



EASY READING

If You Have Cancer of Unknown Primary

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What is cancer of unknown primary (CUP)?

Cancer can start any place in the body. It starts when cells in a certain area grow out of control and crowd out normal cells. This makes it hard for the body to work the way it should.

Cancer is always named for the place where it started, called the **primary site**. Sometimes doctors can't tell where a cancer may have started. When cancer is found in one or more places where it seems to have spread, but the site where it started is not known, it is called a cancer of unknown primary (CUP) or an occult primary cancer. This is a rare kind of cancer.

Sometimes test results may lead to finding where some of these cancers started. Many times, the place the cancer started is never found. But, the main reason to look for the place where CUP started is to help decide on treatment. Knowing where a cancer started tells the doctor what types of treatments are best to use.

Are there different kinds of CUP?

Even when doctors don't know where the cancer started, they do their best to **classify** the type of cancer. They do this by looking at the cancer cells under a microscope in the lab. This can help them know the best treatment to offer.

The kind of cancer cells in a CUP can vary.

- One type is called adenocarcinoma (AD-no-KAR-suh-NO-muh).
- Another kind is squamous cell carcinoma (skway-mus sell car-sin-O-mah).

Your doctor can tell you more about the type you have.

Questions to ask the doctor

- Why do you think I have cancer?
- Is there a chance I don't have cancer?
- Would you please write down the kind of cancer you think I might have?
- What will happen next?

How does the doctor know I have CUP?

Tests that may be done

The symptoms of CUP can be different and depend on what organs it has spread to. Some abnormal things you might want to have checked out are:

- a lump on your skin
- a lump in your neck, under your arms, or in your groin area
- a feeling of fullness in your belly
- shortness of breath
- pain in the chest or belly
- pain in your bones.

Your doctor can help find the reason for these symptoms by asking you questions about your health and physically examining you. The doctor might order blood tests and possibly imaging tests. Here are some of the tests you may need:

Lab tests: Lab tests offer details about your health. They can be used to find problems and guide treatment.

CT or CAT scan: Uses x-rays to take detailed pictures of your insides. This can show the size of the cancer and its spread.

MRI scan: Uses radio waves and strong magnets instead of x-rays to make detailed pictures. This test can show more about the size of the cancer and its spread.

PET scan: Uses a special kind of sugar that can be seen inside your body with a special camera. If there is cancer, this sugar shows up as “hot spots” where the cancer is found. This test can help show if the cancer has spread.

Biopsy: In a biopsy, the doctor takes out a small piece of tissue where the cancer seems to be. The tissue is checked for cancer cells. A biopsy is the only way to tell for sure if you have cancer.

Questions to ask the doctor

- What tests will I need to have?
- 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 cancer?

The doctor will want to try to find out where the cancer started and how far it has spread. This is called **staging**. The stage describes the growth or spread of the cancer through the body. You might have heard other people say that their cancer was stage 1 or stage 2. Your doctor will want to find out the stage of your CUP to help decide what type of treatment is best for you.

Since it is not known where the cancer started, it is difficult to stage CUP. Because of this, **all CUPs are at least a stage 2, and most of them are stage 3 or 4.**

Questions to ask the doctor

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage of the cancer?

- Would you explain to me what my cancer's stage means?
- Based on the stage of the cancer, how long do you think I'll live?
- What will happen next?

What kind of treatment will I need?

There are many ways to treat cancer. Treatment for CUP may include:

- [Surgery](#)¹
- [Radiation](#)²
- [Chemo](#)³
- [Hormone therapy](#)⁴
- [Targeted therapy](#)⁵
- [Other drugs](#)⁶

Surgery

Surgery may be part of the treatment for CUP if it can be done. There are different kinds of surgery. The type that's best for you depends on the kind of cancer, how big it is, and where it is. Ask your doctor what kind of surgery you will have and what to expect.

Side effects of surgery

Any type of surgery can have risks and side effects. Be sure to ask the doctor what you can expect. If you have problems, let your doctors know. Doctors who treat people with CUP should be able to help you with any problems that come up.

Radiation

Radiation uses high-energy rays (like x-rays) to kill cancer cells. It can be aimed at the cancer from a machine outside the body. This is called external beam radiation.

