

# **Coping with Cancer**

# CANCER CHANGES EVERYTHING

Learning that you have cancer can come as a shock. After you hear the word "cancer," you may have had trouble breathing or listening to what was being said. You may not even have believed what the doctor was saying. Even if your friends and family were in the same room with you, you may have felt all alone.

In fact, a diagnosis of cancer will touch your life in many – and sometime unexpected – ways. Beyond coping with the physical illness and emotions that accompany it, many patients also face other adjustments along the way, involving:

**Money:** Cancer can reduce the amount of money your family has to spend or save. If you are not able to work, someone else in your family may feel that he or she needs to get a job. You and your family may need to learn more about health insurance and find out what will be covered and what you need to pay for. Most people find it stressful to keep up with money matters.

**Living arrangements:** People with cancer sometimes need to change where or with whom they live. You may need to move in with someone else to get the care you need. This can be hard because you may feel that you are losing your independence, at least for a little while.

**Daily activities:** Your routine may change as you go through treatment. You may have to take off work, or go on medical leave, or otherwise cut back or stop doing some of the things you did previously.

**Roles and duties:** You may need help with some of the duties that you usually took care of such as paying bills, cooking meals, taking out the garbage or coaching your child's sports team. Asking others to do these things for you can be hard.

**Relationships:** As you look to family members, friends and others for assistance, your relationships can be changed, for the better or the worse. Some relationships are strained by dealing with a serious illness and its added responsibilities, while others are strengthened.

This document discusses some of the changes that you might experience and offers suggestions and ideas that might help you cope.

# TAKING CARE OF YOURSELF

Dealing with cancer is a life-changing event. For most people, living with cancer is the biggest challenge they have ever faced. For many, it can be a time to minimize regrets and make new priorities.



## **Be True to Your Feelings**

Sadness and grief are normal reactions to cancer and will be experienced by everyone at one point or another – from diagnosis to treatment to becoming a survivor. At such times, you may have very little energy, feel tired or not want to eat.

For many, the first few weeks after diagnosis are especially hard. When you are at home, you may have trouble thinking, eating or sleeping. At times, you may:

- Be angry, afraid or worried
- Not really believe that you have cancer
- Feel out of control and not able to care for yourself
- Be sad, guilty or lonely

Yet some people also have a strong sense of hope for the future.

All these feeling and emotions can change from day to day, hour to hour, or even minute to minute. *Yet they also are all normal reactions for people with cancer, and those close to them – even the feeling of hope.* While no one is cheerful all the time, hope is a normal and positive part of your cancer experience. In fact, your chances of living with – and living beyond – cancer are better now than ever.

Be honest and talk about all your feelings, not just the positive ones. Don't act cheerful when you are not. Avoiding your feelings may make you feel worse, not better.

#### Sad or Depressed

If feelings of sadness and despair seem to take over your life, you may have depression. And you
are not alone. One out of four cancer patients – men and women alike – suffers from depression.

- Depression can be treated. Your doctor may prescribe medication. He or she may also suggest that you talk about your feelings with a counselor or join a support group with others who have cancer.

TIP: Holy Cross Hospital offers a variety of support groups and programs. Call 1-855-HCH-HOPE for more information. Research shows that individuals who join a support group have better outcomes from their cancer experience.

Here are some of signs that you might be depressed:

- Feeling helpless and hopeless, or that life has no meaning
- Losing interest in being with your family or friends
- Not wanting to do the hobbies and activities you used to enjoy
- Losing your appetite, or not being interested in food
- Crying for long periods of time, or many times each day
- Sleeping too much or too little
- Changes in your energy level
- Thinking about hurting or even killing yourself
- Having frequent thoughts about death and dying

Let your health care providers know if you have one or more of these signs almost every day. They can help you feel better.



# Eat Well

When you are healthy, eating enough food is often not a problem. But when you have cancer, you need to eat the right amount of calories to maintain a good weight and to keep up your strength to deal with the side effects of treatment. Eating well may help you feel better and give you more energy.

But eating well can be a challenge when you are dealing with cancer and treatment. You may not feel like eating at all, especially during or soon after treatment. You may be uncomfortable or tired. You may find that foods don't taste as good as they used to.

In addition, the side effects of treatment – such as poor appetite, nausea, vomiting or mouth sores – can make it hard to eat well. Your doctor, a registered dietitian, or another health care provider can suggest how to deal with these and other problems. Fortunately, there are many helpful medicines that can manage eating problems as well as certain foods and drinks that are easier to tolerate during cancer treatment.

