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Understanding Recurrence

Some cancers can come back or recur after treatment. The odds of this happening depend on many factors, including the type of cancer. Learn more about cancer recurrence and living with this possibility here.

What Is Cancer Recurrence?
Cancer Recurrence Rates
Can I Do Anything to Prevent Cancer Recurrence?
Coping with Cancer Recurrence

What Is Cancer Recurrence?

Sometimes, cancer can come back after treatment. When it does, it's called cancer recurrence. The cancer might come back in the same place it first started, or it might come back somewhere else in the body. Even if the cancer comes back in a new part of the body, it's still named after the part of the body where it started.

- How likely is a cancer recurrence?
- What are the types of recurrence?
- Describing cancer and cancer recurrence
- Response and remission

How likely is a cancer recurrence?

It's not possible to say how likely a cancer is to recur, but cancer is harder to treat and

more likely to come back if it is:

- Fast growing
- More advanced or widespread

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 first started.
- Distant recurrence means the cancer has come back in another part of the body.

If your cancer recurs, your cancer care team can give you the best information about what type of recurrence you have and what it means, if you'd like to know. If your cancer care team thinks this could be a <u>second cancer</u>¹ (a different type of cancer), they can talk with you about testing to find out what is really happening. They can also talk with you about different <u>options for treatment</u>² and your outlook (prognosis).

Describing cancer and cancer recurrence

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

A doctor may use the term "controlled" or "stable" if your <u>tests or scans</u>³ show that the cancer is still there, but it's not changing over time. Controlled or stable means that the tumor doesn't look like it's growing. Some tumors can stay the same for a long time, even without any 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, your doctor might say that the cancer has progressed. Ask your doctor for details if you'd like to know more about how much it has grown or spread.

What's the difference between recurrence and progression?

Sometimes it's hard to tell the difference between recurrence and progression. Recurrence means the cancer has come back. Progression means the cancer is growing or spreading without ever having gone away completely. For example, if cancer has not been found for a short time before it comes back, it was probably not completely gone. Is this a recurrence or progression? Chances are this is not really a recurrence. In this case, it's likely one of these things happened:

- The surgery done to take out the cancer didn't get all of it. Tiny clusters of cancer cells that couldn't be seen or found on scans or other tests were left behind. Over time they grow large enough to show up on scans or cause symptoms. These cancers tend to be very aggressive (fast-growing and quick to spread).
- The cancer has become hard to treat or resistant to treatment. Cancer cells can become resistant to treatment just like germs can become resistant to antibiotics. This means chemotherapy or radiation may have killed most but not all of the cancer cells. These cancer cells can then grow and show up again.

If the cancer comes back a short time after it was gone, it is important to talk about a care plan with your cancer care team. There's no standard length of time to decide if it's recurrence or progression. But most doctors consider recurrence to be cancer that comes back after you've had no signs of it for at least a year.

Response and remission

Complete response or remission

When a treatment completely gets rid of all tumors that were seen on a test or were measured in some way, it's called a **complete response** or **complete remission**. A complete response or complete remission does not mean the cancer has been cured. It means the cancer is not seen on any tests.

Partial response or remission

In general, a **partial response** (or partial remission) means the cancer responded to treatment, but still has not gone away. A partial response is most often defined as at least a 50% reduction in a tumor that can be measured.) The reduction in tumor size must last for at least a month to qualify as a response. Again, you can ask for more details about the kind of response to treatment the doctor sees, and how long it lasts.

Hyperlinks

- 1. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/second-cancers-in-adults.html</u>
- 2. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/cancer-as-a-chronic-illness.html</u>
- 3. www.cancer.org/cancer/diagnosis-staging/tests.html

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Last Revised: August 28, 2023

Cancer Recurrence Rates

It's common for a cancer survivor to wonder how likely it is for their cancer to come back (cancer recurrence). A cancer recurrence rate can help show generally how often cancer comes back, but it is not the same as your individual risk of cancer recurrence.

- What are cancer recurrence rates?
- Which cancers have the highest and lowest recurrence rates?
- How do I know the recurrence rate for my type of cancer?

What are cancer recurrence rates?

A cancer recurrence is when a cancer that was not detectable comes back. It may come back where it first started or in a different part of the body. A cancer recurrence rate is a measure of how often cancer comes back among a large group of people. Recurrence rates are typically estimates and are different for each type of cancer.

Which cancers have the highest and lowest recurrence rates?

It's hard to know recurrence rates for specific cancer types. Cancer registries track how many new cancers are diagnosed each year, but doctors are not required to report cancers that have recurred. This means recurrence information is not collected by cancer registries where many statistics come from.

