

# Living With Uncertainty: The Fear of Cancer Recurrence

This information is for people who have had a type of cancer that can recur (come back) after treatment. It's intended for people whose cancer required surgery, chemotherapy, and/or radiation treatments. It may not apply to those who were treated for a type of cancer that almost never comes back if it was found early and completely removed, such as a small basal cell skin cancer.

If you have questions about what type of cancer you had and what your risk of recurrence might be, talk to your cancer doctor. Or call the American Cancer Society at 1-800-227-2345 for more information.

### A patient's story

Frances had a mastectomy for breast cancer. She has completed chemotherapy and radiation to her chest. Her doctor has told her that no cancer can be found in her body. Even though she will be seen in his office every 4 to 6 months for the next 5 years, her doctor seems to think the worst is over. But it's hard for Frances to trust that the cancer is gone. She wants to know the chances of the cancer coming back. "I feel like if I knew my exact chances of the cancer coming back, I could deal with it. But when I ask my doctor, he gives me a range of statistics over a number of years. I can't live like this. I need more specifics."

Frances is expressing many of the common concerns a person has after completing cancer treatment (or the main portion of it). Now she's living with the unknown. She wants to feel like a cancer survivor, ready to put the experience behind her. But she's afraid that the cancer may come back and she will be reliving it all again soon. She wants to know the odds of the cancer coming back. But what she really wants is to *know* that she will never have cancer again.

### **Emotions after treatment**

You have completed cancer treatment and are ready to move on with your life. Completing treatment can be both stressful and exciting. All is well – or is it? Once treatment is over, many cancer survivors find they have issues and concerns they did not expect.

### Going back to "normal"

You've been seeing your doctor quite often; now, suddenly, you don't have to visit for many months at a time. When treatment is done, some people feel that they're no longer fighting their cancer. You might feel alone and lost without the support of your health care team. These people may have become an important part of your life. Not seeing them might make you anxious and sad.

You may also find that going back to your role in the family is not as easy as you thought it would be. Things that you did before your cancer are now being done by others. Maybe they're not willing to give your tasks back to you. Or maybe you disagree with how others have done things, but are afraid to say anything. After all, you should be grateful for everything they've done, shouldn't you?

For some people, emotions that were put aside during cancer treatment come flooding back all at once, and they feel overwhelmed with sadness, anger, or fear. Maybe you feel emotionally exhausted and tired all the time. Some of it may be the lingering side effects of treatment, but some of it feels as if your body and spirit are tired and need a long rest. It's been a long time since you could just relax.

All of these feelings make sense. You've just been through a difficult time. You've had to make some major life decisions. Your body has been assaulted by cancer and its treatment. Your outlook and your whole way of life have changed, at least for a time.

### Dealing with the "what ifs?"

You want to believe it's over and put the cancer behind you, but can you? You may notice that you're paying a lot of attention to aches and pains in your body. You may feel like a "sitting duck." The doctor says you have no signs of cancer now, but can you be sure? You may be wondering...

- Will it come back?
- What are the chances it will come back?
- How will I know if it has come back?
- What will I do if it comes back?
- When will it come back?

The fear grips you, and you have trouble sleeping, being close with your partner, and even making simple decisions. You are not alone. One of the most common concerns of cancer survivors is the worry about cancer coming back. The fear of recurrence is normal.

It's important that you understand that there is a chance that after treatment the cancer could come back (recur). Sometimes your healthcare team may not warn you about this. This could be because they are trying to protect you from uncertainty and fear. They want to encourage you – especially when you're first starting treatment. Sometimes the team may think you know that your cancer can return, but when the focus is on a cure or long-term survival, it seems pessimistic to talk about recurrence. It's natural for your healthcare team to want to share that moment of victory over the

cancer with you without talking about anything bad that could happen in the future. But you need to know that cancer recurrence is a very real possibility – it's what we will discuss here.

### What is cancer recurrence?

Cancer recurrence is defined as the return of cancer after treatment and after a period of time during which the cancer cannot be detected. (The length of time is not clearly defined.) The same cancer may come back in the same place it first started or somewhere else in the body. For example, prostate cancer may return in the area of the prostate gland (even if the gland was removed), or it may come back in the bones. In either case it's a prostate cancer recurrence.

