large meals.
- Eat foods cold or at room temperature so you won't be bothered by strong smells.
- Chew your food well for easier digestion.
- If nausea is a problem in the morning, try eating dry foods like cereal, toast, or crackers before getting up. (Do not try this if you have mouth or throat sores or are troubled by a lack of saliva.)
- Drink cool, clear, unsweetened fruit juices, such as apple or grape juice or light-colored sodas such as ginger ale that have lost their fizz and do not have caffeine.

- Suck on mints, or tart candies. (Do not use tart candies if you have mouth or throat sores.)
- Prepare and freeze meals in advance for days when you do not feel like cooking.
- Wear loose-fitting clothes.
- Breathe deeply and slowly when you feel nauseated.
- Distract yourself by chatting with friends or family members, listening to music, or watching a movie or TV show.
- Use relaxation techniques. (See the section “Complementary Therapies.”)
- Try to avoid odors that bother you, such as cooking smells, smoke, or perfume.
- Avoid sweet, fried, or fatty foods.
- Rest but do not lie flat for at least 2 hours after you finish a meal.
- Avoid eating for at least a few hours before treatment if nausea usually occurs during chemotherapy.
- Eat a light meal before treatment.

## *Pain*

Chemotherapy drugs can cause some side effects that are painful. The drugs can damage nerves, leading to burning, numbness, tingling or shooting pain, most often in the fingers or toes. Some drugs can also cause mouth sores, headaches, muscle pains, and stomach pains.

Not everyone with cancer or who receives chemotherapy experiences pain from the disease or its treatment. But if you do, it can be relieved. The first step to take is to talk with your doctor, nurse, and pharmacist about your pain. They need to know as many details about your pain as possible. You may want to

describe your pain to your family and friends. They can help you talk to your caregivers about your pain, especially if you are too tired or in too much pain to talk to them yourself.

You need to tell your doctor, nurse, and pharmacist and family or friends:

- Where you feel pain.
- What it feels like — sharp, dull, throbbing, steady.
- How strong the pain feels.
- How long it lasts.
- What eases the pain, what makes the pain worse.
- What medicines you are taking for the pain and how much relief you get from them.

Using a pain scale is helpful in describing how much pain you are feeling. Try to assign a number from 0 to 10 to your pain level. If you have no pain, use a 0. As the numbers get higher, they stand for pain that is getting worse. A 10 means the pain is as bad as it can be. You may wish to use your own pain scale using numbers from 0 to 5 or even 0 to 100. Be sure to let others know what pain scale you are using and use the same scale each time, for example, “My pain is 7 on a scale of 0 to 10.”

The goal of pain control is to prevent pain that can be prevented, and treat the pain that can't. To do this:

- If you have persistent or chronic pain, take your pain medicine on a regular schedule (by the clock).
- Do not skip doses of your scheduled pain medicine. If you wait to take pain medicine until you feel pain, it is harder to control.
- Try using relaxation exercises at the same time you take medicine for the pain. This may help to lessen tension, reduce anxiety, and manage pain.

- Some people with chronic or persistent pain that is usually controlled by medicine can have breakthrough pain. This occurs when moderate to severe pain “breaks through” or is felt for a short time. If you experience this pain, use a short-acting medicine ordered by your doctor. Don’t wait for the pain to get worse. If you do, it may be harder to control.

There are many different medicines and methods available to control cancer pain. You should expect your doctor to seek all the information and resources necessary to make you as comfortable as possible. If you are in pain and your doctor has no further suggestions, ask to see a pain specialist or have your doctor consult with a pain specialist. A pain specialist may be an oncologist, anesthesiologist, neurologist, neurosurgeon, other doctor, nurse, or pharmacist.

## *Hair Loss*

Hair loss (**alopecia**) is a common side effect of chemotherapy, but not all drugs cause hair loss. Your doctor can tell you if hair loss might occur with the drug or drugs you are taking. When hair loss does occur, the hair may become thinner or fall out entirely. Hair loss can occur on all parts of the body, including the head, face, arms and legs, underarms, and pubic area. The hair usually grows back after the treatments are over. Some people even start to get their hair back while they are still having treatments. Sometimes, hair may grow back a different color or texture.

Hair loss does not always happen right away. It may begin several weeks after the first treatment or after a few treatments. Many people say their head becomes sensitive before losing hair. Hair may fall out gradually or in clumps. Any hair that is still growing may become dull and dry.



### How can I care for my scalp and hair during chemotherapy?

- Use a mild shampoo.
- Use a soft hair brush.
- Use low heat when drying your hair.
- Have your hair cut short. A shorter style will make your hair look thicker and fuller. It also will make hair loss easier to manage if it occurs.
- Use a sun screen, sun block, hat, or scarf to protect your scalp from the sun if you lose hair on your head.
- Avoid brush rollers to set your hair.
- Avoid dying, perming, or relaxing your hair.

Some people who lose all or most of their hair choose to wear turbans, scarves, caps, wigs, or hair pieces. Others leave their head uncovered. Still others switch back and forth, depending on whether they are in public or at home with friends and family members. There are no “right” or “wrong” choices; do whatever feels comfortable for you.

## If you choose to cover your head:

- Get your wig or hairpiece before you lose a lot of hair. That way, you can match your current hair style and color. You may be able to buy a wig or hairpiece at a specialty shop just for cancer patients. Someone may even come to your home to help you. You also can buy a wig or hair piece through a catalog or by phone.
- You may also consider borrowing a wig or hairpiece, rather than buying one. Check with the nurse or social work department at your hospital about resources for free wigs in your community.
- Take your wig to your hairdresser or the shop where it was purchased for styling and cutting to frame your face.
- Some health insurance policies cover the cost of a hairpiece needed because of cancer treatment. It is also a tax-deductible expense. Be sure to check your policy and ask your doctor for a “prescription.”

Losing hair from your head, face, or body can be hard to accept. Feeling angry or depressed is common and perfectly all right. At the same time, keep in mind that it is a temporary side effect. Talking about your feelings can help. If possible, share your thoughts with someone who has had a similar experience.

## *Anemia*

Chemotherapy can reduce the bone marrow’s ability to make red blood cells, which carry oxygen to all parts of your body. When there are too few red blood cells, body tissues do not get enough oxygen to do their work. This condition is called anemia. Anemia can make you feel short of breath, very weak, and tired. Call your doctor if you have any of these symptoms:

- Fatigue (feeling very weak and tired).
- Dizziness or feeling faint.

- Shortness of breath.
- Feeling as if your heart is “pounding” or beating very fast.

Your doctor will check your blood cell count often during your treatment. She or he may also prescribe a medicine that can boost the growth of your red blood cells. Discuss this with your doctor if you become anemic often. If your-red count falls too low, you may need a blood transfusion or a medicine called erythropoietin to raise the number of red blood cells in your body.

### **Things you can do if you are anemic** (See the section “Fatigue”)

- Get plenty of rest. Sleep more at night and take naps during the day if you can.
- Limit your activities. Do only the things that are essential or most important to you.
- Ask for help when you need it. Ask family and friends to pitch in with things like child care, shopping, housework, or driving.
- Eat a well-balanced diet. (See the section “Eating Well During Chemotherapy.”)
- When sitting, get up slowly. When lying down, sit first and then stand. This will help prevent dizziness.

### ***Central Nervous System Problems***

Chemotherapy can interfere with certain functions in your central nervous system (brain) causing tiredness, confusion, and depression. These feelings will go away once the chemotherapy dose is lowered or you finish chemotherapy. Call your doctor if these symptoms occur.

## *Infection*

Chemotherapy can make you more likely to get infections. This happens because most anticancer drugs affect the bone marrow, making it harder to make **white blood cells** (WBCs), the cells that fight many types of infections. Your doctor will check your blood cell count often while you are getting chemotherapy. There are medicines that help speed the recovery of white blood cells, shortening the time when the white blood count is very low. These medicines are called **colony stimulating factors** (CSF). Raising the white blood cell count greatly lowers the risk of serious infection.

Most infections come from bacteria normally found on your skin and in your mouth, intestines and genital tract. Sometimes, the cause of an infection may not be known. Even if you take extra care, you still may get an infection. But there are some things you can do.

### **How can I help prevent infections?**

- Wash your hands often during the day. Be sure to wash them before you eat, after you use the bathroom, and after touching animals.
- Clean your rectal area gently but thoroughly after each bowel movement. Ask your doctor or nurse for advice if the area becomes irritated or if you have hemorrhoids. Also, check with your doctor before using enemas or suppositories. (See the section “Constipation.”)
- Stay away from people who have illnesses you can catch, such as a cold, the flu, measles, or chicken pox.
- Try to avoid crowds. For example, go shopping or to the movies when the stores or theaters are least likely to be busy.
- Stay away from children who recently have received “live virus” vaccines such as chicken pox and oral polio, since they may be contagious to people with a low blood cell count. Call your doctor or local health department if you have any questions.

## Symptoms of Infection

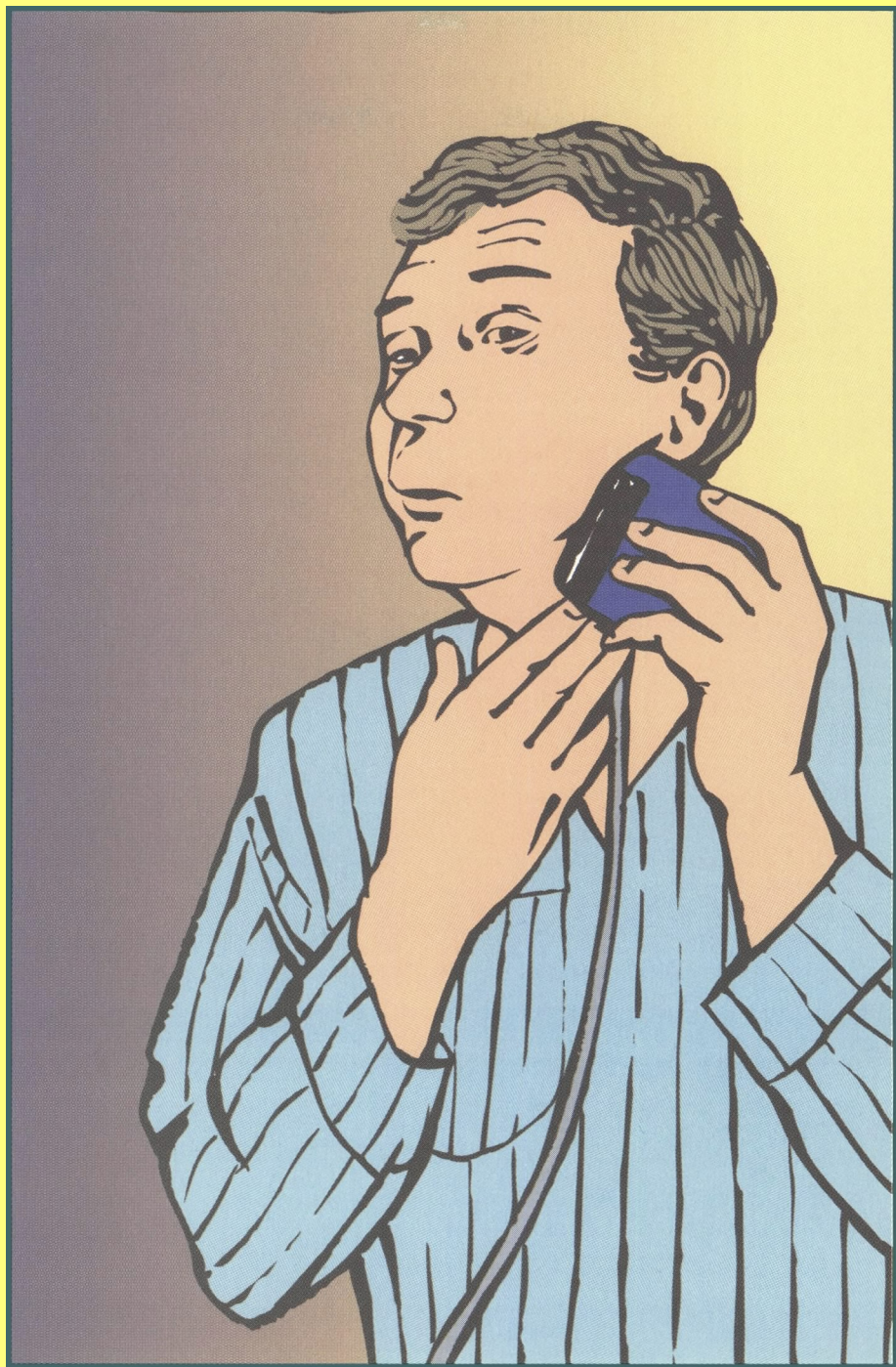
**Call your doctor right away if you have any of these symptoms:**

- Fever over 100° F or 38° C.
- Chills, especially shaking chills.
- Sweating.
- Loose bowel movements.
- Frequent urgency to urinate or a burning feeling when you urinate.
- A severe cough or sore throat.
- Unusual vaginal discharge or itching.
- Redness, swelling, or tenderness, especially around a wound, sore, ostomy, pimple, rectal area or catheter site.
- Sinus pain or pressure.
- Earaches, headaches, or stiff neck.
- Blisters on the lips or skin.
- Mouth sores.

- Do not cut or tear the cuticles of your nails.
- Be careful not to cut or nick yourself when using scissors, needles, or knives.
- Use an electric shaver instead of a razor to prevent breaks or cuts in your skin.

- Maintain good mouth care. (See the section “Mouth, Gum and Throat Problems.”)
- Do not squeeze or scratch pimples.
- Take a warm (not hot) bath, shower, or sponge bath every day. Pat your skin dry using a light touch. Do not rub too hard.
- Use lotion or oil to soften and heal your skin if it becomes dry and cracked.
- Clean cuts and scrapes right away and daily until healed with warm water, soap, and an antiseptic.
- Avoid contact with animal litter boxes and waste, bird cages, and fish tanks.
- Avoid standing water, for example, bird baths, flower vases, or humidifiers.
- Wear protective gloves when gardening or cleaning up after others, especially small children.
- Do not get any immunizations, such as flu or pneumonia shots, without checking with your doctor first.
- Do not eat raw fish, seafood, meat, or eggs.

Report any signs of infection to your doctor right away, even if it is in the middle of the night. This is especially important when your white blood cell count is low. If you have a fever, do not take aspirin, acetaminophen, or any other medicine to bring your temperature down without checking with your doctor first.



## ***Blood Clotting Problem***

Anticancer drugs can affect the bone marrow's ability to make platelets, the blood cells that help stop bleeding by making your blood clot. If your blood does not have enough platelets, you may bleed or bruise more easily than usual, even without an injury.

### **Call your doctor if you have any of these symptoms:**

- unexpected bruising.
- small, red spots under the skin.
- reddish or pinkish urine.
- black or bloody bowel movements.
- bleeding from your gums or nose.
- vaginal bleeding that is new or lasts longer than a regular period.
- headaches or changes in vision.
- warm to hot feeling of an arm or leg.

Your doctor will check your platelet count often while you are having chemotherapy. If your platelet count falls too low, the doctor may give you a platelet transfusion to build up the count. There are also medicines called colony stimulating factors that help increase your platelets.

## How to help prevent problems if your platelet count is low

- Check with your doctor or nurse before taking any vitamins, herbal remedies, including all over-the-counter medicines. Many of these products contain aspirin, which can affect platelets.
- Before drinking any alcoholic beverages, check with your doctor.
- Use a very soft toothbrush to clean your teeth.
- When cleaning your nose blow gently into a soft tissue.
- Take extra care not to cut or nick yourself when using scissors, needles, knives, or tools.
- Be careful not to burn yourself when ironing or cooking.
- Avoid contact sports and other activities that might result in injury.
- Ask your doctor if you should avoid sexual activity.
- Use an electric shaver instead of a razor.

### *Mouth, Gum, and Throat Problems*

Good oral care is important during cancer treatment. Some anticancer drugs can cause sores in the mouth and throat, a condition called **stomatitis** or **mucositis**. Anticancer drugs also can make these tissues dry and irritated or cause them to bleed. Patients who have not been eating well since beginning chemotherapy are more likely to get mouth sores.

In addition to being painful, mouth sores can become infected by the many germs that live in the mouth. Every step should be

taken to prevent infections, because they can be hard- to fight during chemotherapy and can lead to serious problems.