While research and statistics are limited, we do know that recurrence rates are different depending on the type and stage of the cancer. Tumor characteristics and the treatment given for the cancer can also affect whether a cancer is likely to come back.

Many types of cancers that are found at an early stage have a lower chance of recurrence.

The chance of recurrence is higher for:

- People treated for a childhood cancer1
- Adult survivors of <u>Hodgkin lymphoma</u>²
- Glioblastoma, a type of brain cancer³
- Some types of soft tissue sarcoma4
- Cancers of the <u>bladder</u>⁵ and <u>pancreas</u>⁶
- Cancers caused by tobacco use⁷

Some cancers, such as certain types of breast cancer, have tests available to help doctors understand what chance a person's cancer has of coming back. For example, <u>triple-negative</u> (hormone-receptor negative) breast cancer⁸ is more likely to recur than hormone-receptor positive breast cancer.

How do I know the recurrence rate for my type of cancer?

There are many types and subtypes of cancer. Recurrence rates are not available for all types of cancer and are not always useful for knowing your own risk of recurrence. It's important to ask your cancer care team about your risk for recurrence, what to watch for, and what follow-up is needed.

Hyperlinks

- 1. www.cancer.org/cancer/types/cancer-in-children.html
- 2. www.cancer.org/cancer/types/hodgkin-lymphoma.html
- 3. www.cancer.org/cancer/types/brain-spinal-cord-tumors-adults.html
- 4. www.cancer.org/cancer/types/soft-tissue-sarcoma.html
- 5. www.cancer.org/cancer/types/bladder-cancer.html
- 6. www.cancer.org/cancer/types/pancreatic-cancer.html
- 7. www.cancer.org/cancer/risk-prevention/tobacco/health-risks-of-tobacco.html
- 8. <u>www.cancer.org/cancer/types/breast-cancer/about/types-of-breast-cancer/triple-negative.html</u>

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Last Revised: December 13, 2023

Can I Do Anything to Prevent Cancer Recurrence?

Eating right, exercising, and seeing your cancer care team for follow-up visits are helpful ways to try to reduce your risk, but these efforts cannot completely keep cancer from recurring. There are other positive things you can do to be as healthy as possible.

- Diet
- Vitamins and supplements
- Physical activity
- Will cancer ever come back?
- Worrying about a recurrence?
- Help from patient support groups

Diet

After completing cancer treatment, many people decide to eat better in the hope that these changes will improve their chance for survival.

The American Cancer Society recommends that cancer survivors in stable health after treatment follow the same <u>nutrition guidelines</u>¹ as those recommended for cancer prevention. It's thought that the same factors that can increase cancer risk might also promote cancer recurrence after treatment. For example, research has suggested that the risk of breast cancer recurrence might be higher in women who have excess weight and don't eat many fruits and vegetables. Prostate cancer recurrence risk might be higher in men who eat a lot of saturated fats.

What to do

In general, an adult should:

- Eat a variety of vegetables -dark green, red, and orange each day, as well as fiber-rich legumes (beans and peas), and others.
- Eat foods that are high in nutrients in amounts that help you get to and stay at a healthy body weight
- Eat fruits, especially whole fruits with a variety of colors
- Limit or avoid red meat (beef, pork, lamb) and processed meats (foods like hot dogs, sausage, and luncheon meats).
- Select foods made with whole grains rather than refined grains and sugars.
- Avoid sugary beverages

If you have excess weight, consider getting to and staying at a <u>healthy weight</u>². (Check with your cancer care team before starting an exercise program.)

Keeping a healthy weight may help to lower the risks of cancer recurrence

Several types of cancer are linked to <u>alcohol intake</u>³. It is best not to drink, but if you do, women should have no more than 1 drink a day and men no more than 2 a day. 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 with high levels of single nutrients (greater than the Dietary Reference Intakes) may have unexpected harmful effects on cancer survivors.

Blood tests can show if your levels of certain vitamins are low. Based on these tests, your doctor might recommend supplements to raise levels of certain vitamins, but the evidence so far does not show that high vitamin levels help lower cancer risk. It's best to talk with your cancer care team before starting any vitamin or other dietary supplement.

See<u>Dietary Supplements</u>⁴ for more information on vitamins and supplements.

Physical activity

A few studies have looked at the end result of physical activity or exercise on survival of people with cancer. Still, research has not yet shown if physical activity can help prevent cancer recurrence or slow the growth of disease. But studies have shown that regular physical activity⁵ of moderate to very active on most days of the week can reduce fear and depression of overall stress, improve mood, boost self- esteem, and reduce tiredness, nausea, pain, and diarrhea. (Moderate activities are those that make you breathe as hard as you would during a brisk walk. Vigorous activities make you use large muscle groups and make your heart beat faster, make you breathe faster and deeper, and also make you sweat.)

