

## Managing Cancer as a Chronic Illness

Cancer isn't always a one-time event. Cancer can be closely watched and treated, but sometimes it never completely goes away. It can be a chronic (ongoing) illness, much like diabetes or heart disease. This is often the case with certain cancer types, such as [ovarian cancer](#)<sup>1</sup>, chronic [leukemias](#)<sup>2</sup>, and some [lymphomas](#)<sup>3</sup>. Sometimes cancers that have spread or have come back in other parts of the body, like metastatic [breast](#)<sup>4</sup> or [prostate cancer](#)<sup>5</sup>, also become chronic cancers.

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The cancer may be controlled with treatment, meaning it might seem to go away or stay the same. The cancer may not grow or spread as long as you're getting treatment. Sometimes when treatment shrinks the cancer, you can take a break until the cancer starts to grow again. But in either of these cases the cancer is still there – it doesn't go away and stay away – it's not cured.

Living with cancer is different from living after cancer. And it's becoming

more common every day.

## How is chronic cancer described?

A doctor may use the term *controlled* if tests or scans show that the cancer is not changing over time. Another way of defining control would be calling the disease *stable*. Cancers like this are watched closely to be sure that they don't start growing.

## The cycle of recurrence and remission

Most chronic cancers cannot be cured, but some can be controlled for months or even years. In fact, there's always a chance that cancer will go into *remission*. There are different kinds of remission.

- When a treatment completely gets rid of all tumors that could be measured or seen on a test, it's called a *complete response* or *complete remission*.
- A *partial response* or *partial remission* means the cancer partly responded to treatment, but still did not go away. A partial response is most often defined as at least a 50% reduction in measurable tumor. Here, when we refer to a remission it will generally mean a partial remission.

To qualify as either type of remission, the absence of tumor or reduction in the size of the tumor must last for at least one month. There's no way to tell how long a remission will last, so remission does not mean the cancer definitely has been cured.

Some cancers (for example, ovarian), have a natural tendency of recurrence and remission. Often, this repeating cycle of growing, shrinking, and stabilizing can mean survival for many years during which the cancer can be managed as a chronic illness. Treatment can be used to control the cancer, help relieve symptoms, and help you live longer.

## Progression

Cancers that aren't changing may be called *stable disease*. When cancer grows, spreads, or gets worse it's called *cancer progression*. When cancer comes out of remission it's said to have progressed. In the case of chronic cancers, recurrence and progression can mean much the same thing.

Progression may be a sign that you need to start treatment again to get the cancer back into remission. If the cancer progresses during or soon after treatment, it may mean that

a different treatment may be needed.

Progression and recurrence occur when the treatment doesn't kill all of the cancer cells. Even if most of the cancer cells were killed, some were either not affected or were able to change enough to survive the treatment. These cancer cells can then grow and divide enough to show up on tests again.

## How is chronic cancer treated?

Most people want to do anything possible to treat cancer, whether it's the first treatment or the second or third one. Your doctor will talk to you about your treatment options. You may also decide to get a second opinion or get treated at a [comprehensive cancer center](#)<sup>6</sup> that has more experience with your type of cancer. There may be [clinical trials](#)<sup>7</sup> available, too.

Some people get some of the same types of treatment that they had the first time (for instance, surgery or chemo), but some treatments may be less helpful as the cancer progresses. Treatment decisions are based on the type of disease, location of the cancer, amount of cancer, extent of spread, your overall health, and your personal wishes.

## Chemotherapy

Over the long term, cancers are usually treated with [chemotherapy](#)<sup>8</sup> (chemo) in 1 of 2 ways.

- Chemo is given on a regular schedule to keep the cancer under control. This is also called maintenance chemo. This may help curb spread and prolong survival.
- As another option, chemo may only be given when the cancer becomes active again. The cancer is watched closely with things like [imaging tests](#)<sup>9</sup> and blood tests; chemo is started when things change.

Another thing to think about is that cancer cells can become resistant to chemo. The tumors that keep coming back often do not respond to treatment as well as the first tumors did. For example, if the cancer comes back within a year or 2 of getting chemo, it may be resistant to this type of chemo and another drug may be a better option. Sometimes doctors will say, "You've already had this drug, so we need to try another one." This can mean they think you've gotten all the help you can from a certain type of drug and 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 before. For instance, some 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 permanent damage.

