

Living With Colorectal Cancer

*An Information and
Resources Guidebook*



Colon Cancer Alliance

The Colon Cancer Alliance (CCA) is a nonprofit organization started by colorectal cancer survivors, caregivers, and others touched by the disease. The Colon Cancer Alliance brings the voice of survivors to battle colorectal cancer through patient support, education, research, and advocacy.

The Colon Cancer Alliance:

- ❖ Provides patient support services and facilitates access to information
- ❖ Offers information about colorectal cancer and encourages early detection through appropriate screening
- ❖ Supports research for more effective treatments and a cure for colorectal cancer
- ❖ Advocates for increased support to battle all cancers, particularly the prevention and treatment of colorectal cancer.

The Colon Cancer Alliance depends upon gifts, grants, and contributions from the public, including individuals, foundations, and corporations. Please support CCA in its efforts to help all people affected by colorectal cancer.

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Introduction

This booklet is about living with colorectal cancer (CRC). When you were diagnosed, you joined thousands of other people who are living with colorectal cancer. This booklet is meant to help you sort through some of the many new feelings and situations you will face as you learn to live with colorectal cancer. The information provided here is drawn from a large body of professional resources. The booklet also contains many words of wisdom from the true experts — others who have had colorectal cancer. Their words will tell you what they felt and how they managed to get through their experiences with colorectal cancer.

You will find information about coping with a diagnosis of colorectal cancer and how to tell others in your life about your illness. There is information about how to help yourself get through treatment. We also discuss how your moods, work and home situations, and nutrition might be affected. We also provide information about what to expect and how to adjust once you have completed treatment. This booklet is for anyone with colorectal cancer, but may be most useful if you have recently been diagnosed or if you have just finished your treatment.

Throughout the booklet you will see words in *blue*. These are words you may or may not be familiar with, but you will probably hear them often from your doctors, nurses, or others involved in your care. The meaning of each of these words can be found at the end of the booklet in the Glossary. The words are in alphabetical order.

The information provided here is intended to help you know what to expect and to give you examples of ways others have handled some of the more difficult aspects of living with colorectal cancer. We hope the information in this booklet will help you find ways to make your daily life easier and more enjoyable.

We wish you the best on your journey.

About Colorectal Cancer

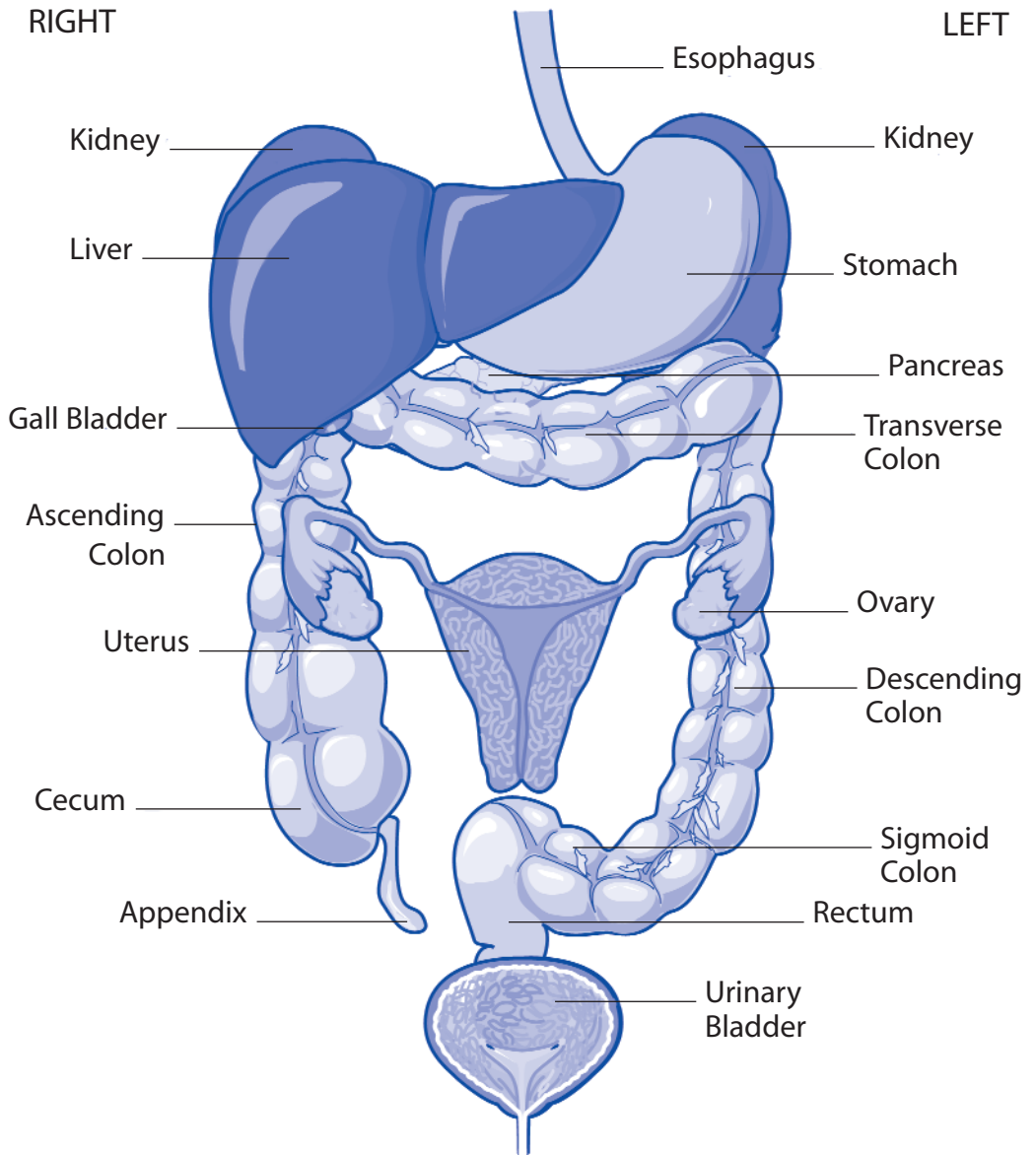
Cancer occurs when a group of *cells* begins to grow and spread in an abnormal way. Colorectal cancer can start either in the *colon* or the *rectum*. The colon is part of the *large intestine* and is located in the *abdomen*. The rectum is at the end of the large intestine and opens to the outside of the body. Both the colon and the rectum are involved in collecting *feces* to be removed from the body.

Each year, more than 130,000 people are diagnosed with colorectal cancer. It is the fourth most common cancer in the United States, the third most common cancer that affects both men and women, and the second most frequent cause of death by cancer. There are thousands of people who have felt many of the same things you are now feeling.

You are not alone.

Colon, Rectum, and Surrounding Organs

not to scale



Responding to Your Diagnosis

Coping with the News

Being told “you have cancer” is one of the hardest and most frightening things any of us will ever have to hear. Many people who have been diagnosed with cancer say they don’t remember hearing what the doctor said to them, let alone understanding it. Some remember thinking the doctor simply made a mistake. Others say they were shocked or felt “numb.” Others experienced intense feelings such as sadness or helplessness. Some experienced all of these feelings one after the other, or in different combinations. The point is that each of us is different, and each of us responds in our own way to a diagnosis of cancer — there is no right or wrong way.

Although each person responds differently to a diagnosis of cancer, there are some experiences that many people with colorectal cancer have in common. You may find it helpful to know how others dealt with their experiences and how they handled the difficult questions, emotions, and uncertainties that go along with having colorectal cancer.

When You First Hear the News

The time right after a diagnosis of colorectal cancer can be very difficult. At first, many people just can’t believe it’s true. This is your

mind’s way of gradually accepting the news. Eventually, you do accept it. Most people find the difficult or uncomfortable feelings they had at the beginning start to subside within a few weeks or months after diagnosis. Once the reality of your diagnosis begins to sink in, you will probably ask yourself some of the same questions that many others with colorectal cancer have asked themselves, such as:

- ❖ What is going to happen to me?
- ❖ Am I going to die?
- ❖ How is this going to affect my family? My work?
- ❖ What do I do now?
- ❖ How do I get the help and treatment I need?

“For some time after my diagnosis, I felt like every experience was my last. My last Christmas, my last birthday, my last summer. Feeling that way was the hardest part of learning to live with cancer. Fortunately, I’m not feeling that way as often now.”

Some people with colorectal cancer have found the following actions helpful in managing the difficult feelings they experienced after hearing their diagnosis. You may also find them helpful.

- ❖ Find a doctor you feel comfortable with to treat your cancer. The more comfortable you are with your doctor, the less anxious you are likely to feel.
- ❖ Work with your doctor to establish a treatment plan. Having a plan may help you regain a sense of control over your life and feel more settled.
- ❖ Try to do as many of your usual activities as you can. Doing the things you usually do can help you feel more “normal” as you face all of the new situations that colorectal cancer creates in your life.

This is a very difficult time in your life, and just as there are some things you can do to help yourself feel better, there are some situations that can make this time even harder. If you are having problems in your marriage or have had a recent divorce, the pain of this situation may make you more vulnerable to the new difficulties you may face as you deal with having colorectal cancer. The recent death of a family member or friend can also stress your ability to cope with your recent colorectal cancer diagnosis. Not having any close relatives or friends living near you, or stressful work or money problems have a similar affect on your ability to cope with your diagnosis. If you are currently trying to deal with one of these situations, or another difficult or emotional situation, you should tell your doctor or nurse. They may be able to suggest other people or resources you might turn to for extra help.

When the News Sinks In

Each new situation has the potential to cause distress, so it's important for you to have ways to manage these situations so that you are able to focus your attention on your health and the people and things that you love.