### **How can I keep my mouth, gums, and throat healthy?**

- Talk to your doctor about seeing your dentist at least several weeks before you start chemotherapy. You may need to have your teeth cleaned and to take care of any problems such as cavities, gum abscesses, gum disease, or poorly fitting dentures. Ask your dentist to show you the best ways to brush and floss your teeth during chemotherapy. Chemotherapy can make you more likely to get cavities, so your dentist may suggest using a fluoride rinse or gel each day to help prevent decay.
- Brush your teeth and gums after every meal. Use a soft toothbrush and a gentle touch. Brushing too hard can damage soft mouth tissues. Ask your doctor, nurse, or dentist to suggest a special toothbrush and/or toothpaste if your gums are very sensitive. Rinse with warm salt water after meals and before bedtime.
- Rinse your toothbrush well after each use and store it in a dry place.
- Avoid mouthwashes that contain any amount of alcohol. Ask your doctor or nurse to suggest a mild or medicated mouthwash that you might use. For example, mouthwash with sodium bicarbonate (baking soda) is non-irritating.

If you develop sores in your mouth, tell your doctor or nurse. You may need medicine to treat the sores. If the sores are painful or keep you from eating, you can try these ideas:

### **How can I cope with mouth sores?**

- Ask your doctor if there is anything you can apply directly to the sores or to prescribe a medicine you can use to ease the pain.

- Eat foods cold or at room temperature. Hot and warm foods can irritate a tender mouth and throat.
- Eat soft, soothing foods, such as ice cream, milkshakes, baby food, soft fruits (bananas and applesauce), mashed potatoes, cooked cereals, soft-boiled or scrambled eggs, yogurt, cottage cheese, macaroni and cheese, custards, puddings, and gelatin. You also can puree cooked foods in the blender to make them smoother and easier to eat.
- Avoid irritating, acidic foods and juices, such as tomato and citrus (orange, grapefruit, and lemon); spicy or salty foods; and rough or coarse foods such as raw vegetables, granola, popcorn, and toast.

### How can I cope with mouth dryness?

- Ask your doctor if you should use an artificial saliva product to moisten your mouth.
- Drink plenty of liquids.
- Ask your doctor if you can suck on ice chips, popsicles, or sugarless hard candy. You can also chew sugarless gum. (Sorbitol, a sugar substitute that is in many sugar-free foods, can cause diarrhea in many people. If diarrhea is a problem for you, check the labels of sugar-free foods before you buy them and limit your use of them.)
- Moisten dry foods with butter, margarine, gravy, sauces, or broth.
- Dunk crisp, dry foods in mild liquids.
- Eat soft and pureed foods.
- Use lip balm or petroleum jelly if your lips become dry.
- Carry a water bottle with you to sip from often.

## *Diarrhea*

When chemotherapy affects the cells lining the intestine, it can cause diarrhea (watery or loose stools). If you have diarrhea that continues for more than 24 hours, or if you have pain and cramping along with the diarrhea, call your doctor. In severe cases, the doctor may prescribe a medicine to control the diarrhea. If diarrhea persists, you may need intravenous (IV) fluids to replace the water and nutrients you have lost. Often these fluids are given as an outpatient and do not require hospitalization. Do not take any over-the-counter medicines for diarrhea without asking your doctor.

### **How can I help control diarrhea?**

- Drink plenty of fluids. This will help replace those you have lost through diarrhea. Mild, clear liquids, such as water, clear broth, sports drinks such as Gatorade, or ginger ale, are best. If these drinks make you more thirsty or nauseous, try diluting them with water. Drink slowly and make sure drinks are at room temperature. Let carbonated drinks lose their fizz before you drink them.
- Eat small amounts of food throughout the day instead of three large meals.
- Unless your doctor has told you otherwise, eat potassium-rich foods. Diarrhea can cause you to lose this important mineral. Bananas, oranges, potatoes, and peach and apricot nectars are good sources of potassium.
- Ask your doctor if you should try a clear liquid diet to give your bowels time to rest. A clear liquid diet does not provide all the nutrients you need, so do not follow one for more than 3 to 5 days.
- Eat low-fiber foods. Low-fiber foods include white bread, white rice or noodles, creamed cereals, ripe bananas, canned or cooked fruit without skins, cottage cheese, yogurt without seeds, eggs, mashed or baked potatoes without the skin, pureed vegetables, chicken, or turkey without the skin, and fish.

- Avoid high-fiber foods, which can lead to diarrhea and cramping. High-fiber foods include whole grain breads and cereals, raw vegetables, beans, nuts, seeds, popcorn, and fresh and dried fruit.
- Avoid hot or very cold liquids, which can make diarrhea worse.
- Avoid coffee, tea with caffeine, alcohol, and sweets. Stay away from fried, greasy, or highly spiced foods, too. They are irritating and can cause diarrhea and cramping.
- Avoid milk and milk products, including ice cream, if they make your diarrhea worse.

## *Constipation*

Some anticancer medicines, pain medicines, and other medicines can cause constipation. It can also occur if you are less active or if your diet lacks enough fluid or fiber. If you have not had a bowel movement for more than a day or two, call your doctor, who may suggest taking a laxative or stool softener. Do not take these measures without checking with your doctor, especially if your white blood cell count or platelets are low.

### **What can I do about constipation?**

- Drink plenty of fluids to help loosen the bowels. If you do not have mouth sores, try warm and hot fluids, including water, which work especially well.
- Check with your doctor to see if you can increase the fiber in your diet (there are certain kinds of cancer and certain side effects you may have for which a high-fiber diet is not recommended). High fiber foods include bran, whole-wheat breads and cereals, raw or cooked vegetables, fresh and dried fruit, nuts, and popcorn.
- Get some exercise every day. Go for a walk or you may want to try a more structured exercise program. Talk to your doctor about the amount and type of exercise that is right for you.

## *Nerve and Muscle Effects*

Sometimes anticancer drugs can cause problems with your body's nerves. One example of a condition affecting the nervous system is **peripheral neuropathy**, where you feel a tingling, burning, weakness, or numbness or pain in the hands and/or feet. Some drugs can also affect the muscles, making them weak, tired, or sore.

Sometimes, these nerve and muscle side effects, though annoying, may not be serious. In other cases, nerve and muscle symptoms may be serious and need medical attention. Be sure to report any nerve or muscle symptoms to your doctor. Most of the time, these symptoms will get better; however, it may take up to a year after your treatment ends.

### **Some nerve and muscle-related symptoms include:**

- tingling
- burning
- weakness or numbness in the hands and/or feet
- pain when walking
- weak, sore, tired or achy muscles
- loss of balance
- clumsiness
- difficulty picking up objects and buttoning clothing
- shaking or trembling
- walking problems
- jaw pain
- hearing loss
- stomach pain
- constipation

## How can I cope with nerve and muscle problems?

- If your fingers are numb, be very careful when grasping objects that are sharp, hot, or otherwise dangerous.
- If your sense of balance or muscle strength is affected, avoid falls by moving carefully, using handrails when going up or down stairs, and using bath mats in the bathtub or shower.
- Always wear shoes with rubber soles (if possible).
- Ask your doctor for pain medicine.

## *Effects on Skin and Nails*

You may have minor skin problems while you are having chemotherapy, such as redness, rashes, itching, peeling, dryness, acne, and increased sensitivity to the sun. Certain anticancer drugs, when given intravenously, may cause the skin all along the vein to darken, especially in people who have very dark skin. Some people use makeup to cover the area, but this can take a lot of time if several veins are affected. The darkened areas will fade a few months after treatment ends.

Your nails may also become darkened, yellow, brittle, or cracked. They also may develop vertical lines or bands.

While most of these problems are not serious and you can take care of them yourself, a few need immediate attention. Certain drugs given intravenously (IV) can cause serious and permanent tissue damage if they leak out of the vein. Tell your doctor or nurse right away if you feel any burning or pain when you are getting IV drugs. These symptoms do not always mean there is a problem, but they must always be checked at once. Don't hesitate to call your doctor about even the less serious symptoms.

Some symptoms may mean you are having an allergic reaction that may need to be treated at once. Call your doctor or nurse right away if:

- you develop sudden or severe itching.
- your skin breaks out in a rash or hives.
- you have wheezing or any other trouble breathing.

## **How can I cope with skin and nail problems?**

### **Acne**

- Try to keep your face clean and dry.
- Ask your doctor or nurse if you can use over-the-counter medicated creams or soaps.

### **Itching and dryness**

- Apply corn starch as you would a dusting powder.
- To help avoid dryness, take quick showers or sponge baths. Do not take long, hot baths. Use a moisturizing soap.
- Apply cream and lotion while your skin is still moist.
- Avoid perfume, cologne, or aftershave lotion that contains alcohol.
- Use a colloid oatmeal bath or diphenhydramine for generalized pruritis.

### **Nail problems**

- You can buy nail-strengthening products in a drug store. Be aware that these products may bother your skin and nails.
- Protect your nails by wearing gloves when washing dishes, gardening, or doing other work around the house.

- Be sure to let your doctor know if you have redness, pain, or changes around the cuticles.

## Sunlight sensitivity

- Avoid direct sunlight as much as possible, especially between 10 a.m. and 4 p.m. when the sun's rays are the strongest.
- Use a sun screen lotion with a skin protection factor (SPF) of 15 or higher to protect against sun damage. A product such as zinc oxide, sold over the counter, can block the sun's rays completely.
- Use a lip balm with a sun protection factor.
- Wear long-sleeve cotton shirts, pants and hats with a wide brim (particularly if you are having hair loss), to block the sun.
- Even people with dark skin need to protect themselves from the sun during chemotherapy.

## Radiation Recall

Some people who have had radiation therapy develop “radiation recall” during their chemotherapy. During or shortly after certain anticancer drugs are given, the skin over an area that had received radiation turns red — a shade anywhere from light to very bright. The skin may blister and peel. This reaction may last hours or even days. Report radiation recall reactions to your doctor or nurse. You can soothe the itching and burning by:

- Placing a cool, wet compress over the affected area.
- Wearing soft, non-irritating fabrics. Women who have radiation for breast cancer following lumpectomy often find cotton bras the most comfortable.

## ***Kidney and Bladder Effects***

Some anticancer drugs can irritate the bladder or cause temporary or permanent damage to the bladder or kidneys. If you are taking one or more of these drugs, your doctor may ask you to collect a 24-hour urine sample. A blood sample may also be obtained before you begin chemotherapy to check your kidney function. Some anticancer drugs cause the urine to change color (orange, red, green, or yellow) or take on a strong or medicine-like odor for 24-72 hours. Check with your doctor to see if the drugs you are taking may have any of these effects.

Always drink plenty of fluids to ensure good urine flow and help prevent problems. This is very important if you are taking drugs that affect the kidney and bladder. Water, juice, soft drinks, broth, ice cream, soup, popsicles, and gelatin are all considered fluids.

### **Tell your doctor if you have any of these symptoms:**

- Pain or burning when you urinate (pass your water).
- Frequent urination.
- Not being able to urinate.
- A feeling that you must urinate right away (“urgency”).
- Reddish or bloody urine.
- Fever.
- Chills, especially shaking chills.

## *Flu-Like Symptoms*

Some people feel as though they have the flu for a few hours to a few days after chemotherapy. This may be especially true if you are receiving chemotherapy in combination with biological therapy. Flu-like symptoms--muscle and joint aches, headache, tiredness, nausea, slight fever (usually <100°F), chills, and poor appetite--may last from 1 to 3 days. An infection or the cancer itself can also cause these symptoms. Check with your doctor if you have flu-like symptoms.

## *Fluid Retention*

Your body may retain fluid when you are having chemotherapy. This may be due to hormonal changes from your therapy, to the drugs themselves, or to your cancer. Check with your doctor or nurse if you notice swelling or puffiness in your face, hands, feet, or abdomen. You may need to avoid table salt and foods that have a lot of salt. If the problem is severe, your doctor may prescribe a diuretic, medicine to help your body get rid of excess fluids.

## *Effects on Sexual Organs*

Chemotherapy may--but does not always--affect sexual organs (testis in men, vagina and ovaries in women) and functioning in both men and women. The side effects that might occur depend on the drugs used and the person's age and general health.

### **Men**

Chemotherapy drugs may lower the number of sperm cells and reduce their ability to move. These changes can result in infertility, which may be temporary or permanent. Infertility affects a man's ability to father a child, but not a man's ability to have sexual intercourse. Other possible effects of these drugs are problems with getting or keeping an erection and damage to the **chromosomes**, which could lead to birth defects.

## What You Can Do:

- Before starting treatment, talk to your doctor about the possibility of sperm banking — a procedure that freezes sperm for future use — if infertility may be a problem. Ask about the cost of sperm banking.
- Use birth control with your partner during treatment. Ask your doctor how long you need to use birth control.
- Use a condom during sexual intercourse for the first 48 hours after the last dose of chemotherapy because some of the chemotherapy may end up in the sperm.
- Ask your doctor if the chemotherapy will likely affect your ability to father a child. If so, will the effects be temporary or permanent?

## Women

**Effects on the ovaries.** Anticancer drugs can affect the ovaries and reduce the amount of hormones they produce. Some women find that their menstrual periods become irregular or stop completely while having chemotherapy. Related side effects may be temporary or permanent.

- **Infertility.** Damage to the ovaries may result in infertility, the inability to become pregnant. The infertility can be either temporary or permanent. Whether infertility occurs, and how long it lasts, depends on many factors, including the type of drug, the dosage given, and the woman's age.
- **Menopause.** A woman's age and the drugs and dosages used will determine whether she experiences menopause while on chemotherapy. Chemotherapy may also cause menopause-like symptoms such as hot flashes and dry vaginal tissues. These tissue changes can make intercourse uncomfortable and can make a woman more prone to bladder and/or vaginal infections. Any infection should be treated right away. (See "Infection.") Menopause may be temporary or permanent.

## Help for hot flashes:

- Dress in layers.
- Avoid caffeine and alcohol.
- Exercise.
- Try meditation or other relaxation methods.

## Relieving vaginal symptoms and preventing infection:

- Use a water or mineral oil-based vaginal lubricant at the time of intercourse.
- There are products that can be used to stop vaginal dryness. Ask your pharmacist about vaginal gels that can be applied to the vagina.
- Avoid using petroleum jelly, which is difficult for the body to get rid of and increases the risk of infection.
- Wear cotton underwear and pantyhose with a ventilated cotton lining.
- Avoid wearing tight slacks or shorts.
- Ask your doctor about prescribing a vaginal cream or suppository to reduce the chances of infection.
- Ask your doctor about using a vaginal dilator if painful intercourse continues.

**Pregnancy.** Although pregnancy may be possible during chemotherapy, it still is not advisable because some anticancer drugs may cause birth defects. Doctors advise women of child-bearing age, from the teens through the end of menopause, to use some method of birth control throughout their treatment, such as condoms, spermicidal agents, diaphragms or birth control pills. Birth control pills may not be appropriate for some women, such as those with breast cancer. Ask your doctor about these contraceptive options.

If a woman is pregnant when her cancer is discovered, it may be possible to delay chemotherapy until after the baby is born. For a woman who needs treatment sooner, the possible effects of chemotherapy on the fetus need to be evaluated.

## *Feelings About Sexuality*

Sexual feelings and attitudes vary among people during chemotherapy. Some people find that they feel closer than ever to their partners and have an increased desire for sexual activity. Others experience little or no change in their sexual desire and energy level. Still others find that their sexual interest declines because of the physical and emotional stresses of having cancer and getting chemotherapy. These stresses may include:

- worries about changes in appearance.
- anxiety about health, family, or finances.
- side effects of treatment, including fatigue, and hormonal changes.

A partner's concerns or fears also can affect the sexual relationship. Some may worry that physical intimacy will harm the person who has cancer. Others may fear that they might "catch" the cancer or be affected by the drugs. Both you and your partner should feel free to discuss sexual concerns with your doctor, nurse, social worker, or other counselor who can give you the information and the reassurance you need.

You and your partner also should try to share your feelings with each other. If talking to each other about sex, cancer, or both, is hard, you may want to speak to a counselor who can help you talk more openly. People who can help include psychiatrists, psychologists, social workers, marriage counselors, sex therapists, and members of the clergy.

If you were comfortable with and enjoyed sexual relations before starting chemotherapy, chances are you will still find pleasure in physical intimacy during your treatment. You may discover, however, that intimacy changes during treatment. Hugging, touching, holding, and cuddling may become more important, while sexual intercourse may become less important. Remember that what was true before you started chemotherapy remains true now: There is no one “right” way to express your sexuality. You and your partner should decide together what gives both of you pleasure.



# *Eating Well During Chemotherapy*

It is very important to eat well while you are getting chemotherapy. Eating well during chemotherapy means choosing a balanced diet that contains all the nutrients the body needs. Eating well also means having a diet high enough in calories to keep your weight up and high enough in protein to rebuild tissues that cancer treatment may harm. People who eat well can cope with side effects and fight infection better. Also, their bodies can rebuild healthy tissues faster.

