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## 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.



## **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

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**Be informed.** Learn what you can do for your health now and about the services

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.)



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

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

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)
  8. [www.cancer.org/cancer/managing-cancer/treatment-types/chemotherapy.html](http://www.cancer.org/cancer/managing-cancer/treatment-types/chemotherapy.html)
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