After Treatment

Living as a CLL Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- What Happens After Treatment for Chronic Lymphocytic Leukemia?
- Lifestyle Changes During and After Treatment for Chronic Lymphocytic Leukemia
- How About Your Emotional Health During and After Treatment for Chronic Lymphocytic Leukemia?

Cancer Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about cancer coming back or treatment no longer working.

- Can I Get Another Cancer After Having Chronic Lymphocytic Leukemia?
- If Treatment for Chronic Lymphocytic Leukemia Stops Working

What Happens After Treatment for Chronic Lymphocytic Leukemia?

Chronic lymphocytic leukemia (CLL) is rarely able to be cured. Still, most people live for many years with the disease. Some people with CLL can live for years without treatment, but most eventually need to be treated. Most people with CLL are treated on and off for years. Treatment may stop for a while, but it never really ends. Learning to live with cancer that does not go away can be difficult and very stressful. See Managing Cancer As A Chronic Illness for more about this.
Follow-up care

Before, during, and after treatment, your doctors will want to watch you closely. It is very important to go to all of your follow-up appointments. During these visits, your doctors will ask questions about any problems you may have and may do exams and lab tests or x-rays and scans to look for signs of cancer or treatment side effects. Almost any cancer treatment can have side effects. Some may last for a few weeks to months, but others can last the rest of your life. This is the time for you to talk to your cancer care team about any changes or problems you notice and any questions or concerns you have. It is important that you report any new symptoms to the doctor right away so that the cause can be found and treated, if needed.

Checkups may include careful physical exams, blood tests, and other tests as needed. A benefit of follow-up care is that it gives you a chance to discuss questions and concerns that can arise.

Treatment of CLL is not expected to cure the disease. This means that even if there are no signs of leukemia after treatment (known as a complete remission), the leukemia is likely to come back again (recur) at some point. Further treatment will depend on what treatments you've had before, how long it's been since treatment, and your overall health. For more information on how recurrent CLL is treated, see Treating Chronic Lymphocytic Leukemia. For more general information on dealing with a recurrence, see Understanding Recurrence.

It is important to keep health insurance. Tests and doctor visits cost a lot, and even though no one wants to think of their cancer coming back, this could happen.

Most people with CLL do not have normally functioning immune systems, which may raise their risk for certain infections. Some treatments for CLL, such as alemtuzumab (Campath) and many chemotherapy drugs, may also raise this risk. Your doctor may recommend vaccines or other medicines to help prevent or control certain infections.

People with CLL are also at increased risk of developing a second cancer. At least some of this increased risk may be due to the effects of CLL on the immune system. Treatments for CLL may also raise the risk of some cancers. The most common second cancers in people with CLL are skin and lung cancers, although other types of leukemia, lymphoma, and other blood cancers are also possible. It is important to be aware of this increased risk and to report any possible symptoms to your doctor right away.

Seeing a new doctor
At some point after your cancer diagnosis and treatment, you may find yourself seeing a new doctor who does not know anything about your medical history. It is important that you be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. Make sure you have the following information handy:

- A copy of your pathology report(s) from any biopsies or surgeries
- If you had surgery, a copy of your operative report(s)
- If you were in the hospital, a copy of the discharge summary that doctors prepare when patients are sent home
- If you had radiation therapy, a copy of the treatment summary
- If you were treated with drugs (such as chemotherapy, monoclonal antibodies, or targeted therapy), a list of the drugs, drug doses, and when you took them

The doctor may want copies of this information for his records, but always keep copies for yourself.

- References
  See all references for Chronic Lymphocytic Leukemia

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Can I Get Another Cancer After Having Chronic Lymphocytic Leukemia?

Cancer survivors can be affected by a number of health problems, but often their greatest concern is facing cancer again. If a cancer comes back after treatment it is called a “recurrence.” But some cancer survivors may develop a new, unrelated cancer later. This is called a “second cancer.” No matter what type of cancer you have had, it is still possible to get another (new) cancer, even after surviving the first.

Unfortunately, being treated for cancer doesn’t mean you can’t get another cancer. People who have had cancer can still get the same types of cancers that other people get. In fact, certain types of cancer and cancer treatments can be linked to a higher risk
of certain second cancers.

People with chronic lymphocytic leukemia (CLL) can get any type of second cancer, but they have an increased risk of:

- Salivary gland cancer
- Cancer of the lip
- Cancers of the nose and nasal cavity
- Cancer of the larynx
- Lung cancer
- Colon cancer
- Hodgkin lymphoma
- Kaposi sarcoma
- Melanoma of the skin
- Kidney cancer

Women with CLL also have an increased risk of rectal cancer.