## *What If I Don't Feel Like Eating?*

On some days you may feel you just cannot eat. You can lose your appetite if you feel depressed or tired. (See “Getting the Support You Need” for advice). Or, side effects such as nausea or mouth and throat problems may make it difficult or painful to eat (see “Mouth, Gum, and Throat Problems” for helpful hints). In some cases, if you cannot eat for a long period of time, your doctor may recommend that you be given nutrition intravenously until you are able to eat again.

When a poor appetite is the problem, try these suggestions:

- Eat frequent, small meals or snacks whenever you want, perhaps four to six times a day. You do not have to eat three regular meals each day.
- Keep snacks within easy reach, so you can have something whenever you feel like it.
- Even if you do not want to eat solid foods, try to drink beverages during the day. Juice, soup, and other fluids like these can give you important calories and nutrients.
- Vary your diet by trying new foods and recipes.

- When possible, take a walk before meals; this may make you feel hungrier.
- Try changing your mealtime routine. For example, eat in a different location.
- Eat with friends or family members. When eating alone, listen to the radio or watch TV.
- Ask your doctor or nurse about nutrition supplements.
- Speak with your dietician about your specific nutrition needs.

The National Cancer Institute's booklet, *Eating Hints for Cancer Patients: Before, During & After Treatment* provides more tips about how to make eating easier and more enjoyable. It also gives many ideas about how to eat well and get extra protein and calories during cancer treatment. For a free copy of this booklet, ask your nurse or call the Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

### *Can I Drink Alcoholic Beverages?*

Small amounts of alcohol can help you relax and increase your appetite. On the other hand, alcohol may interfere with how some drugs work and/or worsen their side effects. For this reason, some people must drink less alcohol or avoid alcohol completely during chemotherapy. Ask your doctor if and how much beer, wine, or other alcoholic beverages you can drink during treatment.

### *Can I Take Extra Vitamins and Minerals?*

You can usually get all the vitamins and minerals you need by eating a healthy diet. Talk to your doctor, nurse, registered dietitian, or a pharmacist before taking any vitamin or mineral supplements. Too much of some vitamins and minerals can be just as dangerous as too little. Find out what is recommended for you.

# *Getting the Support You Need*

Chemotherapy, like cancer, can bring major changes to a person's life. While it can help cure your cancer, it can sometimes affect overall health, cause stress, disrupt day-to-day schedules, and strain personal relationships. It is no wonder, then, that some people feel tearful, anxious, angry, or depressed at some point during their chemotherapy.

These emotions can be perfectly normal, but they can also be disturbing. Fortunately, there are ways to deal with these emotional side effects, just as there are ways to cope with the physical side effects of chemotherapy.

## *How Can I Get Support?*

You can draw on many sources of support. Here are some of the most important:

**Doctors, nurses, and other health professionals.** If you have questions or worries about your cancer treatment, talk with members of your health care team. Tell them if you are feeling anxious or depressed, or if you are experiencing other emotional or physical changes.

**Counseling professionals.** There are many kinds of counselors who can help you express, understand, and cope with your feelings. If you are depressed, you should consider seeking professional help. Feeling hopeless, worthless, guilty, or that life is not worth living are signs of depression. Depending on your preferences and needs, you may want to talk with a psychiatrist, psychologist, social worker, sex therapist, or member of the clergy. There are also medicines that can be used to treat depression. Many cancer centers have “psycho-oncology” programs with psychiatrists, psychologists, and social workers trained to work with cancer patients. Your doctor, nurse, or social worker may be able to suggest who to contact.



**Friends and family members.** Talking with friends or family members can help you feel a lot better. Often, they can comfort and reassure you in ways that no one else can. However, you may need to help them help you. At a time when you might expect that others will rush to your aid, you may have to make the first move.

**Asking friends and family for help.** Many people do not understand cancer, and may withdraw from you because they are afraid of your illness and not know what to do to help you. Others may worry that, they will upset you by saying “the wrong thing.” You can help by being open in talking with others about your illness, your treatment, your needs, and your feelings. By talking openly, you can correct mistaken ideas about cancer. You can also let people know that there is no single “right” thing to

say, as long as their caring comes through loud and clear. Once people know they can talk with you honestly, they may be more willing and able to open up. and lend their support. Accepting help may be hard. When you allow others to help, you make them feel less helpless. In a sense, you are helping others deal with your illness.

The National Cancer Institute's booklet, *Taking Time*, offers useful advice to help cancer patients, their families and friends communicate with one another. For a free copy of this booklet, ask your nurse or call the Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

**Support groups.** Support groups are made up of people who are going or have gone through the same kinds of experiences as you. Many people with cancer find they can share thoughts and feelings with group members that they do not feel comfortable sharing with anyone else. Support groups also can serve as an important source of practical information about living with cancer. Some studies suggest that not only can support groups help with how you are feeling emotionally, but may also help you recover physically from your cancer.

Support can also be found in one-to-one programs that put you in touch with another person very similar to you in age, sex, type of cancer, and so forth. In some programs, this person comes to visit you. In others, a "hotline" puts you in touch with someone you can talk with on the telephone. Later, you may want to help others who are going through the same experience you did.

Sources for information about support programs, counseling advice, financial assistance, transportation to and from treatment, and information about cancer include neighborhood organizations, local health care providers, and your hospital, clinic, or medical center where you are being treated. At public libraries and patient libraries at hospitals, a librarian can help you find books and articles through a literature search. The National Cancer Institute's Cancer Information Service (1-800-4-CANCER) is also an excellent source of information and publications.

## *How Can I Make My Daily Life More Enjoyable?*

- Share your feelings with friends and family.
- Watch funny movies.
- Help someone else.
- Listen to music.
- Try new hobbies and learn new skills.
- Exercise, if you can.
- Do things that interest you.

# *Complementary Therapies*

Many people with cancer are exploring complementary therapies. These methods focus on the mind, body, and spirit. They do not take the place of medical therapies, but add to them. They can reduce stress, lessen side effects from cancer and cancer treatments, and enhance well-being. And they can help you feel more in control; it is something you can do for yourself.

A few of the therapies available are described here. Many more therapies exist such as art therapy, humor, journaling, reiki, music therapy, pet therapy and others. You may want to check with your doctor before using these techniques, especially if you have lung problems. A social worker, psychologist, or nurse may be able to help you with these therapies. You may also want to read books, listen to audiotapes, and watch videotapes about these techniques.

## *Biofeedback*

With training in biofeedback, you can control body functions such as heart rate, blood pressure, and muscle tension. A machine will sense when your body shows signs of tension and lets you know in some way such as making a sound or flashing a light. The machine also gives you feedback when you relax your body. Eventually, you can control your relaxation responses without having to depend on feedback from the machine. Your doctor, nurse, or social worker can refer you to someone trained in teaching biofeedback.

## *Distraction*

Distraction is the use of an activity to take your mind off your worries or discomforts. Talking with friends or relatives, watching TV, listening to the radio, reading, going to the movies, or working with your hands by doing needlework or puzzles, building models, or painting are all ways to distract yourself. Many cancer centers

now have music or creative art therapists who can be very helpful to you while you are getting treatment for your cancer. Ask your nurse or social work department about possible resources in your area.

## *Hypnosis*

Hypnosis puts you in a deeply-relaxed state that can help reduce discomfort and anxiety. You can be hypnotized by a qualified person, or you can learn how to hypnotize yourself. If you are interested in learning more, ask your doctor, nurse, or social worker to refer you to someone trained in the technique.

## *Imagery*

Imagery is a way of daydreaming that uses all your senses. It is usually done with your eyes closed. To begin, breathe slowly and feel yourself relax. Imagine a ball of healing energy-- perhaps a white light--forming somewhere in your body. When you can “see” the ball of energy, imagine that as you breathe in you can blow the ball to any part of the body where you feel pain, tension, or discomfort such as nausea. When you breathe out, picture the air moving the ball away from your body, taking with it any painful or uncomfortable feelings. (Be sure to breathe naturally; do not blow.) Continue to picture the ball moving toward you and away from you each time you breathe in and out. You may see the ball getting bigger and bigger as it takes away more and more tension and discomfort. To end the imagery, count slowly to three, breathe in deeply, open your eyes, and say to yourself, “I feel alert and relaxed.”

## *Massage Therapy*

The idea that touch can heal is an old one. The first written records of massage date back 3,000 years ago to China. Massage therapy involves touch and different methods of stroking and kneading the muscles of the body. A licensed massage therapist should do the therapy. Talk to your doctor before beginning this therapy.

## *Meditation and Prayer*

Meditation is a relaxation technique that allows you to focus your energy and your thoughts on something very specific. This is especially helpful when your mind and body are stressed from cancer treatment. For example, you may want to repeat a word (over and over), or look at an object, such as a picture. Another form of meditation is allowing your thoughts, feelings, and images to flow through your mind. For patients who believe in a higher spiritual power, prayer can provide strength, comfort and inspiration throughout the cancer experience. Whether you pray alone, with family and friends, or as a member of a religious community, prayer may help. A member of the clergy or your spiritual advisor can help you incorporate prayer into your daily life.

## *Muscle Tension and Release*

Lie down in a quiet room. Take a slow, deep breath. As you breathe in, tense a particular muscle or group of muscles. For example, you can squeeze your eyes shut, frown, clench your teeth, make a fist, or stiffen your arms or legs. Hold your breath and keep your muscles tense for a second or two. Then breathe out, release the tension, and let your body relax completely. Repeat the process with another muscle or muscle group.

You also can try a variation of this method, called “progressive relaxation.” Start with the toes of one foot and, working upward, progressively tense and relax all the muscles of one leg. Next, do the same with the other leg. Then tense and relax the rest of the muscle groups in your body, including those in your scalp. Remember to hold your breath while tensing your muscles and to breathe out when releasing the tension.

## *Physical Exercise*

Exercise can help lessen pain, strengthen weak muscles, restore balance, and decrease depression and fatigue. After getting approval from your doctor, you may want to begin by walking 5-10 minutes twice a day and later increasing your activity.

## *Rhythmic Breathing*

Get in a comfortable position and relax all your muscles. If you keep your eyes open, focus on a distant object. If you close your eyes, imagine a peaceful scene or simply clear your mind and focus on your breathing.

Breathe in and out slowly and comfortably through your nose. If you like, you can keep the rhythm steady by saying to yourself, “In, one two; out, one two.” Feel yourself relax and go limp each time you breathe out.

You can do this technique for just a few seconds or for up to 10 minutes. End your rhythmic breathing by counting slowly and silently to three.

## *Visualization*

Visualization is similar to imagery. With visualization, you create an inner picture that represents your fight against cancer. Some people getting chemotherapy use images of rockets blasting away their cancer cells or of knights in armor battling their cancer cells. Others create an image of their white blood cells or their drugs attacking the cancer cells.

## *Yoga*

All you need is a quiet, comfortable place and some time each day to practice breathing, stretching, and meditation. To learn about yoga you may want to take a class and review books, audio-tapes, or videotapes on yoga. Ask your social worker, psychologist, or psychiatrist about yoga classes in your area.

# *Paying for Chemotherapy*

The cost of chemotherapy varies with the kinds and doses of drugs used, how long and how often they are given, and whether you get them at home, in a clinic or office, or in the hospital. Most health insurance policies cover at least part of the cost of many kinds of chemotherapy. There are also organizations who will help with the cost of chemotherapy and with transportation costs. Ask your nurse or social worker about these organizations. Finding the answers to the questions below will help avoid problems in receiving payment later on.

## *What Questions Should I Be Able to Answer About My Insurance?*

- What are the benefits of my insurance plan?
  - What cancer treatments/care does it cover?
  - Do I have a primary care provider? Can I use only certain “preferred providers” under my plan?
  - Am I entitled to a yearly checkup or does my plan only cover office visits when I am sick?
  - What are the benefits if I go outside of my health plan to obtain care?
- What are the rules of my insurance plan?
  - Do I need a referral from a primary care provider?
  - Do I need a written referral form?
  - Do I need to get approval from my health plan (pre-certification) before seeing a specialist, obtaining treatment, tests, and medical equipment or physical therapy services or going to the emergency room or a hospital?

- Does my lab work, including blood work, or pap smear need to go to a special lab?
- Do I have to pay a certain amount (co-pay) at the time of my visit?
- Do I have an amount that I must pay for medical expenses (annual deductible) before the insurance pays for services?
- Do I have a lifetime or annual limit on how much is covered for medical expenses?
- Is there a special pharmacy where I need to get my medications?
- Are all tests and procedures covered both as an in-patient and out-patient?

### *Getting Maximum Coverage of Clinical Trials Costs*

Many clinical trials (treatment studies) offer some part of care free of charge. But some insurers will not cover certain costs when a new treatment is under study. Your doctor can work with you to try to help you. If you are taking part in or considering a clinical trial:

- Ask your doctor about other patients in the trial. Have their insurers paid for their care? Have there been any consistent problems?
- Talk to your doctor about the paperwork he or she submits to your insurer. Often the way the doctor describes a treatment can help or hurt your chances of insurance coverage.
- Find out what is in your policy. Check to see if there is a specific exclusion for “experimental treatment.”

## Getting the Most From Your Insurance

- Get a copy of your insurance policies before treatment and find out exactly what your coverage includes.
- Keep careful records of all your covered expenses and claims.
- File claims for all covered costs.
- Get help in filing a claim if you need it. If friends or family cannot help you, ask a social worker for help. Private companies and some community organizations offer insurance-filing aid.
- If your claim is turned down, file again and inquire about the reasons. Ask your doctor to explain to the company why the services meet the requirements for coverage under your policy. If you are turned down again, find out if the company has an appeals process.

Many insurance companies handle new treatments on a case-by-case basis, rather than having a blanket policy. You can always ask about their coverage of specific therapies. However, some patients say that their questions may have hurt their chances for coverage by raising a red flag. A call from your nurse or social worker to your insurance company about specific coverage may be helpful.

In some states, Medicaid (which makes health care services available for people with financial need) may help pay for certain treatments. Contact the office that handles social services in your city or county to find out whether you are eligible for Medicaid and whether your chemotherapy is a covered expense.

For more information on paying for chemotherapy, call the Cancer Information Service at 1-800-4-CANCER (1-800-422-6237) for the booklet *Facing Forward: A Guide for Cancer Survivors*.

# *National Cancer Institute Information Resources*

You may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

## *Telephone...*

### *CANCER INFORMATION SERVICE (CIS)*

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

**Toll-free:** 1-800-4-CANCER (1-800-422-6237)

**TTY:** 1-800-332-8615

## *Internet...*

These web sites may be useful:

**<http://www.nci.nih.gov>**

NCI's primary web site; contains information about the Institute and its programs.

**<http://cancertrials.nci.nih.gov>**

cancerTrials™; NCI's comprehensive clinical trials information center for patients, health professionals, and the public. Includes information on understanding trials, deciding whether to participate in trials, finding specific trials, plus research news and other resources.

**<http://cancernet.nci.nih.gov>**

CancerNet™; contains material for health professionals, patients, and the public, including information from PDQ® about cancer treatment, screening, prevention, supportive care, and clinical trials, and CANCERLIT®, a bibliographic database.

**<http://chid.nih.gov/ncichid>**

Cancer Patient Education Database; provides information on cancer patient education resources for cancer patients, their family members, and health professionals.

### *E-mail...*

#### *CANCERMAIL*

Includes NCI information about cancer treatment, screening, prevention, and supportive care. To obtain a list of contents, send e-mail to [cancermail@icicc.nci.nih.gov](mailto:cancermail@icicc.nci.nih.gov) with the word “help” in the body of the message.

### *Fax...*

#### *CANCERFAX®*

Includes NCI information about cancer treatment, screening, prevention, and supportive care. To obtain a list of contents, dial 301-402-5874 from a fax machine hand set and follow the recorded instructions.

## *Other Booklets*

Single copies of National Cancer Institute printed materials, including the booklets listed below, are available from the Cancer Information Service free of charge by calling 1-800-4-CANCER.

- *Advanced Cancer: Living Each Day*
- *Eating Hints For Cancer Patients: Before, During & After Cancer Treatment*
- *Facing Forward: A Guide for Cancer Survivors*
- *Questions and Answers About Pain Control* (also available from the American Cancer Society)
- *Radiation Therapy and You: A Guide to Self-Help During Treatment*
- *Taking Time: Support for People With Cancer and the People Who Care About Them*
- *Taking Part in Clinical Trials: What Cancer Patients Need to Know*
- *What You Need To Know About Cancer.* (A series of booklets about different types of cancer.)
- *When Cancer Recurs: Meeting the Challenge Again*
- *When Someone in Your Family Has Cancer*

# Glossary

This glossary reviews the meaning of some words used in *Chemotherapy and You*. It also explains some words related to chemotherapy that are not mentioned in this document but that you may hear from your doctor or nurse.