### **Making treatment choices**

Ask your doctor why a certain course of treatment is recommended at this time. Do you have 2 or 3 treatment options? Find out what you can expect to happen with each treatment. Discuss these choices with your cancer care team, with members of your support group, and especially with members of your family. Then you can make the best decision for you.

“She may not be able to cure my cancer, but my doctor says she’ll help me buy as much time as possible. I’m good with that – I’ll take each day as it comes.” -Stan, living with CML

### **How long can treatment go on?**

This is a very good question to ask, but one that’s very hard to answer. There’s no way to give an exact time limit. The answer depends entirely on your situation and many factors, such as:

- The type of cancer you have
- The treatment schedule or plan
- The length of time between cancer recurrences
- The aggressiveness of the cancer cell type
- Your age
- Your overall health
- How well you tolerate treatment
- How well the cancer responds to treatment
- The types of treatment you get

Because there are no guarantees that you can hold on to, it can be hard to cope with chronic cancer. Talk to your doctor and the rest of your cancer care team about any questions or concerns you have. They know your situation best and may be able to give you some idea of what to expect.

### **How do I know if I should keep getting treatment?**

## **How much is treatment helping?**

For some people, getting cancer treatment helps them feel better and stronger. It also helps control the cancer so they can live longer. But for others, being in treatment works the opposite way – they may reach a point where it only makes them feel worse. Side effects might keep you from enjoying the life you have left. Only you can decide how you want to live your life. Of course, you'll want to know 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 yours.

## **Do the benefits outweigh the side effects?**

When a person has had many different treatments that didn't help stop the cancer, it may mean that it's become resistant to all treatment. At this time you might want 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. Talk to your cancer care team about what you can expect from treatment. They can help you make the best decision for yourself and your family.

## **What is palliative care?**

Palliative care focuses on relief of physical and emotional symptoms related to illness—it's not expected to treat the cancer or other disease. The goal of palliative care is to make your life the best it can be at any time- before treatment, during treatment or after treatment.

This means that symptoms like nausea, pain, tiredness, or shortness of breath are treated and controlled. Palliative care also helps with emotional symptoms such as stress and depression. Sometimes medicines are used, but other types of treatment such as physical therapy and counseling may also be used.

Your cancer care team may include providers who are specially trained in palliative care. If you need help finding good palliative care options, call us.

## **What is hospice care?**

If at some point treatment can no longer control the cancer or the benefits no longer outweigh the side effects, you may feel better with hospice care. The hospice philosophy accepts death as the final stage of life and does not try to stop it or speed it up. The goal of hospice is to help patients live as alertly and comfortably as possible

during their last days. Most of the time, hospice care is given at home. It can also be given in hospitals, nursing homes, and hospice houses. Your cancer may cause symptoms or problems that need attention, and hospice focuses on your comfort. If you'd like to learn more about this, see [Hospice Care](#)<sup>10</sup>.

## **What's "normal" about living with cancer?**

The first few months of cancer treatment are a time of change. But when you're living with cancer that doesn't go away you may feel like you're stuck in this change – you don't know what to expect or what's going to happen next.

Living with cancer is not so much about "getting back to normal" as it is learning what's normal for you now. People often say that life has new meaning or that they look at things differently now. Every day takes on new meaning.

Your new "normal" may include making changes in the way you eat, the things you do, and your sources of support. It may mean fitting cancer treatments into your work and vacation schedule. It will mean making treatment part of your everyday life – treatments that you may be getting for the rest of your life.

"Cancer is just part of my life now, and I always try to have hope." -Marisol,  
living with ovarian cancer

Repeated recurrences, often with shorter time periods in between remissions, can become discouraging and exhausting. It can be even more discouraging if the cancer never goes away at all. The question of whether to keep treating cancer that doesn't go away or comes back again and again is a valid one. Your choices about continuing treatment are personal and based on your needs, wishes, and abilities. There's no right or wrong decision on how to handle this phase of the illness.

Still, it's 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. Many families adjust to this kind of treatment schedule.

Having a cancer that cannot be cured doesn't put you beyond hope or help; you may be living with a disease that can be treated and controlled for a fairly long time.