### The difference between recurrence and progression

When cancer spreads or gets worse it is called *progression*. Sometimes it's hard to tell the difference between recurrence and progression. For example, if cancer has been gone for only 3 months before it comes back, was it ever really gone? Is this a recurrence or progression?

Chances are this is not really a recurrence. It's likely 1 of 2 things happen in cases like this: One is that surgery left behind small clusters of cancer cells that could not be seen or found on scans or other tests. Over time they grow large enough to be detected or cause symptoms. These cancers tend to be very aggressive, or fast-growing.

The second possibility is that the cancer may be resistant to treatment. Chemotherapy or radiation may have killed most of the cancer cells, but some of them were either not affected or changed enough to survive the treatment. Any cancer cells left behind can then grow and show up again.

The less time between when the cancer was thought to be gone and the time it came back, the more serious the situation. Most doctors would agree that 3 months of appearing to be cancer-free before cancer returns is too short to be considered a recurrence. Although there's no standard period of time in the definition of recurrence, most doctors consider it a cancer recurrence if you've had no signs of cancer for at least a year. If your cancer has been gone for only 3 months, this would most likely be a progression of your disease. In this case, the doctors would assume that the cancer never went away totally, even though they could not find it with any tests.

## What are the types of cancer recurrence?

There are different types of recurrence:

- Local recurrence means that the cancer has come back in the same place it first started.
- Regional recurrence means that the cancer has come back in the lymph nodes near the place it started.
- *Distant recurrence* means the cancer has come back in another part of the body, some distance from where it started (often the lungs, liver, bone marrow, or brain).

If you have a cancer recurrence, your doctor can give you the best information about what type of recurrence you have and what it means to have that type.

### What is the risk of recurrence?

The risk of recurrence for cancer survivors is different for each person. It depends on many factors, including the type of cancer, the treatment you had, and how long it's been since your treatment. If you find yourself haunted by questions about recurrence, ask your doctor to talk realistically about the chances of the cancer coming back. You may find this information reassuring or somewhat unsettling. Whatever information you get, remember that each person is unique, no matter what the statistics. There may be factors that may make your case different from the usual.

You may want to ask your doctor or nurse questions like these if you are worried about recurrence:

- Is it possible the cancer can come back?
- When is it most likely to come back?
- Where would it most likely come back?
- How likely is it to come back? (numbers and statistics)
- Is there anything I can do keep it from coming back?
- How will I know if it's back? What should I look for?

### Can I do anything to prevent recurrence?

It's important to eat right, exercise, and see your doctor for follow-up visits, but please understand these measures cannot keep cancer from recurring. Many cancer patients blame themselves for missing a doctor visit, not eating right, or postponing a CT scan for a family vacation. But even if you do everything just right, the cancer still might come back.

### Diet

After completing cancer treatment, many people decide to eat better and exercise in the hope that these changes will improve their quality of life and their chance for survival. Though current research does not prove that nutrition can influence cancer recurrence, it's still a good idea to eat well and do what you can to be as healthy as possible.

The American Cancer Society recommends that cancer survivors in stable health after treatment follow the same nutrition guidelines as those recommended for cancer prevention. It's thought that the same factors that increase cancer risk might also help promote cancer recurrence after treatment. For example, breast cancer research has supported dietary effects by suggesting that the risk of recurrence might be higher in women who are obese and don't eat many fruits and vegetables. Prostate cancer recurrence might be increased by high saturated fat intake.

In general, an adult should eat 2½ cups of vegetables and fruits each day. Limit red meat (beef, pork, lamb) and processed meats (foods such as hot dogs, sausage, and luncheon meats) Select foods made with whole grains rather than refined grains and sugars.

If you are overweight, consider losing weight by cutting calories and increasing your activity. Check with your doctor before starting an exercise program. Be sure to choose activities you enjoy.

Several types of cancer are linked to alcohol intake, so if you drink, limit your intake to 1 drink a day for women and 2 for men. The more you drink, the higher your cancer risk.

### Vitamins and supplements

Sometimes people think taking certain vitamins, herbs, or other dietary supplements will give them an extra edge in preventing recurrence. Available research does not support this belief. In fact, some research has shown that supplements containing high levels of single nutrients (greater than the Dietary Reference Intakes) may have unexpected harmful effects on cancer survivors.