If you are already on a special diet for diabetes, kidney or heart disease, or other health problem, it is even more important to speak with a doctor and dietitian. Your doctor and dietitian can advise you about how to follow your special diet while coping with eating problems caused by cancer treatment. Here are some other helpful tips you can use to make sure you're getting enough protein, vitamins and minerals, even when you're not feeling well:

- Fill the refrigerator, cupboard and freezer with healthy foods. Make sure to include items you can eat even when you feel sick.
- Stock up on foods that need little or no cooking, such as frozen dinners and ready-to-eat cooked foods.
- Cook some foods ahead of time and freeze in meal-sized portions.
- Ask friends or family to help you shop and cook during treatment. Maybe a friend can set up a schedule of the tasks that need to be done and the people who will do them.
- Eat plenty of protein and calories when you can. This helps you keep up your strength and helps rebuild healthy tissues harmed by cancer treatment.
- Eat when you have the biggest appetite. For many people, this is in the morning. You might
  want to eat a bigger meal early in the day and drink liquid meal replacements later on.
- Eat those foods that you can, even if it is only one or two items. Stick with these foods until you are able to eat more. You might also drink liquid meal replacements for extra calories and protein.
- Do not worry if you cannot eat at all some days. Spend this time finding other ways to feel better and start eating when you can. Tell your doctor if you cannot eat for more than two days.
- Drink plenty of liquids. It is even more important to get plenty to drink on days when you cannot eat.



Drinking a lot helps your body get the liquid it needs. Most adults should drink eight to 12 cups of liquid a day. You may find this easier to do if you keep a water bottle nearby.

If you start to have eating problems, let your doctor or nurse know so they can help you. And if you have not been able to eat for more than two days in a row, call your doctor immediately.

# TIP : Holy Cross Hospital offers outpatient nutrition counseling. Call 301-754-7848 for more information.

# Stay Active

Research shows that people with cancer feel better when they are active. Walking, yoga, swimming and other activities can keep you strong and increase your energy. Exercise may reduce nausea and pain and make treatment easier to handle. A bit of exercise everyday also can:

- Improve your chances of feeling better
- Keep your muscles toned
- Speed healing
- Decrease fatigue
- Control or relieve stress
- Increase your appetite
- Decrease constipation
- Help free your mind of bad thoughts

Even if you have never done physical activities before, you can start now. Choose something you think you'd like to do, and get your doctor's okay to try it. You can do some exercises even if you have to stay in bed.

Start slowly, doing an activity for just five or ten minutes a day. When you feel strong enough, you can slowly increase this time to 30 minutes or more.

#### Remember:

- Be sure to talk to your doctor before you start exercising.
- Do not exercise to the point of exhaustion.
- If your activity causes you pain or other problems, let your doctor or nurse know about it.

## Other Ideas

Here are some other tips that may help you deal with your new condition.

Live each day as normally as you can. If you feel well enough, try to keep up with your normal daily routine. This includes going to work, making decisions, doing household chores, engaging in hobbies and even taking trips. Enjoy the simple things you like to do such as spending time with family and friends, petting your cat or watching a sunset. Take pleasure in big events such as a friend's wedding or your grandson's high school graduation.

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**Ask for help when you need it.** Asking for help is not a sign of weakness. Think about chores or activities that your friends or family members could help with. You might be able to find a volunteer through groups in your community. Maybe you will need to hire someone from time to time.

Paid help or volunteers may be able to help with:

- Physical care, such as bathing or dressing
- Household chores, such as cleaning or food shopping
- Skilled care, such as giving you special feedings or medications
- Respite care to give your family members or other caregivers time off to rest, have fun and take care of their other duties. In respite care, someone comes to your home and takes care of you while your family member goes out for a while. Let your doctor or social worker know if you want to learn more about respite care.

**Get enough rest.** Be careful not to tire yourself out, even if you're doing something you enjoy such as gardening or swimming. Some people get depressed when they are too tired. Make sure to get enough rest so you feel strong and enjoy activities.

**Make time for fun.** Who do you like to be with? Who makes you laugh? What makes you feel happy? What are your passions? Ask yourself these questions, then try to spend some time doing those activities or being with those people. Or try something new that you have always wanted to do, such as riding in a hot-air balloon or fishing.