**Adjuvant chemotherapy:** Anticancer drugs or hormones given after surgery and/or radiation to help prevent the cancer from coming back.

**Alopecia:** Hair loss.

**Anemia:** Having too few red blood cells. Symptoms of anemia include feeling tired, weak, and short of breath.

**Antiemetic:** A medicine that prevents or controls nausea and vomiting.

**Biological therapy:** Treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also called immunotherapy.

**Blood cell count:** The number of red blood cells, white blood cells, and platelets in a sample of blood. This is also called complete blood count (CBC).

**Bone marrow:** The inner, spongy tissue of bones where blood cells are made.

**Cancer:** A general term for more than 100 diseases in which abnormal cells grow out of control; a malignant tumor.

**Catheter:** A thin, flexible tube through which fluids enter or leave the body.

**Central venous catheter:** A special thin, flexible tube placed in a large vein. It remains there for as long as it is needed to deliver and withdraw fluids.

**Chemotherapy:** The use of drugs to treat cancer.

**Chromosomes:** Threadlike bodies found in the nucleus, or center part, of a cell that carry DNA, the information of heredity.

**Clinical trials:** Studies that test new medical treatments. Clinical trials are conducted with volunteers and concentrate on one of the following aspects of cancer: preventing cancer, treating cancer, or improving the quality of life of patients with cancer.

**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 to treat cancer.

**Diuretics:** Drugs that help the body get rid of excess water and salt.

**Gastrointestinal:** The digestive tract, which includes the mouth, esophagus, stomach, and intestines.

**Hormones:** Substances produced by the endocrine glands of the body. Hormones are released directly into the bloodstream and have a specific effect on cells and organs in the body, stimulating or turning off their growth.

**Infusion:** Slow and/or prolonged intravenous delivery of a drug or fluids.

**Injection:** Using a syringe and needle to push fluids or drugs into the body; often called a “shot.”

**Intra-arterial (IA):** Into an artery.

**Intracavitary (IC):** Into a cavity or space, specifically the abdomen, pelvis, or the chest.

**Intralesional (IL):** Into the cancerous area in the skin.

**Intramuscular (IM):** Into a muscle.

**Intrathecal (IT):** Into the spinal fluid.

**Intravenous (IV):** Into a vein.

**Malignant:** Used to describe a cancerous tumor.

**Mucositis:** See stomatitis.

**Palliative care:** Treatment to relieve, rather than cure, symptoms caused by cancer. Palliative care can help people live more comfortably.

**Peripheral neuropathy:** A condition of the nervous system that usually begins in the hands and/or feet with symptoms of numbness, tingling, burning and/or weakness. Can be caused by certain anticancer drugs.

**Per os (PO):** By mouth; orally.

**Platelets:** Blood cells that help stop bleeding.

**Port:** A small plastic or metal container surgically placed under the skin and attached to a central venous catheter inside the body. Blood and fluids can enter or leave the body through the port using a special needle.

**Radiation therapy:** Cancer treatment with radiation (high-energy rays).

**Red blood cells:** Cells that supply oxygen to tissues throughout the body.

**Remission:** The partial or complete disappearance of signs and symptoms of cancer.

**Stomatitis:** Sores on the lining of the mouth.

**Subcutaneous (SQ or SC):** Under the skin.

**Tumor:** An abnormal growth of cells or tissues. Tumors may be benign (noncancerous) or malignant (cancerous).

**White blood cells (WBC's):** The blood cells that fight infection.

## Notes

## Notes

The National Cancer Institute (NCI) is the lead Federal agency for cancer research. Since Congress passed the National Cancer Act in 1971, NCI has continued to collaborate with top researchers and medical facilities across the country to conduct innovative research leading to progress in cancer prevention, detection, diagnosis and treatment. These efforts have resulted in a recent decrease in the overall cancer death rate, and have helped improve and extend the lives of millions of Americans.



NATIONAL<sup>®</sup>  
CANCER  
INSTITUTE

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Drug Information Sheets:

Bicalutamide/Casodex

Cyclophosphamide/Cytosan

Diethylstilbestrol/Stilphostrol

Docetaxel/Taxotere

Doxorubicin hydrochloride/chemotherapy drug

Estramustine/Estracyte

Etoposide/VePesid

Finasteride/Proscar

Flutamide/Eulexin

Goserelin acetate/Zoladex

Leuprolide acetate/Lupron

Mitoxantrone/Novantrone

Pacitaxel/Taxol

Prednisone/Apo-Prednisone

Thalidomide/Thalomid

Vinblastine/Velban



**Drug Name:**

bicalutamide

**Trade Names:**

Casodex

**Category:**

Hormone or Hormone Antagonist

**Classification:**

Bicalutamide belongs to the general group of drugs known as hormones. It is a nonsteroidal anti-androgen and is used to treat advanced prostate cancer.

**Action:**

Bicalutamide stops the growth of cancer cells that depend on male hormones. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Bicalutamide is given orally in a single dose, and should be taken at around the same time each day. Keep pills in a tightly closed container and out of the reach of children.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated. Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

***Precautions:***

Bicalutamide is usually given along with another medicine to block testosterone.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:******More Common Side Effects:***

Swelling of the breasts

Tenderness of the breasts

***Less Common Side Effects:***

Hot flashes

Constipation

***Rare Side Effects:***

Nausea

Diarrhea

Headache

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**

**Drug Name:**  
cyclophosphamide

**Trade Names:**  
Cytosan

**Category:**  
Chemotherapy Drug

**Classification:**  
Cyclophosphamide belongs to a general group of drugs known as alkylating agents. It is used to treat several types of cancer including breast cancer.

**Action:**  
Cyclophosphamide disrupts the growth of cancer cells, which are then destroyed. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**  
Tablets are taken by mouth in morning or early afternoon to allow adequate excretion. Keep pills in a tightly closed container, and out of reach of children. Cyclophosphamide may also be given intravenously, over 30-60 minutes.

**How Should I Take This Drug?**  
Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated. Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives (“the pill”) without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
    - Chickenpox or exposure to chickenpox
    - Gout
    - Heart disease
    - Congestive heart failure
    - Shingles
    - Kidney Stones
    - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

***Precautions:***

While you are being treated with cyclophosphamide, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

Cyclophosphamide can cause bleeding in your bladder. This is prevented by giving you extra fluid intravenously, and asking you to drink extra liquids. Your nurse or doctor will give you specific instructions.

Cyclophosphamide can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Cyclophosphamide can cause a decrease in your white blood cell count, especially 1-2 weeks after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Cyclophosphamide can cause a decrease in the platelet count. This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Getting a wig before starting treatment may make it easier to deal with hair loss. Talk to your nurse or doctor about this. If your insurance does not cover it, there may be other resources to help you. Hair loss is temporary, and your hair will grow back after treatment.

***Tell all the doctors, dentist, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:******More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Hair loss

Nausea

Vomiting

Loss of appetite

Sores in mouth or on lips

Diarrhea

Stopping of menstrual periods in women

Decreased sperm production in men

***Less Common Side Effects:***

Decreased platelet count (mild) with increased risk of bleeding

Blood in urine

Darkening of nail beds

Acne

Fatigue

Fetal changes if becoming pregnant when taking cyclophosphamide

***Rare Side Effects:***

Lung fibrosis with cough and shortness of breath

Heart changes with high doses

***Side Effects/Symptoms of This Drug:***

Because of the way this drug acts on the body, there is a chance that after receiving large total doses of the drug, it can cause other side effects that may not occur until months or years after the drug is used. These very rarely can induce certain types of cancer. Discuss this with your doctor.

***Other side effects not listed above may also occur in some patients.  
Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.  
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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**



**Drug Name:**

diethylstilbestrol

**Trade Names:**

Stilphostrol, Stilbestrol, DES

**Category:**

Hormone or Hormone Antagonist

**Classification:**

Diethylstilbestrol is an estrogen and belongs to the general group of drugs known as hormones. It is used to treat advanced breast cancer in women who are postmenopausal, and advanced prostate cancer.

**Action:**

Diethylstilbestrol stops the growth of cancer cells that depend on the male hormone (androgen) or the female hormone (estrogen) to grow and divide. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Diethylstilbestrol is given orally. Keep pills in a tightly closed container and out of the reach of children.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated.

Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
    - Chickenpox or exposure to chickenpox
    - Gout
    - Heart disease
    - Congestive heart failure
    - Shingles
    - Kidney Stones
    - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

***Precautions:***

Diethylstilbestrol should be used cautiously in patients with heart, kidney, or liver damage.

Diethylstilbestrol may rarely cause blood clots to form in the legs or in the lungs. Tell your doctor right away if you develop any of the following: pain, redness or swelling in the calf of your leg, shortness of breath, sudden severe headache, changes in vision, weakness or sensation of pins and needles in your arm or leg, chest pain, coughing up blood, or feeling faint.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:******More Common Side Effects:***

Increase in breast size  
Decreased sexual desire  
Change in voice  
Breast tenderness

***Less Common Side Effects:***

Nausea and vomiting, which go away after a few weeks of treatment  
Uterine bleeding  
Loss of bladder control

***Rare Side Effects:***

Blood clot in leg or lungs  
Increased calcium blood level for a short time after the drug is started

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**

**Drug Name:**

docetaxel

**Trade Names:**

Taxotere

**Category:**

Chemotherapy Drug

**Classification:**

Docetaxel belongs to the general group of drugs known as taxanes. It is also called a mitotic inhibitor because of its effect on the cell during mitosis. It is used to treat some types of cancer including breast cancer.

**Action:**

Docetaxel disrupts the growth of cancer cells, which are then destroyed. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Docetaxel is given by intravenous infusion over 1 hour.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives (“the pill”) without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

While you are being treated with docetaxel, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor’s okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

Docetaxel can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will

check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Doxetaxel can cause a decrease in your white blood cell count, especially 9 days after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Doxetaxel can cause a decrease in the platelet count. This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising, or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Getting a wig before starting treatment may make it easier to deal with hair loss. Talk to your nurse or doctor about this. If your insurance does not cover it, there may be other resources to help you. Hair loss is temporary, and your hair will grow back after treatment.

Rarely, it is possible to have an allergic reaction when docetaxel is given. You may receive medicines to prevent this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

### ***Side Effects:***

#### ***More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Decreased platelet count with increased risk of bleeding

Hair thinning or loss

Diarrhea

Loss of appetite

Nausea

Vomiting

Rash

Numbness and tingling in hands and/or feet related to peripheral nerve irritation or damage

#### ***Less Common Side Effects:***

Sores in mouth or on lips

Swelling of ankles or hands

Increased weight due to fluid retention

Fatigue

Muscle aches

#### ***Rare Side Effects:***

Severe allergic reaction

Redness, swelling and pain in hands and/or feet

### ***Side Effects/Symptoms of This Drug:***

Tell your doctor or nurse if you develop swelling of the ankles, shortness of breath, weight gain, or your clothes feel too tight at the waist.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

**Drug Name:**

doxorubicin hydrochloride

**Trade Names:**

Adriamycin

**Category:**

Chemotherapy Drug

**Classification:**

Doxorubicin belongs to the general group of drugs known as anthracycline antibiotics. It is used to treat several kinds of cancer including Non-Hodgkin's Lymphoma.

**Action:**

Doxorubicin disrupts the growth of cancer cells, which are then destroyed. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Doxorubicin hydrochloride is given by intravenous push method. Tell the nurse immediately if you feel stinging or burning in the vein during or after the drug is administered.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

While you are being treated with doxorubicin, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

Doxorubicin can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Doxorubicin can cause a decrease in your white blood cell count, especially 10-14 days after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Doxorubicin can cause a decrease in the platelet count. This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising, or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Getting a wig before starting treatment may make it easier to deal with hair loss. Talk to your nurse or doctor about this. If your insurance does not cover it, there may be other resources to help you. Hair loss is temporary, and your hair will grow back after treatment.

Doxorubicin is given intravenously. If the drug accidentally leaks out of the vein where it is given, it may damage the tissue and cause scarring. Tell the nurse right away if you notice redness, pain, or swelling at the place of injection.

Doxorubicin can cause injury to the heart muscle when large total doses are given. Your doctor will do a heart function test before you receive your first treatment, and then during the treatment. This way, any early damage can be found early. Talk to your doctor about this.

Doxorubicin can cause radiation recall which means it can recall skin damage from prior radiation therapy. Let your doctor or nurse know if your skin gets red in areas where radiation was given.

Doxorubicin can cause severe nausea and vomiting. Your doctor or nurse will give you medicines to prevent the nausea and vomiting. If you do get this side effect, talk to your doctor right away about ways to lessen this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

### ***Side Effects:***

#### ***More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Decreased platelet count with increased risk of bleeding

Loss of appetite

Darkening of nail beds and skin creases of hands

Hair loss

Nausea

Vomiting

#### ***Less Common Side Effects:***

Sores in mouth or on lips

Radiation recall skin changes

Fetal abnormalities if taken while pregnant or if becoming pregnant while on this drug

#### ***Rare Side Effects:***

Temporary changes in electrocardiogram (EKG)

Irregular heart beat

Heart damage with congestive heart failure

### ***Side Effects/Symptoms of This Drug:***

Doxorubicin causes the urine to turn reddish color, which may stain clothes. This is not blood. It is normal and lasts for 1 to 2 days after each dose is given.

After you stop receiving doxorubicin, the drug may still produce some side effects that need attention. Tell your doctor or nurse if you get any irregular heart beats, shortness of breath, or swelling of the ankles, feet or lower legs.

***Other side effects not listed above may also occur in some patients.  
Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**



**Drug Name:**

estramustine

**Trade Names:**

Estracyte, Emcyt

**Category:**

Chemotherapy Drug

**Classification:**

Estramustine is an alkylating agent. It is a combination of nitrogen mustard and estradiol phosphate. It is used to treat several types of cancer including prostate cancer.

**Action:**

Estramustine enters cells with estrogen receptors and causes the cell to die. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Total daily dose should be divided into 3 or 4 divided doses. Take each dose 1 hour before, or 2 hours after your meal. Do not take with milk, milk products, or foods high in calcium. The drug may also be given intravenously.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated.

Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

***Precautions:***

Tell your doctor if you have or have had blood clots in your legs or elsewhere in the body, peptic ulcers, liver problems, heart attack, hypertension, or diabetes.

Based on an investigational protocol, estramustine may be given intravenously. If the drug accidentally leaks out of the vein where it is given, it can damage the tissue and cause scarring. Tell the nurse right away if you notice redness, pain, or swelling at the place of injection.

While you are being treated with estramustine, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:******More Common Side Effects:***

Breast enlargement

Nipple tenderness

Itching

Dry skin

Night sweats

***Less Common Side Effects:***

Itching and pain in the perineal area

Numbness of mouth

Rash

Peeling skin of fingertips

Thinning hair

Fatigue

Pain in eyes

Nausea

Vomiting

***Rare Side Effects:***

Blood clots in legs, lungs, heart, or brain

***Side Effects/Symptom of This Drug:***

Stop the drug and tell your doctor or nurse right away if you have pain in your leg (calf) or chest, difficulty breathing, changes in your thinking or headache.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

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**Patient name:** \_\_\_\_\_

**Drug Name:**

Etoposide

**Trade Names:**

VePesid, Etophophos, VP-16

**Category:**

Chemotherapy Drug

**Classification:**

Etoposide belongs to the general class of drugs known as plant alkaloids. It is used to treat several types of cancer including lung and testicular cancers.

**Action:**

Etoposide disrupts cell division, resulting in cell death. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Etoposide can be given by capsules or by intravenous infusion over 30-60 minutes. Capsules should be taken in a single dose, or the dose may be divided. Store the capsules in the refrigerator in a tightly closed container and out of the reach of children.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated.

Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
    - Chickenpox or exposure to chickenpox
    - Gout
    - Heart disease
    - Congestive heart failure
    - Shingles
    - Kidney Stones
    - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some

drug products can cause drowsiness and may affect activities such as driving.

***Precautions:***

While you are being treated with etoposide, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

Etoposide can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Etoposide can cause a decrease in your white blood cell count, especially 10-14 days after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Etoposide can cause a decrease in the platelet count. This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising, or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Etoposide capsules can cause nausea and vomiting. Your doctor or nurse will give you medicines to prevent the nausea and vomiting. If you do get this side effect, talk to your doctor or nurse right away about ways to lessen this.