After the first few weeks or months, you will find you are adjusting to the fact that you have colorectal cancer. The methods you use to adjust to stressful, new situations, including a diagnosis of cancer, are called coping skills or strategies. You will most likely face a series of new and stressful situations as you go through the different phases of colorectal cancer. For example, you may be faced with having major surgery just when you've begun to adjust to having cancer. If you have had surgery and are adjusting to new scars or perhaps an ostomy, you may find yourself in another new situation in which you have to deal with chemotherapy or radiation therapy, or both.

Just as your personality is different from anyone else's, so are your coping mechanisms. You most likely use different coping mechanisms in different situations. How you cope with the stresses of having colorectal cancer is important. For example, being in a constant state of emotional upset uses up your strength and energy, both mentally and physically.

When you undergo cancer treatment, you need all of your strength and energy to take care of your own needs, the needs of the people you love, and other things that matter to you.

From the experiences of people with colorectal cancer and other cancers, we've iden-

tified a number of coping mechanisms that have been very helpful in reducing the stress and anxiety of having cancer. The following is a list of some of these helpful coping mechanisms, along with suggestions about how you might use them in your life with colorectal cancer.

Having a Positive Attitude

At times, it may seem impossible to remain positive with everything that is happening to you. But others living with colorectal cancer have found that keeping a positive attitude can be very helpful in relieving the many stresses they face. Focusing on things that make you happy and on the good people in your life may relieve some of your anxiety and give you a break from thinking about all of the difficulties you are dealing with. It also helps to remind you that there is a lot about you that is important other than the fact that you have colorectal cancer.

"It was fairly easy to maintain a positive attitude after diagnosis, although it took some soul searching and some effort to begin to look beyond myself, but I did. What helped was the realization that, whatever happened to me, the pain and suffering of my caregivers and family would be worse and longer than anything I might suffer. Focusing on their needs made me realize my attitude and behavior had a major impact on how they felt. As hard as it has been at times, I have always tried to present a positive and enthusiastic outlook to all. It does help a great deal — both me and those around me."

You might try some of the following to create a positive attitude. Many people with colorectal cancer have used these methods to “practice” their positive attitudes.

- ❖ Take favorite photographs of family or friends to your chemotherapy or radiation therapy treatments. Showing photographs to other people getting treatments, the nurses, or the technicians can be a powerful reminder of how much you love the people in your life — and how much they love you.
- ❖ Keep a piece of paper by your bed. Before you go to bed at night, write down something you are looking forward to the next day. When you wake up in the morning, look at the paper as a reminder of something good in your life that day.
- ❖ Visit a place that has special memories for you. Special memories can be very comforting in a stressful situation.
- ❖ Reread a favorite book, rent a movie you like, or listen to your favorite music. These activities can take your mind far away from day-to-day concerns and may help remind you there are still many simple pleasures in your life.

Becoming Active in Your Treatment and Care

People who are active participants in their own treatment and care are often better able to cope with the stresses of living with colorectal cancer than those who are not. Active participation can take many forms. Many people with colorectal cancer have found that being a part of their own care makes them feel more in

control of what is happening and helps reduce the feelings of helplessness and hopelessness.

Some ways you can take an active role include:

- ❖ Working with your doctors to make treatment decisions, rather than letting the doctors make the decisions without your input
- ❖ Getting more information about your treatments so you will know what to expect and can make your own choices
- ❖ Working with your doctor or nurse as they try to help you with troubling symptoms or side effects; when it comes to knowing what helps and what doesn't, you are the expert

Focusing on Others

Although there is a real need to focus on your own health and mental state when you have colorectal cancer, many people living with cancer have found that thinking about others often greatly relieves their stress.

"When I was in the hospital recovering from my surgery, I kept thinking that when I got better, I would do everything I could to educate other people about colon cancer. I am doing that now because I want to prevent others from having to go through the pain and frustration I have."

You may find that being diagnosed with a serious illness has caused you to re-examine your life. Many people find that this examination often reminds them of how much the people around them mean to them. If you are a religious or spiritual person, this examination

of your life may cause you to further your commitment to your religious or spiritual community, in addition to your family and friends.

If you have found yourself doing this type of examination of your life, you may find you want to direct some of your energy into focusing on others. This will let your loved ones know how you feel about them, and may help you cope with the stresses of life with colorectal cancer.

"Most of all, my faith in God helped me through this. It has grown stronger with the ensuing time. If I didn't know it before, I know it clearly now — shifting your focus from yourself to loving and helping others brings new joys to life." — caregiver of a CRC survivor

Some ideas for ways to focus on others include:

- ❖ Participating in a support group as a "veteran" and sharing your experiences with others who are newly diagnosed with colorectal cancer
- ❖ Doing volunteer work, which you may be able to do from home if your energy level is low
- ❖ Simply asking others in your family or group of friends about what is happening in their lives can be a great source of comfort for both you and them

Having a Sense of Humor

People living with colorectal cancer have found that being able to hold on to their sense of humor has helped them get through many

difficult moments during their cancer experience.

Some things you might try that others have found helpful in keeping their sense of humor include:

- ❖ Watching your favorite funny television shows or movies
- ❖ Going to the zoo and watching the funny things that animals do, or just watching the antics of your pets
- ❖ Talking with and listening to children
- ❖ Recalling and talking with your friends and family about funny or silly experiences

Taking a Break from Cancer

Dealing with cancer is often a full-time job. There are many difficult decisions to be made. There are often many trying situations to get used to and to learn how to manage. Thinking about cancer all of the time gets very tiring and causes a lot of painful and difficult emotions. You may find that forcing yourself to think of other thing and putting cancer out of your mind for a while eases the stress. Some of the things others have found to be good ways to “take a break from cancer” that you may want to try are:

- ❖ Create something — Creativity can take many forms — knitting a sweater, building a birdhouse, refinishing a piece of furniture, drawing, painting, writing poems or letters to friends, planting seeds, taking photographs; the list is endless — just do whatever you like to do.

- ❖ Play — Sometimes we forget to play, especially when there are so many serious things on our minds. But play can be a great way to take a break from cancer. Perhaps you like to play cards, or chess, or checkers, or board games. If you’re up to it, you may want to go to the driving range and hit a bucket of balls, play some touch football with the children in your life, or show your kids how you’re really supposed swing on a swing. How you play doesn’t matter, as long as you’re having fun.

Letting It Out

As simple as it sounds, being able to talk about and express your most painful or difficult thoughts and feelings is one of the best ways to help deal with them. The ability to share your thoughts and feelings can help keep you from being overwhelmed by them. This can be difficult for many of us because we don’t want to hurt or burden others. But, most of the time, others are glad to listen and may even feel special because you’ve shared something very important with them. There are lots of ways for you to express your thoughts and feelings. No one way of “letting it out” is better than any other — do whatever is most comfortable for you.

Some of the ways others with colorectal cancer have found to express their thoughts and feelings include the following:

- ❖ Talk with your loved ones — Your family and friends can be of great help and comfort by allowing you to talk freely about the difficulties of living with colorectal cancer.

Communicating with your family and friends will not only help you, it may also help them understand what you need and how they can best help you. Just as you may sometimes feel helpless in your struggle with colorectal cancer, your loved ones may sometimes feel the same way because they want to do things for you, but don't know what you need. Open and honest communication can make all of you feel better.

- ❖ **Join a support group** — There are support groups just for people with colorectal cancer. Other groups may be for people with any form of cancer. Most groups have a leader who will guide the group's discussions. The whole point of a support group is to provide a place where you can share your thoughts, feelings, and experiences. Sometimes, you may find it hard to talk about having cancer with your family or your friends because you don't want to upset them. A support group may offer a place where you can talk about these things with people who understand, but who will not be emotionally upset by hearing them. There are also support groups on the Internet where people communicate with each other using e-mail. These groups generally do not have a leader, but can be a very real source of friendship, comfort, and support.
- ❖ **Find confidants** — Some of your thoughts and feelings may be too personal for you to feel comfortable expressing to a group of people. You may worry that talking to your loved ones about these thoughts and feelings will be too difficult for them. If this happens,

you might find it helpful to talk to someone you trust who is not an intimate part of your life. This person may be a clergyman or woman, a counselor or therapist, a social worker, or another person you trust.

- ❖ **Look to yourself** — Many of us are very private. Sharing our thoughts and feelings with others may not come easily. Although it is important for you to try to communicate some of your thoughts and feelings to others, you may find some things are just too personal to talk to someone else about. If this is your situation, you may find that writing your thoughts and feelings down on paper will help you release them. Writing things down can also be useful in trying to sort out your thoughts and coming up with plans to move forward.

The coping strategies just listed are those that tend to be the most helpful in reducing the stresses of living with colorectal cancer. However, there are some other common coping strategies that can actually create more problems for you than they solve. None of these coping mechanisms is "bad." In fact, we all use them to some extent every day. However, problems can come about if you find yourself using one of the following coping mechanisms without using some of the stress-reducing strategies, too.

Being Isolated

Many of us like to be by ourselves when we are upset or worried. It gives us a chance to think and time when we don't have to worry about what others think about how we're

behaving. This is normal and healthy. But you have a lot to handle right now, too much to handle on your own. Take your time alone, but remember it's also important to come back to those who love you. Share your thoughts and feelings as much as you can. This is a time when you need the love others have to give you — and don't forget, they need you, too.

Being Pessimistic

Everyone with cancer at some time or another finds themselves asking, "Why me?" There are days when it seems as if everything that possibly could go wrong has gone wrong. When you're feeling particularly bad physically, it may seem impossible to believe that there is anything good left for you. Everyone with cancer has these thoughts and feelings — they are a normal reaction to a very difficult situation.

If you have these kinds of thoughts and feelings most of the time, life in general becomes very difficult. If you find you are struggling to get these kinds of thoughts out of your head, it's important to talk to your doctor or nurse about it. There are many ways to help you through this, but only if others know you are struggling.

