



When Cancer Comes Back: Cancer Recurrence

You have completed your cancer treatment and are ready to move on with your life. You've gotten used to seeing your health care team less often and things are getting back to normal. Maybe you feel as if you are ready to go back to work full time, or to become a more active member of your household. Or, you may still feel emotionally exhausted and tired from the treatments you had. Maybe you feel tired in body and spirit and need a long rest. You've just survived the biggest battle of your life, but now the doctor tells you it's not over – you haven't won the battle yet. Your cancer has returned.

Once treatment is completed, many cancer survivors find they have issues and concerns that they did not expect. The most significant and devastating one is cancer recurrence.

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 where 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 is a cancer recurrence.

The difference between recurrence and progression

Progression is when cancer spreads or gets worse. Sometimes it is hard to tell the difference between recurrence and progression. For example, if the 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 is 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 (chemo) 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 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. There is no standard period of time within the definition of recurrence, but most doctors consider a cancer to be a recurrence if you have 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 recurrence?

There are different types of cancer 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 (or the chance that cancer will come back) is different for each person. It depends on many factors, including the type of cancer, the treatment you had, and how long it has been since your treatment. If you find yourself haunted by questions of 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's situation is unique, no matter what statistics are given. There may be factors in your case that make your situation different.

Could I have done something to prevent the recurrence?

Although eating right, exercising, and seeing your doctor for follow-up visits are important, please understand that there probably was nothing you could do to keep your cancer from coming back. Many patients blame themselves for missing a doctor visit, not

eating right, or putting off a CT scan for a family vacation. But even if you do everything just right, the cancer might still come back.

Sometimes people think taking certain vitamins, herbs, or other dietary supplements will give them an extra edge in preventing recurrence. But the available research does not support this belief. In fact, some research has shown that supplements containing high levels of single nutrients (more than the Dietary Reference Intakes and the tolerable upper intake limits) may have unexpected harmful effects on cancer survivors. To learn more about supplements, you may want to read our document called *Dietary Supplements: How to Know What Is Safe*.

It would be very satisfying to have something we could use 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 that there were such a magic potion or formula. But at this time **there is nothing you could have done to make sure the cancer would not come back**. Even with our current understanding of the process of cancer development and growth, this disease is mostly a mystery and not within human control.

Common questions about cancer recurrence

Can a person ever be sure the cancer will never come back?

No, it is not possible to guarantee that a person who has completed cancer treatment will never have the cancer come back. Even though 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 is always a chance that some cancer cells are left in your body and survived, even though they cannot be seen or found with any test used today. Over time, these cells can begin to grow and cause the cancer to recur.

And while you don’t want to ever think about the chance of having a second cancer – one that is 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.

Why won’t 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 cancer that your doctor could finally detect as a recurrence.

Just as it happened the first time, there is also a chance that some of 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 segment of DNA) to change (mutate). When genes mutate, they can become *oncogenes*, which can allow cells to become cancer cells that divide too quickly and out of control.

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 a brake keeps 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 cells 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 *Oncogenes, Tumor Suppressor Genes, and Cancer* to learn more about this.)

Not all of the growth factors for cancer cells have been found yet. Even though treatment may 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 be “asleep” and 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. The result is a cancer recurrence.

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 (survival outcome).

You may also hear the term 5-year *relative* survival rate. Relative survival compares survival among cancer patients to that of people not diagnosed with cancer, but of the same age, race, and sex. It is used to adjust for normal life expectancy when cancer is not present. 5-year relative survival rates are considered to be 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 first 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 is 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 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 are cured"?

Most doctors avoid using the word "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. Be aware that it is 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. Another way of defining control would be calling the disease *stable*. Controlled means that the tumor does not appear to be growing. 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 then 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 able to be measured or seen on a test in some way, it is called a *complete response* or *complete remission*. The decrease in tumor size must last for at least one month to count as a response. This does not mean the cancer has been cured.

In general, a *partial response* or *partial remission* means the cancer partly responded to treatment, but still has not gone away. If you are 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 1 month to qualify as a response.