Getting a wig before starting treatment may make it easier to deal with hair loss. Talk to your nurse or doctor about this. If your insurance does not cover it, there may be other resources to help you. Hair loss is temporary, and your hair will grow back after treatment.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:***

***More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Decreased platelet count with increased risk of bleeding

Mild nausea

Mild vomiting

Loss of appetite

Changes in taste including metallic taste of foods

Hair loss

Fetal damage if pregnancy occurs while taking this drug

***Less Common Side Effects:***

Constipation

Diarrhea

Pain in stomach

Radiation recall skin changes

***Rare Side Effects:***

Decrease in blood pressure

Difficulty breathing during drug infusion

Rash

Itching

Heart changes

Numbness and tingling in hands and/or feet related to nerve irritation or damage

Fever

Chills

Allergic reactions

***Side Effects/Symptoms of This Drug:***

After you stop receiving etoposide, the drug may still produce some side effects that need attention. Tell your doctor or nurse if you get any irregular heart beats, shortness of breath, or swelling of the ankles, feet or lower legs.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**



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## **Proscar Tablets(Merck)**

### **Patient Information about**

**PROSCAR® (Prahs-car)**

**Generic name: finasteride**

**(fin-AS-tur-eyed)**

**PROSCAR\* is for use by men only.**

Please read this leaflet before you start taking PROSCAR. Also, read it each time you renew your prescription, just in case anything has changed. Remember, this leaflet does not take the place of careful discussions with your doctor. You and your doctor should discuss PROSCAR when you start taking your medication and at regular checkups.

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### **Why your doctor has prescribed PROSCAR**

Your doctor has prescribed PROSCAR because you have a medical condition called benign prostatic hyperplasia or BPH. This occurs only in men.

### **What is BPH?**

BPH is an enlargement of the prostate gland. After age 50, most men develop enlarged prostates. The prostate is located below the bladder. As the prostate enlarges, it may slowly restrict the flow of urine. This can lead to symptoms such as:

- a weak or interrupted urinary stream
- a feeling that you cannot empty your bladder completely
- a feeling of delay or hesitation when you start to urinate
- a need to urinate often, especially at night
- a feeling that you must urinate right away.

In some men, BPH can lead to serious problems, including urinary tract infections, a sudden inability to pass urine (acute urinary retention), as well as the need for surgery.

### **Treatment options for BPH**

There are three main treatment options for symptoms of BPH:

- **Program of monitoring or "Watchful Waiting".** If a man has an enlarged prostate gland and no symptoms or if his symptoms do not bother him, he and his doctor may decide on a program of monitoring which would include regular checkups, instead of medication or surgery.
- **Medication.** Your doctor may prescribe PROSCAR for BPH. See **"What PROSCAR does"** below.
- **Surgery** Some patients may need surgery. Your doctor can suggest several different surgical procedures for BPH. Which procedure is best depends on your symptoms and medical condition.

There are two main treatment options to reduce the risk of serious problems due to BPH:

- **Medication** Your doctor may prescribe PROSCAR for BPH. See “What PROSCAR does” below.
- **Surgery** Some patients may need surgery. Your doctor can suggest several different surgical procedures for BPH. Which procedure is best depends on your symptoms and medical condition.

## What PROSCAR does

PROSCAR lowers levels of a key hormone called DHT (dihydrotestosterone), which is a major cause of prostate growth. Lowering DHT leads to shrinkage of the enlarged prostate gland in most men. This can lead to gradual improvement in urine flow and symptoms over the next several months. PROSCAR will help reduce the risk of developing a sudden inability to pass urine and the need for surgery. However, since each case of BPH is different, you should know that:

- Even though the prostate shrinks, you may NOT notice an improvement in urine flow or symptoms.
- You may need to take PROSCAR for six (6) months or more to see whether it improves your symptoms.
- Therapy with PROSCAR may reduce your risk for a sudden inability to pass urine and the need for surgery.

## What you need to know while taking PROSCAR

- **You must see your doctor regularly.** While taking PROSCAR, you must have regular checkups. Follow your doctor's advice about when to have these checkups.
- **About side effects.** Like all prescription drugs, PROSCAR may cause side effects. Side effects due to PROSCAR may include impotence (an inability to have an erection) or less desire for sex. Some men taking PROSCAR may have changes or problems with ejaculation, such as a decrease in the amount of semen released during sex. This decrease in the amount of semen does not appear to interfere with normal sexual function. In some cases these side effects went away while the patient continued to take PROSCAR. In addition, some men may have breast swelling and/or tenderness. Some men have reported allergic reactions such as rash, itching, hives, and swelling of the lips and face. Rarely, testicular pain has been reported.

You should discuss side effects with your doctor before taking PROSCAR and anytime you think you are having a side effect.

- **Checking for prostate cancer.** Your doctor has prescribed PROSCAR for symptomatic BPH and not for cancer--but a man can have BPH and prostate cancer at the same time. Doctors usually recommend that men be checked for prostate cancer once a year when they turn 50 (or 40 if a family member has had prostate cancer). These checks should continue while you take PROSCAR. PROSCAR is not a treatment for prostate cancer.
- **About Prostate-Specific Antigen (PSA).** Your doctor may have done a blood test called PSA. PROSCAR can alter PSA values. For more information, talk to your doctor.
- **A warning about PROSCAR and pregnancy.** PROSCAR is for use by MEN only. Women who are or may potentially be pregnant must not use PROSCAR. They should also not handle crushed or broken tablets of PROSCAR. If a woman who is pregnant with a male baby absorbs the active ingredient in PROSCAR after oral use or through the skin, it may cause the male baby to be born with abnormalities of the sex organs. PROSCAR tablets are coated and will prevent contact with the active ingredient during normal handling, provided that the tablets are not broken or crushed.

If a woman who is pregnant comes into contact with the active ingredient in PROSCAR a doctor should be consulted.

Remember, these warnings apply only when the woman is pregnant or could potentially be pregnant.

## How to take PROSCAR

Follow your doctor's advice about how to take PROSCAR. You must take it every day. You may take it with or between meals. To avoid forgetting to take PROSCAR, it may be helpful to take it at the same time every day.

Do not share PROSCAR with anyone else; it was prescribed only for you.

Keep PROSCAR and all medicines out of the reach of children.

FOR MORE INFORMATION ABOUT 'PROSCAR' AND BPH, TALK WITH YOUR DOCTOR. IN ADDITION, TALK TO YOUR PHARMACIST OR OTHER HEALTH CARE PROVIDER.

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**Drug Name:**

flutamide

**Trade Names:**

Eulexin

**Category:**

Hormone or Hormone Antagonist

**Classification:**

Flutamide belongs to the general group of drugs known as hormones. It is used to treat advanced prostate cancer.

**Action:**

Flutamide, an antiandrogen, stops the growth of cancer cells that depend on the male hormone (androgen) to grow and divide. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Flutamide is given orally in divided doses. Keep capsules in a tightly closed container and out of the reach of children.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated. Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

It is important to continue taking flutamide, even if you feel well, or if you have side effects. Talk to your doctor or nurse about ways to lessen the side effects.

*Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.*

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

**Side Effects:****More Common Side Effects:**

Hot flashes or sweating

**Less Common Side Effects:**

Decreased sexual interest

Decreased sexual ability

Swelling of breasts

Diarrhea

Nausea

*Other side effects not listed above may also occur in some patients.*

*Report any problems to your doctor.*

**FDA Approval:** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**

**Drug Name:**

goserelin acetate

**Trade Names:**

Zoladex

**Category:**

Hormone or Hormone Antagonist

**Classification:**

Goserelin acetate belongs to the general group of drugs known as hormones. It is used to treat advanced prostate and breast cancers.

**Action:**

Goserelin acetate is a synthetic version of the body's luteinizing hormone-releasing hormone (LHRH). It blocks the release of sex hormones, testosterone in men and estrogen in women. Cancers which are stimulated to grow by these hormones stop growing. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Goserelin acetate is given by injection under the skin. Goserelin acetate is given as a monthly injection, and slowly releases the drug over a period of a month.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

After the first injection, there may be a "flare" of symptoms, such as bone pain. This will go away in a few days.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:***

***More Common Side Effects:***

Hot flashes  
Decrease in sexual desire  
Menses will stop in women  
Vaginal dryness  
Swelling of breasts  
Decrease in ability to have erections

***Less Common Side Effects:***

Breast tenderness

***Rare Side Effects:***

Irregular heart beat  
Increased blood pressure  
Chest pain  
Depression  
Chills  
Fever  
Anxiety  
Vomiting  
Increased weight  
Constipation  
Diarrhea  
Stroke  
Heart attack  
Headache  
Increased blood sugar  
Urinary tract infection  
Kidney damage  
Decreased circulation in extremities

***Side Effects/Symptoms of This Drug:***

Tell your doctor or nurse right away if you get pain in your chest, shortness of breath, painful urination, or leg pain.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Drug Name:**  
leuprolide acetate

**Trade Names:**  
Lupron

**Category:**  
Hormone or Hormone Antagonist

**Classification:**  
Leuprolide acetate belongs to the general class of drugs known as hormones. It is used to treat advanced prostate cancer, and some other types of cancer.

**Action:**  
Leuprolide acetate is an anti-hormone, and reduces the production of FSH(follicle-stimulating hormone) and LH(luteinizing hormone) from the pituitary gland. The LH causes the reduction in testosterone. This prevents cancer cells that depend on testosterone from growing. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**  
Leuprolide acetate is given intramuscularly once a month or subcutaneously daily.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives (“the pill”) without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**  
Leuprolide acetate can cause a “flare” reaction after you start taking the drug. You will feel increased pain in bone and/or the tumor site, and men may have difficulty urinating. This will last about 2 weeks. Tell your doctor right away

if the flare reaction lasts longer than this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:***

***More Common Side Effects:***

Hot flashes

Headache

Dizziness

Menses will stop in females

“Flare” reaction with initial dose

***Less Common Side Effects:***

Breast tenderness

Decreased sexual desire

Decreased sexual ability

***Rare Side Effects:***

Swelling of the hands and feet

Increased breast size

Loss of appetite

Nausea

Vomiting

***Side Effects/Symptoms of This Drug:***

It is important to continue taking the medicine even if you feel well.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**

**Drug Name:**

mitoxantrone

**Trade Names:**

Novantrone

**Category:**

Chemotherapy Drug

**Classification:**

Mitoxantrone belongs to a general group of drugs known as antibiotics. It is used *to* treat **several types** of cancer including leukemia.

**Action:**

Mitoxantrone disrupts the growth of cancer cells, which are then destroyed. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Mitoxantrone is given by the intravenous push method.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives (“the pill”) without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
    - Chickenpox or exposure to chickenpox
    - Gout
    - Heart disease
    - Congestive heart failure
    - Shingles
    - Kidney Stones
    - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

While you are being treated with mitoxantrone, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor’s okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

Mitoxantrone can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will

check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Mitoxantrone can cause a decrease in your white blood cell count, especially 9-10 days after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Mitoxantrone can cause a decrease in the platelet count This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising, or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Mitoxantrone turns the urine blue/green for about 24-48 hours, and then the urine returns to a normal color. Rarely, the whites of the eyes may turn light blue temporarily.

Mitoxantrone can cause injury to the heart muscle when large total doses are given. Your doctor will do a heart function test before you receive your first treatment, and then during the treatment. This way, any damage can be found early.

*Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.*

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

### ***Side Effects:***

#### ***More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Mild nausea

Mild vomiting

#### ***Less Common Side Effects:***

Hair loss

Fetal damage if pregnancy occurs while receiving this drug

#### ***Rare Side Effects:***

Decreased platelet count with increased risk of bleeding

Allergic reaction: rash, difficulty breathing, itching

Heart damage with congestive heart failure

Sores in your mouth or on lips

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**

**Drug Name:**

paclitaxel

**Trade Names:**

Taxol

**Category:**

Chemotherapy Drug

**Classification:**

Paclitaxel belongs to the general group of drugs known as taxanes. It is also called a mitotic inhibitor because of its affect on the cell during mitosis (cell division). It is used to treat several types of cancer including breast and lung cancers.

**Action:**

Paclitaxel disrupts cell division, resulting in cell death. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Paclitaxel is given intravenously over one or more hours.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
    - Chickenpox or exposure to chickenpox
    - Gout
    - Heart disease
    - Congestive heart failure
    - Shingles
    - Kidney Stones
    - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

Paclitaxel can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Paclitaxel can cause a decrease in your white blood cell count, especially 7-10 days after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Paclitaxel can cause a decrease in the platelet count. This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising, or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Getting a wig before starting treatment may make it easier to deal with hair loss. Talk to your nurse or doctor about this. If your insurance does not cover it, there may be other resources to help you. Hair loss is temporary, and your hair will grow back after treatment.

Rarely, you may have an allergic reaction when paclitaxel is given to you. You may receive medicines to prevent this.

While you are being treated with paclitaxel, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

### ***Side Effects:***

#### ***More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Fatigue

Numbness and tingling in hands and/or feet related to peripheral nerve irritation or damage

Muscle and bone aches for 3 days

Hair loss

Nausea

Vomiting

Mild diarrhea

Mild stomatitis

#### ***Less Common Side Effects:***

Allergic reaction: increased heart rate, wheezing, swelling of face

#### ***Rare Side Effects:***

Severe allergic reaction(anaphylaxis)

Decreased platelet count with increased risk of bleeding

### ***Side Effects/Symptoms of This Drug:***

Tell your doctor or nurse right away if you develop burning or pain in your hands or feet.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Drug Name:**

prednisone

**Trade Names:**

Apo-Prednisone, Deltasone, Orasone, Prednisone

**Category:**

Hormone or Hormone Antagonist

**Classification:**

Prednisone is a glucocorticoid steroid. It is similar to a steroid hormone made by the adrenal glands in the body.

**Action:**

Prednisone decreases inflammation by preventing white blood cells from completing an inflammatory reaction. This drug can cause lymphocytes, a type of white blood cell, to break apart and die. Thus, it is an important drug used in combination with other chemotherapy agents to treat many different cancers. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Prednisone is given orally. Prednisone can cause irritation of the stomach so the pill must be taken with food or milk. Keep pills in a tightly closed container and out of the reach of children.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you. This drug can be given at different strengths depending on the type of cancer being treated.

Dosage will vary depending on your body weight and the type of cancer being treated.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some

drug products can cause drowsiness and may affect activities such as driving.

***Precautions:***

While you are being treated with prednisone, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

If you have a stomach ulcer, you may not be able to take this drug, or need extra medicines to protect your stomach. Check with your doctor about this. When you take this drug, if you develop stomach pain, or vomit any blood, tell your doctor immediately.

This drug may suppress the immune system, and increase your susceptibility to infections. In addition, the drug may mask the signs of infection, such as fever.

The dose and number of days you should take the medicine will be prescribed by your physician, and depends upon the type of cancer being treated.

If you take prednisone for a long period of time, do not stop the medicine abruptly, as this can cause a decrease in the adrenalin your body makes (adrenal insufficiency). Symptoms of this are nausea, loss of appetite, tiredness, dizziness, difficulty breathing, joint pain, depression, low blood sugar, low blood pressure.

If you are a diabetic, this medicine will increase your blood sugar levels, and you may need to take extra diabetes medicine. Talk to your doctor about this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:***

***More Common Side Effects:***

Delayed wound healing

Mood changes

Depression

Increased blood sugar

Increased appetite with weight gain

Bruising of the skin

Sleep disturbance

Increased risk of infection

Sodium and fluid retention with swelling in ankles, increased blood pressure, and congestive heart failure

***Less Common Side Effects:***

Decrease in potassium blood level (symptoms are loss of appetite, muscle twitching, increased thirst, increased urination)

Weakness

Fracture of weak bones

Fungal infections (white patches in the mouth, vagina)

Sweating

Diarrhea

Nausea

Headache

Increased heart rate

Loss of calcium from bones

***Rare Side Effects:***

Cataracts

Personality changes

Blurred vision

Stomach ulcer which may bleed (hemorrhage)

***Side Effects/Symptoms of This Drug:***

Tell your doctor or nurse right away if you develop any of the following: 1) stomach pain or vomiting of blood; 2) signs of infection such as fever, bad cough with sputum, burning when you pass your urine, sore throat.

With prolonged use, a Cushingoid state may occur. Changes include moonface, acne, abnormal hair growth on face, and purple spots on skin.

Report any changes or new problems to your doctor or nurse.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

This information was selectively taken from the *Oncology Nursing Handbook* and does not cover all possible uses, actions, precautions, side effects, or interactions of this drug.

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**



**Drug Name:**

thalidomide

**Trade Names:**

Thalomid

**Category:**

Anorexia / Cachexia

**Classification:**

Thalidomide belongs to a general class of drugs called alpha Tumor Necrosis Factor inhibitors. It also belongs to the group of non-barbiturate sedatives.