## **Living with uncertainty**

Here are some ideas that have helped others feel more hopeful and deal with the uncertainty and fear of cancer that doesn't go away:

- **Be informed.** Learn what you can do for your health now and about the services available to you and your loved ones. This can give you a greater sense of control.
- **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 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 needlessly worrying.
- **Express feelings** of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried and better able to enjoy each day. People have found that when they express strong feelings, like anger and fear, they're better 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 may be helpful to find a way to express your feelings.
- **Enjoy the present moment** rather than thinking of an uncertain future or a difficult past. If you can find a way to be 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, scary, and confusing.
- **Make time for what you really want.** You may find yourself thinking about all the things you've always wanted to do but never made time for. It's OK to pursue these things, and don't forget to enjoy everyday pleasures and have fun, too.
- **Work toward having a positive attitude,** which can help you feel better about life even if a cure is out of reach. Nearly everyone can find things to feel grateful for or hopeful about. But don't try to be upbeat or positive all the time – no one is! You need to pay attention to your feelings, even the so-called “negative” ones. You're allowed to have bad days, feel sad or angry, or grieve whenever you need to.
- **Use your energy to focus on what you can do now to stay as healthy as possible.** Try to [make healthy changes in what you eat](#)<sup>11</sup>. If you're a person who uses tobacco, this is a good time to [quit](#)<sup>12</sup>, and encourage others to quit with you.
- **Find ways to relax** and enjoy time alone and with others.
- **Exercise** and be as active as you can. Talk with your cancer care team about what's realistic for you.

Control what you can. Some people say that putting their lives in order makes them feel less fearful. Being involved in your health care, trying to find your “new normal,” 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 to not dwell on the fearful ones.

## Grief and loss

It's normal to feel sad when you find out that the cancer cannot be cured. This sadness may not go away, even if you know that there's a good chance you can live a long time with cancer. You may find yourself grieving the loss of what you thought would be your future. This is hard for anyone to handle without emotional support.

Grief can affect a person physically, emotionally, and mentally. It can interfere with everyday activities. It takes time and energy to adjust to these major changes in your life. Many people find it helps to have people they can talk to about all these things. If no one comes to mind, you might want to think about finding a counselor or support group. (See "Getting support" below.)

## Dealing with depression

Some degree of depression and anxiety is common in people who are coping with cancer every day. But when a person is emotionally upset for a long time and is having trouble with their day-to-day activities, they may have depression or severe anxiety that needs medical attention. These problems can cause great distress and make it harder for you to enjoy life and 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 help make your mood better.

Anxiety and 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. Please see [Emotional, Mental Health, and Mood Changes](#)<sup>13</sup> to learn more about this.

## Getting support

Support in any form allows you to talk about your feelings and develop coping skills. Studies have shown that many people who take part in support groups have a better quality of life, including better sleep and appetite.



A support group can be a powerful tool for both patients and families. Talking with others who are in situations like yours can help ease loneliness. Others who have had the same experiences may also share ideas that might help you. Contact your American Cancer Society to find out about [sources of support in your area](#)<sup>14</sup>.

## Types of support

You can find support programs in many different formats, such as one-on-one counseling, group counseling, and support groups.

**Counseling.** You may enjoy a personal connection with a counselor who can give you one-on-one attention and encouragement. It's important to find a counselor who has had some training and experience in taking care of people with cancer. Your cancer care team is the best way to get names of counselors in your area. Another resource for finding a counselor is Mental Health America. Their [website](#)<sup>15</sup> offers ideas on how to find a counselor as well as things to consider when choosing one.

**Support groups.** Some support 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 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're thinking about joining to make sure that there are patients in all phases of treatment, including some with cancer that can't be cured. 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 cancer that doesn't go away.

Online support groups may be another option. The Cancer Survivors Network, an online support community supported by your American Cancer Society, is just one example. (You can find it at [csn.cancer.org](http://csn.cancer.org)<sup>16</sup>.) There are many other reputable communities on the Internet that you can join, too.

“Having someone to talk to who knows exactly how I feel is great. The people in my group understand like no one else can.” -Ed, living with follicular non-Hodgkin lymphoma

## 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 people with cancer and their families.

Spirituality is important to many people, even those who do not observe a traditional religion. Many people are comforted by recognizing that they are part of something greater than themselves, which can help them find meaning in life. The practice of forgiveness or performing small acts of kindness helps some people. Others meditate, spend time in nature, or practice gratitude – these are just a few of the many ways that people attend to their spiritual needs.

If it's a struggle to find meaning in your life, or make peace with yourself, you may wish to spend time with a respected counselor or member of the clergy who can help you with this important work.