Blood test results now can show if your levels of certain vitamins are low. Your doctor might recommend supplements that improve your level of certain vitamins, but the evidence so far does not show that high vitamin levels actually lower cancer risk. It's best to talk with your doctor before starting any vitamin or other dietary supplement.

To learn more, you may want to read our document called *Dietary Supplements: What Is Safe?* 

### Physical activity

A few studies have looked at the effect of physical activity on survival of people with cancer. Researchers have not yet been able to find out whether physical activity can prevent cancer recurrence or slow the progression of disease. But studies have shown that regular physical activity can reduce anxiety and depression, improve mood, boost self-esteem, and reduce symptoms of fatigue, nausea, pain, and diarrhea. These benefits can be gained through moderate physical activity on most, if not all days of the week.

Moderate activities are those that make you breathe as hard as you would during a brisk walk. Activities like walking, biking, and swimming are considered moderate, and so are activities like yard work and brisk house cleaning. Adults should try to get at least 150 minutes of moderate intensity or 75 minutes of vigorous intensity activity each week (or a combination of these). It's best if this can be spread throughout the week. And, try to limit the amount of time you spend sitting.

A little bit of physical movement is far better than none. It helps if you start slowly and build up to greater amounts of physical activity. In choosing a level of activity, it's important to think about your physical abilities and your recent levels of activity. It's also important to talk to your doctor before changing your type or level of physical activity.

### **Bottom line**

It would be very comforting to have a sure way to keep cancer from coming back after treatment. We want a real weapon to fight back with – something that will give us insurance against the cancer coming back. Both doctors and patients wish for cures. At this time there's nothing you can do to be sure the cancer will not come back. Even with our current understanding of how it develops and grows, cancer is still a mystery in many ways.

### Some common questions after treatment

### Can I ever be sure the cancer will never come back?

No, it's not possible to guarantee that once you have completed cancer treatment the cancer will never come back. Although your doctor may say, "The cancer is gone" or "I think I removed all the cancer" or "I see no evidence of any cancer," the fact remains that there's always a chance that there are some cancer cells left in your body that survived, even though they cannot be seen or found with any test used today. Over time, these cells can begin to grow again, and the cancer recurs.

And while you don't want to ever think about the chance of having a second cancer – one that's not related to the first cancer – this is also possible. Having one cancer doesn't make you immune to having a second or even a third different cancer.

Some people find it very hard to get these thoughts out of their minds. While it is useful to take some measures to prepare for the chance that the cancer can return, for some people the thought becomes a fear that interferes with daily life. Some people deal with these thoughts by distraction, or by focusing on what's most important to them each day. Others take measures such as joining a peer support group or seeing a mental health professional. After the stress of cancer, the way you deal with the emotional pain can be key to moving on with your life.

### Can my doctor give me a "no-cancer guarantee?"

Cancer is not predictable. No doctor can guarantee cancer will stay gone forever.

A recurrent cancer starts with cancer cells that the first treatment didn't fully remove or destroy. This does not mean that you got the wrong treatment. It does not mean that you did anything wrong after treatment, either. It means that a small number of cancer cells survived the treatment you had. There were probably too few to be detected on tests or scans. But over time, these cells grew into tumors or the same type of cancer as the first one.

Not all of the growth factors for cancer cells have been found yet. Even though treatment might seem to have gotten rid of all of the cancer, there may be just one tiny cancer cell left someplace in the body. This cell may not cause any harm for many years. Suddenly, something can happen that will change the immune system and "wake up" the cell. When it becomes active, it can grow and make other cells. Finally, it's big enough for your doctor to detect it as a recurrence.

Just as it happened the first time, there is also a chance that your normal cells may, for any number of reasons, develop damage in their DNA. (DNA holds genetic information on cell growth, division, and function.) This damage then causes a gene (a small section of DNA) to change (mutate). When genes mutate, they can become oncogenes, which can allow cells to become cancer cells that divide quickly and out of control. Damage to DNA can result in a second type of cancer, just as it caused the first one.

There are also *tumor suppressor genes*, which tell cells when to repair damaged DNA and when to die (a normal process called *apoptosis*, or programmed cell death). These genes are like the brakes on a car. Just as the brakes keep a car from going too fast, a tumor suppressor gene keeps the cell from dividing too quickly. When tumor suppressor genes are mutated or turned off – that is, when the brakes fail – the cells divide very fast, allowing cancer to develop. Changes in tumor

suppressor genes can be inherited (you are born with them), but more often, they happen during your life. (See our document called *Genes and Cancer* to learn more about this.)