Side effects of radiation treatments

If your doctor suggests radiation treatment, talk about what side effects might happen. Side effects depend on the type of radiation that's used. The most common side effects of radiation are:

- Skin changes where the radiation is given
- Feeling very tired
- Nausea and vomiting
- Diarrhea

Most side effects get better after treatment ends. Some might last longer. Talk to your cancer care team about what you can expect.

Chemo

Chemo is the short word for chemotherapy – the use of drugs to fight cancer. The drugs may be given into a vein or taken as pills. These drugs go into the blood and spread through the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Most of the time, 2 or more chemo drugs are given. Treatment often lasts for many months. Chemo can be given before or after surgery. It can also be given together with radiation. Ask your doctor what to expect.

Side effects of chemo

Chemo can make you feel very tired, sick to your stomach, have diarrhea, mouth sores, and cause your hair to fall out. But these problems go away after treatment ends. There are ways to treat most chemo side effects. If you have side effects, be sure to talk to your cancer care team so they can help.

Targeted therapy

Targeted therapy drugs are newer treatments that may be used for some types of CUP. These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatment doesn't. These drugs have side effects different from chemo and they are often not as bad.

Other drugs

Immunotherapy is treatment that boosts the immune system or uses man-made parts of the immune system to help fight off or kill cancer cells. (The immune system is how the body resists and fights germs and some kinds of cancer.) These drugs may be given into a vein or as a shot under the skin.

Side effects of immunotherapy

Immunotherapy effects depend on which drug is used. These drugs can often make you feel tired, sick to your stomach, and can cause fever, chills, and rashes. Most of these problems go away after treatment ends. There are ways to treat most of the side effects caused by immunotherapy. If you have side effects, talk to your cancer care team so they can help.

Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better. Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time. Clinical trials are one way to get the newest cancer treatment.

If you would like to be in a clinical trial, start by asking your doctor if your clinic or hospital takes part in clinical trials.

What about other treatments that I hear about?

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may 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 harmful. 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

- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the cancer?
- 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's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- 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 should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

What will happen after treatment?

You'll be glad when treatment is over. For years after treatment ends, you will see your cancer doctor. Be sure to go to all of the follow-up visits. During these visits, they will ask about symptoms and examine you. Lab tests, imaging tests, and endoscopy may be done depending on your symptoms. Follow-up is needed to watch for treatment side effects and to check for cancer that has come back or spread.

At first, your visits may be every 3 to 6 months. Then, the longer you're cancer-free, the less often the visits are needed. After 5 years, they may happen once a year.

Having cancer and dealing with 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 cancer care team to find out what you can do to feel better.

You can't change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

Hyperlinks

1. www.cancer.org/cancer/cancer-unknown-primary/treating/surgery.html
2. www.cancer.org/cancer/cancer-unknown-primary/treating/radiation.html
3. www.cancer.org/cancer/cancer-unknown-primary/treating/chemotherapy.html
4. www.cancer.org/cancer/cancer-unknown-primary/treating/hormone-therapy.html
5. www.cancer.org/cancer/cancer-unknown-primary/treating/targeted-therapy.html
6. www.cancer.org/cancer/cancer-unknown-primary/treating/other-drugs.html
7. www.cancer.org

Words to know

Adenocarcinoma (AD-no-KAR-suh-NO-muh or AD-uh-no-KAR-suh-NO-muh): Cancer that starts in the gland cells that line certain organs and make and release substances into the body, such as mucus, digestive juices, or other fluids.

Advanced cancer: A general term describing stages of cancer in which the disease has spread to other parts of the body.

Biopsy (BY-op-see): Taking out a small piece of tissue to see if there are cancer cells in it.

Carcinoma (CAR-sin-O-muh): Cancer that starts in the lining layer of organs. Most cancers are carcinomas. **Lymph nodes** (limf nodes): Small, bean-shaped sacs of immune system tissue found all over the body and connected by lymph vessels; also called lymph glands.

Metastasis (muh-TAS-tuh-sis): Cancer cells that have spread from where they started to other places in the body.

Occult [uh-kult or o-kult]: Hidden or concealed. Cancers of unknown primary might be called occult tumors because it's not known where they started.

Primary site: The place where cancer begins. In cancers of unknown primary, this is unknown.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (www.cancer.org)⁷. 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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