**Action:**

Thalidomide appears to increase appetite, weight, and lean body mass in patients with cancer or HIV-related cachexia (loss of appetite, weight, and muscle mass) by blocking the effect of Tumor Necrosis Factor. Tumor Necrosis Factor is a body protein that normally is protective, but in cancer or advanced HIV infection, appears to break down body protein (muscle). Thalidomide is also being studied in higher doses as an anti-cancer agent as it appears to stop cancer cells from building blood vessels, so they starve to death. Finally, thalidomide appears to cause sedation.

**How Drug Is Given:**

Thalidomide is given orally. Take the medication at bedtime. If you have to take doses during the day, you will get used to the drowsiness after a few days. DO NOT drink alcohol while taking this drug as it will make the drowsiness and dizziness worse.

**How Should I Take This Drug?**

Take this drug exactly as directed by your doctor. If you do not understand these instructions, ask your doctor or nurse to explain them to you.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

*Before taking this drug, notify your doctor if you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.*

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

Thalidomide causes damage to the unborn fetus. Thus, women of childbearing age must have a negative pregnancy test before starting the drug, and the test is repeated every 2 weeks for 2 months, then every month. Women must use both barrier and hormonal contraception, and men must use barrier contraception. You should continue using the contraception for 1 month after the drug is discontinued.

Patients must be enrolled in a clinical trial or in a government monitored registry. Prescriptions can be written by precertified doctors. Only a 28-day supply will be given.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.

- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

***Side Effects:***

***More Common Side Effects:***

Birth defects in unborn fetus

Numbness and tingling in hands and/or feet related to peripheral neuropathy

Drowsiness

Dizziness

Mild constipation

***Less Common Side Effects:***

Rash with itching

***Rare Side Effects:***

Decreased white blood cell count with increased risk of infection

***Side Effects/Symptoms of This Drug:***

If you are of childbearing age, it is very important to comply with contraception instructions. Talk to your doctor or nurse about this.

Stop the drug and call your doctor or nurse if you have numbness or tingling in your arms, hands, feet, or legs, or if you have trouble walking.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** Yes

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**Patient name:** \_\_\_\_\_

**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**

**Drug Name:**

vinblastine

**Trade Names:**

Velban

**Category:**

Chemotherapy Drug

**Classification:**

Vinblastine belongs to the general group of drugs known as plant (vinca) alkaloids. It is used to treat several types of cancer including some lymphomas, testicular cancer, and kaposi's sarcoma.

**Action:**

Vinblastine disrupts cell division, resulting in cell death. *The drug cannot distinguish between cancer and normal cells, so some normal cells are affected, causing side effects (see Side Effects).*

**How Drug Is Given:**

Vinblastine is given intravenously through a running intravenous line. Tell your nurse immediately if you feel burning or stinging in the vein during or after the drug is given.

**Remember:** *You should read and understand the following information. If any of it causes you special concern, check with your doctor.*

**Before taking this drug, notify your doctor of any of the following:**

- If you are pregnant, breast feeding or planning children in the future, inform your doctor of this before treatment. This drug may cause birth defects if either the male or female is taking it at the time of conception or during pregnancy. Men and women who are taking this drug need to use some kind of birth control. However, do not use oral contraceptives ("the pill") without checking with your doctor.
- If you are thinking about wanting to have children in the future, be sure to discuss this with your doctor. Many chemotherapy drugs can cause sterility.
  - If you have any of the following medical problems:
  - Chickenpox or exposure to chickenpox
  - Gout
  - Heart disease
  - Congestive heart failure
  - Shingles
  - Kidney Stones
  - Liver disease
- If you are taking any other prescription or over-the-counter drugs, including vitamins and herbals.

**Should I avoid any other medications, foods, alcohol, and/or activities?**

Your prescription and nonprescription medications may interact with other drugs, causing a harmful effect. Certain foods or alcohol can also interact with drug products. Never begin taking a new medication, prescription or nonprescription, without asking your doctor or nurse if it will interact with alcohol, foods or other medications. Some drug products can cause drowsiness and may affect activities such as driving.

**Precautions:**

Vinblastine can cause lowering of your blood counts (white blood cells, red blood cells, platelets). Your doctor will check your blood counts before each treatment, and after to see its effect on your blood counts. Your doctor or nurse will give you specific instructions for lowered blood counts.

Vinblastine can cause a decrease in your white blood cell count 4-10 days after the drug is given. This can increase your risk of getting an infection. Report fever of 100.5 F or higher, or signs of infection such as pain on passing your urine, cough, and bringing up sputum.

Vinblastine can cause a decrease in the platelet count. This can increase your risk of bleeding. DO NOT take any aspirin or aspirin-containing medicines. Report unusual bruising, or bleeding such as nose bleeds, bleeding of gums when you brush your teeth, or black, tarry stools.

Vinblastine can cause constipation that may lead to a serious problem (paralytic ileus). Tell your doctor right away if you get constipation with severe abdominal pain or muscle cramping.

Getting a wig before starting treatment may make it easier to deal with hair loss. Talk to your nurse or doctor about this. If your insurance does not cover it, there may be other resources to help you. Hair loss is temporary, and your hair will grow back after treatment.

Vinblastine is given intravenously. If the drug accidentally leaks out of the vein where it is given, it may damage the tissue and cause scarring. Tell the nurse right away if you notice redness, pain, or swelling at the place of injection.

While you are being treated with vinblastine, and after you stop treatment, do not have any immunizations (vaccinations) without your doctor's okay. Try to avoid contact with people who have recently taken the oral polio vaccine. Check with your doctor about this.

***Tell all the doctors, dentists, and pharmacists you visit that you are taking this drug.***

- Most of the following side effects probably do not occur.
- Your doctor or nurse will want to discuss specific care instructions with you.
- Your doctor or nurse can help you anticipate and understand these side effects and help you deal with them.

### ***Side Effects:***

#### ***More Common Side Effects:***

Decreased white blood cell count with increased risk of infection

Decreased platelet count with increased risk of bleeding

Hair loss

#### ***Less Common Side Effects:***

Constipation

Numbness and tingling in the hands and/or feet related to peripheral nerve irritation and possibly damaged nerves

#### ***Rare Side Effects:***

Depression

Headache

Jaw pain

Difficulty emptying the bladder

Increased heart rate

Dizziness when changing position

Changes in vision

Nausea

Vomiting

Sores in mouth or on lips

### ***Side Effects/Symptoms of This Drug:***

Call your doctor right away if you develop difficulty walking, cramping in your legs, or redness and pain of injection.

***Other side effects not listed above may also occur in some patients.***

***Report any problems to your doctor.***

***FDA Approval:*** This drug is approved for cancer treatment

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**Doctor:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Nurse:** \_\_\_\_\_ **Number:** \_\_\_\_\_

**Comments:**





## INCONTINENCE

**Description:** Men who have been treated for-prostate cancer sometimes develop urinary incontinence, which is the leakage of urine. This can be a temporary, or more rarely, a long-term side effect of prostate cancer treatment.

A tube, called the urethra, carries urine from the bladder through the penis, where it is released from the body. The prostate surrounds the urethra just below the bladder, very close to muscles that control urine flow. These muscles, called sphincters, work by relaxing during urination and tightening once urination is done. Before cancer treatment, the sphincter muscles and prostate both help a man control his urine. After the prostate is removed, the urinary sphincter muscles must adapt to keeping urine in the bladder without the help of the prostate. External radiation treatments also can damage the sphincters and prostate, causing incontinence or other symptoms like painful or difficult urination. Whatever the causes, there are three types of urinary incontinence: *stress incontinence*, *urge incontinence*, and *overflow incontinence*.

**Stress incontinence** is caused by activity or movement that puts pressure on the bladder. This might include lifting heavy objects, getting up from a chair, sneezing, coughing, laughing, or swinging a golf club. Stress incontinence usually results when the muscles that keep urine in the bladder are damaged. Stress incontinence is the most common type of incontinence following prostate surgery.

**Urge incontinence** occurs when bladder contractions force urine out of the bladder. Usually, the bladder holds urine until it receives a message from the brain to release it. With urge incontinence, the bladder begins to expel urine before receiving “permission” from the brain. Men with urge incontinence release urine with little or no warning. They may have a strong need to urinate frequently and may awaken several times during the night to urinate. The urine stream can begin by simply thinking about urinating or by hearing running water.

**Overflow incontinence** results from having a full bladder that cannot empty completely. This can happen when a narrowed urethra or

bladder neck blocks urine flow, or when the nerves that control the bladder don't work properly due to damage or medications.

Symptoms of overflow incontinence may include: feeling like the bladder is not fully emptied; not being able to urinate, even when you feel a strong urge to do so; having a weak or dribbling urine flow; or leaking small amounts of urine often during the day and night.

**Duration:** Many men have some temporary incontinence after prostate surgery. The length of time until a man regains urinary control depends on his age, type of cancer treatment, and overall health. Some men regain control within days after the urinary catheter is removed. Many will be continent a few months following surgery. Most men have adequate urinary control one to two years after their initial treatment. Only a small percentage of men never regain complete control; this varies from 3-5% in younger men to 10% in men over 70. Incontinence after radiation is much less likely than after surgery, but can occur. When incontinence occurs after radiation therapy, it can last longer. Incontinence that continues more than one year should be evaluated by an urologist.

## SELF-CARE MEASURES

1. Strengthen your pelvic muscles by practicing exercises called "Kegels" (see the back page for the Kegels Exercise Program). Incontinence may be improved by strengthening these muscles.
2. Train your bladder to empty at your command. Start by urinating every hour whether you have the urge to go or not. Gradually increase the time between visits to the bathroom.
3. Limit caffeine and alcohol. These draw water out of your body tissues, which means you will make more urine. Remember that certain foods such as cola drinks, tea, and chocolate also contain caffeine. Read food and over-the-counter medications labels, as many contain either caffeine or alcohol. Some people also experience difficulty with spicy foods.

## KEGELS EXERCISE PROGRAM / LOG SHEET

Use this sheet to record one week of Kegels exercises. You should practice 3-4 times each day. There is space to record the number of muscle squeezes you do, twice in the morning and twice in the afternoon/evening. You may copy the sheet as needed.

DATE	TIME	Long Kegels		Short Kegels	
		# squeezes held 10 seconds		# sets of 5 one-second squeezes	
	AM				
	PM				
	AM				
	PM				
	AM				
	PM				
	AM				
	PM				
	AM				
	PM				
	AM				
	PM				
	AM				
	PM				



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## KEGELS EXERCISE PROGRAM / LOG SHEET

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DATE	TIME	Long Kegels # squeezes held 10 seconds	Short Kegels # sets of 5 one- second squeezes	
	AM			
	PM			
	AM			
	PM			
	AM			
	PM			
	AM			
	PM			
	AM			
	PM			
	AM			
	PM			
	AM			
	PM			
	AM			
	PM			



Helping Families Through Research

- 4.** Watch your fluid intake. Whenever possible, drink water instead of other beverages.
- 5.** Keep your bowels regular. A full rectum presses against the bladder and interferes with bladder emptying. Try to have a bowel movement as soon as you have the urge. Avoid constipation by eating a diet high in fiber, including whole grain breads and cereals, raw fruits and vegetables, and nuts.
- 6.** Maintain a healthy weight. Most men who gain weight store the extra fat around their abdomen, where it can put pressure on the bladder. Keep your body in good shape with regular exercise.
- 7.** Cross your legs and do a Kegel if you feel a cough or sneeze coming. Empty your bladder before physical activity and going to bed.
- 8.** Wear incontinence pads or undergarments to protect clothing and furniture. Most are not noticeable. They come in a range of sizes and absorbency, so you can choose a product based on the amount of incontinence you have. Keep an extra pad, and perhaps an extra pair of underwear and trousers, with you when you are away from home.
- 9.** After urinating, allow a little extra time for your urethra to drain completely before zipping up your pants.
- 10.** If necessary, use a waterproof mattress cover or smaller disposable pads to protect your bed. Keep a urinal at your bedside if you need to urinate a lot during the night.
- 11.** Keep your skin clean and dry. Skin that stays wet from constant contact with urine can become tender, red, and even develop sores. Use products that block moisture from the skin such as petroleum jelly or A&D ointment. Neutrogena makes a product called Aquaphor that works well, but can be expensive.
- 12.** Try to discuss your feelings about incontinence with your partner, close friend, or family member. Together you may think of ways to help manage the situation so you can continue to enjoy an active social and family life.

## Reasons to consult your doctor or nurse:

You should talk to your doctor or nurse if your incontinence continues to bother you. There are a number of medications your doctor can prescribe to help manage incontinence. Surgical interventions, including collagen injections and artificial sphincters, may be helpful. Call your health provider if you have pain with urination or if you have blood in your urine.

### **KEGELS EXERCISE PROGRAM** Check with your doctor before doing Kegels.

Initially, you learn to perform Kegels by trying to stop the flow of urine in midstream and counting to three. This involves squeezing or tightening the muscles of the buttocks and anus. Once you have located these muscles, a conditioning program can be started.

You can do Kegels anytime. A convenient time to practice is in the bathroom after urinating. Or, Kegels can be done while sitting standing watching TV or reading. If you do the Kegels correctly, no one can tell you are doing them. Remember to breathe during the muscle squeezes. The exercises should only take about 5 minutes.

#### **Long Kegels**

- Squeeze your pelvic muscles tightly for 10 seconds (not more).
- Relax for 10 seconds (not less).
- Continue the 10-second squeeze-relax sets up to 10-15 repetitions.
- Rest for at least 30 seconds before continuing with Short Kegels.

#### **Short Kegels**

- Squeeze your pelvic muscles for 1 second, relax for 1 second.
- Do these one-second squeeze-relax sets 5 times.
- Rest for 10 seconds.
- Repeat the 5 one-second squeeze-relax sets, followed by a 10-second rest, for a total of 4-5 times.

Strong squeezing is more important than the number of squeezes. Start each practice session with Long Kegels. When you can no longer hold a tight squeeze for 10 seconds, switch to the Short Kegels. Stop when your muscles are tired. Practice three or four times daily. It is normal to start slowly, but with practice you will build up to longer and more squeezes. You may want to keep track of your progress on the Kegel log sheet.



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## SEXUAL CONCERNS for prostate cancer patients



**Description:** A man's sex drive and ability to have an erection may be changed by prostate cancer treatments. However, the ability to enjoy sex, to feel physical pleasure with touching and to have an orgasm usually continues after treatment.

Sex drive (libido) involves a combination of emotional and physical factors in both partners. The emotional part of a person's sex drive is easily affected by worry or fatigue. Learning that you or your partner has cancer can affect sexual interest in either of you, even before any treatment is started. Physical factors related to aging can affect sex drive. Hormone medications or chemotherapy used to treat prostate cancer can greatly reduce sex drive. More subtle loss of desire can be a side effect to medications used for pain, nausea, anxiety or depression.

Erections may be affected by cancer treatment. Nerves close to the prostate help direct blood flow into the penis to produce an erection. Prostate cancer surgery or radiation can damage these nerves or the small blood vessels of the penis. This damage may cause problems getting or keeping erections.

Sexual pleasure, including orgasm and other erotic feelings, is still possible after prostate cancer treatment, even if a man has problems with erections. After prostate cancer treatments men may experience "dry orgasms". This means that they still feel the pleasure of orgasm, but little or no semen is released during ejaculation. Dry orgasms occur because the prostate gland no longer makes the liquid that mixes with sperm.

**Duration:** After stopping hormone therapy, a man's desire for sex may recover in weeks to months. However, some men have trouble feeling sexual again after lengthy periods of hormone therapy.

After prostate surgery, erections are usually poor for the first several months. If the nerves near the prostate were not removed, erections may improve over the course of one or two years. Men are more likely to recover erections if they are under age 65 at the time of surgery.

After radiation, a common pattern is to see erections gradually

decrease in firmness. Such changes may not begin until 6 to 12 months after treatment, but this can also occur several years after radiation treatments were completed.

## **SELF-CARES MEASURES**

1. Many couples continue to share sexual intimacy and pleasure even if intercourse is not possible. The single most important thing you and your partner can do is to talk openly and honestly about your feelings and needs.
2. Your partner should be present when discussing sexual concerns with your health care provider. This way both of you can learn about sexual changes resulting from cancer treatment.
3. Expressing your love and caring with hugs, kisses, cuddling and holding hands is an important part of a relationship. These gestures can be as meaningful as more “sexual” kinds of touch.
4. Prostate cancer is not contagious. Partners will not get cancer through intercourse, kissing or other intimate contact with a man who has prostate cancer.
5. Be creative and try new ways of sharing intimacy with your partner. Touches and caresses with your hands, lips or tongue can be very pleasurable and satisfying. Orgasms can occur from hand caressing or oral sex for both partners.
6. If you are having problems with fatigue, plan to be well rested before starting sexual activities. If urinary leaking is a problem, empty your bladder before sex, or wear a condom.
7. Problems with erections can be a side effect of some medications. Discuss all your medications, including over the counter medicines with your doctor or nurse.

