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After Chronic Lymphocytic Leukemia Treatment

Living as a CLL Survivor

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

- [Living as a Chronic Lymphocytic Leukemia Survivor](#)

Cancer Concerns After Treatment

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

- [Second Cancers After Chronic Lymphocytic Leukemia](#)
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Living as a Chronic Lymphocytic Leukemia Survivor

Chronic lymphocytic leukemia (CLL) can rarely be cured. Still, most people live with the disease for many years. Some people with CLL can live for years without treatment, but over time, most will 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. Life after cancer means

returning to some familiar things and also making some new choices. Learning to live with [cancer that does not go away](#)¹ can be difficult and very stressful.

Follow-up care

Before, during, and after treatment, your doctors will want to watch you closely. It's very important to go to all of your follow-up appointments. During these visits, your doctors will talk with you about any problems you might have and might order exams and lab tests 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.

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 (recur) at some point. Further treatment will depend on what treatments you've had before, how long it's been since the last treatment, and your overall health. For more information on how recurrent CLL is treated, see [Treating Chronic Lymphocytic Leukemia](#)².

Most people with CLL do not have normally functioning immune systems, which may raise their risk for certain infections. Some of the drugs used to treat CLL, such as alemtuzumab (Campath) and many chemotherapy drugs, may also raise this risk. Your doctor may recommend vaccines, certain medicines, or other treatments to help prevent or control certain infections. (To learn more about this see [Supportive Care for Chronic Lymphocytic Leukemia](#)³.)

Ask your doctor for a survivorship care plan

Talk with your doctor about developing a [survivorship care plan](#)⁴ for you. This plan might include:

- A suggested schedule for follow-up [exams and tests](#)⁵
- A schedule for other tests you might need in the future, such as [early detection \(screening\) tests](#)⁶ for other types of cancer, or tests to look for long-term health effects from your cancer or its treatment
- A list of possible late- or long-term side effects from your treatment, including what to watch for and when you should contact your doctor
- [Diet and physical activity](#)⁷ suggestions
- Reminders to keep your appointments with your primary care provider (PCP), who

will monitor your general health care

Keeping health insurance and copies of your medical records

Even after treatment, it's very important to keep health insurance. Tests and doctor visits cost a lot and life-long CLL treatment may be needed.

At some point after your cancer treatment, you might find yourself seeing a new doctor who doesn't know about your medical history. It's important to keep copies of your medical records to give your new doctor the details of your diagnosis and treatment. Learn more in [Keeping Copies of Important Medical Records](#)⁸.

Can I lower my risk of CLL progressing or coming back?

If you have CLL, you probably want to know if there are things you can do that might lower your risk of the cancer growing or [coming back](#)⁹, such as exercising, eating a certain type of diet, or taking nutritional supplements. Unfortunately, it's not yet clear if there are things you can do that will help.

Adopting healthy behaviors such as [not smoking](#)¹⁰, [eating well](#)¹¹, [getting regular physical activity](#)¹², and [staying at a healthy weight](#)¹³ might help, but no one knows for sure. Still, we do know that these types of changes can have positive effects on your health that can extend beyond your risk of CLL or other cancers.

About dietary supplements

So far, no [dietary supplements](#)¹⁴ (including vitamins, minerals, and herbal products) have been shown to clearly help lower the risk of CLL progressing or coming back. This doesn't mean that no supplements will help, but it's important to know that none have been proven to do so.

Dietary supplements are not regulated like medicines in the United States – they do not have to be proven effective (or even safe) before being sold, although there are limits on what they're allowed to claim they can do. If you're thinking about taking any type of nutritional supplement, talk to your health care team first. They can help you decide which ones you can use safely while avoiding those that might be harmful.

Could I get a second cancer after treatment?

People who've had CLL can still get other cancers. In fact, CLL cancer survivors are at higher risk for getting some other types of cancer. Learn more in [Second Cancers After Chronic Lymphocytic Leukemia](#).

Getting emotional support

Some amount of feeling [depressed, anxious, or worried](#)¹⁵ is normal when cancer is a part of your life. Some people are affected more than others. But everyone can benefit from help and [support](#)¹⁶ from other people, whether friends and family, religious groups, support groups, professional counselors, or others.

Hyperlinks

1. www.cancer.org/treatment/survivorship-during-and-after-treatment/when-cancer-doesnt-go-away.html
2. www.cancer.org/cancer/chronic-lymphocytic-leukemia/treating.html
3. www.cancer.org/cancer/chronic-lymphocytic-leukemia/treating/supportive-care.html
4. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html
5. www.cancer.org/treatment/understanding-your-diagnosis/tests.html
6. www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines.html
7. www.cancer.org/treatment/survivorship-during-and-after-treatment/staying-active.html
8. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
9. www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html
10. www.cancer.org/healthy/stay-away-from-tobacco.html
11. www.cancer.org/healthy/eat-healthy-get-active/eat-healthy.html
12. www.cancer.org/healthy/eat-healthy-get-active/get-active.html
13. www.cancer.org/healthy/eat-healthy-get-active/take-control-your-weight.html
14. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine/dietary-supplements.html
15. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/emotional-mood-changes.html
16. www.cancer.org/treatment/support-programs-and-services.html

Last Revised: May 10, 2018

Second Cancers After Chronic Lymphocytic Leukemia

Cancer survivors can be affected by a number of health problems, but often their greatest concern is facing cancer again. Chronic lymphocytic leukemia (CLL) is seldom cured, but it can often be treated and controlled for a long time. During this time, some people with CLL may develop a new, unrelated cancer later. This is called a **second cancer**.

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 CLL can get any type of second cancer, but they have an increased risk of:

- [Skin cancer](#)¹
- [Melanoma of the skin](#)²
- [Cancer of the larynx](#)³
- [Lung cancer](#)⁴
- [Colon cancer](#)⁵
- [Kaposi sarcoma](#)⁶
- [Soft tissue sarcoma](#)⁷

People with CLL need to see their doctors regularly. Let your doctor know if you have any new symptoms or problems. These may be from the CLL, or they may be from some other cancer or disease. Also be sure to get your routine [cancer screening tests](#)⁸ and well check-ups. These can help find problems early, when they're usually easier to treat.

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.

See [Second Cancers in Adults](#)⁹ for more information about causes of second cancers.

Hyperlinks

1. www.cancer.org/cancer/salivary-gland-cancer.html
2. www.cancer.org/cancer/melanoma-skin-cancer.html
3. www.cancer.org/cancer/laryngeal-and-hypopharyngeal-cancer.html
4. www.cancer.org/cancer/lung-cancer.html
5. www.cancer.org/cancer/colon-rectal-cancer.html
6. www.cancer.org/cancer/kaposi-sarcoma.html
7. www.cancer.org/cancer/soft-tissue-sarcoma.html
8. www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines.html
9. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/second-cancers-in-adults.html

Last Revised: May 10, 2018

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Chaabouni H, Kacem K, Zriba S, et al. Solid tumors after chronic lymphocytic leukemia patients: Report of six cases and review of the literature. *Gulf J Oncolog*. 2015;1(19):28-32.

Leukemia & Lymphoma Society. Chronic lymphocytic leukemia: Disease Complications. Accessed at <http://www.lls.org/leukemia/chronic-lymphocytic-leukemia/disease-complications> on April 18, 2018.

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