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# After Castleman Disease Treatment

## Living Well After Treatment

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

- [Living With Castleman Disease](#)

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# Living With Castleman Disease

For many people with Castleman disease (CD), treatment can remove or destroy the disease. Completing treatment can be both stressful and exciting. You may be relieved to finish treatment, but find it hard not to worry about the CD coming back. (When the disease comes back after treatment, it is called [recurrence](#)<sup>1</sup>.) This is a very common concern in people with serious diseases such as CD.

For some people, CD may never [go away completely](#)<sup>2</sup>. These people may get regular treatments with [chemotherapy](#)<sup>3</sup>, [corticosteroids](#)<sup>4</sup>, or other [therapies](#)<sup>5</sup> to help keep the CD in check for as long as possible. Learning to live with CD as a more of a chronic disease can be difficult and very stressful. It has its own type of uncertainty.

## Follow-up care

If you have completed treatment, frequent follow-up exams are very important for several years after the treatment is finished. The doctors will continue to watch you for

signs of recurrent disease, as well as for short-term and long-term side effects of treatment. It's important to report any new symptoms to the doctor right away, so that relapse or side effects can be treated.

Checkups usually include careful physical exams, [imaging tests](#)<sup>6</sup> such as CT scans when needed, and [lab tests](#)<sup>7</sup> to look for signs of CD or treatment side effects. Almost any type of treatment can have side effects. Some can last for a few weeks to months, but others can last the rest of your life.

CD can come back in some people. Multicentric CD may come back as soon as the first year after treatment. If the CD does recur at some point, further treatment will depend on what treatments you've had before, how well they worked, how long it's been since treatment, and your overall health.

Some people with multicentric CD (especially those who are HIV-positive) might develop [non-Hodgkin lymphoma](#)<sup>8</sup> or [Kaposi sarcoma](#)<sup>9</sup> at some point. These cancers can be hard to treat, so it helps to diagnose and treat them as early as possible.

## Hyperlinks

1. [www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html)
2. [www.cancer.org/treatment/survivorship-during-and-after-treatment/when-cancer-doesnt-go-away.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/when-cancer-doesnt-go-away.html)
3. [www.cancer.org/cancer/castleman-disease/treating/chemotherapy.html](http://www.cancer.org/cancer/castleman-disease/treating/chemotherapy.html)
4. [www.cancer.org/cancer/castleman-disease/treating/corticosteroids.html](http://www.cancer.org/cancer/castleman-disease/treating/corticosteroids.html)
5. [www.cancer.org/cancer/castleman-disease/treating.html](http://www.cancer.org/cancer/castleman-disease/treating.html)
6. [www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-tests-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/imaging-radiology-tests-for-cancer.html)
7. [www.cancer.org/treatment/understanding-your-diagnosis/tests.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests.html)
8. [www.cancer.org/cancer/non-hodgkin-lymphoma.html](http://www.cancer.org/cancer/non-hodgkin-lymphoma.html)
9. [www.cancer.org/cancer/kaposi-sarcoma.html](http://www.cancer.org/cancer/kaposi-sarcoma.html)

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See all references for Castleman Disease ([www.cancer.org/cancer/castleman-disease/references.html](http://www.cancer.org/cancer/castleman-disease/references.html))

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