Follow-up

People with CLL need to see their doctors regularly. They can have CLL for a long time without needing treatment. Let your doctor know if you have any new symptoms or problems. These may be from the CLL and mean that treatment is needed, or they may be from some other cancer or disease. Treatment doesn’t cure this cancer, but can cause it to regress or go away for a time. Then, if the leukemia comes back or worsens, treatment may begin again.

All people with CLL should avoid tobacco smoke, as smoking increases the risk of many cancers and might further increase the risk of some of the second cancers seen in patients with CLL.

To help maintain good health, survivors should also:

- Achieve and maintain a healthy weight
- Adopt a physically active lifestyle
- Consume a healthy diet, with an emphasis on plant foods
- Limit consumption of alcohol to no more than 1 drink per day for women or 2 per day for men

These steps may also lower the risk of some cancers.
Lifestyle Changes During and After Treatment for Chronic Lymphocytic Leukemia

You can't change the fact that you have had cancer. What you can change is how you live the rest of your life – making choices to help you stay healthy and feel as well as you can. This can be a time to look at your life in new ways. Maybe you are thinking about how to improve your health over the long term. Some people even start during cancer treatment.

Making healthier choices

For many people, a diagnosis of cancer helps them focus on their health in ways they may not have thought much about in the past. Are there things you could do that might make you healthier? Maybe you could try to eat better or get more exercise. Maybe you could cut down on alcohol, or give up tobacco. Even things like keeping your stress level under control may help. Now is a good time to think about making changes that can have positive effects for the rest of your life. You will feel better and you will also be healthier.

You can start by working on those things that worry you most. Get help with those that are harder for you. For instance, if you are thinking about quitting smoking and need help, call the American Cancer Society for information and support. This tobacco cessation and coaching service can help increase your chances of quitting for good.
Eating better

Eating right can be hard for anyone, but it can get even tougher during and after cancer treatment. Treatment may change your sense of taste. Nausea can be a problem. You may not feel like eating and lose weight when you don't want to. Or you may have gained weight that you can't seem to lose. All of these things can be very frustrating.

If treatment caused weight changes or eating or taste problems, do the best you can and keep in mind that these problems usually get better over time. You may find it helps to eat small portions every 2 to 3 hours until you feel better. You may also want to ask your cancer team about seeing a dietitian, an expert in nutrition who can give you ideas on how to deal with these treatment side effects.

One of the best things you can do after cancer treatment is put healthy eating habits into place. You may be surprised at the long-term benefits of some simple changes, like increasing the variety of healthy foods you eat. Getting to and staying at a healthy weight, eating a healthy diet, and limiting your alcohol intake may lower your risk for a number of types of cancer, as well as having many other health benefits.

Rest, fatigue, and exercise

Extreme tiredness, called fatigue, is very common in people treated for cancer. This is not a normal tiredness, but a "bone-weary" exhaustion that doesn't get better with rest. For some people, fatigue lasts a long time after treatment, and can make it hard for them to exercise and do other things they want to do. But exercise can help reduce fatigue. Studies have shown that patients who follow an exercise program tailored to their personal needs feel better physically and emotionally and can cope better, too.

If you were sick and not very active during treatment, it is normal for your fitness, endurance, and muscle strength to decline. Any plan for physical activity should fit your own situation. Someone who has never exercised will not be able to take on the same amount of exercise someone who plays tennis twice a week. If you haven't exercised in a few years, you will have to start slowly – maybe just by taking short walks. You can read more in Nutrition and Physical Activity During and After Cancer Treatment: Answers to Common Questions.

Talk with your health care team before starting anything. Get their opinion about your exercise plans. Then, try to find an exercise buddy so you're not doing it alone. Having family or friends involved when starting a new exercise program can give you that extra boost of support to keep you going when the push just isn’t there.
If you are very tired, you will need to balance activity with rest. It is OK to rest when you need to. Sometimes it's really hard for people to allow themselves to rest when they are used to working all day or taking care of a household, but this is not the time to push yourself too hard. Listen to your body and rest when you need to. For more information on dealing with fatigue, see *Fatigue in People With Cancer* and *Anemia in People With Cancer*.

Keep in mind that exercise can improve your physical and emotional health.

- It improves your cardiovascular (heart and circulation) fitness.
- Along with a good diet, it will help you get to and stay at a healthy weight.
- It makes your muscles stronger.
- It reduces fatigue and helps you have more energy.
- It can help lower anxiety and depression.
- It can make you feel happier.
- It helps you feel better about yourself.