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

The first treatment given for cancer is based on the past 20 to 30 years of clinical experience in treating that kind of cancer. But no 2 cases are exactly alike, and response to treatment cannot always 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.

When cancer recurs

When cancer comes back it can be devastating for you and the people closest to you. The medical work-up is difficult and all of the emotions you had when you were first diagnosed can resurface – and may be even stronger this time. You may feel more cautious, guarded, and less hopeful than ever before. You may be disappointed in your body and your health care team. Many issues and questions come with cancer recurrence. We have tried to address the more common ones here.

Is it a recurrence or a new cancer?

“I had breast cancer. Now they say I have liver cancer? How is that related to breast cancer? Is this a recurrence?”

It is possible to have 2 different types of cancer, but it is more likely that the first cancer has come back and spread to a new part of your body, like your liver. When cancer spreads to a new location in the body, it is said to have *metastasized*. The new cancer growths in the new locations are said to be *metastases*. But even when cancer has spread to a new area, it is still named after the part of the body where it started. For example, if prostate cancer spreads to the bones, it is still called prostate cancer, and if breast cancer spreads to the liver it is still breast cancer. A person with breast cancer that has spread to the liver is said to have breast cancer with liver metastases.

If in this case, breast cancer cells have spread to the liver, they will still look like breast cancer cells (even though they are in the liver). They will not look like cancer cells that started in the liver. The liver is a very common area of spread or metastasis in breast cancer, along with the lungs, lymph nodes, brain, and bones (usually the ribs and spine).

You will have tests to see if the cancer is the same type as you had before. Although it is not possible to predict how likely cancer is to recur, experience has shown that aggressive cancers (those that are fast growing), cancers that are more widespread, or those in later stages are harder to treat and more likely to come back. Most types of cancer recur in a typical pattern – your doctor can tell you more about this if it is something you would like to know.

If tests show a new area of cancer is a different type of cancer from the first type, you would be said to have 2 types of cancer. These 2 types of cancer will have started in different kinds of cells and look different under the microscope. This is much rarer than cancer recurrence, but it does happen.

Let's say, for example, you were treated for breast cancer, and there is no evidence of it on your checkup. Then the doctor finds a tumor in your liver. This tumor turns out to be the type of cancer that starts in the liver cells, and not breast cancer that has spread to the liver. Then you would be said to have breast cancer (in remission) **and** liver cancer – 2 different kinds of cancer. You would be offered treatment for liver cancer, which is different from the treatment you would get for recurrent breast cancer.

Treating recurrence

Many people want to do anything possible to treat cancer that has come back. Your doctor will talk to you about different treatment options. You may also decide to get a second opinion or get your health care in a comprehensive cancer center that has more experience with your type of cancer. There are usually clinical trials offered for patients with a cancer recurrence, too.

It is very important to research your insurance coverage along with the medical care options you are thinking about. If you need information quickly, please contact your American Cancer Society directly at 1-800-227-2345. Cancer Information Specialists are there 24 hours a day to answer your questions.

“Why can't I have the same treatment for my recurrence as I did for my first cancer?”

Some people do end up having some of the same types of treatment that they had for their first bout with cancer. For example, a woman with breast cancer that recurs in the area of the original cancer may have surgery again to remove the tumor. She may also get radiation therapy, especially if it had not been given before. Next, she and her doctor may consider chemotherapy and/or hormone therapy.

Treatment decisions are based on the type of disease, when it recurs, where it recurs, how much it has spread, your overall health, and your personal wishes. For example, your doctor will probably not suggest radiation or surgery for cancer that has spread throughout the body because these local treatments can only treat cancer that is in a limited number of places.

Another thing to think about is that cancer cells can become resistant to chemo. Tumors that come back often do not respond to treatment as well as the first tumors did. For example, if the cancer came back within 2 years of getting chemo, it is possible the cancer was able to grow despite treatment. It may be resistant to this type of chemo and not respond as well as it did the first time. Sometimes doctors will say, “You've already seen this drug, so we will try another drug.” This means that they feel that you have gotten all the help you can from a certain drug and that another one will probably better kill the cancer cells because it works in a different way.