Coping with colorectal cancer is a huge job. Thoughts, feelings, and worries change from day to day with some days being a lot worse than others. There is no right or wrong way to handle these stresses, only what works best for you to keep yourself from being overwhelmed. Coping is finding your way of living with

colorectal cancer without it becoming your whole life. Don't be afraid to ask for help.

Sharing the News

Deciding who to tell about your diagnosis and how and what to tell them can be another hard decision. Who you decide to tell and when is entirely up to you. There is no right or wrong decision, only what feels most comfortable for you. However, as you decide, you may want to consider the following things:

- ❖ A diagnosis of colorectal cancer is not something to be ashamed of or embarrassed about.
- ❖ Talking about your diagnosis with others may ease the burden of having to deal with it alone.
- ❖ If your loved ones know what is happening to you and how you are feeling, they can support you in many ways.
- ❖ The process of telling others can help you accept the reality of the situation.

Even if you have decided to tell certain people about your diagnosis, actually sitting down and doing it can be hard. But remember, there is no right or wrong way to do it. Trust your own judgment.

“Remembering how, in the past, I felt a loss in such situations, I told them I didn’t want anyone to only think of me in terms of having cancer. I am still ME. Yes, I have cancer, feel free to ask about it, but don’t feel that’s predominantly all that I am about now. Everyone offered to help initially, and I realized by accepting help and TELLING others exactly what I needed was a win-win situation for us all. It made them feel useful and less awkward and was a big help during the times I was very fatigued.”

Each person reacts differently to shocking news. It’s possible you may get a reaction you don’t like or that bothers you when you tell someone about your diagnosis. It’s important to understand that this doesn’t necessarily mean the person is intending to hurt or reject you. Family members and friends may be very frightened or overwhelmed with sadness because they are afraid they may lose you. People often just don’t know what to say, and are afraid of saying the wrong thing, so they say nothing at all.

If someone reacts in a way that doesn’t feel “right,” try to explain how it made you feel. This will give that person a chance to tell you how he or she is actually feeling. Although this may be awkward or uncomfortable, talking with the person about your struggles will ultimately benefit both of you.

“Initially, everyone was really supportive, but after a while one of my closest friends kept making excuses not to get together. I ignored it for a while and finally confronted her in a gentle way wanting to know why she never seemed to have time for me. She just blew up and screamed and told me she never wanted to see me again. I had insulted her just by suggesting that she was avoiding me. There is nothing you can do about such people. These attitudes hurt, but the problem is theirs not yours, and the only solution is to move on. I made a real effort to reach out to all my friends and let them know that they needn’t walk on eggshells around me or watch what they say. Soon things pretty much returned to normal. The subject of my cancer rarely crops up, and when it does no one feels uncomfortable.”

Telling Your Spouse or Partner

If your spouse or partner was not with you when you got your diagnosis, telling him or her may be the first hurdle to overcome. Your spouse or partner will probably have many of the same thoughts and emotions you are having, and, like you, their thoughts and emotions will change over time. The best way you can help each other through this very difficult time in your life together is by trying to communicate as openly and as honestly as you can. This may not be easy because you might not know how to talk to each other about these feelings and emotions that may be new to both of you. But it is important now, more than ever, that you have each other. Some suggestions you

might want to consider to make it easier to break the news to your mate include:

- ❖ Pick a time when you can be alone together without interruptions. Choosing a time when you are not likely to be called away to do something else will give you both the freedom to talk about what is happening without feeling rushed.
- ❖ Choose someplace private for this discussion. This will allow you both to express your thoughts and feeling without having to worry about someone else overhearing your conversation.

Although you and your spouse or partner may have been together for a long time, trying to predict how someone will react to this kind of news is usually not possible. Be aware that your spouse or partner may not react the way they usually do, or the way you expect them to. Try not to let this alarm you or bother you too much because your spouse or partner needs you as much as you need him or her right now.

Telling the Children in Your Life

Adult Children

Although your children may be grown up, they are still your children, and hearing that a parent has a life-threatening illness can be very upsetting for them. You have been a constant in their lives from the time they were born. The thought of something happening to you will likely cause them great pain and worry. Remember, too, although they are your children, they are now adults, and as adults, they can be a great source of support and help. Allowing them to help you through this time

will help all of you. Some things others with colorectal cancer have found helpful in telling adult children about their diagnosis are listed below.

- ❖ If possible, telling your children in person may make it easier for all of you. Being able to be with you in person may help reassure them and provide some comfort as they adjust to the news.
- ❖ If you have more than one child, you may want to tell all of your children at the same time. This may be easier for you in that you only have to tell the news one time. It may also be easier for your children because they will have each other to talk to about their thoughts and feelings.

Young Children

Many people with colorectal cancer have young children in their lives: their own, grandchildren, nieces, and nephews. Often, as adults, we believe it's best to "protect" children from troubling news or experiences. However, regardless of their ages, children can usually sense when something is wrong. Not knowing what is happening can cause children much more anxiety than being told the truth about a situation.

"After learning of my cancer diagnosis, I had decided I would not tell my two children (ages 14 and 10) ... about this situation unless necessary. Well, when my eldest came home from school, she found me crying and demanded to know what was wrong. Not wanting to lie, I told her. To my surprise, she handled it quite well. I told my younger child after my surgery, and she also handled it well."

If you are trying to decide how to tell children about your illness, you might keep the following things in mind:

- ❖ Tell children the facts as you know them, but in words they can understand.
- ❖ Keep it simple. Children tend to be very literal, so a very simple explanation that directly addresses their immediate concern is often all they need.
- ❖ Reassure children that it is nobody's fault that their loved one got sick. Children tend to see themselves as the center of the world. Because of this, it is very common for children to think their loved one's cancer happened because they misbehaved or had angry feelings toward the person who got sick. For this reason, children need to be reminded frequently that their loved one's cancer is not their fault.
- ❖ Let the child take the lead. Children will usually tell you exactly what they want to know. You may find a child comes back to you over and over again asking the same question. Be patient, and answer the question the same way every time. It is not that

the child is trying to be difficult, but rather he or she is having a hard time understanding or accepting the answer.

- ❖ If you find you are too tired to deal with a child's questions, ask another adult to be your spokesperson. This is okay as long as the child understands there was nothing wrong with asking questions.
- ❖ Picture books can be helpful for young children if they are having a hard time understanding what the disease is about. Older children may want information that is written for their age levels. Ask your nurse, librarian, or support group members for recommendations on books for children dealing with cancer in their families.

"We've been faced with a lot of the same questions with the kids. The best thing we found was to tell them the truth: 'Mommy is very sick with cancer and needs weekly treatments at the doctor's office.' That sort of thing. The important thing is to be honest with them at all times. This doesn't mean to tell them Mom might die, but answer the questions as best you can. Like, 'Mom is undergoing treatments to stop the cancer,' etc."

Telling Other Family Members

Again, who to tell about your diagnosis is up to you. You may find it is easier in the beginning when you are still trying to come to grips with your diagnosis to have only a few people know. In time, as you get used to the news, you may find you want to tell others.

If your parents are living, you will probably want to tell them. This can be tricky, especially

if your parents are not in good health themselves. Try to reassure them, but be honest about your limitations at the moment. If you are used to doing some of the day-to-day chores for your parents, friends or other family members may be very helpful by acting as your temporary substitute. It is very difficult for parents to have a sick child, no matter how grown up he or she is. You may all benefit if you are able to tell your parents how they can help you during this difficult time in your life.

You may want other family members to be aware of your diagnosis, as well. Depending on the size of your family, this can be an exhausting task. You may want to consider having another family member or a friend do this for you.

Emotional Support During Treatment

Living with colorectal cancer can seem like an endless series of decisions: “I’m too tired to do more than one thing today, so which should I do — the doctor or the store?” “Who can I get to watch my children or my pets while I am at the doctor for my checkup?” “What am I going to eat today?”. The decision-making can sometimes seem overwhelming. This is a time in your life when you might need to allow others to help you.

You may have heard the phrase, “cancer affects the whole family.” In addition to the physical and emotional toll colorectal cancer is taking on you, it exacts a toll on your family, too. Whether you are part of a couple with no children living at home, have small children, or are single and your family is comprised of close friends, someone close to you may benefit from some kind of support during your illness.

The bad news is that, at times, having colorectal cancer will be at the center of your life. The good news is that you absolutely do not have to go through it alone. Having a strong support network can help you maintain some balance, control, and normalcy in your life.

Support Networks

If you are interested in joining a support group as part of your *support network*, you may

want to enlist the assistance of a social worker or a caseworker at your treatment facility. This person will be able to tell you about support groups in your area. He or she can also be of tremendous assistance in directing you to other resources that you may not have thought of, such as:

- ❖ Assistance with meals during treatment
- ❖ Assistance with transportation to and from appointments
- ❖ Financial aid
- ❖ Child care during treatment

If you live in a large city or metropolitan area, you have a good chance of having a wide variety of services available to you. But don’t let size fool you. Sometimes small towns have extremely strong support options for residents. You’ll never know unless you ask.

Many of the resources you locate will also have support services for your family. Let your family members know that support may be available for them as well. Many people with cancer find only another person with cancer can really understand what it’s like to have cancer. The same holds true for caregivers, other family members, and friends. Support groups allow you to interact with other people

who are in a similar situation. In this way, support group peers can be a very valuable source of advice and comfort.

Colon Cancer Alliance Support Programs

The Colon Cancer Alliance (CCA) was created *by* people whose lives have been touched by colorectal cancer *for* people whose lives are touched by colorectal cancer. CCA offers support and information services to survivors and caregivers. The CCA Connections Program currently offers two types of peer support for people affected by colorectal cancer. While CCA offers no professional advice or counseling, the peer support available through these services may be invaluable to you and your loved ones.