## **Family members, loved ones, and caregivers**

You may worry about how your illness and care will affect your family and loved ones. This is a very tough journey to travel alone, and everyone needs help and support from those close to them. It can be hard to know how to start – who to talk to and what to say. You may want to read [Telling Others About Your Cancer](#)<sup>17</sup>. If there are children in your family, you may also want to read [Helping Children With Cancer in the Family](#)<sup>18</sup>.

If you're part of a couple, your partner may step up and offer to help you get back and forth to treatment, go with you to appointments, and help you deal with treatment side effects. Singles may need to find a friend or family member who can help in these ways. Whether it's your spouse, partner, friend, or other relative, the person who helps you get your cancer treatments and manage side effects is called a *caregiver*. This is someone who wants to help and support you, but in order to do that they will need their own support and help. They can start by reading [What It Takes to Be a Caregiver](#)<sup>19</sup> or call us for more information.

## **Paying for cancer treatment**

Finances are often a very real concern for people with cancer. Treatment costs a lot. Hopefully, you have been able to keep your [health insurance](#)<sup>20</sup>. Sometimes there are insurance options that people with cancer may not be aware of. Talk to your cancer care team, your facility's financial counselors, or a social worker. You can also call us

for help finding possible sources of financial assistance.

## Questions to ask your cancer care team

- How long do you think I can live with this cancer? What's the range of survival times for people in my situation?
- How will I know if the cancer is getting worse?
- What do you think I should expect at this point?
- What symptoms do I need to watch for and tell you about?
- How often will I need treatment or need to see the doctor?
- What's the goal of treatment right now? Control of the cancer? Comfort?
- What tests will I need to watch for changes in the cancer?
- What can be done for symptoms I have (pain, fatigue, nausea, etc.)?
- Are there any support groups I can go to?
- How will I pay for treatment? Will my health insurance cover it?

## Hope

Most people think of cancer as a disease that people get, have treated, and either are cured of or die from. When cancer is first found, the hope is for a cure. And for some people that hope is possible. But there are a lot of people who have cancer, are treated, and aren't cured – they live with cancer.

If the cancer has already spread, the hope may be that the cancer can be stopped or slowed down. There's hope for time, for being with loved ones, and finishing important tasks. Some people have cancer that can be controlled with treatment and they can live for a long time.

If treatment stops working, the hope may change again. It may be hope for time to prepare family and loved ones who will be left behind, for telling them what they have meant to you and what you hope for their futures. This can allow a deep closeness to the people you love.

There can also be hope for time to plan the end of your life – where you want to spend your last days and what you do and don't want. This can ease the burden of uncertainty your loved ones may have about what to do and what you'd want. Your clear plans can be a very important gift to them and help them be at peace with the hard choices they may have to make when you can no longer say what you want.

Whatever your hope is, find the support and help you need to try and make it happen.

## Hyperlinks

1. [www.cancer.org/cancer/types/ovarian-cancer.html](http://www.cancer.org/cancer/types/ovarian-cancer.html)
2. [www.cancer.org/cancer/types/leukemia.html](http://www.cancer.org/cancer/types/leukemia.html)
3. [www.cancer.org/cancer/types/lymphoma.html](http://www.cancer.org/cancer/types/lymphoma.html)
4. [www.cancer.org/cancer/types/breast-cancer.html](http://www.cancer.org/cancer/types/breast-cancer.html)
5. [www.cancer.org/cancer/types/prostate-cancer.html](http://www.cancer.org/cancer/types/prostate-cancer.html)
6. [www.cancer.org/cancer/managing-cancer/finding-care/where-to-find-cancer-care.html](http://www.cancer.org/cancer/managing-cancer/finding-care/where-to-find-cancer-care.html)
7. [www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html](http://www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html)
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14. [www.cancer.org/support-programs-and-services.html](http://www.cancer.org/support-programs-and-services.html)
15. [www.mhanational.org/choosing-provider](http://www.mhanational.org/choosing-provider)
16. [csn.cancer.org](http://csn.cancer.org)
17. [www.cancer.org/cancer/diagnosis-staging/telling-others-about-your-cancer.html](http://www.cancer.org/cancer/diagnosis-staging/telling-others-about-your-cancer.html)
18. [www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer.html](http://www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer.html)
19. [www.cancer.org/cancer/caregivers/what-a-caregiver-does/taking-care-of-yourself.html](http://www.cancer.org/cancer/caregivers/what-a-caregiver-does/taking-care-of-yourself.html)
20. [www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html](http://www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance.html)

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