### What should I look for if I am worried about a recurrence?

It's easy to obsess about every ache and pain if you're worried about cancer returning. But really, there are only a few major symptoms that could mean serious problems. If you have any of the problems listed below, tell your doctor at once.

- Return of the cancer symptoms you had before (for example, a lump or new growth where your cancer first started)
- New or unusual pain that seems unrelated to an injury and does not go away
- Weight loss without trying
- Bleeding or unexplained bruising
- A rash or allergic reaction, such as swelling, severe itching, or wheezing
- Chills or fevers
- Headaches
- Shortness of breath
- Bloody stools or blood in your urine
- Lumps, bumps, or swelling
- Nausea, vomiting, diarrhea, loss of appetite, or trouble swallowing
- A cough that doesn't go away
- Any other signs mentioned by your doctor or nurse or any unusual symptoms that you just can't explain

Whenever you have a symptom, your first thought might be that your cancer has returned. Remember that there are illnesses and medical problems that have nothing to do with the previous cancer. You can still get colds, infections, arthritis, heart problems, etc. – just like anyone else. As with any illness, your doctor is the best person to find the cause of your symptoms. But if you are seeing a new doctor, be sure that he or she knows about your history of cancer and its treatment.

## What about future health problems I might get from cancer treatment?

You should also know that some cancer treatments may cause health problems later on. These problems might not appear right away and some don't show up until years after treatment. Ask your doctor:

- If the treatment you had will put you at risk for short- or long-term problems
- What those problems are and how you can recognize them

- What you should do if you notice them
- What you should do to take care of your health

### What does "5-year survival rate" mean?

The 5-year survival rate refers to the percentage of patients who are alive at least 5 years after their cancer is diagnosed. Many of these people live much longer than 5 years after diagnosis, but the 5-year rate is used as a standard way to discuss the prognosis (outlook).

You may also hear the term 5-year *relative* survival rate. Relative survival compares survival among cancer patients to that of people of the same age, race, and sex who don't have cancer. It's used to adjust for normal life expectancy when cancer is not present. Five-year relative survival rates are considered a more accurate way to describe the prognosis (long-term outlook) for groups of patients with a certain type and stage of cancer. But they cannot predict how long you or any other person may live.

If you look at these survival rates, keep in mind that 5-year rates are based on patients who were diagnosed and treated more than 5 years ago. These statistics may no longer be accurate because improved treatments often result in better outcomes for those who were diagnosed more recently.

There's another point to remember when talking about survival rates: Survival rates look at survival only, not whether the person is cancer-free 5 years after diagnosis. They are based on a group of people of all ages and health conditions diagnosed with a certain type of cancer. These statistics usually include people diagnosed early and those diagnosed late. As with any statistics, they should only be used to get an idea of the overall picture. They cannot be used to predict any one person's outcome.

### Why won't the doctor say, "You're cured"?

Most doctors avoid using the term "cure" because it implies that the cancer is gone forever. As we have discussed, this is almost impossible to say in any case of cancer. The best a doctor can do is say that they can find no signs of cancer in your body at this time. This is most often stated as "No evidence of disease."

Your doctor may continue to watch you closely for many years and do tests to watch for any signs of cancer recurrence. There's no harm in assuring yourself that you are cancer-free if that's what all the evidence shows. Enjoy the feeling that you do not have cancer. But it's still possible for cancer to come back even after you have been cancer-free for 5 years or more.

### What does it mean if the doctor says, "The cancer is controlled"?

A doctor may use the term *controlled* if your tests or scans show that the cancer is not changing over time. Controlled means that the tumor doesn't appear to be growing. Another way of defining control would be calling the disease *stable*. Some tumors can stay the same for a long time, even without any treatment. Some stay the same size because of the cancer treatment and are watched to be sure that they don't start growing again.

## What does it mean if the doctor says, "The cancer has progressed"?

If the cancer does grow, the status of your cancer changes and your doctor might say that the cancer has *progressed*. Most clinical trials define a tumor as progressive when there is a 25% measured growth in the tumor. (See the section "The difference between recurrence and progression" for more on this.)

