After a Uterine Sarcoma Diagnosis

Uterine sarcoma is a rare type of cancer that starts in the uterus. If you have been told you have uterine sarcoma, you've probably already had an ultrasound, scans, an endoscopy, and a biopsy (a test that takes some tissue to check for cancer). Other tests might have been done on the cancer cells to check for certain proteins and gene changes called biomarkers. You might also have other procedures to find out if the cancer has spread. These tests help your doctor know what type of uterine sarcoma you have, what stage it is, and what treatment might help.

Treatment for uterine sarcoma

Your treatment will depend on the type and stage of the uterine sarcoma. Your treatment options will also depend on test results on the cancer cells, your health, if you are still having menstrual periods, and your personal preferences.

In many cases, more than one type of treatment is needed for uterine sarcoma. Surgery to remove the cancer is the main treatment for early-stage disease. Sometimes other organs might also be removed, such as the ovaries. Other treatment options may include radiation, chemotherapy (chemo), hormone therapy, targeted therapy, and immunotherapy. Your doctor will help you decide which treatments are best for you.

Surgery and some other treatments can cause changes in your menstrual periods. Your periods might stop, even if you haven't gone through menopause. These treatments could also affect your ability to get pregnant, but there may be ways to preserve your fertility. Talk with your doctor early, before your treatment starts. They can help you understand what to expect.

Be sure to ask:

- What type of uterine sarcoma do I have?
- What stage is the uterine sarcoma, and what does that mean?
- Will I need more tests?
- What treatment do you think is best for me?
- What is the goal of treatment?
- Will treatment include surgery? Will my uterus be removed? Will my ovaries be removed?
- Will I need other types of treatment, too?
- Will the treatment put me into menopause early?
- Will I be able to have children after treatment?
- What are my treatment options if I want to have children in the future?

What to expect before and during treatment

Your cancer care team will explain your treatment plan to you. This team may include different doctors, nurses, and other healthcare workers, depending on the type of treatment you need. For example, if you need surgery, you will work with a surgeon. They will tell you what to expect before, during, and after treatment. If you need other types of treatment, your cancer care team will explain how it is given, help you get ready for it, keep track of how you're doing, and help you with any side effects. You might also get blood tests, scans, or other tests at certain times to see how well your treatment is working.

Not everyone going through treatment for uterine sarcoma will have the same side effects. For example, the side effects of surgery are different from the side effects of radiation, chemo, hormone therapy, targeted therapy, or immunotherapy. And people getting the same treatment might have different side effects.

Be sure to ask:

- What side effects might I have, and what can I do about them?
- How will we know if the treatment is working?
- How often will I get treatment? How long will it last?
- Where will I go to get treatment? Can I drive myself?
- How will treatment affect my daily life?
- Will treatment affect my sex life? If so, how and for how long? What can I do about it?
- Are there any clinical trials that might be right for me?

What to expect after treatment

After treatment, ask your cancer doctor for a treatment summary and follow-up plan. This is called a survivorship care plan. Your cancer doctor will work with your family or primary care doctor to help manage side effects from treatment and check your general health. You will have regular tests to check if the cancer has come back or if a new cancer has started in a different part of your body.

You might be faced with changes to your body after treatment. If you had menstrual periods before surgery, you'll stop having them after your uterus is removed. Your ability to get pregnant will change, too. Treatment may also make your vagina dry. You may have bleeding or pain during or after sex. Ask your doctor what to expect, and let them know if you have any problems.

People who have had uterine sarcoma are at risk of having it again or getting certain other types of cancer. Even if you feel fine after finishing treatment, it's important to ask your cancer care team about a regular schedule for follow-up tests to check if the uterine sarcoma has come back.

For some people, the cancer might not go away completely. They might continue to get treatment, and tests will still be needed to see how well it's working.

Be sure to ask:

- Where do I get a copy of my treatment summary and follow-up plan?
- How often do I need to see my cancer care team?
- When and how should I contact them?
- Will I need tests to see if my cancer has come back, or to check for problems from my treatment?
- Do I need any screening tests, like a mammogram or colonoscopy, to find other cancers early?
- Are there late or long-term side effects from treatment that I should watch for?
- Where can I find my medical records after treatment?

Staying healthy

Be sure to tell your doctor or cancer care team if any treatment side effects don't go away or if you have any new symptoms.

There are things you can do to keep yourself healthy during and after treatment. Getting to and staying at a healthy weight, eating well, being active, not smoking, and avoiding alcohol can help you stay healthy. These things may also help lower your risk of getting a new uterine sarcoma or other cancers.

Dealing with your feelings

Having uterine sarcoma might make you feel scared, sad, or nervous. It's normal to have these feelings, and there are ways to help you cope with them.

- Don't try to deal with your feelings by yourself. Talk about them, no matter what they are.
- It's OK to feel sad or down once in a while, but let your cancer care team know if you have these feelings for more than a few days.
- If your doctor says it's OK, continue doing things you enjoy like spending time outdoors, going to a movie or sporting event, or going out to dinner.
- Get help with tasks like cooking and cleaning.

You might want to reach out to friends, family, or religious leaders or groups. Counseling can also help. Some people find it helpful to talk with others who've been through the same things. A support group can offer that. Tell your cancer care team how you're feeling. They can help you find the right support.

For more information and support, visit the American Cancer Society website at **cancer.org/uterinesarcoma** or call us at **1-800-227-2345**. We're here when you need us.

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