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EASY READING

If You Have Merkel Cell Skin Cancer

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What is Merkel cell skin cancer?

Cancer can start any place in the body. Cancer that starts in the Merkel cells of the skin is called Merkel cell carcinoma or MCC. Carcinoma is another word for cancer. Merkel cells are found in the top layer of the skin. They're very close to nerves linked to touch. MCC starts when these cells grow out of control and crowd out normal cells. This makes it hard for the body to work the way it should.

Cancer cells can spread to other parts of the body. MCC can sometimes travel to the lungs, liver, brain, or bone and grow there. When cancer cells do this, it's called metastasis. To doctors, the cancer cells in the new place look just like the MCC cells in your skin.

Cancer is always named for the place where it starts, because when the cancer cells grow in a new place, they still look the same as the cells where the cancer started. So when MCC spreads to the lung (or any other place), it's still called MCC. It's not called lung cancer unless it starts from cells in the lung.

MCC is a rare kind of skin cancer. Merkel cells were first described in the late 1800s by

a German doctor named Friedrich Merkel.

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 Merkel cell cancer?

If your doctor thinks you may have Merkel cell cancer (MCC) or any other kind of skin cancer, you probably will need to have some tests. You'll be asked when the spot or lump first showed up and if it has changed in size or the way it looks. The rest of your skin will be checked. Your doctor will check the size, shape, color, and texture of any skin changes. The doctor will also feel nearby lymph nodes. These are small bean-shaped sacs of immune system tissue found all over the body. Cancer can spread to them. Here are some of the [tests](#)¹ you might need.

Skin biopsy: In a skin biopsy, the doctor takes all or some of the changed tissue to check it for cancer cells. A biopsy is the only way to tell for sure if you have skin cancer and what kind it is. There are many kinds of skin biopsies. The choice depends on your own case. Ask your doctor what kind you need. Each type has pros and cons.

Lymph node biopsy: MCC often spreads to the lymph nodes close to it. If a node feels swollen, a needle may be used to take out a tiny piece of it to check for cancer cells. Lymph nodes are also checked when surgery is done to remove the MCC tumor.

CT or CAT scan: Uses x-rays to make pictures of your insides. This test may be used to see if nearby lymph nodes are swollen. It can also be used to check other organs, like the lungs, to see if there are spots that might be the spread of MCC. If any spots are found, a CT scan might be used to guide a needle into the spots to do a biopsy.

MRI scan: Uses radio waves and strong magnets instead of x-rays to make detailed pictures of your insides. This test can help show if MCC has spread.

PET scan: PET scans use a special kind of sugar that can be seen inside your body with a special camera. If there's cancer, this sugar shows up as "hot spots" where the cancer is found. This test can help look at your whole body to see if and where MCC has spread.

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?

If you have MCC, the doctor will want to find out how big the tumor is and how far the cancer has spread. This is called staging. You may 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 cancer to help decide what type of treatment is best for you.

The stage describes the size of the tumor and its growth or spread through your skin. It also tells if it has spread to other organs of your body that are close by or far away.

Your cancer can be stage 0, 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 4, means a more serious cancer that has spread beyond the skin. Be sure to ask the doctor about the cancer stage and what it means for you.

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 the stage means in my case?
- What will happen next?

What kind of treatment will I need?

There are many ways to treat MCC. The main types of treatment are surgery , immunotherapy , chemotherapy , and radiation -. Most early-stage MCCs can be treated with surgery. More advanced cancers need other treatments.

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

- The stage of the cancer
- Where the tumor is
- The chance that a type of treatment will cure MCC
- Your age
- Other health problems you have
- Your feelings about the treatment and the side effects that come with it

Surgery

Surgery is used to treat most MCCs. There are different kinds of surgery for this type of skin cancer. The type that's best for you depends on how large the MCC 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 MCC 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. Radiation is seldom used alone unless surgery can't be done. It's often used after surgery to help keep the cancer from coming back. It can be used to treat MCC that has spread to other organs, too.

Side effects of radiation treatments

If radiation treatment is an option, talk about what side effects might happen. Side effects depend on the part of the body that's treated. The most common side effects of radiation are:

- Sunburn-like skin changes where the radiation is given
- Hair loss where the radiation is given
- Feeling very tired

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, short for chemotherapy, is the use of drugs to fight cancer. The drugs are given into a vein. They go into the blood and spread through the body. They kill cells that grow fast, both cancer cells and good cells, like blood cells and hair.

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.

Side effects of chemo

Chemo can make you feel very tired, sick to your stomach, 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, talk to your cancer care team so they can help.

Immunotherapy

Immunotherapy is treatment that either boosts your own immune system or uses man-made versions of parts of the immune system that attack cancer cells. Immunotherapy is a new treatment for MCC. The drugs are given into a vein every 2 or 3 weeks.

Side effects of immunotherapy

Immunotherapy can cause many different side effects depending on which drug is used. These drugs often make you feel tired, sick to your stomach, and 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.

If you'd like to learn more about clinical trials that might be right for you, start by asking

your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials²](#) to learn more.

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.

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

- How far has the MCC spread in my skin?
- Has it spread to any other part of my body?
- 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](#)³. For years after treatment ends, you will see your cancer doctor. Be sure to go to all of these follow-up visits. You will have exams, blood tests, and maybe other tests to see if the cancer has come back.

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 3 years, they may be done once or twice 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/merkel-cell-skin-cancer/detection-diagnosis-staging/how-diagnosed.html
2. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
3. www.cancer.org/cancer/merkel-cell-skin-cancer/after-treatment/living-as-a-merkel-cell-carcinoma-survivor.html
4. <http://www.cancer.org>

Words to know

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.

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>)⁴. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

Last Revised: October 9, 2018

Written by

The American Cancer Society medical and editorial content team (www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

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