### How is the response to treatment described?

When a treatment completely gets rid of all tumors that were seen on a test or that doctors can measure in some way, it's called a *complete response* or *complete remission*. The decrease in tumor size must last for at least a month to count as a response. A complete remission does not mean the cancer has been cured, only that it can no longer be seen on tests.

In general, a *partial response* (or *partial remission*) means the cancer responded to treatment, but still has not gone away. If you're in a clinical trial this usually is defined more precisely. A partial response is most often defined as at least a 50% reduction in measurable tumor. The reduction in tumor size must last for at least a month to qualify as a response.

## How long is treatment given before the doctor can tell if there's a response?

The first treatment given for cancer is based on the last 20 to 30 years of clinical experience in treating that kind of cancer. But no 2 cases are exactly alike, and response to treatment can't be predicted.

Standard practice is to wait for 2 full cycles of treatment before looking for any response to it. This usually takes about 2 to 3 months. Response is checked by repeating the tests that show the cancer. If the tumor doesn't respond to the first treatment, changes will be made, perhaps to another chemotherapy combination that has shown promise in similar cases.

## **Preparing for recurrence**

While no one wants to think about it, every cancer survivor needs to be prepared for the possibility that their cancer may come back some day. This is very hard to think about, especially right after successful cancer treatment. But not being aware of this possibility could be dangerous to your long-term health. Here are some things you can do and things you should know that will help you deal with the uncertainty of cancer recurrence. You don't have to think about them every day, but knowing about them can help you if cancer does show up again.

### Keep your health insurance

You already know that having cancer is very expensive. Your cancer tests and treatment probably cost a lot of money. You might have had to change your work schedule or job status because of the side effects of certain treatments. Your partner may have had to take time off work to help you. These changes affect your finances.

Though money may be tight, keep your health insurance if at all possible after you have finished your first cancer treatment. You will need regular follow-up care for many years. Unless you are over 65 and can get Medicare, it can be hard to get medical insurance, especially if the cancer comes back. Insurance costs a lot, but cancer treatment is even more costly. There are some options for uninsured people who need cancer treatment, but they are not easy to get and they're expensive. There are no "free" government programs to pay for cancer care.

For some people, going back to work after cancer is very hard to do, but they feel they cannot look for a different job because they are afraid to lose their health insurance. Although the Health Insurance Portability and Accountability Act (HIPAA) is supposed to help you get insurance coverage when you change jobs, some people worry about the risk of having different coverage in a new job.

Although employers are not legally allowed to discriminate against hiring people who have had cancer, cancer survivors are often afraid to look for a new job. They are also afraid to discuss their cancer with a new employer. For ideas on how to handle this, you may want to see *Financial Guidance for Cancer Survivors and Their Families: Off Treatment*, which you can read online or get by calling our toll-free number. It also helps to know what rules the employer must follow. You may want to read our documents about the *Americans With Disabilities Act*, *HIPAA*, and *COBRA*. They are listed in the "To learn more" section.

### Keep your follow-up visits with your doctor

While there is no guarantee that seeing your doctor regularly will keep the cancer from coming back, it will help find any recurrence as early as possible. The earlier cancer is found, the easier it is to treat. It's also reassuring to know that your doctor is watching you closely to be sure there are no signs of cancer recurrence. Continue to talk with your health care team. Let them know how you are feeling and discuss any concerns you might have. One of the greatest benefits you will get from the follow-up visits with your doctor will be peace of mind.

### Get the tests your doctor suggests

You will need to have some tests done as part of your follow-up after cancer treatment. These will help your doctor be sure that you stay in remission (without evidence of disease). The tests will vary depending on the type of cancer you had.

For example, if you have prostate cancer treated with surgery or radiation therapy, follow-up tests might include a digital rectal exam (DRE) and prostate-specific antigen (PSA) test every 6 months for the first 5 years. Testing is often done at least yearly after that, and extra tests would be done any time it looked like the cancer might be growing.

The follow-up for certain early-stage bladder cancers after treatment includes a visit to your doctor every 3 months for the first year, then at regular intervals after that. During these visits, your doctor will likely do a *cystoscopy* (look at the inside of your bladder with a cystoscope – a slender tube with a lens and a light) and collect a urine sample to check for bladder cancer cells.

As you can see, each follow-up schedule is different based on the type of cancer. Talk to your healthcare team about what your follow-up care is going to be, what is expected of you, and what you can expect of them during this time.