Sometimes your doctor will not want to use a certain drug because of the risk of a certain side effect, or because you have had that drug in the past. For example, certain chemo drugs can cause heart problems or nerve damage in your hands and feet. To keep giving

you that same drug would risk making those problems worse or even lead to a long-term side effect.

Ask your doctor why a certain course of treatment is recommended for your recurrence at this time. Do you have 2 or 3 treatment options? Discuss these choices with your nurse or doctor, with members of your support group, and especially with members of your family. Only you can make the best decision for you.

“My doctor has recommended surgery for my cancer recurrence but we can’t schedule the surgery for a month and a half. I want this thing out like yesterday! How long is too long to wait – how much will the cancer spread while I am waiting for the doctor to work me into his schedule?”

While research is still being done on questions like this, for most cancers there is some time, certainly a few weeks, before you must decide on your treatment for recurrence. Remember that cancer cells divide, multiplying until they grow enough to form a tumor or something that can be seen in a blood test or on a scan. This takes time. Usually there is some time to make a thoughtful decision about the right treatment option for you. Try not to panic when you learn about the recurrence. Talk to your doctor if you are worried about waiting to start treatment. You may even want to take the time to get a second opinion. And be sure to discuss all the options with your health care team and your family. You need to be comfortable with your decision.

“Exactly what are the chances of treatment working this time? What are the chances of the cancer coming back again after this treatment? It seems like it will just go on and on and keep coming back...”

This is a very normal question to ask but one that is very hard to answer. There is no way to answer with exact percentages. The answers depend entirely on your situation and many different factors. Some of these include the type of cancer you have, the length of time between the original diagnosis and recurrence, the aggressiveness of the cancer cell type, your age, your overall health status, how well you tolerate treatment, the length of time you are able to take treatment, and the types of treatment you get.

Scientists are studying genetic tests that may predict how likely it is that cancers such as breast, colon, and melanoma will come back. For some types of cancer, there are formulas that can help estimate the chance of recurrence. Prostate cancer is one type of cancer for which recurrence projections can be made, based on stage and grade of cancer at the time of diagnosis. Still, for most people, the uncertainty of recurrence cannot be avoided. This is one reason recurrence is so hard to cope with. There are no guarantees that you can hold on to.

What happens if treatment is no longer working?

Sometimes the cancer keeps growing after one kind of treatment, or it comes back. It is often possible to try another treatment that might destroy the cancer or shrink the tumors enough to help you live longer and feel better. When a person has had many different treatments that did not help stop the cancer, it may mean that it has become resistant to all treatment. At this time it's important to weigh the possible limited benefit of a new treatment against the possible downsides, including the stress of getting treatment and the side effects that go with it. Everyone has a different way of looking at this.

This is likely to be the toughest time in your battle with cancer – when you have tried everything available and it's just not working anymore. Your doctor may offer you a new treatment, but you need to consider that at some point, continuing treatment is not likely to improve your health or change your survival.

If you want to continue treatment to fight your cancer as long as you can, you still need to think about the chances that it will help. In many cases, your doctor can estimate the response rate for the treatment you are considering. Some people are tempted to try more chemo or radiation, for example, even when their doctors say that the odds that it will help are less than 1 in 100. In this case, you need to think about and understand your reasons for wanting this kind of treatment.

No matter what you decide to do, it is important that you be as comfortable as possible. Make sure you are asking for and getting treatment for any symptoms you might have, such as pain or nausea. This type of treatment is called *palliative* treatment.

Palliative treatment helps relieve cancer-related symptoms, but it is not expected to cure the disease. Its main purpose is to improve your quality of life. Sometimes, the treatments that are used to control your symptoms are much like the treatments used to treat cancer. For example, radiation therapy might be used to help relieve bone pain from bone metastasis. Or chemo might be given to help shrink a tumor and keep it from blocking your bowel. But this is not the same as getting treatment to try to cure the cancer.

