If You Have Castleman Disease

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What is Castleman disease?

Tumors can grow anywhere in the body and happen when cells in the body begin to grow out of control. Some tumors may have cancer cells in them, and some may not. (To learn more about how cancers start and spread, see What Is Cancer?[^1])

Castleman disease (CD) is not cancer. It is a rare disease of lymph nodes, also called a lymphoproliferative disorder. This means there are many cells growing very fast within the lymph system. CD affects lymph nodes, which are bean-sized collections of immune cells found mainly in the neck, underarm, chest, abdomen (belly), and groin.

Even though CD is not cancer, sometimes it can act like a type of cancer called lymphoma (cancer of the lymph nodes). In fact, some people with CD go on to get lymphoma. Whether or not a person with CD has lymphoma, CD is often treated with chemotherapy or radiation therapy. This is why it is included in the American Cancer Society’s cancer pages. (For information about lymphoma, see Hodgkin Lymphoma[^2] and Non-Hodgkin Lymphoma[^3].)

Are there different kinds of CD?
CD is named by how much of the body it affects. The main types of CD are:

- Localized or unicentric CD
- Multicentric CD

**Localized (unicentric) CD**

This is the more common type. It affects one group of lymph nodes. CD makes the lymph nodes grow, and some may look like lumps under the skin. The large lymph nodes may press on other body parts and organs near them.

Most of the time, localized CD is treated with surgery. People with localized CD are usually cured when the enlarged lymph nodes are removed.

**Multicentric CD (MCD)**

MCD affects more than one group of lymph nodes and is much harder to treat than localized CD. MCD can also affect other body parts and organs in the lymph system. People with MCD have a higher risk for getting lymphoma.

People with MCD sometimes also have human immunodeficiency virus (HIV), the virus that causes AIDS. MCD is more serious than localized CD. This is especially true in people who also have HIV because MCD can make the immune system weak. This means serious infections and other problems can happen. You can read more about HIV infection in HIV, AIDS, and Cancer.

Another virus called human herpesvirus-8 (HHV-8) or Kaposi sarcoma herpesvirus (KSHV) is often found in the lymph nodes of people with MCD.

**Other ways to group CD**

Doctors believe it’s most important to know if CD is unicentric or multicentric. But CD can also be grouped based on what the lymph node cells look like in the lab, as well as if it is linked to a virus such as HIV or HHV-8.

**Questions to ask the doctor**

- Would you please write down the kind of CD you think I might have?
- Do I also have HIV or another infection?
• Am I at risk of getting cancer from this kind of CD?
• What will happen next?

How does the doctor know I have CD?

CD is usually found because a lymph node has become enlarged or a blood test result comes back as abnormal. These or other signs or symptoms may lead the doctor to order other tests\(^7\). Here are some of the tests that may be done. Ask your doctor what tests you may need.

• Physical exam
• Blood tests
• X-rays and other scans
• Biopsy of the lymph node
• Special lab tests

Questions to ask the doctor

• What tests will I need?
• Who will do these tests?
• Where will they be done?
• Who can explain them to me?
• How and when will I get the results?
• Who will explain the results to me?
• What do I need to do next?

How serious is my disease?

If you have CD, you and the doctor need to know some information and test results. How serious CD is depends on the kind of CD it is. Knowing how many lymph nodes are affected, and if it has spread to other parts of the body, helps to know how serious it is.

Other tests can also help show how serious the CD is, including tests for HIV and other viruses.
Questions to ask the doctor

- Do you know how serious my CD is?
- If not, when will you know how serious it is?
- Based on how serious my CD is, how long do you think I’ll live?
- What will happen next?

What kind of treatment will I need?

The treatment plan that’s best for you will depend on:

- The type of CD you have
- If the CD has become lymphoma
- If you also have an infection, such as HIV
- Your overall health
- Your feelings about the treatment and the side effects that may come with it

It’s important to begin treatment as soon as possible after CD is found.

Here are the main ways to treat CD. Sometimes the best treatment includes 2 or more of these.

- Surgery\(^9\) (main treatment)
- Radiation therapy\(^9\)
- Corticosteroid (steroid) drugs\(^10\)
- Chemotherapy (chemo)\(^11\)
- Immunotherapy\(^12\) (drugs that affect the immune system)
- Anti-viral (anti-virus) drugs\(^13\)

What about other treatments that I hear about?

When you have a tumor or a condition that may lead to cancer, you might hear about other ways to treat it or your symptoms. These might not always be standard medical treatments. These treatments might be vitamins, herbs, special diets, and other things. You may wonder about these treatments.

Some of these are known to help, but many have not been tested. Some have been
shown not to help. A few have even been found to be dangerous. Talk to your doctor about anything you’re thinking about using, whether it’s a vitamin, a diet, or anything else.

Questions to ask the doctor

It is important to discuss all of your treatment options, including their goals and possible side effects, with your doctors to help make the decision that fits your needs. It’s also very important to ask questions if there is anything you’re not sure about. Some questions to ask are:

- What treatment do you think is best for me?
- What’s the goal of this treatment? Do you think it could cure my CD?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- Will I need other types of treatment, too?
- What side effects\(^{14}\) could I have from these treatments?
- Will I be able to have children after treatment?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?
- What will happen after treatment?

Help getting through treatment for CD

Your health care team will be your first source of information and support, but there are other resources for help when you need it. You might or might not need ongoing treatment and care for CD. Tests and check-ups may be needed to follow-up even if more treatment is not needed. Ask your doctor what to expect.

Having CD and dealing with surgery and treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your health care team to find out what you can do to feel better.

You can’t change the fact that you have or had CD. What you can change is how you live the rest of your life – making healthy choices\(^ {15}\) and feeling as good as you can.
Hyperlinks

7. www.cancer.org/treatment/understanding-your-diagnosis/tests.html
15. www.cancer.org/healthy.html

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (http://www.cancer.org)16. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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