# FAMILY AND FRIENDS

A diagnosis of cancer affects the whole family, not just the person with the disease. How your family reacts to your cancer may depend a lot on how you have faced hard times in the past. Many families have trouble getting used to the changes that may be required when a loved one has cancer.

This section offers some information and tips to help you, your family and friends talk about and deal with your cancer and the changes it may bring.

## **Spouses and Partners**

Some people cannot accept that cancer is a serious illness. Others try too hard to be "perfect" caregivers.

And some people refuse to talk about cancer. You and your spouse or partner may both feel anxious, helpless or afraid. You also may find it hard to be taken care of by someone you love. Here are some steps you can both take during this time:

**Share information.** Include your spouse or partner in treatment decisions. You can meet with your doctor together and learn about your type of cancer, treatment choices and their side effects. This information will help both of you plan for the future. Your spouse or partner also will need to know how to help take care of your body and your feelings.

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**Stay close.** Everyone needs to feel needed and loved. You may have always been the "strong one" in your family, but now is the time to let your spouse or partner help you. This can be as simple as letting the other person fluff your pillow, bring you a cool drink, or read to you.

You may not be interested in sex when you are in treatment because you are tired, sick to your stomach, or in pain. During this time, you and your spouse or partner may need to find new ways to show that you care about each other. This can include touching, holding, hugging and cuddling.

**Spend some time apart.** Your spouse or partner also needs to keep a sense of balance in his or her life. The other person needs time to take care of personal chores and errands, and to sort through his or her own feelings about cancer. And most importantly, everyone needs time to rest. If you do not want to be alone when your loved one is away, think about getting respite care or asking a friend to stay with you.

**Think about the future.** Even though most people do not want to think about it, make plans in case you do not survive. You and your spouse or partner may find it helpful to meet with a financial planner or a lawyer.

#### **Young Children**

Some parents with cancer worry about breaking the news to their children. Will they be able to cope with the news? How much and when should you tell them? As difficult as it may be, telling your children you have cancer, and doing it as soon as possible, is always best. Children as young as 18 months begin to think about what is going on around them and can sense when something is wrong.

They will see that you do not feel well or are not spending as much time with them as you used to. They may notice that you have a lot of visitors and phone calls or that you need to be away from home for treatment and doctors appointments.

If possible, you should be the one to tell your children. It is OK to cry. It shows your children that it is OK for them to cry, too, and to be sad and afraid. If you are concerned that you won't be able to maintain reasonable emotional control, ask a close relative or a doctor to tell your children instead.

Here are some suggestions on how to help your young children deal with your cancer:

**Tell the truth.** Even though your children will be sad and upset when they learn about your cancer, do not pretend that everything is OK. It is important to be honest and tell your children that you are sick and the doctors are working to make you better. Telling them the truth is better than letting them imagine the worst. But don't overburden them with unnecessary details, such as financial concerns.

**Use words they can understand.** For example, say "doctor" instead of "oncologist" or "medicine" instead of "chemotherapy."



**Listen to their questions.** Give your children time to ask questions and express their feelings. And if they ask questions that y ou can't answer, let them know you will find the answers for them.

**Sh re your feelings.** Tell your children how much you love them. Suggest ways they can help with your care or do something nice for you, such as washing dishes or drawing you a picture. Together, read books about cancer that are written for children.

**Reassure them.** Let them know they will be loved and taken care of. But don't make any promises you may not be able to keep.

Let other adults in your child en's lives know about your cancer. This includes teachers, neighbors, coaches or other relatives who can spend extra time with them, as well as listen to their feelings and concerns.

**Talk to your doctor, nurse or social worker.** They can help by talking with your children and answering their questions. Regardless of their age, your children may react to your cancer in many different ways. For example, they may:

- Be confused, scared or lonely
- Feel guilty and think that something they did or said caused your cancer
- Feel angry when they are asked to be quiet or do more chores around the house
- Miss the amount of attention they are used to getting
- Regress and behave as they did when they were much younger
- Be clingy and afraid to leave the house
- Get into trouble at school or at home

#### Teenagers

Teens are at a time in their lives when they are trying to break away and be independent from their parents.

But when a parent has cancer, breaking away can be hard for them to do. They may become angry, act out or get into trouble. Try to get your teens to talk about their feelings. Tell them as much as they want to know about your cancer.

Ask them for their opinions and, if possible, let them help you make decisions.