At some point, you may benefit from hospice care. Most of the time, this can be given at home. It can also be given in hospitals, nursing homes, and hospice houses. Your cancer may be causing symptoms or problems that need attention, and hospice is focused on your comfort. You should know that getting hospice care doesn't mean you can't have treatment for the problems caused by the cancer or other health conditions, but you will need to find out in advance what your hospice will do. Hospice is focused on helping you live your life as fully as possible and feel as well as you can at this difficult time. If you'd like to learn more about this, please see our document called *Hospice Care*.

Remember that staying hopeful is also important. Your hope for a cure may not be as bright, but there is still hope for good times with family and friends – times that are filled with happiness and meaning. In a way, pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now may be the time to do some of the things you've always wanted to do.

How do people cope emotionally when cancer recurs?

Not everyone has the same emotions and thoughts when cancer comes back. And not everyone has the responses shared here, but many have concerns and questions like these.

“I am so angry and upset! The cancer was gone! These are supposed to be my golden retirement years. Now I am facing more treatment. It’s all my doctor’s fault.”

It is understandable to be very upset when you expect one thing to happen and the opposite does. The last thing anyone expects is to have to go through more treatment for a cancer that they thought was gone. It is normal to want to strike out at and blame someone. A natural choice is your doctor. After all, this is the person who treated you the first time and said you appeared to be cancer-free. If you’re like most people, you really wanted to believe that you’d be cancer-free forever. Now you’re hearing the bad news about recurrence, finding out about a new treatment plan, and here you are going through this difficult time – again.

You may feel that your doctor didn’t do something right during your first treatment. Maybe you think your doctor did not follow up with you closely enough. Or maybe you feel you were not listened to as closely as you should have been. Whatever your feelings, they must be dealt with now. There are some things you can do to help resolve any issues you have at this time. You might try discussing your concerns with your doctor. See if you can clear up any bad feelings you have about how your treatment was handled.

It is highly unlikely that any doctor would intentionally not treat you as well as possible the first time. When you think about it that just doesn’t make sense. Your doctors want you to do well; this is what makes the doctor successful, too. But if you feel it is not possible to work with your current doctor, it may be wise to find a new one. You may find that a fresh start with a new health care team will help you improve your attitude and feel better about your current situation.

Feeling angry and upset about a cancer recurrence is completely normal, and you might need support and someone to talk to about these feelings. There are different sources for this type of support. For some, their support community is their place of worship. For others, a formal support group or online support group can be helpful. Other cancer survivors who have faced recurrence can understand and offer support like no one else. Still, some people prefer the privacy of one-on-one counseling. Ask your friends, family, or a trusted doctor for a referral. Just make sure that you are finding an outlet for your feelings. You deserve to be heard.

Some degree of depression and anxiety is common in people who are coping with cancer recurrence. But when a person is emotionally upset for a long time or is having trouble with their day-to-day activities, they may have a depression or severe anxiety that needs

medical attention. These problems can cause great distress and make it harder for you to follow a treatment schedule.

Even if you are clinically depressed or anxious, you have some things going for you.

- Depression can often be treated and treatment usually works well.
- Improving your physical symptoms and taking action will probably make your mood better.
- You have already been in a battle with cancer once and you learned a lot along the way. Try the things you that helped you then. Those same relationships and coping skills may help you now.

Family and friends should be alert for symptoms of distress. If they notice symptoms of depression or anxiety, they should encourage the person to seek the help of a health care professional. Anxiety and clinical depression can be treated many ways, including medicine, psychotherapy, or both. These treatments can help a person feel better and improve the quality of their life.

“I am only 35 years old. How am I supposed to deal with cancer recurrence? I am too young to die.”

Cancer is hard at any age, but it is especially hard to cope with when you are young and supposed to have a full, long life ahead of you. Cancer recurrence may seem even more unfair then. Cancer often is more aggressive in the younger cancer survivor – it may grow and spread faster. This aggressiveness means that it may come back earlier and be harder to treat.