The Buddy Network

The Buddy Network can match you with someone whose situation is similar to yours. You can talk with your buddy on the telephone or correspond via e-mail or written correspondence, or all three. A buddy can share his or her personal experiences as someone living with colorectal cancer. The Buddy Network is also available to caregivers. To apply for a buddy, contact CCA on the Internet at www.CCAAlliance.org or by calling 1-877-422-2030.

"I found statistics and trends and facts that pertained to folks over 45. I couldn't find one single incidence of colon cancer in a young woman. I couldn't find anyone out there who resembled me. Then I came upon CCA. I signed up for a buddy, never expecting to get one, and I met not one, but two other women in the young 30s with colon cancer. Rejoicing would be too strong of a word for what I did, but I did feel a great sense of relief in knowing that I was not alone."

Internet Resources

Since CCA evolved from an Internet discussion group, the Internet continues to be a major tool for communication and education for CCA members. Currently, CCA hosts nine live regular Internet chat meetings per week as well as special chats on specific colorectal cancer related topics. The chats are a great way to get information about colorectal cancer, but they're also a way for people to just talk. Discussions can be about anything: politics, religion, families, or life in general. Please feel free to invite people to the chat room. You can check the CCA Internet site at www.CCAAlliance.org for a calendar of chat sessions.

"I would hate to lose this colon cancer Internet discussion list. Please keep sending posts! This list has been a source of inspiration, love, information, friendship, and encouragement to me. Let's keep it rolling!"

For other support resources, see page 38.

Your Emotional Well-Being During Treatment

Living with colorectal cancer is one of the biggest challenges you will face in your lifetime — mentally, physically, and spiritually. We have discussed throughout this booklet the numerous new and changing stresses you may be facing. Undergoing chemotherapy or radiation therapy, or both, for colorectal cancer brings another new set of stresses and worries.

For some people, the time they are going through chemotherapy or radiation treatments is when they physically feel the worst. Feeling bad when you're trying to get better can be hard to handle. Feeling worse because of treatment may cause you to question whether you've made a good choice. You may find it gets harder to keep your spirits up day after day when you feel lousy. This can be made worse by the very common question that stays in the minds of nearly everyone in active treatment for colorectal cancer, "Is this working?"

Financial pressures may begin to mount during this time. Taking care of day-to-day household tasks may become too burdensome for you. For many people, being in a position of having to depend on others on a daily basis can be quite an uncomfortable position. You may have trouble eating during this time. New aches and pains, demanding treatment schedules,

and seemingly endless appointments and procedures can wear you down. It's certainly more than enough to overwhelm even the toughest among us.

There are some very common and normal reactions people have when they are placed under this kind of stress. These can include anger, fear, bewilderment, sadness, self-pity, dread, grief, and others. There are two other common reactions, anxiety and depression, that, while normal, can get out of control. It's important to recognize these reactions because, if they do begin to take over your thoughts and feelings, they can make your life very difficult. Anxiety and depression are described below along with how to recognize if they are becoming a problem for you.

Anxiety

Anxiety is the uncomfortable feeling we have when we're worried or scared about something. Certainly there are many new worries and fears that you are facing as a person with colorectal cancer. The anxiety you feel is called *situational anxiety*. It is a normal response to real worries and stresses.

Although anxiety is normal when you are dealing with a situation as serious as cancer, there are times when you may need help

managing your anxiety. Some of symptoms of anxiety that may indicate a need for some additional help include:

- ❖ Trembling, twitching, restlessness, or feeling “shaky”
- ❖ Shortness of breath or a smothering sensation
- ❖ Fast heart rate or a feeling of your heart pounding in your chest
- ❖ Dry mouth, trouble swallowing, or feeling like you have a lump in your throat
- ❖ Sweating, chills, or hot flashes
- ❖ Cold or “clammy” hands
- ❖ Feeling keyed up, edgy, or irritable
- ❖ Exaggerated startle response, or jumpiness
- ❖ Difficulty concentrating, or your mind going blank
- ❖ Trouble getting to sleep or staying asleep

“I can’t wait for the surgery to be over with and to start the rest of my life. I’m getting impatient to end my sense of dread and feelings of uncertainty.”

Anxiety is nothing to be ashamed of or embarrassed about. If you are having some of the symptoms listed above, tell your doctor or nurse. There are medications you can take to help you get rid of many of these uncomfortable symptoms so you can concentrate on other things.

Depression

Being diagnosed with colorectal cancer brings about many feelings, and those feelings tend to differ from person to person. But

sadness is one emotion that nearly all people diagnosed with cancer experience. A diagnosis of colorectal cancer can lead to many changes for you, such as changes in your body, alterations in your daily routine, work disruptions, adjustments in your relationships with loved ones, and others. Having colorectal cancer may mean giving up, at least temporarily, some of the things you most enjoy.

All of these changes are losses of one kind of another, and one of the normal responses to loss is sadness or depression. When we are depressed, we are often quieter than usual. Many of us want to be alone. You may find yourself crying more than usual or feeling as though you might cry at any moment. All of these experiences are normal responses to loss and sadness. However, if you find you feel like this nearly all the time, or that you used to be able to “shake” these feelings, but now you can’t, you may need some help to get past these feelings.

Sometimes, it’s difficult to know if the sadness you’re feeling is turning into depression. Depression that lasts or takes over your feelings can be a serious medical problem. Below is a list of questions to try to figure out if you are having a problem with depression:

- ❖ Are you depressed or irritable most of the day, nearly every day?
- ❖ Do you find you have no interest or pleasure in any of your day-to-day activities?
- ❖ Do you have a hard time falling asleep or staying asleep most of the time? Or do you sleep all the time, yet still feel tired?

- ❖ Do you feel restless or like you don't want to move at all most of the time?
- ❖ Do you feel worthless or guilty nearly all of the time?
- ❖ Are you having a hard time thinking or concentrating? Or are you feeling like you can't make a decision?
- ❖ Do you have thoughts of death most of the time?

If you answered yes to one or more of these questions, it is nothing to be embarrassed about. But it may mean that your depression is becoming a problem for you. Depression affects many people who are going through cancer treatment. Remember, you are not alone.

The most important thing you can do if you are having trouble with depression is to tell your doctor or nurse. There are many different and effective medicines you can take that can help you manage these feelings as you go through treatment.

"True depression isn't just an attitude that can be reconstituted or wished away. It is an inexplicable grief and sadness, an outlook that is driven by chemistry, not will. Thank goodness for anti-depressant medicines."

Your Physical Well-Being During Treatment

Diet and Nutrition

As you go through treatment for colorectal cancer, your diet and nutrition are very important. Both chemotherapy and radiation therapy create extra energy demands on your body. Yet, both of these treatments can also interfere with your appetite and digestion. It is especially important during this time that you make sure you are getting enough nutrition.

Appetite and Nausea

Most people receiving treatment for colorectal cancer, whether chemotherapy, radiation therapy, or both, have some change in their appetites.

"On Saturday I felt a slight case of 'almost nauseated' and Sunday had it again, only a little more pronounced. Today, at work, I experienced the same thing. I called my oncologist, and he phoned in a prescription to my pharmacy for something to take care of it."

People getting chemotherapy may experience *nausea*. Although there are very effective medicines called *antiemetics* to control the nausea and vomiting that chemotherapy drugs can cause, some people find they still have a low level of nausea that makes it difficult for them to eat.

Chemotherapy can also cause mouth sores in some people. The sores, which are much like the canker sores we've all had at one time or another, make it painful to eat. Other people taking chemotherapy find their tastes change, or that foods taste metallic, or that food seems to have no taste at all. All of these things make it very hard to eat enough and to maintain a well-nourished body.

"At that time, the oncologist cut the chemotherapy dosage in half and put me on a three weeks on, one week off schedule. I became very affected by smells. Each time I went into the doctor's office and smelled coffee, I got sick."

Radiation treatments, especially if they are directed toward your abdomen, can cause stomach cramps or nausea, or both. If you have these side effects from your treatment, you may also have diarrhea, which can further deplete your body's energy. Each of these side effects may affect your desire to eat and your ability to stay strong.

Diarrhea

Diarrhea is a common problem for people with colorectal cancer. If you have had surgery in which all or part of your large intestine was removed, it is likely that the stool that is

discharged from either your ostomy stoma or rectum is liquid or only partially formed. This is because one of the main functions of the large intestine is to absorb water and electrolytes from the liquid stool coming from the small intestine. Removal of all or part of the large intestine leads to a loss of ability to absorb water, resulting in watery stools or diarrhea.

Diarrhea, in terms of an increased number of bowel movements each day, is also a common side effect of both chemotherapy and radiation therapy (to the abdomen or pelvis) for colorectal cancer. It is very important for you to monitor how much diarrhea you experience because diarrhea can lead to dehydration, malnutrition, weight loss, or any combination of these medical problems.

Weight Loss

Having cancer can cause you to lose weight. This is because cancer cells use your body's energy faster than healthy cells do. The weight loss from cancer, which is called *cachexia*, is not a good form of weight loss.

When you are getting treatment for colorectal cancer, it is more important than ever to be sure your body is getting enough nutrition. Good nutrition provides the energy your body needs to destroy the cancer cells and to replace the healthy cells that may be destroyed by your treatments.

Suggestions for Maintaining Your Weight During Treatment

There are a number of things you can do to help maintain your body weight during treat-

ment. Some of the more common and successful methods are mentioned below, but there are others, too. If you are having a problem keeping your weight up because of changes in appetite or diarrhea, or if what your doctor has recommended is not working, keep talking about it with your doctor because there are many ways to help you with this very common problem. You may also want to talk to other people with colorectal cancer to see what they found helpful in dealing with this problem.