Encourage your teenage children to talk about their fears and feelings with other people they trust and feel close to. Friends can be a great source of support, especially those who also have serious illness in their family. Other family members, teachers, coaches, and spiritual leaders also can help.

Ask your social worker about Internet resources for this group. Many have online chats and forums for support.



#### What All Children Need to Know:

- Nothing he or she did, thought, or said caused you to get cancer.
- You can't catch cancer from another person. Just because you have cancer does not mean that others in your family will get it, too.
- Just because you have cancer does not mean you will die from it. In fact, many people live with cancer for a long time. Scientists are finding many new ways to treat cancer.
- Your child is not alone. There are other children whose parents have cancer.
- It is okay to be upset, angry or scared about your illness.
- He or she can't do anything to change the fact you have cancer. But they can help you by doing nice things such as washing the dishes, drawing a picture or pitching in with household chores.
- Family members may act differently because they are worried about you.
- He or she should still go to school and take part in sports and other fun activities.
- He or she can talk to other adults such as teachers, family members and religious leaders.
- You will make sure that your children are taken care of, no matter what happens to you.

## Adult Children

When they learn that you have cancer, many adult children realize how important you are to them. They may feel guilty if they haven't been close with you. Or they may feel bad if they cannot spend a lot of time with you because they live far away or have other duties. And even adult children worry their parents will die.

Their concerns and feelings combined with yours may change your relationship. For example, you may find yourself counting on them, often for the first time, to:

Take on new duties, such as paying bills or taking care of the house.

**Help with health care.** You might want them to go with you to the doctor so they also can hear what the doctors are telling you. Or you might rely on them to explain some of the information you've received from your doctor or to help in making health care decisions.

**Provide emotional support.** For instance, you may ask them to act as "go-betweens" with friends or other family members.

#### Spend a lot of time with you .

At the same time, you may find it hard to receive – rather than give – comfort and support from your children, even if they are grown. And you may feel awkward when they help with your physical care, such as feeding or bathing.

For all these reasons, it is important to talk about your cancer with your adult children, no matter how hard it is or if they get upset. Here are some useful tips:

– Include them when talking about your treatment.



- Let them know your thoughts and wishes. They should be prepared in case you don't recover.
- Make the most of your time together. Talk about how much you mean to each other.
- Express all your feelings. Not just love, but also anxiety, sadness and anger. Don't worry about saying the wrong thing. It's better to share your feelings rather than hide them. If you have trouble talking with your adult children, ask your doctor or nurse to suggest a counselor who can help.

## Parents

Since people are living much longer these days, many people with cancer also may be helping to care for their aging parents. Your aging parents may even live with you.

Only you can decide how much to tell your parents about your cancer. Your decision may depend on your parents' health and how well they can understand and cope with the news.

Now that you have cancer, you may need extra help caring for your parents. You may only need help while you are in treatment. Or you may need to make long-term changes in your parents' care. Talk with your family members, friends, health care professionals, and community agencies to see how they can help.

## **Close Friends**

Once friends learn of your cancer, they may begin to worry. Some will ask you to tell them ways to help.

Others will wonder how they can help but may not know how to ask.

You can help your friends cope with the news by letting them help you in some way. Think about the things your friends do well and don't mind doing, and make a list of things you might need. Here are some ideas to get you started:

- Baby-sit on days that I go to treatment.
- Prepare frozen meals for my "down days."
- Put my name on the prayer list at my place of worship.
- Bring me a few books from the library when you go.
- Visit for tea or coffee when you can.
- Let others know that it is alright to call or visit me (or let others know that I'm not ready for visitors just yet).

TIP: Holy Cross Hospital offers a variety of social work services. Call 301-592-9124 to learn more.

# AT WORK

People with cancer often want to continue working, even during treatment. Or get back to work as soon as possible.

Their jobs not only give them an income but also a sense of routine. Work helps people feel good about themselves.

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They are getting back to the life they had before being diagnosed with cancer. Before you go back to work, talk with your doctor as well as your boss. Make sure you are well enough to do your job. Some people feel well enough to work while they are having chemo or radiation treatment. Others need to wait until their treatments are over.

Those who continue to work during cancer treatment often find they need to cut their hours back or do their job in a different way. Plus, you may have to take time off for doctor's appointments or treatments, or on those days when you just feel too sick.

This section gives some important tips on dealing with your relationships at work, both during and after cancer.