Having a recurrence does not mean you will die, but there is no denying that it is something you will and should think about. It is a terribly painful prospect, one that requires much thoughtful processing and even preparation. First of all, a talk with your doctor can give you some idea how realistic your fears and concerns are. Even when you are healthy, it never hurts to be prepared for the chance you could die. You will want to make provisions for your family if the worst happens. You also need to get support that works for you so you can talk about and express your feelings about recurrence. Sometimes our lives have a purpose and meaning we cannot see clearly. It can be very helpful to discover that purpose and take pleasure from it when it seems there is no hope.

“How do I deal with the sense that recurrence means things are hopeless?”

There are a lot of different ways to look at and talk about cancer that has come back. There are many things can affect your outcome. Is there a chance you might not survive your cancer recurrence? Yes. Does that mean there is no hope? No. When cancer comes back, you may find that your hopes are very different from those you had when you were first diagnosed.

To be more precise, the type of cancer you have and your response to treatment will dictate your outcome. Today, a cancer recurrence may not mean you will not live long. Advances in cancer treatment and the management of treatment side effects continue to improve. There is no denying the situation is more serious if the cancer has come back, but for many patients this simply means that treatment will be different and perhaps more aggressive than it was at first.

At the same time, cancers that come back or get worse despite treatment tend to be harder to treat and control. It is important for you to talk to your cancer care team. They can give you a good idea of what you can expect to happen. It may be that your cancer is not likely to be cured, but there are things that can be done to treat it. You and your family should be clear about the goal of any treatment you're having. With any new treatment, ask if the goal is cure, control of the cancer, or comfort.

It is often very hard to think about starting more treatment for cancer. You may have feelings of panic and desperation. But there often are more (or different) treatment options available. If you are unsure about more treatment, it may help to get a second opinion from a doctor at a cancer center or university teaching hospital. Make sure you have covered all your bases and given yourself every chance to get the best treatment available to fight your illness.

“The cancer has already spread to many parts of my body. Should I still think about more treatment?”

There is no one answer to this question. It depends on the type of cancer, the effect it is having on your body, what your health care team is telling you, and what you and your family are thinking and feeling about the situation. During cancer treatment (even if the treatment is not working well), you are under a doctor's care, the cancer's progress is being slowed, and side effects and symptoms are being watched and treated. For some, getting cancer treatment helps them feel better and stronger, because they are doing something to fight the cancer. For others, being in treatment works the opposite way – it may make them feel more tired or less free. Only you can decide how you want to live your life. Of course, you will want to hear how your family feels about it, too. Their feelings are important since they are living through the cancer with you. But keep in mind, the final decision is up to you.

Whether or not you want aggressive cancer treatment, there is always the option of supportive care. This is also called *palliative care*, and you can ask for it at any time. It can be used along with more aggressive treatment, but is better known for its role in promoting comfort when aggressive treatment is no longer working. Palliative care is treatment of symptoms – it is not expected to cure the cancer. It is care that focuses on making your life the best it can be, even if there is not a good chance of curing the cancer. This means treating and controlling symptoms like nausea, pain, tiredness, or shortness of breath. Sometimes medicines are used, but other types of treatment may also be used. If you need help finding good palliative care options, call us for more information.

Along with people getting treatment that is expected to cure the cancer (curative treatment) and those getting palliative or supportive care, there are people who are treated for cancer for long periods of time. Even though the cancer isn't likely to be cured by treatment, for many patients, it can be kept under control for years. Treatment can be used to shrink the cancer, help relieve symptoms, and help you live longer. Even though it can be hard to do, many families adjust to this kind of treatment schedule. See the section "Treating cancer as a chronic illness."

"Is having a positive attitude important in fighting the cancer? My friends say it is, but I feel sad and discouraged."

When you have cancer, grief and sadness are normal.