## **OTHER TREATMENTS FOR ERECTION PROBLEMS**

1. Techniques are available to restore firmer erections. But, keep your expectations realistic. Even with treatment, your sexual

experiences may be different from the way they were before. Many remedies involve some hassles and loss of spontaneity. Your partner needs to understand and accept the treatment too.

2. A realistic goal is to achieve erections that are firm enough to allow penetration. Talk with your doctor to see if one of the following options might work for you.

**a. Viagra, Cialis, Levitra:** These medications, taken by mouth, allow chemicals that promote an erection to build-up in the penis. These drugs do not cause an erection automatically. With sexual stimulation they will increase your ability to get an erection. These drugs are more likely to work following prostatectomy if the nerves close to the prostate were not removed. They are also more likely to work in men who get partial erections and just need more firmness to have intercourse. Headache, facial flushing and nasal congestion sometimes occur with these drugs. They cannot be used if you are taking certain heart medications. Your doctor can determine if you can safely take them.

**b. MUSE (alprostadil):** With this medicine, a small pellet is inserted into the opening of the penis. As the pellet melts, the medication is absorbed. If it works, an erection will begin within 8-10 minutes and last from 30-60 minutes. Some men report burning in the penis which may last for a short time. This side effect will prevent about 10% of men from using it.

**c. Caverject (alprostadil):** This is the same medication as MUSE, but it is injected into the base of the penis. The needles used for this are tiny and cause very little, if any, discomfort. Erections last between 40-60 minutes. One disadvantage is a 5-10% risk of developing scar tissue near the injection site. In rare cases, permanent curvature of the erect penis may occur. If this happens, it can only be corrected with plastic surgery.

**d. A vacuum device** is used to bring blood into the penis to create an erection. The soft penis is placed inside a plastic tube that attaches to a pump. Starting the pump creates a vacuum

that draws blood into the penis. A ring is placed at the base of the penis to keep blood from leaving. This produces a firm erection in almost all men. It costs anywhere from \$150 to \$600. It is covered by many insurances including Medicare. The more expensive vacuum pumps require a prescription. Many manufacturers of these products offer telephone hotlines. These advice lines can be very helpful in overcoming problems you may be having with the device. The vacuum device is a good solution for men who are likely to have natural erections return in time. Disadvantages include: 1) the loss of spontaneity from needing to use a mechanical device; 2) discomfort or problems with ejaculation caused by the ring at the base of the penis; and 3) the need to remove the ring after 30-40 minutes to allow blood flow through the penis.

**e. Implants:** Penile implants are placed inside the body with surgery. Cylinders inserted into the penis fill with fluid to create an erection in the same manner that blood would normally fill these areas during sexual arousal. Different types of implants are available. The surgical procedure lasts from 30 minutes to two hours. Recovery after the surgery takes from 1-3 weeks. Ask your doctor to explain the different models that are available. Since having an implant will permanently damage a man's own, natural erection reflex, many men prefer to try other treatments before considering this option.

## REASONS TO CONSULT YOUR DOCTOR OR NURSE

1. You have questions or concerns about your sexual functioning. A referral to a respected sex therapist may be helpful for you and your partner.
2. You wish to try a different treatment for erection problems.
3. The treatment you try is not satisfying to you or to your partner.



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Revised 2001 Mood D.\*, Walker J\*\*, Schafenacker A\*\*, Northouse L\*\*, Sanda M\*\*

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## NAUSEA AND VOMITING

**Description:** Cancer treatment may cause a feeling of “being sick to your stomach,” a symptom called nausea. This may lead to vomiting. Nausea and vomiting can occur when cells of your digestive tract are damaged or irritated by cancer treatments. The damaged cells may release chemicals, which stimulate the vomiting center in the brain. Some chemotherapy drugs can also directly affect the vomiting center.

If you experienced nausea with previous cancer treatments, just returning to the cancer center may cause a feeling of nausea even before any treatment is given. This is called anticipatory nausea. Not all cancer patients experience nausea or vomiting during treatment.

**Duration:** Nausea with or without vomiting can begin before a treatment (anticipatory) or usually one to four hours after a treatment. With some chemotherapy drugs, it may take 12 to 48 hours before nausea occurs. Nausea and vomiting will usually disappear within 1 or 2 weeks after you complete your course of treatment as the lining of your digestive tract heals.

## SELF-CARE MEASURES

1. Tell your cancer doctor or nurse if you have nausea or vomiting. Very effective medications for controlling these symptoms are available.
  - a. Some anti-nausea medications are given through an injection or IV shortly before chemotherapy or radiation. Ask if these medications might be helpful for you.
  - b. If an anti-nausea medication is prescribed for you, follow the directions carefully. Some should be taken on a regular schedule to maintain enough medicine in your body to work. Others will be prescribed to take ½ to 1 hour before eating.

## **2. Foods to avoid when you are nauseated**

- a.** Avoid hot foods and beverages. Cooking and brewing odors can make you feel more nauseated.
- b.** Avoid greasy, fried and fatty foods because they take longer to leave the stomach and may make nausea worse.
- c.** Avoid solid foods if you are feeling very sick to your stomach. Liquids are easier to digest when you are nauseated.
- d.** Avoid eating your favorite foods when you are nauseated. This may keep you from associating your favorite foods with nausea. Instead, after the nausea passes, use your favorite foods to perk up your appetite.

## **3. Foods to try when you are nauseated**

- a.** Dry foods such as toast or soda crackers may settle your stomach and help prevent dry heaves. If you wake up feeling nauseated, eat soda crackers before you get out of bed. Eating soda crackers when you take medicines such as pain pills may also decrease any nausea caused by those medications.
- b.** Try foods that are low in fat such as lean meats, veal, chicken or turkey without the skin, tuna packed in water, low fat milk, low fat yogurt and broths.
- c.** Try small sandwiches with bland fillings. Bland foods such as applesauce, toast, mashed potatoes and custard are often well tolerated. Sweet and salty foods may also appeal to some people who have nausea.
- d.** Take fluids you can tolerate. Clear, cool drinks are most helpful. Try Jello<sup>®</sup> or Jello<sup>®</sup> water, ice cubes made of any kind of liquid (juice, pop), apple juice, popsicles, sherbets, and clear soup. Drink most of your fluid between meals. Combining solid food and liquids may increase nausea.
- e.** Some people find it helpful to eat a light snack about 2 hours before treatment. Others prefer to avoid food and fluids for 1-2 hours before and after each treatment.

#### **4. Suggestions if you are vomiting**

- a.** Rest your stomach for about one hour immediately after vomiting. You may want to rinse your mouth, but without swallowing. Then, try a small sip of a clear liquid (or ice chips) every 5-10 minutes until you are certain the vomiting will not recur.
- b.** If you vomit frequently, be sure to take fluids that contain salt, to make up for the water and salt your body has lost. Gatorade® and broth are usually well tolerated.
- c.** Some people find colas, gingerale and 7-UP® helpful. However, carbonation can upset the stomach. Let these drinks sit open for awhile to release the fizz before drinking them.
- d.** Avoid unpleasant or strong odors that can trigger vomiting.

#### **5. Mealtime suggestions**

- a.** Chew your food well so you can digest it more easily.
- b.** Eat and drink slowly so that only small amounts of food and fluid enter your stomach at one time.
- c.** Eat small meals and nutritious snacks during the day instead of 3 large meals.
- d.** Rest in a quiet environment after meals. Activity can make the nausea worse. If you lay down after meals, make sure your head is 4 inches higher than your feet. Do NOT lay flat.

#### **ADDITIONAL SUGGESTIONS**

- 1.** When you're nauseated, try to distract yourself with activities like listening to music, reading, sleeping, talking about other things, doing a relaxation exercise, or breathing slowly and evenly through your mouth.
- 2.** Sometimes fresh air can help. When possible, sit by an open window, or sit outdoors.

3. Avoid doing your own cooking, if possible, especially if cooking odors nauseate you. Let others cook for you, or bring you already prepared meals.
4. Wear loose fitting clothes to avoid pressure on the stomach or neck.
5. Keep track of your nausea/vomiting patterns. Note when you start to feel sick and how long it lasts. Then discuss this with your doctor. Anti-nausea medication or your treatment schedule may be changed to better manage your nausea and vomiting.

## REASONS TO CONSULT YOUR NURSE OR DOCTOR

1. You have been unable to eat because of continued problems with nausea or vomiting.
2. Your anti-nausea medicine doesn't seem to be effective.
3. You are noticing symptoms of dehydration due to frequent vomiting. These include dry skin and mouth, decreased urination, and a great deal of fatigue.



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## HORMONE CHANGES

**Description:** Certain cancer treatments, as well as normal aging, can cause symptoms because of hormone changes. Some medications and chemotherapy drugs alter the hormone balance in your body. Symptoms might include hot flashes, breast tenderness or swelling, decreased sex drive (libido), changes in body hair and muscle mass, osteoporosis (bone thinning), mood swings, fatigue, and weight gain. In addition, with hormone treatment, men are likely to have erection problems, and women may experience vaginal dryness.


Hot flashes occur because blood vessels temporarily become less stable. They can suddenly dilate (relax and get larger). This allows blood to rapidly flow into veins causing you to feel hot and begin perspiring. This feeling usually lasts a few minutes, but can happen several times during the day or night. You might wake up during the night with your pajamas soaked from perspiration. Some cancer patients receiving hormone treatments are only mildly bothered by hot flashes, while others may be bothered a great deal by hot flashes.

**Duration:** Hormonal symptoms can begin as soon as the medication is started or at any time during treatment. Hot flashes related to hormone therapy gradually stop, usually within a few months, after the treatment is ended.

## SELF-CARE MEASURES


### General tips

1. The physical and emotional changes that come with hormone treatments can be very troubling. One of the best things you can do is to share your feelings and thoughts about these changes with your partner or a close friend. Attending a support group or going online to cancer web sites may be helpful. Some recommended websites include:
  - [www.cancer.org](http://www.cancer.org)
  - [www.CancerSymptoms.org](http://www.CancerSymptoms.org)
  - [www.canceradvocacy.org](http://www.canceradvocacy.org).

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2. Be gentle on yourself. Try to accept the fact that you may have sudden mood swings. These are caused by hormone changes and are not a sign of poor coping.
  3. Some hormone treatments can cause weight gain. Work toward keeping your normal weight. After stopping hormone treatments, your weight may not return to its normal level. Try to eat a healthy diet and exercise regularly. Good nutrition and exercise also help with fatigue and emotional well being, and prevent some bone loss.
  4. Changes in your sex drive can be very upsetting to you and your partner. Make a conscious effort to show your love and affection to your partner with hugs, cuddling and hand holding even if you don't feel an interest in sex. Partners can help by asking for a hug or kiss when they need one.

### **For hot flashes**

1. Take cool showers or baths as needed. Place a cold, wet cloth around your neck.
2. Set a small, quiet fan next to where you are sitting and at your bedside.
3. Dress in layers in comfortable, loose-fitting clothes. Breathable fabrics like cotton are best. Remove outer clothing when you begin to feel hot.
4. Watch for what might trigger your hot flashes and avoid those things, Alcohol, caffeine, cayenne pepper, citrus, tomatoes, tyramine (found in aged cheese and red wine) and hot drinks have all been reported to trigger hot flashes.
5. Eat several small meals throughout the day, rather than a few large ones. Drink lots of water and suck on ice chips.

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6. Feeling anxious or upset can make your hot flashes worse. Find ways to avoid or eliminate stressful situations in your life. Use relaxation techniques that work for you. Your intervention nurse has an instructional tape of various techniques.
  7. Some complementary therapies, such as acupuncture, may be helpful. Talk with your doctor before starting these treatments.
  8. Some medications (vitamin E, belladonna, Effexor, Celexa and Megace) have helped reduce hot flashes. Medication may be needed if hot flashes are interrupting your sleep and you are not getting the rest you need. Ask your doctor if these medications might help you.

### **For vaginal dryness**

1. Vaginal lubricants like Astroglide or KY jelly can make sexual intercourse more comfortable. Another product called Replens can help restore vaginal moisture, but is used several times each week, not at the time of intercourse.
2. Vaginal estrogen products may be useful in some women. These products require a prescription and come in several forms including vaginal creams, tablets or rings. It would be important to discuss the use of vaginal estrogen products with your doctor and follow the prescribed dose carefully.

### **For breast changes**

1. Sometimes a sports bra, which can flatten and support breasts, will help alleviate breast tenderness. Ask your doctor about other safe binding techniques for breast swelling.
2. Acetaminophen (Tylenol®) or ibuprofen (Advil®, Motrin®) may relieve some breast tenderness. Cold or heat applications may also be helpful.

3. If you have nipple tenderness, wear soft fabrics and loose fitting shirts.

### **Other measures**

1. Your doctor might recommend radiation to the breasts before cancer treatment to decrease breast swelling.
2. Discuss treatments to prevent osteoporosis with your doctor.

### **REASONS TO CONSULT YOUR DOCTOR OR NURSE**

1. Your symptoms are affecting your quality of life or interrupting your sleep.
2. You want a referral to a mental health professional to help you cope more effectively with your cancer treatment.
3. Talk to your doctor or nurse about your concerns and questions. You may ask them to put you in contact with another patient who has gone through similar treatments.

### **See also**

- Fatigue
- Emotional Reactions
- Sexual Concerns



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## FATIGUE

**Description:** Cancer treatments may, cause you to feel fatigued or very tired. It is a tiredness that is not relieved by rest. It keeps you from doing the things you want, which can be very troubling. Fatigue is a common problem for cancer patients and their family members.


Patients and their families can also have “mental fatigue.” Facing many decisions and tasks related to the cancer leads to this type of fatigue. Emotional strain and worry that lasts a long time can add to mental fatigue. People with mental fatigue have difficulty concentrating, feel less alert, have trouble focusing on tasks, and may be irritable.

**Duration:** Physical or mental fatigue may be constant or may come and go in cycles. Fatigue due to radiation treatments usually begins in the first week of treatment and peaks in 2 weeks. Fatigue caused by chemotherapy usually starts within one month and can continue throughout the treatment. Some cancer survivors report lingering fatigue even after their treatments are over.

## SELF-CARE MEASURES

### 1. Conserve your energy.

- a. Prioritize your activities. Do only those activities that are the most important to you. Save the others for another day.
- b. Pace yourself. Spread big jobs out and do a little each day. Schedule activities during the time each day when you usually have the most energy. Plan short rest periods when you are usually most tired.
- c. Use the help of family and friends for chores, transportation, meal preparation, yard work, and other activities. This will allow you to save your energy for healing and recovery.
- d. Sit whenever possible during activities rather than stand. Propping your legs up when sitting can help too.

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- e. Don't fight your fatigue. Listen to your body and watch for signs that you are becoming tired. Then take a break for a while.

## **2. Restore your energy.**

- a. Schedule time for fun, but relaxing activities. Doing things that you enjoy helps you re-energize. These activities need to catch your interest and not be boring.
- b. Activities that involve nature can be very helpful for restoring your energy. Some examples are gardening, watching wildlife, taking a walk, gazing out the window, and visiting a park.
- c. Other restorative activities can include quiet times such as meditating, watching a fire, or reading an interesting book.
- d. Plan to do your favorite restorative activity at least three or four times a week, for 20-30 minutes.

## **3. Exercise regularly.**

- a. Even though you may feel fatigued, regular exercise such as walking, is one of the best ways to reduce your fatigue.
- b. Try to start a walking program. Begin with short walks at a slower pace. Gradually increase the distance and the amount of time that you walk. Some people find it helpful to follow a specific course so that their walk becomes a regular routine for them. Check with your physician about your exercise plan.

## **4. Get enough sleep.**

- a. Short naps may be helpful as long as they don't interfere with your nighttime sleep. After a nap, do something active, like walking.
- b. Follow a regular bedtime routine that works for you.

## **5. Eat a healthy diet.**

- a.** Eat a well-balanced diet that includes foods high in iron.
- b.** Drink plenty of fluids, especially water. Fatigue can be a symptom of dehydration.

## **6. Try distraction.**

- a.** Some activities such as watching a movie or listening to music can distract you from thinking about your fatigue.
- b.** Socializing with others can also be helpful as long as you keep the length of time reasonable.

## **REASONS TO CONSULT YOUR DOCTOR OR NURSE**

- 1.** You are extremely fatigued. Some causes of fatigue, such as anemia, dehydration, hypothyroidism or depression, require medical treatments.
- 2.** You are short of breath or feel dizzy.
- 3.** You have trouble sleeping. A short-term sleep medication may be helpful.