If you're struggling with a loss of appetite, nausea, a change in your tastes, or are eating but still losing weight, the following are some suggestions that others with colorectal cancer have found helpful:

- ❖ Talk with a nutritionist. He or she will help you figure out what your energy needs are or how many calories you need in order to maintain your body weight. You can discuss what kinds of foods you like and don't like. Often, the nutritionist will provide you with specific meal plans to make it easier for you to know that you're getting enough nutrition. You may need to meet with the nutritionist several times before you come up with some solutions that work for you.
- ❖ Eat when you're hungry. Sometimes we think we should eat three meals a day with no snacks in between. But many people receiving cancer treatments find it is easier to eat smaller amounts throughout the day.
- ❖ If you are trying to eat a meal, try limiting the amount of liquids you have because

liquids may fill you up before you've had much of a chance to eat any solid food.

- ❖ If you are feeling up to it, you may try taking a short walk or doing some other form of light exercise before a meal. Exercise stimulates the appetite.
- ❖ Try foods you ate as a child. Many people who have had cancer say the foods they ate as children were the only foods that tasted good to them when they were receiving treatment.
- ❖ If the smell of food bothers you, cool or cold foods may be easier to eat because they usually don't smell as strong as hot foods.
- ❖ If your weight loss is particularly fast or if other approaches are not working well enough to stop you from losing weight, your doctor may want to prescribe medicines that will stimulate your appetite.
- ❖ Some people, especially those with mouth sores, find it is easier to take in liquids than it is to eat solid foods. For these people, milkshakes or blended fruit and protein drinks, which some people call "smoothies," can provide needed nutrition and calories. Canned nutritional supplements such as Boost®, Ensure®, or Sustacal® are also good sources of high-calorie, concentrated nutrition.

These are just a few suggestions that have helped other colorectal cancer survivors. However everyone's experience is different, and if you are having problems maintaining your weight, it is very important to let your doctor and nurse know this. There are many options

available for you. Your nutrition is very important not only to the success of your treatment, but to how well you feel as you go through it.

Fatigue

Many people experience a general sense of tiredness called fatigue at some time during their treatment. Fatigue can be a direct side effect of chemotherapy or radiation therapy, or it can be the result of *anemia*. Everyone's experience with fatigue is different. Some people with mild fatigue describe it as feeling "a little more tired than usual." Those with severe fatigue describe the feeling as being "too tired to breathe." For many people, their experience with fatigue depends on their treatment schedule and what kind of treatment they are receiving. Some people undergoing treatment for colorectal cancer report their fatigue tends to get worse the longer they are on their treatment. Others find that their body seems to get used to the treatments, and their fatigue actually lessens after a period of time on treatment. Whatever your experience, these are a few tips that others with colorectal cancer have found helpful to reduce their fatigue:

- ❖ Rest when you are tired. This sounds very simple, but many of us are used to pushing ourselves even if we are tired because we feel we must. However, cancer-related fatigue is not like your usual experience of being tired. Fatigue when you are undergoing treatment for cancer is your body's way of telling you it needs you to conserve your energy — to help fight the cancer and to help restore the healthy cells that may be destroyed or

injured during your treatments. Also, unlike “regular” tiredness, you cannot push yourself through the fatigue that comes with cancer treatments. Trying to push yourself will only make you feel more tired.

- ❖ Don't forget to keep moving. Sometimes, cancer-related fatigue is so intense that people find they do little but eat, sleep, and go to the bathroom for days at a time. Although this may be exactly what your body needs for a day or two, it is important when you start to feel your energy level increasing to begin moving about again. You will probably want to ease into this, perhaps starting with just walking around the house and gradually doing more while being careful not to get overly tired. This gradual increase in activity can actually help your energy level return more quickly.

Work-Related Issues During Treatment

For some of us, working a part- or full-time job is strictly about getting a paycheck. For others, work is an opportunity to acquire new skills, to build new relationships, to accomplish goals, to contribute to society. For people facing a major health problem such as colorectal cancer, work can be a welcome diversion from physical discomfort and worry.

Deciding whether to continue working can be a tough choice. Stopping work may create a financial hardship. Reviewing your company's benefits package including health insurance, life insurance, disability insurance, sick leave, extended medical leave, and other benefits programs may help as you consider your options. If your company doesn't participate in a disability program, you may want to consider speaking with a social worker or caseworker where you receive treatment. Whether you have to or choose to stop working, these professionals can provide you with information on Social Security Insurance (SSI) and assist you in completing the forms. Even if you choose to continue working, they may be able to provide you with options to discuss with your employer such as flexible hours, a temporary change of duties or responsibilities, or a leave of absence.

"You may choose at least for now not to take any medications but perhaps just talking with a professional can help you to sort out your feelings and reach some decisions as to how to proceed: continue full-time work, go part-time, quit altogether, chemotherapy or no chemotherapy. You have a lot of things to think about, and maybe the help of a professional is needed to help you look at these questions."

Even if you are not sure whether or not you will need to stop working for a while, you may want to consider applying for disability insurance or SSI because getting these benefits approved can take a long time. You can always withdraw your application if you don't need the payments. But applying early will shorten the time before you start receiving payments if you find you do need them.

Insurance Considerations

Employment benefits provide many people with something of tremendous value, especially someone recently diagnosed with colorectal cancer — health insurance. When you have the opportunity, it may be helpful to review your company's medical benefits. Some medical insurance programs are capitated, meaning there is a limit on the amount of

money that can be spent on an individual's care. These limits may be for all of your health-care over the lifetime of your policy or they may be disease-specific. As treatments can be very expensive, you will probably want to know what your policy limitations are so that you can make your plans and decisions accordingly.

If you choose not to work, for whatever reason, you may find it helpful to know about a Federal law regarding health insurance benefits. This law requires employers who offer health insurance benefits and employ 20 or more people to offer employees and their dependents the option to continue their health, dental, and vision insurance through the company's group policy after the employee leaves the company. The law is called the Consolidated Omnibus Budget Reconciliation Act (COBRA). To maintain your medical insurance under COBRA, you will be required to pay the policy premiums once you leave your job. Under COBRA, you can keep your health insurance for up to 18 months and can keep health insurance for your dependents for up to 36 months.

If you are considering *changing* jobs, there are some important insurance issues to think about:

- ❖ Will your new health insurance begin immediately, or is there a waiting period for pre-existing conditions?
- ❖ Will the amount you are required to pay for prescriptions go up?

- ❖ If you have life insurance at your current job, can you take it with you without penalty or having to reapply?

Continuing your life insurance may not seem like a high priority, but it is an excellent example of how having all the facts before making decisions can be helpful. There are now companies that will purchase or loan you money against your life insurance policy. The money you receive for your life insurance could be used to meet a number of needs, such as:

- ❖ Treatment that you might not otherwise be able to afford
- ❖ A second honeymoon (or a first one you never had)
- ❖ A dream vacation you have always wanted to take

Job Changes

It is not uncommon for people to consider a job change after they have been diagnosed with cancer. One of the things people living with cancer often look at closely is work. You may have begun to think about how much time you spend at work. Some people decide that work takes too much time away from their family and personal life. Some people decide work is causing too much stress in their life. While many people will adjust their work habits if they feel a change is necessary, some feel that changing to a less stressful, or even a lower paying job, may be better for them. At first glance, changing to a lower paying job may not seem like a practical decision, but many large companies have very good medical benefits packages that begin on the first day of employ-

ment and will cover the cost of your treatments. In this case, it may actually be better economically to take a lower paying job if the costs you are required to pay for your healthcare are reduced or the quality of healthcare you receive will improve.

You may think that since you have been diagnosed with colorectal cancer, you are stuck in your current job because you won't be hired elsewhere because you have cancer. This is not true. First, it is against the law to discriminate against someone with cancer under the Americans with Disabilities Act (ADA). This act is explained in more detail in the following section. Second, when you are looking for a job, you are not required to disclose your condition unless it directly affects your ability to do the job.

An employment specialist, a social worker, or caseworker where you receive treatment may be able to help you sort through everything you should consider before making a change in your employment.

Job Discrimination

Discrimination can be a real issue for people with cancer. It is important that you know your rights in case you experience discrimination because you have cancer. As we mentioned in the previous section, cancer is considered a disability under the Americans with Disabilities Act.

Under this act, any employer with 20 or more employees must comply with the following regulations:

- ❖ An employer cannot refuse to hire nor can he or she fire a person with a disability, as long as that person is otherwise able and qualified to do the job.
- ❖ An employee cannot be demoted or fired because of disability, or because the employer thinks there will be a disability.
- ❖ An employer cannot refuse insurance or other benefits to an employee with a disability, when the same insurance or other benefits are provided to other employees.
- ❖ Employers must provide certain types of help to people with disabilities, if they need that help to perform their jobs. Examples include retraining, special devices, or a change in some other part of the job.

In order to protect yourself in case there is a problem, you may want to keep written records of all performance evaluations, promotions, or demotions. You may also want to document any comments, conversations, memos, or other exchanges that you think reflect discrimination. Be sure to document anyone who was involved in each incident.

Making Adjustments and Finding Support After Treatment

There are several possible outcomes after treatment for colorectal cancer:

- ❖ The treatment got rid of all visible evidence of cancer; this is called a *remission*
- ❖ The treatment stopped the cancer from growing, or maybe even caused it to shrink some, but it did not get rid of all of the cancer; this is called a *partial response*
- ❖ The cancer continued to grow or spread in spite of the treatment; this is called a nonresponse

Whichever group you are in, you will experience new and different concerns and stresses.

Living with Remission

If your treatment was successful and your cancer is in remission, you may feel as though you have a new lease on life, with every day seeming like a gift. However, fear of recurrence may also be part of the aftermath of colorectal cancer treatment. Many survivors have described this as “waiting for the other shoe to drop.”

The possibility of a cancer recurrence can be very frightening. Some people find that the “regular” aches and pains of life now cause them great worry, as they fear every new pain represents the return of the cancer. Fearing a

recurrence of cancer can sometimes make it difficult for you to resume your life.