In recent years, much attention has been paid to the importance of having a positive attitude. Some go so far as to suggest that such an attitude will stop the cancer from growing or prevent death. Patients are even told that they will never beat the cancer if they don't stop feeling sad, bad, depressed, or other so-called "negative" feelings. This kind of message is destructive to people who are dealing with cancer and recurrence. They are fighting for their lives and then are told they are responsible for causing their own illness. And to make matters worse, they may feel as if they aren't supposed to grieve or feel sad over the new hardships and major changes in their lives. Please do not allow others' misguided attempts to encourage positive thinking to place the burden of your cancer on you. That is not accurate, and it is not fair to you.

Cancer can't be controlled by a positive attitude.

Cancer is not caused by a person's negative attitude nor is it made worse by a person's thoughts. You might be better able to manage your life and cancer treatment when you are able to look at things in a positive light, but that is not always possible either. It is much healthier to admit that having cancer can make you and your loved ones feel sad. Once you can admit that reality, it is easier to get on with your life, whether that life is measured in days, months, or years. Some of those days will be good some will be not so great. Most of us know that this is the natural course of life anyway – with or without cancer.

People may tell you about studies that show that patients with a positive attitude live longer. These studies often offer anecdotal evidence (people's stories) based on too few patients and questionable research methods. No solid, well-accepted research has shown that a patient's attitude has anything to do with whether the person will live or die. There are patients who live longer than they are expected to, but researchers do not know why. If they did, they could certainly use that information to try to help many people. So don't let the positive attitude myths stop you from telling your loved ones or your cancer team how you feel. People with positive attitudes still die from cancer. People with negative attitudes often live a normal lifespan despite their cancer. Everyone gets through cancer in their own way.

What do I do when others tell me about God's plans for me?

Along those same lines, there may be times when friends or relatives try to reassure you with comments like “God doesn’t give us anything we can’t handle,” or “God must have a reason that this has happened.” While people say these things with the very best of intentions, if you are struggling with spiritual doubts, the thoughts and feelings invoked by such comments might only add to your stress. Sometimes people say these things because they just don’t know what else to say. You may feel very annoyed and even angry. Sometimes this can be a good topic to talk over with another cancer patient or your nurse or support group. They will understand where you are coming from. How do you respond to such comments? Many times this is a battle you just don’t want to fight! Since these people are trying to help, just a simple “thank you” and changing the subject may be the best response.

What about the “why” questions?

“So many people live the rest of their lives without their cancer coming back! Why me?”

For some people, looking for an answer to the “why” question can cause many sleepless nights and incredible soul searching. Others find that it doesn’t really matter why something has happened – how to best deal with it is more important. Many people think that if they knew why something has happened – and then they can do or stop doing something – somehow the situation will change. While this notion is not usually rational, it helps to understand the way people think. We all look for reasons for what happens in our lives. It is hard to accept that cancer can be a random event and that there may be no answer to why a person develops cancer. Many things can influence the development of cancer – these can be genetic, environmental, or related to something a person did. Most people never know why they have cancer, so trying to find the answer to this question only leads to frustration, sadness, or anger. This is the kind of question that doesn’t help right now. Rather than look for an answer, most people would rather spend their time and energy trying to get better and enjoying time with loved ones.

The bottom line in answering the “why” question is that knowing the answer to the question will not change what happens next. Worrying about “why” can drain people of energy which is better used in coping with the illness. Consider getting some counseling if you find yourself unable to move beyond this question.

“I keep thinking of every unhealthy thing I’ve ever done. Was it something I did that made the cancer come back?”

For some people, the answer to the “why” question might relate to something they did, such as smoking, tanning, or drinking a lot. These people can have a much harder time living with their choices because they feel guilty that they did something that could have caused their cancer. Their job is to forgive themselves. If they can’t let go of the guilt and self-blame, living with the cancer is that much harder. Many times it helps to talk to an oncology social worker or cancer counselor to make peace with these issues.

Get support

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

“I tried going to a support group after I was diagnosed with recurrence. Everyone in there was newly diagnosed. I felt really out of place and like I was bumming everyone out. Plus I didn’t get any support...”