It's tempting to avoid following all the steps and tests required in follow-up. By the time you have completed treatment for cancer, you may be tired of being a cancer patient – you may just want to forget about this part of your life and move on. It's understandable to want to avoid tests and doctors that make you face the possibility that your cancer has returned. This is a natural impulse, but not a wise choice.

### Keep copies of your cancer treatment records and tests

As you complete your cancer treatment, talk with your doctors about getting copies of all your important cancer treatment information. Most hospitals and treatment facilities keep patient records only for a few years before destroying them. Even if your cancer doesn't come back, your primary care doctor will need to know about your surgery, biopsies, chemo drugs, and radiation dose. And if you change doctors, it's important that you be able to give your new doctor the details of your diagnosis and treatment. Make sure you have this information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- A copy of your operative report(s) if you had surgery
- Copies of x-rays and scans (on a CD if you can get them in that format)
- A copy of the discharge summary that doctors prepare when patients are sent home, if you were hospitalized
- A copy of the treatment summary, if you had radiation therapy
- A list of your drugs, drug doses, and when you took them, if you had chemo or targeted therapy

Future doctors may want copies of this information to add to your record, but always keep copies for yourself.

## Learning to live with uncertainty

Worrying about the cancer coming back (recurring) is normal, especially during the first year after treatment. This is one of the most common fears people have after cancer treatment. And even many years after treatment, this fear may still be in the back of your mind. As time goes by, many people say that their fear of cancer returning decreases and they find themselves thinking less often about cancer. But even years after treatment, some events can make you worry about your health. These may include:

- Follow-up visits or certain medical tests
- Anniversary events (like the date you were diagnosed, had surgery, or ended treatment)
- Birthdays
- Illness of a family member
- Learning that someone you know has had a recurrence
- Symptoms much like the ones you had when you first found you had cancer

- New symptoms you don't understand
- The death of someone who had cancer

Here are some ideas that have helped others deal with uncertainty and fear and feel more hopeful:

- Be informed. Learn what you can do for your health now and about the services available to you. This can give you a greater sense of control.
- Check with your doctor for a list of common signs of recurrence of your type of cancer. Call your doctor if you have questions about any changes you notice.
- Be aware that you do not have control over some aspects of your cancer. It helps to accept this rather than fight it.
- Be aware of your fears, but don't judge them. Practice letting them go. It's normal for these thoughts to enter your mind, but you don't have to keep them there. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle. However you do it, letting them go can free you from wasting time and energy on needless worry.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried. People have found that when they express strong feelings, like fear, they are more able to let go of these feelings. Thinking and talking about your feelings can be hard. If you find cancer is taking over your life, it often helps to find a way to express your feelings.
- Take in the present moment rather than thinking of an uncertain future or a difficult past. If you can find a way to feel peaceful inside yourself, even for a few minutes a day, you can start to recall that peace when other things are happening when life is busy and confusing.
- Work toward having a positive attitude, which can help you feel better about life now. Just remember you don't have to act "positive" all the time. Don't beat yourself up or let others make you feel guilty when you're feeling sad, angry, anxious, or distressed.
- Use your energy to focus on wellness and what you can do now to stay as healthy as possible. Try to make healthy diet changes. If you are a smoker, this is a good time to quit.
- Find ways to help yourself relax.
- Be as physically active as you can.
- Control what you can. Some people say that putting their lives back in order makes them feel less fearful. Being involved in your health care, getting back to your normal life, and making changes in your lifestyle are among the things you can control. Even setting a daily schedule can give you more power. And while no one can control every thought, some say they've resolved not to dwell on the fearful ones.

### Get support

Emotional support can be a powerful tool for both survivors and families. Talking with others who are in situations like yours can help ease loneliness. You can also get useful ideas from others that might help you.

There are many kinds of support programs, including individual or group counseling and support groups. Some groups are formal and focus on learning about cancer or dealing with feelings. Others are informal and social. Some groups are made up of only people with cancer or only caregivers, while some include spouses, family members, or friends. Other groups focus on certain types of cancer or stages of disease. The length of time groups meet can range from a set number of weeks to an ongoing program. Some programs have closed membership and others are open to new, drop-in members.

It's very important that you get information about any support group you are considering. Ask the group leader or facilitator what types of patients are in the group and if anyone in the group is dealing with fears about recurrence or survival.