Helping Families Through Research

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**Description:** Cancer treatments can injure both normal and cancer cells, especially when they are dividing. Hair cells divide rapidly and are sensitive to cancer treatments. You may lose some or all of your hair if you are receiving radiation or chemotherapy. Radiation causes hair loss only in the area being treated.

Chemotherapy can cause hair loss in various areas of your body, including your scalp, eyelashes, eyebrows, underarms, facial, and pubic areas. Hair loss usually occurs within 2 to 3 weeks after the start of therapy and generally begins on the crown and sides of your head. Hair loss may be rapid or gradual (over 3 to 4 weeks). You may experience increased scalp sensitivity, scalp soreness, scalp dryness, and loss of body -heat with hair loss.

**Duration:** Usually your hair will grow back after you have finished treatment. However, if you receive a dose of radiation that is large or the entire skull is being treated, hair loss may be permanent. Regrowth typically occurs within 2 or 3 months, but the new hair may be a different color or texture.

## SELF-CARE MEASURES

### 1. To minimize the amount of hair loss:

- a. Keep your hair clean, but avoid excessive shampooing. Wash gently with a mild shampoo (baby shampoo) every 4 to 7 days, followed by a cream rinse or hair conditioner.
- b. Use a soft bristle brush or wide-toothed comb to remove tangles. Avoid too much brushing and combing.
- c. Avoid hair dyes, other products (such as hair spray), and blow dryers, which can make your hair brittle and cause it to fall out more easily.
- d. Use a satin pillowcase to decrease hair loss from friction when your head rubs against the pillow.
- e. You may want to cut your hair to a short length prior to your treatments. This may reduce hair loss by decreasing the weight on the scalp and can disguise hair thinning. Some people may choose to shave their heads before they start losing their hair.

## **2. To manage your hair loss:**

- a.** Buy a wig if you wish. Wigs are tax deductible medical expenses and may be covered by your insurance if you obtain a prescription for the wig from your physician.
- b.** It may be helpful to look for a wig before hair loss begins. You may wish to match your own hair color. Some people find that beginning to wear a wig before hair is lost helps to ease the transition.
- c.** Remove your wig for periods of time to allow your scalp to “breathe.” You may want to alternate wearing a wig with a comfortable hat. Some people choose baseball caps or other types of hats.
- d.** Protect your head. Avoid sun exposure to your scalp by wearing a hat or wig and using sun screen (at least SPF 15). Wear eyeglasses or sunglasses to protect your eyes if you have lost eyelashes. A hat or cap may help keep your head warm during cooler weather and may help prevent scalp irritation.

## **3. To cope with emotional reactions to hair loss:**

- a.** Talk with your physician, nurse, family or friends about any feelings or questions you have about the change in your appearance. Hair loss can be very emotionally upsetting, and may cause you to feel anger, sadness, embarrassment or fear.
- b.** Talk to other people who have lost their hair due to cancer treatments. They may have suggestions that could help you.
- c.** You may want to try using makeup or accessories you enjoy such as jewelry, brightly colored scarves, shirts or ties, to help you feel more positive about your appearance.
- d.** Continue your social activities. Your confidence will grow as you spend time with other people. This can help you cope with and adjust to changes in your appearance.



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## EMOTIONAL REACTIONS

**Description:** When you or a family member has cancer, your sense of well-being can be threatened. Common emotional reactions to cancer include anxiety, depression, fear, and loneliness. These are all normal responses to the stress that may be occurring in your family's life.

**Duration:** Emotional reactions can occur at any time during cancer treatment and continue throughout the course of therapy. Sometimes these reactions don't occur until after the treatments have ended. Recognizing the symptoms of emotional distress is important. Once you have identified the symptoms, then you can use strategies to help you cope with the distress.


## SELF-CARE MEASURES

### 1. Watch for the symptoms of emotional distress.

- a. Nervousness, confusion, and a feeling of losing control are some symptoms of anxiety. Anxiety can also cause physical symptoms such as headaches, upset stomach, diarrhea, difficulty breathing, or a racing heart.
- b. People who are depressed have a general sense of sadness. Other symptoms of depression include difficulty sleeping, problems concentrating, lack of energy, appetite changes, and a loss of interest or pleasure in activities you previously enjoyed. Thoughts of suicide occur in very severe cases of depression.
- c. Other signals of distress include avoiding people, having excessive guilt, or feeling a lack of purpose. Thoughts that will not leave, even when you try to think about something else, can also be a sign of emotional distress.

### 2. When you're feeling anxious, try some of the following strategies:

- a. Identify the thoughts that are making you nervous. Facing the specific fears that are causing you to worry may allow you to get control of your anxiety.

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- b.** Talk with someone who has been through a similar situation. This may help you feel that you are not alone.
  - c.** Increase your physical activity or begin some form of exercise. Exercise helps to release some of the “anxious energy” that comes with emotional distress.
  - d.** Set aside a short, specific time for worrying, rather than worrying through the whole day. Some people call this a “worry appointment.”
    - Plan a time when you will concentrate on worries and do nothing else. Do not schedule the worry appointment at the beginning or end of the day.
    - As you go through the day and find yourself worrying, stop and write down your concerns. After writing the concerns on paper, stop thinking about them until your worry appointment. Instead, get busy with some other activity that is productive (like getting grocery shopping or another chore done, or calling a friend to meet for coffee).
    - Come back to your concerns during the worry appointment.
    - Limit the amount of time for worrying to 5 minutes. Use a timer if necessary. During your worry appointment, focus on your worries, don’t try to problem-solve. Give yourself permission to just worry during this time.
    - When your appointment time is over, stop thinking about your worries, and do something else that helps you be active (like working on a hobby or watching a program on television that distracts you from worrying).
  - e.** Practice muscle relaxation techniques.
    - Close your eyes and breathe deeply.
    - Concentrate on tensing and then relaxing each body part. Start with your toes and work your way up to your head.
    - Once relaxed, think of a pleasant place or pleasurable experience.
    - It may help to learn these techniques by listening to a relaxation tape.
  - f.** Pray or meditate to create a sense of calmness within you.

### **3. When you're feeling down or depressed, try some of the following strategies:**

- a.** Spend time with positive people. They may help you turn your attention away from problems and toward pleasant experiences.
- b.** Set reasonable goals. It is better to set a low goal and be successful, than to set a high goal and feel frustrated.
- c.** Try not to be too hard on yourself. You are dealing with a lot. Give yourself permission to feel sad at times, but don't let the sadness take over your life.
- d.** Make an effort to focus on small joys in your everyday life. You may enjoy watching a sunset or the playfulness of a pet.
- e.** Do some type of physical exercise like walking.
- f.** Plan activities to break up boredom. Read a book or magazine, listen to music, or watch an interesting program on television. If you have difficulty concentrating, read a short magazine that doesn't take a lot of effort.

### **4. For any kind of emotional distress, keep your attention focused on the present.**

- a.** Today is the only day you need to think about. Do something that will make you feel good today. Take care of today's business only.
- b.** Yesterday is over and there's nothing you can do to change what has already passed. Practice letting go of past problems.
- c.** Tomorrow will come soon enough and you can decide what to do when it comes.

### **5. Try to talk openly with you'r family or friends about how you're feeling.**

- a.** "Bottling up" negative feelings like fear, anger, and sadness may cause you to feel worse.

- b.** When you share your emotions, you are not imposing on others or being a burden. Your family and friends care about you and may be waiting for you to tell them how you feel.
  - While it's helpful to express your feelings, constantly “dumping” negative emotions onto your primary support person may become overwhelming to that person.
  - If you find yourself in this situation, it may help to talk with other people or a professional.
- c.** By sharing your thoughts and feelings, you will help others around you feel more comfortable and closer to you.

## **ADDITIONAL SUGGESTIONS**

- 1.** Do not abruptly stop taking your medication if it has been prescribed for anxiety or depression.
- 2.** Avoid alcohol and other recreational drugs. These substances cause fatigue and drowsiness, and can worsen feelings of depression.
- 3.** Talk with your physician or nurse. They may have additional suggestions to help you deal with your specific problems.

## **REASONS TO CONSULT YOUR NURSE OR DOCTOR**

- 1.** You are seriously considering dropping out of cancer treatment.
- 2.** You had treatment for depression, anxiety, or other mental health problems, and your symptoms might be returning.
- 3.** You are using alcohol or other recreational drugs to help you cope with feelings.
- 4.** You are experiencing wide mood swings that include periods of depression and periods of agitation or high energy.
- 5.** Your emotions interfere with your ability to take care of yourself.
- 6.** You are thinking about hurting or killing yourself.
- 7.** You would like a referral to a mental health nurse practitioner, social worker, psychologist, or other counselor to help you cope with your feelings.



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## URINARY PROBLEMS AFTER RADIATION

**Description:** External radiation treatment of the prostate gland, which lies just below the bladder, may damage the bladder lining or urethra. This can lead to problems with urination. If this happens, you may find that you have to urinate frequently and urgently, throughout the day and night. You may feel the need to urinate, but have difficulty starting your stream. You may also have pain or burning when you urinate and notice pus or small amounts of blood in your urine.

**Duration:** Bladder irritation is usually temporary. Injured cells will be replaced by new cells and the bladder will heal within 23 weeks after your treatments end. In some cases, symptoms of frequent or difficult urination can persist. Rarely, blood in the urine can recur months or years after your treatment due to scarring of the bladder. However, such bleeding into the urine is usually of no consequence other than causing the urine to turn red and occasional clots to pass.

### SELF-CARE MEASURES

#### 1. Decrease the risk of infection.

- a. Drink plenty of fluids, especially water. Eight to ten glasses (8-ounce size) each day is recommended. This will dilute your urine and reduce the chance of infection. It will also help flush out pus or blood from the bladder and promote healing if an infection has already developed.
- b. Try to drink 10 to 12 ounces of cranberry juice a day. This will make your urine more acidic, which can help prevent the growth of bacteria. Since vitamin C supplements also can make your urine more acidic, ask your doctor if you should be taking some extra vitamin C.
- c. Urinate frequently. Do not ignore the need to empty your bladder.

## **2. Avoid further irritation of the bladder.**

- a.** Drinks that contain caffeine, such as coffee, tea, cola, and hot chocolate, are irritating and should be avoided.
- b.** Any alcoholic or carbonated drinks can irritate the bladder. Limit your use of these beverages.
- c.** Avoid spices such as pepper and curry.
- d.** Tobacco products also irritate the bladder.

## **3. Comfort measures:**

- a.** As soon as symptoms begin, talk to your doctor about medications that can reduce pain and burning (such as Pyridium<sup>®</sup>, Detrol<sup>®</sup>, or Ditropan<sup>®</sup>) or make it easier to urinate (such as Cardura<sup>®</sup>, Hytrin<sup>®</sup>, or Flomax<sup>®</sup>). A medication called Proscar may help to lessen bleeding from the prostatic urethra.
- b.** In the meantime, if you have the urge to urinate but can't start your stream, or you have severe pain when you urinate, try sitting in a warm sitz or tub bath before or during urination.

## **OTHER MEASURES**

- 1.** Your physician may order blood or urine tests if you develop signs and symptoms of a bladder infection.

## **REASONS TO CONSULT YOUR DOCTOR OR NURSE**

- 1.** You develop any of the signs or symptoms of a bladder infection: frequency, urgency, or pain with urination; blood or pus in your urine; dull aching back pain; fever.
- 2.** You are unable to urinate for 12 hours.



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## BOWEL AND RECTAL PROBLEMS AFTER RADIATION THERAPY



**Description:** Radiation treatments for prostate cancer may affect the abdomen, pelvis, and rectum. The lining of the bowel and rectum are very sensitive to the effects of radiation and can become temporarily irritated. Symptoms may include cramping, burning and tenderness in the rectum, mucus discharge, diarrhea, and pain or bleeding with bowel movements.

**Duration:** Many patients experience bowel and rectal problems starting at the third or fourth week of radiation treatments. Usually the symptoms resolve several weeks after the treatments have ended. A small percentage of patients will develop chronic bowel symptoms.

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### SELF-CARE MEASURES

#### **1. Tell your doctor about your bowel symptoms; this may be the best thing you can do.**

- a.** Many people are embarrassed to discuss bowel and rectal problems with their doctors. However, doctors are familiar with patients having these symptoms. They can suggest treatments that may bring you relief from these distressing symptoms.
- b.** Keep a log of your symptoms including diarrhea (number/consistency of stools, blood/mucus in stools), pain, cramping, gas or rectal skin problems. Record any foods or activities that trigger your symptoms. Take this log to your appointment with the doctor.
- c.** Medications, dietary adjustments, and other lifestyle changes are often used successfully to treat bowel problems caused by radiation treatments.

#### **2. Ask your doctor or nurse about medications for your symptoms.**

- a.** There are prescription and over-the-counter medications for



diarrhea, such as Kaopectate<sup>®</sup>, Imodium<sup>®</sup> and Lomotil<sup>®</sup>.

Follow your doctor's instructions carefully to avoid becoming constipated. Other medications may be recommended to relieve cramping or pain.

- b.** Special creams and foams can help with rectal tenderness and skin problems. You may need a prescription-strength cream. Ask your doctor which products are recommended.

### **3. If you develop bowel symptoms, try making some changes in your diet.**

- a.** Eat small meals 5-6 times per day rather than 3 large meals.
- b.** Eat foods at room temperature. Very hot or cold foods are more difficult to tolerate.
- c.** Highly spiced foods may further irritate the rectal tissue. Avoid foods spiced with pepper, chili powder, curry and cloves. However, adding nutmeg to foods may help, because it slows down the intestines.
- d.** Avoid foods and drinks that increase gas and cramps such as carbonated drinks, beans, and cabbage. Don't chew gum. Eat slowly so you swallow less air during meals.
- e.** There are other foods that should be avoided or added to your diet.

#### ***AVOID:***

- High-fiber foods like whole wheat bread, bran cereals, nuts, seeds, popcorn, fresh or dried fruits, raw vegetable's and high-fiber vegetables (broccoli, cabbage, cauliflower, peas, corn, dried beans), raw salads.
- Fried, greasy or fatty foods including potato chips, rich pastries and gravies.
- Most milk products (if you are sensitive to lactose). However, buttermilk, live-culture yogurts, and supplements like Ensure<sup>®</sup> are okay.

### ***TRY TO EAT:***

- Baked or broiled fish, skinned poultry, and lean meats; mild processed cheese; eggs (not fried); and smooth peanut butter.
- Bananas, applesauce, canned peaches or pears, peeled apples, and apple or grape juice.
- White bread or toast, rice, noodles, Cream of Wheat<sup>®</sup>.
- Baked, boiled or mashed potatoes (no skin), well-cooked mild vegetables like asparagus tips, green beans, carrots and squash.

## **4. Drink plenty of liquids, especially if you are losing fluids through diarrhea.**

- a. Drink water frequently, at least 8-10 glasses per day. Watch your fluid intake carefully, especially if your diarrhea is severe (more than 5 stools per day) or lasts more than one day.
- b. With frequent diarrhea, you may also lose electrolytes such as sodium and potassium. Beverages like Gatorade<sup>®</sup> or other sports drinks may help. Try to eat some of the following foods to replace potassium: bananas, potatoes, red meat and vegetable juices.
- c. Limit caffeinated beverages including coffee, tea, and soft drinks. Taper your use of caffeinated drinks gradually if you usually drink a lot. Caffeine is a bowel stimulant and can also worsen dehydration.
- d. Report signs of dehydration to your doctor, including decreased urination, dry mouth/eyes/skin, increasing fatigue and weakness.

## **5. Other lifestyle changes may be helpful, too.**

- a. Cut down on alcohol and tobacco since these increase bowel activity and may worsen diarrhea.

- b.** Consciously work on decreasing stress in your life by using relaxation techniques that work for you.
- c.** Use simple comfort measures such as sitting in a warm sitz bath. Check your local pharmacy where you can buy an insert for your toilet that holds warm water. Sometimes, resting with a hot water bottle, wrapped in a towel on your abdomen, may relieve cramping.
- d.** Use good skin care. Practice gentle cleansing (try mild baby wipes) and drying after bowel movements. Then apply soothing lotions or ointments like Tucks<sup>®</sup> or Anusol<sup>®</sup>.

## REASONS TO CONSULT YOUR DOCTOR OR NURSE

- 1.** The diarrhea or rectal pain continues with no relief.
- 2.** You notice red blood, on the tissue when you wipe after a bowel movement.
- 3.** You have a fever above 100.5 F. with diarrhea.
- 4.** You become weak and feel dizzy.
- 5.** You have signs of dehydration.



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