“Fear of recurrence? Oh yes, it’s always there. At this stage, I am said to be cancer-free. That sounds wonderful, but I am also realistic. I know what the facts and percentages are. I know it is possible that some time in the future (the far future, I hope), I may have a recurrence. What will I do if that happens? Why, the same thing I did the first time — fight it! Fight it with all I have, and never give up!”

Some colorectal cancer survivors have found that active participation in maintaining their own health is helpful in dealing with the fear of recurrence. This participation can take many forms, including some or all of the following:

- ❖ Eat healthy — Be sure your diet is low in fat and contains adequate fruits and vegetables (only those that agree with your digestive system).
- ❖ Establish a regular exercise program — If you have been relatively inactive during your treatment because of fatigue or weight loss, be sure to talk to your doctor before beginning a new exercise program. Start slowly, and gradually build your endurance as any athlete does. Remember, exercise can take many forms, not just walking or running.

Activities like biking, dancing, swimming, and hiking are all good forms of exercise. The key to sticking to any exercise program is finding an activity you enjoy.

- ❖ Manage your stress — Many of us are so used to stress that we accept it as part of our daily lives. Although we all have some stress in our lives, too much stress wears down the immune system and makes us more susceptible to disease. Managing your stress may mean asking someone else to take over some of your responsibilities. Many people find activities such as reading, meditation, or yoga to be great relievers of stress and anxiety. Other people manage their stress by learning as much as they can about how to maintain their health and making changes in their life based on what they have learned.

"I have learned quite a lot about different CT scanners and their settings, how these affect the reliability of the CT findings, and how it can make comparing CT scans difficult. With this knowledge, I was able to persuade the x-ray technician to do this week's scan at a more precise setting than the previous scan."

Knowing that your doctor will be keeping a very close eye on you in the coming months and years can be reassuring. Regular checkups with your oncologist are very important. He or she will have a very specific schedule for office visits and for follow-up examinations. These examinations may include x-rays, CT scans, barium studies, colonoscopies, blood tests for carcinoembryonic antigen (CEA), or other tests.

Although the use of x-rays, scans, and visualizing the intestines with a fiberoptic scope is standard procedure for monitoring nearly all colorectal cancer survivors, the use of the CEA blood test is more variable. CEA is a protein that may be released into the blood by some cancer cells, but can also be released by noncancerous cells when there is another medical problem. Because CEA is found in the blood with illnesses other than colorectal cancer and because not everyone with colorectal cancer has an elevated amount of CEA in their blood, using CEA to monitor for disease recurrence may or may not be helpful for you. CEA is most helpful for those people who:

- ❖ Had an elevated CEA at the time of diagnosis, and
- ❖ Had their CEA return to normal after treatment

For this group of people, a rise in blood CEA may indicate a cancer recurrence, although as mentioned, there are a number of other reasons for an elevated blood CEA.

Whatever colorectal cancer surveillance program you and your doctor decide on, it is important for you to stick to the surveillance program. This will give your doctors the opportunity to monitor you to make sure there are no signs of cancer recurrence, and may help reduce your anxiety about a recurrence.

It is not uncommon for people with colorectal cancer to find that many of the people who were very helpful and supportive during treatment seem to be less available for

them once treatment has ended. This sense of being alone with your worries about what lies ahead can be very upsetting. Even if you did not participate in a support group during treatment, this may be an ideal time for you to consider joining a colorectal cancer survivor group — either in person or on the Internet. For information about support groups, see the Resources section at the end of this booklet.

When Treatment Does Not Produce a Remission

For people whose treatment has not produced a remission, the worries, stresses, and feelings that come with the completion of treatment are quite different. It's most important to keep reminding yourself that sometimes treatments fail people, but people do not fail treatments. It is not uncommon for people whose treatment has been unsuccessful to feel as if somehow they are to blame. This is not true. A treatment may fail for any number of reasons — none of which are your fault.

If your treatment did not work, you may be feeling many of the same feelings you experienced when you were first diagnosed: anger, disappointment, sadness, fear, grief, and bewilderment, among others.

"After the treatment had worked so well, it was a shock to learn that it was no longer working, and that we'd have to go on to something else."

You may also find that once the news of treatment failure sinks in, you will be able to move on to your next set of decisions. If you are finding this transition difficult, think about

how you coped during the time right after your diagnosis. This time is similar, and what helped you then will very likely help you now.

Some people who undergo treatment have what is called a partial response. This means the tumor or tumors got smaller, but have not gone away completely. People who experience this kind of treatment response find their feelings and reactions to the news are somewhere between those who have had a remission and those whose cancer did not respond to treatment. You may feel a mixture of disappointment and gratitude, sadness and happiness, hope and despair. If you have had a partial response, you may be tempted to think about what you could have done differently that might have led to a complete response. Try not to fall into this trap. You are not to blame for the fact that the cancer did not completely respond to treatment.

Whether you have had a partial response to treatment or the cancer did not respond at all, you will have new decisions to make. Some people may try another type of treatment; others may not want to pursue that course. There are no right or wrong decisions, only the decisions that are most comfortable for you. As you face these decisions, the same coping mechanisms you used when you first started treatment may help you through this, too.

Hope

Regardless of whether completion of treatment has left you in a state of remission or not, you and your family will still face a very emotional time. Each person's experience with

colorectal cancer, or any other cancer, is different. But, if there is one thing that nearly all those living with cancer have found to be essential on their journey, it is hope.

Hope can mean very different things to different people. What we hope for at different times in our lives is very different, too. But the presence of hope in our lives keeps all of us going from one day to the next. Maybe when you were first diagnosed, you hoped there had been a mistake. During treatment, you may have hoped for a cure. If your treatment was never expected to achieve a cure, maybe your hope has been to spend more time with your loved ones. For one person with colorectal cancer, hope may take the form of seeing another summer; for another, it may be seeing one more sunset.

The point is that hope sustains life. No matter what the outcome of your treatment is, there is always room for hope. It may be hard to see what there is to hope for at times, and when you find it is, talk to your loved ones. Their love and affection for you will help you see where your hope lies when the times are the hardest.

There is no rule book when it comes to having cancer. The problems and disappointments, the ups and downs can be overwhelming at times. Others with colorectal cancer have found that focusing on something you are truly looking forward to, whether it is later on today, or next month, or next summer, can help you get through many difficult moments.

Returning to Work

Whether or not to return to work can be a very difficult decision for many people who have completed treatment for colorectal cancer. The need for a regular income is very important for many people. For others, the desire to focus on something other than colorectal cancer is the main reason for wanting to return to work.

Probably the most important considerations for you in making this decision are your health and the expectations likely to be placed on you if you return to work. Each person will have a different experience with colorectal cancer, its treatment, and its side effects.

Sometimes, side effects take a long time to disappear; other times they disappear right away. Sometimes, they just become a little easier to tolerate. Occasionally, side effects will show up many months after treatment. You will need to honestly look at your current health status and decide whether or not you think you can manage the expectations that will be placed on you if you decide to return to work.

Other factors may need to be carefully considered. If you have an ostomy, the privacy of the restroom facilities at work may play a part in your decision. You will certainly need follow-up appointment and tests. Will your

employer be flexible enough for you to keep these appointments without causing too much distress? Other factors to consider when you are trying to decide about a possible return to work include such things as how physically strenuous your work is and any travel requirements.

Many people have a desire to return to work, but they either cannot or do not want to resume all of their previous responsibilities. A part-time schedule provides the opportunity for such things as readjusting to getting up for work every day, incorporating the timing of any post-treatment medications into your new schedule, and working out how and when you need to rest. Although your employer may allow you to do this, you need to be aware that part-time work may disqualify you from Social Security or disability benefits, depending on how much you work. Talk to a social worker or caseworker where you receive treatment for more specific information about how to negotiate this type of arrangement with your employer and possible options for retaining your medical benefits.

Once you have carefully considered all of your options and rights and you feel certain you want to return to work in some capacity, it

is probably time to meet with your supervisor. You and your supervisor can discuss what the best situation would be for both you and the company. When discussing the situation with your supervisor, do not be discouraged if he or she is resistant to some of your ideas. Your supervisor may not understand what colorectal cancer is and how it affects you. If you feel he or she is hesitating because they aren't sure if you're physically up to the job, reassure them of your situation. It is best to be completely honest about your physical and emotional situation. This will allow you and your supervisor to come up with a realistic and workable compromise that will benefit both you and the company you work for.

"I didn't work for eight and a half months. I finished treatments in October and started back part-time in December. My employers have been very understanding and flexible since then — letting me work at home sometimes. But it's got to be at least twenty hours a week so I can keep my insurance benefits. My boss and I have identified certain projects that I can do without having to access the company database, so they can be performed off-site. This also helps with my continuing, never-ending schedule of doctor appointments after treatments. Feels like I've got at least two a week every week for one thing or another."

If you decide to return to work, be aware that some of your coworkers may treat you differently than they did before your cancer diagnosis. They may ask you how you are doing, but at the same time sound as if they

don't want to hear the answer. They may just be afraid of saying the wrong thing. Others may seem to be avoiding you. It may be that you having cancer frightens them because it makes them realize it could happen to them, too.

If most of your coworkers already know about your diagnosis, you may consider sending everyone a memo or an e-mail thanking them for their concern and telling them of your health status. At the same time, you can let them know the best way to talk with you. You may decide you don't want to "bring your cancer to the office." Whatever you decide, it is best that you tell people how you want them to communicate with you.

Finally, if you make a decision to return to work, but find the situation is too much for you, or if your health status changes, talk with your employer as soon as you recognize the problem. It may be possible for your duties or hours to be limited or rearranged. However, it will be best for both you and your employer if you recognize and deal with a situation that is not working as soon as possible.

Maintaining a Sexual Relationship

Because of the day-to-day decisions and problems that people with colorectal cancer face, sex may be the last thing on their minds. However, for many people, sex remains a part of their lives.