What to do

Talk to your cancer care team about an exercise plan that's good for you. The American Cancer Society recommends cancer survivors:

- Take part in regular physical activity.
- Limit time sitting or lying down and return to normal daily activities as soon as possible.
- Try for at least 150 to 300 minutes per week of moderate intensity activity or 75 to

150 minutes per week of "very active" activity.

• Include strength training exercises at least 2 days per week.

A little physical movement is much better than none. Do something you enjoy. It helps if you start slowly and build up over time. In choosing a level of activity, it's important to think about your physical abilities and what you've been able to do recently.

Talk to your cancer care team about an exercise plan that's good for you. The American Cancer Society recommends cancer survivors:

Will cancer ever come back?

There's no way 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, there may be a chance that there are some cancer cells left in your body, even though they can't be seen or found with any test used today. Over time, these cells might begin to grow again.

Worrying about a recurrence?

It's easy to worry over every ache and pain if you've had cancer. Check with your cancer care team for a list of common signs of recurrence of your type of cancer.

There are only a few symptoms that could mean serious problems. If you have any of the problems listed below, tell your cancer care team.

- 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's unrelated to an injury and doesn't go away
- Weight loss without trying
- Easy bleeding or unexplained bruising
- A rash or allergic reaction, such as swelling, severe itching, or wheezing
- Chills or fevers
- Frequent headaches
- Shortness of breath
- Bloody stools or blood in your urine
- New lumps, bumps, or swelling with no known cause
- Nausea, vomiting, loss of appetite, or trouble swallowing

- · Diarrhea,
- A cough that doesn't go away
- Any other signs your cancer care team has talked to you about or any unusual symptoms that you just can't explain

Whenever you have a symptom, your first thought might be that your cancer has come back. Remember that there are illnesses and medical problems that have nothing to do with your previous cancer. You can still get colds, infections, arthritis, heart problems, and so on – just like anyone else. As with any illness, your primary care provider is the best person to find the cause of your symptoms. If you're seeing a new doctor, be sure they know about your history of cancer and its treatment.

Help from patient support groups

Some people find it very hard to not worry about cancer coming back and these thoughts interfere with daily life. Some handle these thoughts by distraction, or by focusing on what's most important to them each day. Others take actions such as joining a peer support group or seeing a mental health professional.

Talk to your cancer care team or primary care team about your worries and concerns. Get help if you need it to <u>deal with your emotions</u>⁶ and live life to the fullest.

Hyperlinks

- 1. <u>www.cancer.org/cancer/risk-prevention/diet-physical-activity/acs-guidelines-nutrition-physical-activity-cancer-prevention.html</u>
- 2. www.cancer.org/cancer/risk-prevention/diet-physical-activity/body-weight-and-cancer-risk.html
- 3. <u>www.cancer.org/cancer/risk-prevention/diet-physical-activity/alcohol-use-and-cancer.html</u>
- 4. <u>www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine/dietary-supplements.html</u>
- 5. www.cancer.org/cancer/risk-prevention/diet-physical-activity/get-active.html
- 6. <u>www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes.html</u>

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Last Revised: August 28, 2023

Coping with Cancer Recurrence

If cancer comes back it can be shocking 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 return – and might be even stronger this time. You might feel more cautious, guarded, and less hopeful than ever before. Many issues and questions come with cancer recurrence. Here are some of the more common ones.

- Could I have prevented the recurrence?
- Why me?
- On treating cancer recurrence
- How do I know if I should keep getting treatment?
- On emotions when cancer recurs

Could I have prevented the recurrence?

Many people blame themselves for missing a medical appointment, not eating right, or putting off blood work or imaging test. But even if you do everything just right, cancer

may come back. Even with our current knowledge of how cancer develops and grows, it's still a mystery in many ways.

Why me?

For some people, looking for an answer to "Why me?" can cause sleepless nights and incredible soul searching. Others find that it doesn't really matter why something has happened – how best to deal with it is more important.

Worry can drain people of energy they need to help cope with the illness. If you find yourself unable to move beyond this question, talk with your cancer care team. You may need a referral to a mental health professional who can help you work through these feelings.

On treating cancer recurrence

If cancer comes back, your doctor will talk with you about treatment options and how <u>helpful</u>¹ each one is likely to be.

Be sure you understand the goal of each treatment you are considering. Is it to control the cancer? Is it to cure the cancer? Is it to make you more comfortable? You might also decide to get a <u>second opinion</u>² or get treated at a <u>cancer center</u>³ that has more experience with your type of cancer.