## **Know Your Rights**

Before you tell your boss or supervisor that you have cancer, it is important to know your rights. It is against federal and state laws to discriminate against, or treat unfairly, workers who have disabilities such as cancer.

These national laws protect your rights as a worker:

- The Federal Rehabilitation Act of 1973
- The Americans With Disabilities Act of 1990

While many companies and supervisors are very understanding and supportive when an employee has a major illness like cancer, some are not. Some people with cancer face roadblocks when they try to go back to work or get a new job. Even those who had cancer many years ago may still have trouble.

Employers may not treat them fairly because they believe myths that aren't true. They may believe cancer can be spread from person to person, or people with cancer take too many sick days. Some employers also think people with cancer are poor insurance risks. Yet research shows that people who have had cancer who continue to work are as productive on the job as other workers.

As a person with cancer, you have certain rights and benefits. Make sure you know what they are by:

Talking with your social worker about laws in your stat e and your rights. He or she also can give you the name of the state agency that protects your rights as an employee.

**S peaking with the Human Resource office where you work.** There are benefits you may be entitled to, such as the Family and Medical Leave Act. This law allows most workers to take up to 12 weeks of unpaid time off to deal with certain family and medical problems.

To make your transition back to work easier, you also might want to try these tips:



- Ask your doctor or nurse to find times for follow-up visits that don't conflict with your other responsibilities.
- Get your doctor to write a letter to your employer or personnel officer explaining how, if at all, your cancer may affect your work or your schedule.

If you still have questions or concerns, here are some other sources of information:

- Maryland's Department of Labor or Licensing and Regulation
- Your state Representative or Senator. You can find out who represents your district and how to contact this person by looking on the Internet or at a library.
- The U.S. Department of Labor at www.dol.gov
- Your attorney

#### On the Job

Some people may not understand your ability to perform work while having or recovering from cancer treatment. They may think you aren't able to work as hard as before or that having had cancer means you are going to die soon. Sometimes, fear and lack of knowledge result in unfair treatment.

There is no right way to deal with others about your illness. But you do need to think about what you'll say when you're back on the job. Some people with cancer don't want to focus on it or be linked in people's minds with the disease. Others are very open, speaking frankly with their boss or other workers to air concerns, correct wrong ideas and decide how to work together. The best approach is the one that feels right to you.

You might find that your boss and coworkers treat you differently than they did before you had cancer. They may say nothing because they don't know what to say and don't want to hurt your feelings. Or they may not know if you want to talk about your cancer or would rather just focus on work.

Let your boss and coworkers know if, and when, you want to talk about your cancer. If you can, use humor or make a joke. Humor can help break the ice and make people feel more at ease. You may find that it's easier than you thought it would be.

#### Handling Problems

If you're having problems at work that you did not have before your cancer, there are several different ways to handle them:

**Fulfilling your duties.** If you can't do your job the way you used to, ask your employer to adjust to your needs. Your employer may be able to do things that would make it easier for you to keep your job, such as allowing you to work flextime or from home, or by installing special equipment at work. You could start by talking informally to your supervisor, personnel office, employee assistance counselor, shop steward, or union representative. Keep a record of each request and its outcome for yourself and your protection.



**Dealing with coworkers.** If a friend or coworker's feelings about cancer are hurting you, try to resolve the problem with that person face-to-face. Talking with a friend, family member, or counselor also may help you come up with ideas for handling it. However, if a coworkers attitude or remarks are still affecting your work after that, it's a problem for management to address. Talk to your manager, shop steward, company medical department, employee assistance counselor, or personnel office for help.

If you're still having difficulties, you might want to ask yourself the following questions:

- What are my rights as an employee?
- Am I willing to take action to correct a problem?
- Do I still want to work there? Or would I rather look for a new job?

If you do decide to look for a new job, remember: you have no legal obligation to talk about your cancer history unless your past health has a direct impact on the job you seek. You can take legal action (sue) if you think that you are not being hired for a job because of your cancer.

## If You Can't Go Back To Work

Some people can't return to their jobs because of their cancer. For instance, you may no longer be able to lift heavy boxes if that task is a part of your job. If you can't do the work you did before, contact your state Rehabilitation Program. Ask about training programs that teach you the skills you need for other kinds of work. To learn more, look under the state government section in the blue pages of your phone book or check your state's website: http://www.dllr.state.md.us/