Living with colorectal cancer will include many situations that will require extra patience and effort in communicating. For many people, talking about sex is not easy. But the only way your spouse or partner can know how you're feeling and what you want is if you tell them. Likewise, the only way you will know what your partner needs and wants is if he or she tells you. Otherwise, you'll both be guessing, and, all too often, incorrectly.

Some couples have success resolving the new sexual issues they are facing with colorectal cancer without any outside help. However, you might find it useful to see a therapist to help the two of you through this adjustment. A therapist can help you focus on the issues that are most important for both of you. A therapist can also be helpful in identifying incorrect assumptions that may be creating problems. For example, you may think that your spouse or partner is not interested in sexual activity because you have an ostomy. Your spouse or partner may in fact be inter-

ested in sex, but is waiting for you to initiate the activity because they are not sure if you are able or interested.

In the next few pages we will describe some common questions, fears, obstacles, and concerns about maintaining a sexual relationship — and possible ways to address them.

Physical Concerns

One of the more difficult barriers to overcome for many people affected by colorectal cancer is how they feel about their bodies. Unlike most other cancers, colorectal cancer often involves an ostomy. The ostomy may be a reminder to both you and your spouse or partner that you have cancer. The thought of cancer can quickly counteract sexual desire in many people. Some people find the ostomy bag unattractive and worry about their spouse or partner's response to it, too. Even if the ostomy bag doesn't matter to your partner, he or she may be uncomfortable touching you because they are afraid of dislodging the bag or hurting you. This can easily be misinterpreted as rejection. It may be that even the possibility of rejection causes you to avoid sex, even though you may want very much to have that intimacy in your life.

These examples are some of the very genuine and frequent concerns of people living with colorectal cancer. There are many things you and your spouse or partner can do to work through this time of sexual adjustment. Here are a few things other people with colorectal cancer have found helpful in re-establishing a satisfying sex life:

- ❖ If you normally keep the lights on during sex, try using candles or turning the lights off. The lowered light may help you to feel less self-conscious, especially in the beginning while you are regaining your confidence.
- ❖ If there are parts of your body you are uncomfortable having touched, gently direct your spouse or partner's hands away from these areas. It may be helpful if the two of you discuss this ahead of time so that your spouse or partner does not feel rejected.
- ❖ The two of you may try deciding ahead of time what activity will take place. In doing this, you can select activities that are most comfortable for you and still provide the intimacy and pleasure you are both seeking.
- ❖ If the ostomy bag bothers either one of you, consider emptying or changing to a smaller bag before sexual activity. You may also consider using a stoma cap to cover your ostomy and placing a bandage over it. However, if you use a bandage, be very careful when removing it. You can discuss these options with your enterostomal therapy nurse as he or she is used to dealing with issues related to ostomies and sexual

activity. However, if you are uncomfortable discussing sexual matters, it isn't necessary to go into details.

"This disease is cancer... not leprosy. He is still the same dear man I married and of course the interest in sex is still the same. The only way it wouldn't be is if he were in pain and I were afraid of hurting him." — wife of a CRC survivor

Colorectal cancer surgery itself can have a serious impact on sexual activity. If you are a man, there can be damage to the nerves that cause you to get and maintain an erection. For some men, this nerve damage heals over time, but for others, there may be permanent damage.

There are treatment options for men with nerve damage that include *penile injections*, *vacuum constriction devices*, and *penile implants*. Your doctor can refer you to a *urologist* if you want to discuss which option(s) may be best for you. Some men believe if they are unable to get or maintain an erection, they will not be able to have an orgasm. This is most often not the case. Also, don't think that having a problem with incontinence because of surgery means you're also going to have a sexual problem. This is also often not the case because the two processes are completely separate.

Some women who have had colorectal cancer surgery find they have pain during intercourse. *Adhesions*, or scar tissue, can develop after surgery. During intercourse, the movement can pull on the scar tissue and

cause pain. You may find some relief by doing *Kegel exercises*. Your doctor can advise you about whether or not this might be helpful for you. Kegel exercises involve flexing or squeezing, then relaxing the muscles used to stop the flow of urine. These muscles not only help you control the flow of urine, but also surround the vagina. Exercising and strengthening these muscles around the vagina has helped some women reduce or eliminate the pain they experience during intercourse. Another option to discuss with your doctor is the use of vaginal dilators, which may also help diminish pain during intercourse.

"I discovered after my treatment that a woman may have a problem if she has been treated with radiation because this can cause damage to the delicate vaginal tissues thus making sex uncomfortable. The libido may not be affected but discomfort could cause her to shy away from sex. This type of damage can be treated by a gynecologist."

Contraception

If you and your partner are of childbearing age, it is important for you to practice some reliable form of contraception during active treatment with either chemotherapy or radiation therapy. This is important for men because, although sperm production may be greatly reduced during treatment, the sperm that are produced have a chance of being abnormal. For women, chemotherapy and radiation are both known to be harmful to the baby, especially during the very early stages of pregnancy before you may even realize that you

are pregnant. Discuss birth control with your doctor before beginning any new treatment.

Prescriptions and Over-the-Counter Products

A loss of sexual desire or difficulty being sexual can be the result of factors other than surgery, chemotherapy, or radiation therapy. Some people who take antidepressants experience some form of *sexual dysfunction*. Blood pressure medicines, ulcer medications, and other drugs can also have this side effect. Ask your doctor if it is possible that one or more of your medications may be the cause of any sexual problems you are experiencing.

Romance and Intimacy

There may be times during your illness when you and your partner or spouse may not feel like having intercourse. You may feel too anxious or too tired, yet you may still want some physical closeness. Many couples find this intimacy through kissing, hugging, and fondling. You may also want to consider some other alternatives to intercourse such as oral sex, mutual stimulation, or sensual massage.

However, sex and intimacy aren't necessarily the same thing. Sometimes, getting dressed up and going out on a date can create tremendous romantic feelings. You may find, just as many other couples have found, that reliving your courtship can not only be fun, but can help you remember all the special things about your spouse or partner that caused you to fall in love in the first place.

It is very important for you to remember that, while you may have gone through tremen-

dous physical changes, your partner has not. He or she still has the same needs and desires. It may be difficult for your spouse or partner to adjust to a different or less active sex life. It will be up to you to let your partner or spouse know that even though physical lovemaking may be diminished, your love and desire for him or her has not.

“As trite as it may sound, sexuality is in the head more than any other place. I have found that if you have a willing heart and imagination, sexual gratification can be readily given and received. However, in any discussion about sexuality, one cannot discount the importance of romance and love in all encounters. The forgoing is not a panacea for all situations, but if love is present, then patience and understanding are also likely to be present. These may be needed to overcome the physical, mental, and emotional limitations of both the patient and the partner.”

Talking With Your Doctor

There are other possible problems that may arise from colorectal cancer treatment that may affect intercourse. Ask your surgeon or oncologist, or both, to speak to you and your spouse or partner about the possible impact the treatment you have decided on may have on your sex life. Your doctor may be able to provide you with options that will allow you to continue to enjoy sexual intimacy.

Be sure to discuss with your doctor any options you choose to allow you to continue your sex life. For example, something as simple as a lubricant could be a problem. Many over-

the-counter lubricants contain alcohol and may cause irritation. Though it may be awkward at times, it is best to discuss everything with your doctor just to be safe.

“Everyone is different, of course, but in my case during treatment, sexual intimacy was not important for me; cuddling and hugging were enough. After treatment, as I began to feel better again, interest resumed. My gynecologist was helpful in dealing with radiation damage and menopause problems that arose, and now everything is just about back to normal.”

However you choose to approach sexual activity in your relationship, try to remember that it is an ongoing process. Because of the changes you have gone through, you may feel somewhat clumsy or shy, much like when you first began having a sexual relationship. But just as time, patience, and a caring partner turned your shyness into comfort and pleasure before, the same things are possible for you now. Try to take it slow — and try not to put too much pressure on yourself or your spouse or partner. You’re both learning, again. Steps you take now to maintain your sexual relationship will be of tremendous value as you continue your life.

Summary

Many people describe their experiences with colorectal cancer as a journey. As you continue on this journey, you will have to make many decisions about what paths to take. There is no right or wrong way to take in this journey. There is only your journey, your path. This is your life.

When you are uncertain, try to bring yourself back to what feels right for you. Your healthcare team is there to give you information and guide you. Your loved ones are there to give you what you need, when you need it — and to let you know how very much you are needed and loved. But the choices along this journey are ultimately yours.

No matter where you are in your journey, we wish you well.

Resources

The following is a sampling of the many helpful Internet and print resources available for people with colorectal cancer. You may find them useful in getting additional information about the topics discussed in this booklet. If you are uncertain about how to get any of the books or booklets listed, consult the CCA Internet site at www.CCAAlliance.org. The CCA Internet site has reviews of print resources, links to many of the sites listed below, and easy links for purchasing books about colorectal cancer.

Internet Resources

General

www.CCAAlliance.org — The Colon Cancer Alliance Internet site has extensive resource information covering a wide range of topics that affect colorectal cancer survivors, including clinical trials information. The site offers access to CCA's support services and many links to other helpful Internet sites. For additional information, CCA also has a Helpline that can be reached toll-free at 1-877-422-2030.

www.acor.org — The Association for Online Cancer Resources (ACOR) has many topic-specific e-mail list servers that you can join, including one for colorectal cancer. The topics range from general communication about the disease to the complex emotional and physical challenges that many cancer survivors face.

www.cancercare.org — Cancer Care's Internet site provides emotional support, information, and practical help to people with cancer and their loved ones. In addition, Cancer Care offers educational teleconferences and a toll-free Counseling Line at 1-800-813-4673.

cancer.med.upenn.edu/disease/colon — OncoLink is hosted by the University of Pennsylvania Cancer Center. It is a comprehensive, searchable database with disease-specific menus. The site contains information on psychosocial support, screening, prevention, clinical trials, and a number of other cancer-related topics. It also has extensive links to other helpful Internet sites.

www.cansearch.org — This Internet site of the National Coalition for Cancer Survivorship offers information on a number of cancer-related topics such as clinical trials, basic research, cancer publications, end-of-life issues, gaining inspiration, and others. There are also many helpful links to other Internet sites for people with cancer.

www.cancer.org — This Internet site for the American Cancer Society is a good starting point for information about all cancers, including colorectal cancers. You can locate your local ACS office, learn about cancer patient resources, review terms in the glossary, and gather much more information about the status of cancer in the United States.

cis.nci.nih.gov — This National Cancer Institute Cancer Information Service Internet site has a great deal of information ranging from prevention and complementary medicines to patient education and supportive care. This site has links to other helpful sites, including NCI's home page. The Cancer Information Service can also be reached by phone, toll-free at 1-800-4-CANCER.