Counseling and support groups

It is very important that you gather information about any support group you are thinking about joining to make sure that there are patients in all phases of treatment, including some with recurrence and disease progression. Ask the group leader or facilitator to tell you what types of patients are in the group and if anyone in the group is dealing with recurrence.

You can find support programs in many different formats, such as one-on-one counseling, 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 only of people with cancer or only caregivers while others 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.

Another option for support may be online support groups. The Cancer Survivors Network, an online support community supported by your American Cancer Society, is just one example. (You can visit this community online at <http://csn.cancer.org/>.) There are many other reputable communities on the Internet that you can join, too. You may also enjoy a personal connection with a counselor who can give you one-on-one attention and encouragement. Your doctor may be able to refer you to a counselor who works with cancer patients.

Religion and spirituality

Religion can be a source of strength for some people. Some find new faith during a cancer experience. Others find that cancer strengthens their existing faith or their faith provides newfound strength. 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. Meditation, practicing gratitude, and

spending time in nature are just a few of the many ways that people address spiritual needs.

Finding support

Support in any form allows you to talk about 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. You can contact your American Cancer Society to find out about sources of support that are available in your area.

“I can’t afford to have cancer again. Even though I have insurance, the coverage is not very good. My deductible is really high and my medicines cost a lot. I’m already working fewer hours because my last treatment left me unable to think as quickly as I could before. I feel really trapped. I can’t afford not to have treatment, but I can’t afford to have it either...”

Financial issues are often very real concerns for cancer survivors facing recurrence. For many, as this survivor describes, the problems began with the first cancer illness.

Hopefully, you have been able to keep your health insurance coverage. Sometimes there are insurance options cancer survivors have that they may not be aware of. Talk to your doctor, your facility’s financial counselors, or a social worker. You can also call 1-800-227-2345 for help finding possible sources of financial assistance.

Treating cancer as a chronic illness

“My cancer has come back 3 times. I just keep fighting, even though I know there’s a good chance that treatment won’t make the cancer go away forever...”

Cancer may not be a one-time event. Cancer can come back a second and third time and can even become a chronic (ongoing) illness that never goes away completely. In some cases, especially with certain cancer types, this is true. Although recurrent disease may not be cured, it can often be controlled for months or even years. In fact, there’s always a chance that the cancer will go back into remission. The natural tendency of some cancers (for example, ovarian), is one of recurrence and remission. Often, this repeating cycle can translate into survival over many years during which the cancer can be managed as a chronic illness. Treatment can be used to shrink the cancer, help relieve symptoms, and help you live longer.

Repeated recurrences, often with shorter time periods in between disease-free intervals, can become discouraging and exhausting. The question of whether to continue treating cancer that keeps coming back is a valid one. Your choices about ongoing treatment are personal and based on your needs, wishes, and abilities. There is no right or wrong decision on how to handle this phase of the illness.

Still, it is important to know that even those who are not cured of cancer may go on living for months or years, even though there may be changes in their lives. And though it can be hard to do, many families adjust to this kind of treatment schedule. For these people, cancer can be much like diabetes or heart disease – a chronic illness that is mostly controlled with treatment.

Having a recurrence does not put you beyond hope or help; you may be living with a disease that can be treated or controlled.

To learn more

We have selected some related information that may also be helpful to you. These materials may be read on our Web site or ordered from our toll-free number.

Caring for the Patient With Cancer at Home (also available in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Recurrence or Progressive Illness

Health Insurance and Financial Assistance for the Cancer Patient (also available in Spanish)

Advance Directives

Nearing the End of Life

Advanced Cancer (also available in Spanish)

Coping With the Loss of a Loved One (also available in Spanish)

Oncogenes, Tumor Suppressor Genes, and Cancer

Complementary and Alternative Methods for Cancer Management (also available in Spanish)

Dietary Supplements: How to Know What Is Safe

Guidelines for Using Complementary and Alternative Methods

A Message of Hope: Coping With Cancer in Everyday Life (also available in Spanish)

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