Online support groups may be another option for support. The Cancer Survivors Network, an online support community supported by your American Cancer Society is just one example. You can visit this community at http://csn.cancer.org/. There are many other good communities on the Internet that you can join as well, although you'll want to check them out before joining. See the "To learn more" section for some online support group information.

Some people feel better having a person-to-person connection with a counselor who can give oneon-one attention and encouragement. Your doctor may be able to recommend a counselor who works with cancer survivors.

Religion can be a great source of strength for some people. Some find new faith during a cancer experience. Others find that cancer informs their existing faith or their faith provides newfound strength. Still others find themselves questioning their faith. If you are a religious person, a minister, rabbi, other leader of your faith, or a trained pastoral counselor can help you identify your spiritual needs and find spiritual support. Some members of the clergy are specially trained to help minister to people with cancer and their families.

Spirituality is important to many people, even those who don't practice a formal religion. Many people are comforted by recognizing that they are part of something greater than themselves, which helps them find meaning in life. Spiritual practices can help foster connection to others, to the present moment, and to the sacred or significant. Meditation, practicing gratitude, helping others, and spending time in nature are just a few of the many ways that people address spiritual needs.

Support in any form allows you to express your feelings and develop coping skills. Studies have found that people who take part in a support group have an improved quality of life, including better sleep and appetite. Contact your American Cancer Society to find out about available sources of support in your area.

### When treatment ends

When treatment ends, people begin a new chapter in their lives, one that can bring hope, happiness – and fear. The fear of recurrence is common among cancer survivors and can sometimes be quite

intense. No two people are alike. Each person has his or her own way of coping and learning to manage these emotions will take time and practice.

Keep in mind that you are a cancer survivor and remember the good news: You are one of more than 13 million Americans alive today who has had cancer, and the survival rate is improving all the time.

### To learn more

Here's more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

### Living with cancer

Coping With Cancer in Everyday Life (also in Spanish)

Find Support Programs and Services in Your Area

Distress in People With Cancer

Attitudes and Cancer

Helping Children When a Family Member Has Cancer: Understanding Psychosocial Support Services

**Learning About New Cancer Treatments** 

When Your Cancer Comes Back: Cancer Recurrence

### Complementary and alternative treatments

Dietary Supplements: What Is Safe?

Complementary and Alternative Methods and Cancer

#### Finances and health insurance

Health Insurance and Financial Assistance for the Cancer Patient

How to Find a Financial Professional Sensitive to Cancer Issues: Financial Guidance for Cancer Survivors and Their Families

Financial Guidance for Cancer Survivors and Their Families: Off Treatment:

### Legal protections at work

What is COBRA? (also in Spanish)

What is HIPAA? (also in Spanish)

Americans With Disabilities Act: Information for People Facing Cancer (also in Spanish)

### National organizations and websites\*

Along with the American Cancer Society, other sources of information and support include:

#### CancerCare

Toll-free number: 1-800-813-4673 Website: www.cancercare.org

Free professional support, such as phone counseling, online support groups, and educational materials, for people with cancer, their loved ones, and caregivers. Also offers CancerCare for Kids at www.cancercareforkids.org or CancerCare's main number, above. This program is for kids with a parent, sibling, or other family member who has cancer. It offers practical support, education, and counseling to parents and children.

### **Cancer Hope Network**

Toll-free number: 1-877-467-3638 Website: www.cancerhopenetwork.org

Volunteers provide free and confidential one-on-one telephone support for people with cancer and family members.

### **Cancer Support Community**

Toll-free number: 1-888-793-9355

Website: www.cancersupportcommunity.org

Provides support for those living with cancer and their loved ones. Offers information, stress management, and online support groups led by professionals, including some in Spanish; has a special subsite (http://grouploop.org/) for teens and parents.

### American Association for Marriage and Family Therapy

Telephone: 703-838-9808 Website: www.aamft.org

Sponsors www.therapistlocator.net which provides referrals to local marriage and family therapists. The site also contains educational materials on helping couples live with illness, as well as other issues related to families and health.

### **National Cancer Institute (NCI)**

Toll-free number: 1-800-422-6237

TTY: 1-800-332-8615 Website: www.cancer.gov

An excellent source of up-to-date information about cancer for patients and their families.

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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<sup>\*</sup>Inclusion on this list does not imply endorsement by the American Cancer Society.

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For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org