Print Resources

General Information

Colon and Rectal Cancer: A Comprehensive Guide for Patients and Families

by Lorraine Johnston

This comprehensive, full-length book for people with colorectal cancer and their families covers a wide variety of topics on colorectal cancer such as diagnosis, treatment, quality of life, supportive care, experimental treatments, end-of-life issues, sexuality, ostomy care and maintenance, and emotional issues that accompany a diagnosis of colorectal cancer.

Colorectal Cancer

by Bernard Levin, MD

This book published by the American Cancer Society includes topics on prevention, diagnosis, staging, treatment, and more. The author offers general guidelines to follow when evaluating complementary and alternative medicines and their sources. As a specialist in colon and rectal cancer, Dr. Levin writes compassionately and with experience and authority about the many decisions and obstacles people with colorectal cancer face in their journey toward better health.

What to Do if You Get Colon Cancer: A Specialist Helps You to Take Charge and Make Informed Decisions

by Paul Miskovitz, MD and Marian Bentacourt

This comprehensive and easy-to-read book is a helpful resource to anyone diagnosed with colorectal cancer. The book covers a number of topics, from polyps and their diagnostic importance, to treatment for all stages of colon cancer. This book is written for patients, and helps guide people battling colorectal cancer by preparing the reader to discuss and take a proactive approach to his or her treatment.

The Cancer Survival Cookbook: 200 Quick & Easy Recipes With Helpful Eating Hints

by Donna L. Weihofen and Christina Marino

This book addresses one of the major problems associated with cancer and its associated treatments, maintaining a healthy diet. The authors used their years of nutritional experience to formulate this cookbook for cancer patients. Most of the recipes are quick and easy, and the authors have included all relevant nutritional information in order to help you choose meals that appeal to you during chemotherapy and/or radiation treatments. The recipes also indicate how to increase calories in the meals in order to prevent weight loss.

Resources For Caregivers

Surviving Your Spouse's Chronic Illness: A Compassionate Guide

by Chris McGonigle

This book is an honest attempt to provide support for caregivers of all kinds. The author was the caregiver for her chronically ill husband and provides first-hand advice for those in the same position. This book compassionately discusses how to cope with issues such as denial, anger, stress over home and monetary issues, and physical love.

The Complete Bedside Companion : A No-Nonsense Guide to Caring for the Seriously Ill

by Rodger McFarlane and Philip Bashe

This book captures the essence of what it is like to care for a seriously ill loved one. The first part of the book gives advice on caring for the seriously ill and takes the reader through issues such as legal affairs, insurance providers, home nursing skills, financial affairs, support groups, preparing for death, and the grief process. The second part of the book address disease specific issues, including cancer. Both authors are experienced caregivers, and the information is provided in a clear, organized way.

When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients

by Elise NeeDell Babcock

Ms. Babcock has over 20 years of personal and professional experience dealing with how cancer affects both the afflicted person and his or her loved ones. The book balances refreshing wit with indispensable information for readers on how to care for a loved one with cancer. Because of her own personal experience, the author writes with a kinship to the reader. She gives specific examples of her own struggle, and provides a beacon for those who give their time, energy, and love to a person with cancer.

Resources For Children of Cancer Patients

How to Help Children Through a Parent's Serious Illness

by Kathleen McCue and Ron Bonn

This comprehensive book is an invaluable resource for parents who are battling a life-changing illness. The authors candidly talk about how to communicate with children of all ages about life changing illness and what impact it can have on a family. The book addresses warning signs children of various ages exhibit when they are having difficulty adjusting to the illness and its impact. Also included are tips on where to find help for children in distress, preparing children for hospital visits, and how to help children cope with the loss of a parent.

Once upon a Hopeful Night

by Risa S. Yaffe and Troy Cramer (Illustrator)

This beautifully illustrated children's book is a wonderful tool for a parent with cancer to begin a discussion about the illness with their child. The book touches on issues of anger, fear, sadness, and hope that many children experience when told their mom or dad has cancer. This book reinforces the love of the child's parents, and takes valuable first steps in presenting a cancer diagnosis to children.

The Paper Chain

by Claire Blake and Eliza Blanchard

This illustrated children's book is recommended for children from preschool through second grade. The book explains in factual, but nonfrightening language the procedures that a person goes through after a cancer diagnosis. Chemotherapy, radiation, and surgery are explained in an easily understood manner. The fatigue a parent may go through and other ways cancer affects the family are also presented. Commonly experienced feelings such as anger, resentment, fear and concern are also addressed.

Daddy's Promise

by Cindy Klein Cohen, John T. Heiney, and Michael J. Gordon (Illustrator)

This book is recommended for children age four through eight. It is the story about a little boy and how he comes to know and understand the death of his father. All the questions that plague a young child in these circumstances are answered by his mother and in a series of dreams where "Daddy" provides the answers and teaches him about life, death, and life after death. Through his experience, the little boy comes to accept death not as an ending, but as a beginning to something more.

Glossary

Abdomen (AB-deh-men): the part of the body below the chest and above the hips.

Adhesion (ad-HEE-zhun): scar tissue that binds connecting surfaces; often causes complications, such as pain or constipation, in a postsurgical patient.

Anemia (a-NEE-mee-a): any condition in which the blood is deficient in red blood cells or hemoglobin.

Antiemetic (AN-tie i-MET-ik): a remedy intended to control nausea and vomiting.

Anxiety (ang-ZI-eh-tee): state of intense apprehension, uncertainty, and fear resulting from the anticipation of a threatening event or situation.

Cachexia (ka-KEK-see-a): general weight loss and muscle wasting that occurs during the course of a chronic illness such as cancer.

Calorie (KAL-o-ree): a unit of measure that reflects how much energy is present in a food.

Carcinoembryonic antigen (CEA): a protein marker in the blood that may be present with some cancers and other diseases; may be used in some cases of colorectal cancer to monitor response to treatment or disease recurrence.

Cell (SELL): the smallest living unit capable of independent existence. Humans are made up of billions and billions of cells.

Colon (KO-len): the part of the large intestine that extends from the end of the small intestine to the rectum.

Dehydration (dee-hi-DRAY-shun): a loss of total body water; in colorectal cancer, this can occur because of vomiting, diarrhea, or low fluid intake.

Depression (de-PRESH-un): a psychological disorder with symptoms such as sadness, inactivity, difficulty in thinking and concentration, significant increase or decrease in appetite and time spent sleeping, feelings of dejection and hopelessness, and sometimes thoughts of suicide.

Feces (FE-sees): the matter discharged from the bowel during bowel movements consisting mostly of the waste material from food.

Kegel exercises: named for a 20th century U.S. gynecologist; these exercises consist of alternately contracting and relaxing the perineal muscles in order to gain more control over their movement. These exercises can be used to counteract urinary incontinence, decrease painful intercourse, or gain active control of the perineum.

Large intestine (in-TES-tine): the last part of the digestive tract; it is divided into cecum, colon, and rectum, and is concerned especially with the reabsorption of water, and the formation and collection of feces.

Nausea (NAW-zee-a): a symptom resulting from the inclination to vomit.

Partial response: a result of cancer treatment that was not able to completely rid the body of the cancer, but did result in either stopping the growth of tumor(s) or caused shrinkage in the tumor(s).

Penile implant (PEE-nile): a flexible and/or inflatable device surgically placed along the length of the penis in order to provide penile rigidity; used for men who have problems either getting or maintaining an erection, to enable them to have sexual intercourse.

Penile injection (PEE-nile): process in which medication is injected into the penis to allow the production and maintenance of an erection; used for men who have problems either getting or maintaining an erection, to enable them to have sexual intercourse.

Rectum (REK-tum): the last part of the large intestine leading to the anus (external opening of the digestive system).

Remission (re-MISH-un): in oncology, a period of time during which there is an apparent absence of cancer in the body.

Sexual dysfunction (SEK-shu-al dis-FUNK-shun): abnormal functioning of the sexual organs, or difficulty engaging in sexual activity.

Situational anxiety: a painful or apprehensive uneasiness due to a stressful situation such as a long-term illness.

Support network: friends, family, coworkers, and others who provide care during a person's lifetime, but particularly when illness strikes.

Urologist (yeu-ROWL-e-jest): a physician who specializes in urinary or urogenital tract diseases and disorders.

Vacuum constriction device: a device placed over the penis that, when pumped, creates a vacuum around the penis and causes it to become engorged with blood (become erect)

This booklet has been reviewed in draft form by a number of people chosen for their diverse perspectives and technical expertise. The purpose of this independent review was to ensure that the material is scientifically sound and responsive to the needs of the broad constituency of people affected by colorectal cancer. The Colon Cancer Alliance wishes to thank the following people for their assistance in the production of this booklet:

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While the persons listed above have provided constructive comments and suggestions, responsibility for the final content of this booklet rests entirely with the Colon Cancer Alliance.



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EIN #86-0947831

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This booklet was funded by an unrestricted educational grant from
Bristol-Myers Squibb Oncology