And long term, we know that getting regular physical activity plays a role in helping to lower the risk of some cancers, as well as having other health benefits.

- References

*See all references for Chronic Lymphocytic Leukemia*

How About Your Emotional Health During and After Treatment for Chronic Lymphocytic Leukemia?

When treatment is over (even for a while), you may find yourself overcome with many different emotions. This happens to a lot of people. You may have been going through so much during treatment that you could only focus on getting through each day. Now it may feel like a lot of other issues are catching up with you.
You may find yourself thinking about death and dying. Or maybe you're more aware of the effect the cancer has on your family, friends, and career. You may take a new look at your relationship with those around you. Unexpected issues may also cause concern. For instance, as you feel better and have fewer doctor visits, you will see your health care team less often and have more time on your hands. These changes can make some people anxious.

Almost everyone who has been through cancer can benefit from getting some type of support. You need people you can turn to for strength and comfort. Support can come in many forms: family, friends, cancer support groups, church or spiritual groups, online support communities, or one-on-one counselors. What's best for you depends on your situation and personality. Some people feel safe in peer-support groups or education groups. Others would rather talk in an informal setting, such as church. Others may feel more at ease talking one-on-one with a trusted friend or counselor. Whatever your source of strength or comfort, make sure you have a place to go with your concerns.

The cancer journey can feel very lonely. It is not necessary or good for you to try to deal with everything on your own. And your friends and family may feel shut out if you do not include them. Let them in, and let in anyone else who you feel may help. If you aren’t sure who can help, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you. You may also want to read Distress in People with Cancer.

- References

See all references for Chronic Lymphocytic Leukemia

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If Treatment for Chronic Lymphocytic Leukemia Stops Working

When chronic lymphocytic leukemia (CLL) keeps growing or comes back after one treatment, another treatment plan is likely to help, at least for a while. But when a person has tried many different treatments and the cancer has not gotten any better, the
cancer tends to become resistant to all treatment. If this happens, it’s important to weigh the possible limited benefits of a new treatment against the possible downsides. Everyone has their own way of looking at this.

This is likely to be the hardest part of your battle with cancer when you have been through many medical treatments and nothing’s working anymore. Your doctor may offer you new options, but at some point you may need to consider that treatment is not likely to improve your health or change your outcome or survival.

If you want to continue to get treatment for as long as you can, you need to think about the odds of treatment having any benefit and how this compares to the possible risks and side effects. In many cases, your doctor can estimate how likely it is the cancer will respond to treatment you are considering. For instance, the doctor may say that more chemo or radiation might have about a 1% chance of working. Some people are still tempted to try this. But it is important to think about and understand your reasons for choosing this plan.

No matter what you decide to do, you need to feel as good as you can. Make sure you are asking for and getting treatment for any symptoms you might have, such as nausea or pain. This type of treatment is called palliative care.

Palliative care helps relieve symptoms, but is not expected to cure the disease. It can be given along with cancer treatment, or can even be cancer treatment. The difference is its purpose - the main purpose of palliative care is to improve the quality of your life, or help you feel as good as you can for as long as you can. Sometimes this means using drugs to help with symptoms like pain or nausea. Sometimes, though, the treatments used to control your symptoms are the same as those used to treat cancer. For instance, radiation might be used to help relieve bone pain caused by cancer that has spread to the bones. Or chemo might be used to help shrink a tumor and keep it from blocking the bowels. But this is not the same as treatment to try to cure the cancer. You can learn more about the changes that occur when curative treatment stops working, and about planning ahead for yourself and your family, in Nearing the End of Life and Advance Directives.

At some point, you may benefit from hospice care. This is special care that treats the person rather than the disease; it focuses on quality rather than length of life. Most of the time, it is given at home. Your cancer may be causing problems that need to be managed, and hospice focuses on your comfort. You should know that while getting hospice care often means the end of treatments such as chemo and radiation, it doesn't mean you can't have treatment for the problems caused by your cancer or other health conditions. In hospice the focus of your care is on living life as fully as possible and feeling as well as you can at this difficult time. You can learn more in Hospice Care.
Staying hopeful is important, too. 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. Pausing at this time in your cancer treatment gives you a chance to refocus on the most important things in your life. Now is the time to do some things you've always wanted to do and to stop doing the things you no longer want to do. Though the cancer may be beyond your control, there are still choices you can make.

- References
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