Clinical trials usually are offered for patients with cancer recurrence, too. If you're thinking about a clinical trial, you'll want to know the goal of the clinical trial and its chances of helping you.

Please remember: It's very important to check on your insurance coverage along with the medical care options you are thinking about.

Why won't I get the same treatment for the recurrence as I did the first time?

Some people may end up having some of the same types of treatment that they had for their first time with cancer. For instance, a woman with breast cancer that recurs in the breast 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:

- Type of cancer
- When it recurs
- · Where it recurs
- · How much it has spread
- Your overall health
- Your personal values and wishes

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.

Another reason your doctor may use a different treatment is because of the risk of its side effects. For example, certain chemo drugs can cause heart problems or nerve damage in your hands and feet. To keep giving you that same drug might risk making those problems worse or lead to long-term side effects.

Ask your cancer care team why a certain treatment is recommended for the cancer recurrence. Discuss your options with your team, with members of your support group, and especially with members of your family.

If surgery is needed for a cancer recurrence, how long is too long to wait? Will the cancer spread while I wait?

For most cancers there is time before you must decide on a treatment for recurrence. Remember that cancer cells multiply 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's some time to make a thoughtful decision about the right treatment option for you.

You might take time to get a second opinion. And be sure to discuss all the options with your cancer care team and your family. You need to feel like you've made the best decision for you. Talk to your doctor if you are worried about waiting to start treatment.

What are the chances of recurrence after this treatment?

This question is very hard to answer. There's no way to answer with exact numbers. The answers depend on your situation and many different factors including:

- Type of cancer you have
- Length of time between the original diagnosis and recurrence
- Aggressiveness of the cancer cell type
- Your age

- Your overall health status
- Your treatment regimen
- How well you tolerate treatment
- The length of time you are able to take treatment

Scientists are studying <u>genetic tests</u>⁸ that may predict how likely it is that cancers such as breast, colon, and melanoma will come back. There are methods that can help estimate the chance of recurrence for a few types of cancer. Even with using methods to estimate There may be risk of cancer recurrence.

How do I know if I should keep getting treatment?

There's no one answer to this question. It depends on the type of cancer, how it's affecting you, what your cancer care team is telling you, and what you and your family are thinking and feeling about the situation. For some, getting cancer treatment helps them feel better and stronger, because they're doing something to fight the cancer. For others, being in treatment works the opposite way – it might 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.

It is important for you to voice your concerns and what you want to your family and cancer care team. This will help you make a decision on whether you continue treatment or not.

Whether or not you want cancer treatment, you should ask to get <u>supportive or palliative</u> <u>care</u>⁹. Palliative care focuses on treating symptoms and making your life the best it can be.

For many people, cancer can be controlled with treatment this way 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.

On emotions when cancer recurs

Everyone does not have the same feelings and thoughts when cancer comes back. And everyone does not have the same responses shared here, but many have these concerns.

Placing blame

It's 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's normal to want to blame someone. No one is to blame. Talk to your cancer care team to help you through your feelings.

Whatever your feelings are, they should be talked about with your family and cancer care team..

Anger

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 places to find 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. 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 find ways to release your feelings. You deserve to be heard.

Depression and anxiety

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 depression or worry a lot and need medical attention. These problems can cause you to feel sad 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 be treated and treatment usually works well.
- Improving your physical symptoms and taking action may help make your mood better.
- You've learned a lot when you had cancer the first time. Try the things that helped you then. Those same coping skills may help you now.

Family and friends should watch 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.

Fear of death

Cancer is hard at any age, but it's especially hard to cope with when you are young and believe you have a full, long life ahead of you. Cancer recurrence may seem even more unfair then.

The thought of death may be difficult, but talk with your cancer care team to get an idea of how realistic your fears and concerns are. You need to get support that works for you so you can talk about and express your feelings about recurrence. You can also learn more about yourself and explore the meaning of your life. 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's no hope.

Hopelessness

There are different ways to look at and talk about cancer that has come back. If cancer comes back, you may find that your hopes are very different from those you had when you were first diagnosed.

If the cancer comes back, this means that treatment will be different and maybe stronger than it was at first. It's important for you to talk to your cancer care team. They can give you a good idea of what you can expect to happen. There are things that can be done to keep the cancer from growing. You and your family should be clear about the goal of any treatment.

Hyperlinks

- 1. <u>www.cancer.org/cancer/survivorship/long-term-health-concerns/cancer-as-a-chronic-illness.html</u>
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Last Revised: August 28, 2023

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