
What to do if you have received a diagnosis of Leiomyosarcoma



Find a sarcoma oncologist. Since sarcomas are rare, and leiomyosarcomas even more so, it is best if you seek treatment from an oncologist (cancer doctor) who has a specialized interest in sarcomas. Generally, these are oncologists who practice at a sarcoma clinic or a sarcoma center and see at least 100 sarcoma patients a year. A sarcoma oncologist will recognize that leiomyosarcomas require specific treatments, and will be familiar with the latest options.

Further, a sarcoma oncologist practicing in a sarcoma center will be part of a multidisciplinary team with expertise in sarcomas. These teams will consist of one or more sarcoma medical oncologists, oncological surgeons for various areas of the body, sarcoma pathologists, oncological orthopedic surgeons and radiation oncologists. This multidisciplinary team deals with each patient's case, verifying the diagnosis and working out the best plan of care.



After finding your sarcoma oncologist ask your primary care physician to refer you to him/her for a second opinion. State that you have a rare cancer and have heard that this doctor, the sarcoma oncologist, treats many patients with this particular type of rare cancer. Patients' survival rates are better if their sarcoma treatment is overseen by a sarcoma center. Assert that you would like a referral to this doctor for treatment decisions and management of your condition.

If you live a considerable distance away, the sarcoma oncologist might be suggesting treatment that your oncologist nearer home will be carrying out. Go to your local general medical oncologist and state that you are being referred to this sarcoma oncologist who treats many cases of leiomyosarcoma. Ask if he/she would be willing to carry out treatment recommendations made by the sarcoma oncologist.



Remember, your choice of doctors is very important, and you need to seek out those doctors who have an expertise in sarcomas. Sarcoma oncologists tend to be

interested, encouraging, helpful and hopeful, because they are more aware of the current choices available. Seeking a second opinion is a routine option for many diseases. Most oncologists will welcome colleagues' opinions, and consider their suggestions. If your needs are not being met, you should consider changing doctors.

Once the referral is made you will be asked to furnish such things as tissue samples, X-rays and scans, operation and pathology reports, names and addresses. You have probably had a CT scan of the chest, abdomen and pelvis with and without contrast. You will need those scans. You will need a case summary of your whole medical history, not just the cancer. Your primary care physician should be able to provide one. **All of this is information to which you are entitled.**

Send or take copies of all of this information to the sarcoma oncologist, as requested. Prior to your visit to the sarcoma oncologist **make a list of questions** that you would like to have answered. Take them with you, and take notes, or have a friend take notes, or make an audio tape of the consultation.

Treatment options that may be recommended



If it is possible, surgical removal of the tumor with wide clear borders is the treatment of choice, **because** LMS responds poorly to chemotherapy and radiation. This does not mean that chemotherapy and radiation are not effective, but simply that the treatment of preference will be surgery if it is possible.

Chemotherapy and/or radiation may be recommended by your doctor to shrink the cancer prior to surgery, or to shrink or stabilize cancers that are inoperable. **The important thing to note, however, is that there ARE treatment options available.**

Because leiomyosarcoma is very prone to return locally, or spread to other areas beyond the primary site, your sarcoma oncologist will likely require that you have regular scans and/or X-rays. Usually these tests are performed on an every three-month schedule to catch any recurrence early, so it can be treated early.

The information provided here is not a substitute for professional medical advice.

Further Sources for Information and Support

■ National Cancer Institute [NCI]

Questions and Answers about cancer <http://cancer.gov/cancerinformation>
Soft Tissue Sarcoma section

<http://cancer.gov/cancerinfo/types/soft-tissue-sarcoma>
Uterine Sarcoma section <http://cancer.gov/cancer.info/types/uterinesarcoma>

OR call the NCI's Cancer Information Service at: 1-800-4-CANCER. The call is free and a trained information specialist is available to answer your questions. The National Cancer Institute has booklets and other materials that discuss types of cancer, methods of cancer treatment, coping with cancer ...

OR write to this address: National Cancer Institute Office of Communications
31 Center Drive, MSC 2580 Bethesda, MD 20892-2580

■ L-M-SARCOMA ListServ at ACOR

<http://listserv.acor.org/archives/lmsarcoma.html>

An online support and discussion group of leiomyosarcoma patients, families, and caregivers. Hosted by the Association of Cancer Online Resources (ACOR) you may subscribe at the above URL. **ACOR is an excellent source of support and information for many rare cancers. It is free.**

■ **Leiomyosarcoma is a rare cancer.** www.leiomyosarcoma.org.uk & www.leiomyosarcoma.info Mirror sites of an encyclopedic nature compiled by professionals and laypersons, all of whom have personal experience with LMS. **This is an excellent source for information.**

■ **Sarcoma.org** <http://www.sarcoma.org> Center for Orthopedic Oncology and Musculoskeletal Research at the Washington Cancer Institute

■ **Cancerbacup.org** <http://www.cancerbacup.org.uk/info/sarcomas.htm> An information booklet written to help you understand more about soft tissue sarcoma

■ **The Sarcoma Alliance** <http://www.sarcomaalliance.org> To guide, educate and support adults with sarcomas and their family, friends, and caregivers.

■ **Sarcoma UK UK** <http://www.sarcoma-uk.org>

Website focusing on support information relevant to UK patients and the NHS - but also offering quick short-cuts to a good range of general information on soft tissue sarcoma. Sarcoma UK is working to create a support organisation specifically for UK patients and is representing sarcoma patient interests within the NHS.

Leiomyosarcoma

Information about leiomyosarcoma and soft tissue sarcomas in general

Leiomyosarcoma (LMS) is a rare cancer that is part of a family of cancers known as sarcomas. Sarcomas are cancers that arise in the body's connective tissues, which include fat, muscle, blood vessels, deep skin tissues, bones, and cartilage. Sarcomas are either soft tissue tumors or bone tumors. This sheet's purpose is to provide information and support for caregivers and patients diagnosed with a soft tissue sarcoma, and especially those diagnosed with LMS.

Soft tissue sarcomas are cancers in which wildly growing cells developed from a soft tissue part of the body. Leiomyosarcoma is a cancer of the smooth muscle cells that make up the involuntary muscles-- found in the uterus, skin, intestines, and the walls of blood vessels throughout the body.

This cancer will start in one place, and be very unpredictable. It can stay and grow in one place, or it can spread widely all over the body, quickly. Or it can be quiet for a long time, and then erupt after 20 years. It is also a resistant cancer, not curable by chemotherapy or radiation. Therefore, the best outcome occurs when it is surgically removed early with wide margins clear of tumor cells, before it can spread. Both chemotherapy and radiation can sometimes be used to shrink or control tumors which may not be operable.



Joyce wrote this flyer with loving kindness, with some help from Alison, Dick, BethG & Marcia of the L-M-Sarcoma List at ACOR.