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EASY READING

If You Have Malignant Mesothelioma

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What is mesothelioma?

Cancer can start any place in the body. Cancer that starts in the linings of certain parts of the body is called malignant mesothelioma. It most often happens in the linings of the chest or abdomen (belly). It starts when cells in the lining 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. Cancer cells in the lining can sometimes travel to nearby organs and tissues and grow there. When cancer cells spread, it's called metastasis. To doctors, the cancer cells in the new place look just like the ones from the lining.

Cancer is always named for the place where it starts. So when mesothelioma in the chest spreads to the spine (or any other place), it's still called mesothelioma. It's not called bone cancer unless it starts from cells in the spinal bones.

Different types of mesothelioma

- **Pleural** mesothelioma starts in the chest around the lungs. This is by far the most

common type.

- **Peritoneal** mesothelioma starts in the lining in the abdomen or belly.
- **Pericardial** mesothelioma starts in the lining that covers the heart.
- Mesothelioma **of the tunica vaginalis** starts in the cover around the testicles.

Mesothelioma is also grouped into 1 of 3 types based on how the cancer cells look:

- About half of all mesotheliomas are **epithelioid** tumors and tend to have a better outlook.
- **Sarcomatoid or fibrous** tumors are about 1 out of 10 mesotheliomas.
- **Mixed or biphasic** tumors have parts that look like both of the other types. About 3 or 4 out of 10 are this type.

Questions to ask the doctor

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

How does the doctor know I have mesothelioma?

The doctor asks you questions about your health and does a physical exam. If signs are pointing to mesothelioma, you will need to have more tests.

Here are some of the tests you may need:

Chest x-ray: This is often the first test done to look for problems with your lungs. If a change is seen, you'll need more tests.

CT scan: This is also called a "CAT scan." It's a special kind of x-ray that takes pictures of your insides. CT scans can also be used to help do a biopsy (see below).

PET scan: In this test, you are given a special type of sugar that can be seen inside your body with a camera. If there's cancer, the sugar shows up as "hot spots" where the cancer is found. This test looks at the whole body. It can help if the doctor thinks the

cancer has spread, but doesn't know where.

MRI scan: This test uses radio waves and strong magnets instead of x-rays to make detailed pictures. MRI scans are helpful in looking at soft tissues.

Blood tests: Blood tests are not used to find mesothelioma. But they can tell the doctor more about your health.

Biopsies: The doctor takes out a small piece of tissue or fluid that's built up where the cancer seems to be. It's checked for cancer cells. A biopsy is the best way to tell for sure if you have cancer. There are many types of biopsies and ways to do them. Ask your doctor what kind you will need. Each type has pros and cons. The choice of which type to use depends on your own case.

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 mesothelioma, the doctor will want to find out how far it has spread. This is called staging. You might have heard other people say that their cancer was "stage 2" or "stage 3." Your doctor will want to find out the stage of your cancer to help decide what type of treatment is best for you.

Only pleural mesothelioma has a formal staging system. It describes the spread of the cancer through the lining in the chest. It also tells if the cancer has spread to other organs of your body that are close by or farther away.

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

Can the tumor be taken out?

Instead of using a staging system, most doctors talk about mesothelioma and offer treatment options based on whether the cancer can be removed with surgery.

If most, or maybe all of the cancer can be taken out, it's called **resectable**. If it cannot be, and surgery is not an option, it's called **unresectable**.

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?
- Can the cancer be taken out with surgery?
- Based on what you know about 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 mesothelioma.

- Surgery and radiation are used to treat only the cancer. They do not affect the rest of the body. This is called local treatment.
- Chemo drugs go through the whole body. They can reach cancer cells anywhere in the body. They are called systemic treatment.

Doctors may use both local and systemic treatments to treat mesothelioma. The treatment plan that's best for you will depend on:

- Where the cancer is
- The stage of the cancer or whether it's resectable
- The type of mesothelioma
- The chance that a type of treatment will help
- Your age
- Other health problems you have
- Your feelings about the treatment and the side effects that may come with it

Surgery

If your cancer is small and/or hasn't spread, your doctor may suggest surgery, along with other treatments. If surgery can be done, it offers the best chance of a cure. It can also be used to ease problems caused by the cancer.

Sometimes, fluid collects in the chest and causes breathing problems. This fluid can be taken out by putting a small tube in the chest. After the fluid is drained out, a drug is put into the tube. This helps seal the space and keep fluid from building up again.

Most of the time, radiation and/or chemo is used along with surgery.

Side effects of surgery

Any type of surgery can have some risks and [side effects](#)¹. Be sure to ask the doctor what you can expect. If you have problems, let your doctor know. Doctors who treat people with mesothelioma should be able to help you with any problems that come up.

Radiation treatment

Radiation uses high-energy rays (like x-rays) to kill cancer cells. In mesothelioma, it's most often used after surgery to kill any cancer cells that may be left behind. Radiation can also be used to relieve symptoms such as pain, bleeding, trouble swallowing, or other problems. It's given in small doses every day for many weeks.

Side effects of radiation treatments

If your doctor suggests radiation as your treatment, talk about what side effects might happen. The most common side effects of radiation are:

- Skin changes 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 (the short word 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. Chemo is

often the main treatment for mesothelioma that cannot be taken out with surgery.

Chemo is given in cycles or rounds. Each round of treatment is followed by a break. This gives the body time to recover. 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, be sure to talk to your cancer care team so they can help.

Other treatments that may be used

Drugs that stop tumor blood vessel growth: For cancer to grow, new blood vessels are needed to “feed” the tumor. A targeted therapy drug called Avastin[®] can be used along with chemo to keep new blood vessels from forming.

Drugs that help your immune system: Immunotherapy drugs help your immune system find and kill cancer cells. They can help control mesothelioma tumors when chemo isn't working.

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 state-of-the-art cancer treatment. They are the only way for doctors to find better ways to treat cancer. If your doctor can find one that's looking at the kind of mesothelioma 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

- 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?
- 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. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. 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 mesothelioma has come back.

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 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 well as you can.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html
2. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
3. <http://www.cancer.org>

Words to know

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

Echocardiogram: A test where a small wand is moved around on the skin of your chest over your heart. It gives off sound waves and picks up the echoes as they bounce off tissues. The echoes are made into a picture on a computer screen. These pictures can show if there's fluid around your heart or the lining is thicker than it should be.

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>)³. 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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