

A guide to Soft Tissue Sarcoma

This booklet will help you understand what sarcoma is and how it is treated.

Review this booklet and bring it with you when you meet with your sarcoma treatment team.

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IMPORTANT

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

This material is also available through the MUHC Patient Education Office website www.muhcpatienteducation.ca



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Introduction

This booklet will:

- Help you answer the question: What is sarcoma?
- Describe symptoms and diagnosis
- Explain your main treatment options: surgery, radiotherapy and chemotherapy.
- Give you information to help you cope with your sarcoma

Your sarcoma treatment team

As your team of healthcare providers, we will support you at every step of your diagnosis, treatment, and recovery. Here are some of the key people on your treatment team:



Surgeon:

- A doctor who makes the diagnosis of your sarcoma and performs your surgery.
- He or she will follow you as you recover from surgery and for a few years after surgery.

Radiation Oncologist

 A doctor who provides radiotherapy treatments and follows you during treatment, and sometimes afterwards as well.

Nurse Clinician:

 A nurse who provides care for you at all steps of your treatment.

Pivot Nurse:

- A nurse who is an expert in working with and supporting people who have sarcoma.
- Helps you to find the resources you need during your treatment.
- Answers questions you may have about the next step of your care.

Medical Oncologist:

 A doctor who provides chemotherapy treatments and follows you during treatment and sometimes afterward as well.

Nurse Practitioner:

- A nurse who is expert in working with people who have cancer.
- Can order tests that are necessary at different steps of your care.
- Can prescribe certain medications to help control symptoms.

Social Worker:

 A professional who can help you and your family cope with any emotional, social and financial difficulties you may be facing because of your sarcoma.

Fellow:

 A certified medical specialist who has finished being a Resident and is doing extra training in a more specialized area.

Resident:

 A doctor who has graduated from medical school and is now training in a specific area of medicine such as Radiation Oncology, Orthopaedic Surgery or Medical Oncology.

Research Assistant:

- A professional who can tell you about research studies that you can participate in.
- He or she will tell you what is necessary to be a part of a research study and what you can expect.

Physiotherapist:

- A professional who can help you to do exercises to improve your strength and mobility.
- Makes sure you can return home safely.
- Helps you adjust to a limb prosthesis, if necessary.

Dietitian:

 A professional who can make sure you are getting the right nutrition during and after treatment.

What is sarcoma?

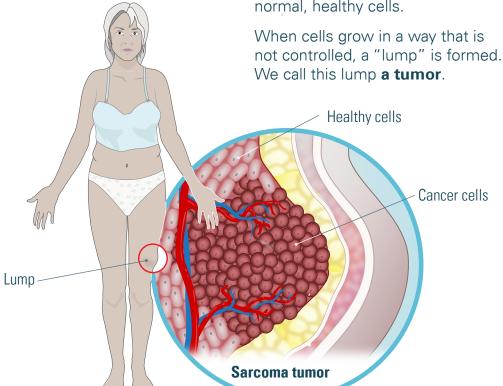
Sarcoma is a rare kind of cancer.

Before learning more about sarcoma, it is important to know about cancer.

What is Cancer?

Cells make up the tissues and organs of your body. When a cell gets old or is damaged, it is either repaired or replaced by a new cell. Normally, cells grow in a regular and controlled way.

Sometimes, cells start to grow out of control. More cells are created than needed. This can happen because of a change in your genes which we call a 'mutation'. These cells look and act differently from normal, healthy cells.



A tumor that doesn't spread more is usually called benign (not cancer). A tumor that can spread to other parts of the body is called malignant (cancer).

Most cancers start in one of your body's organs like the lung, breast or liver.

Sarcoma is different; it starts in your body's **connective tissues**.

Connective tissues are tissues between organs that support or connect parts of our bodies. Some connective tissue is hard (bones) and some is soft (muscles, fat, nerves and blood vessels).

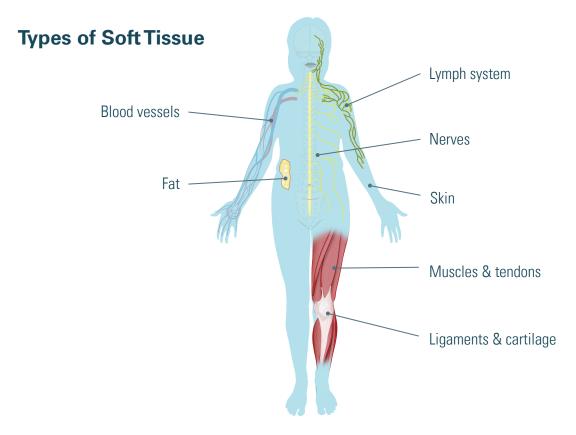
Risk factors

We don't know yet exactly what causes sarcoma. There are some things that can make us more likely to have cancer. We call these risk factors. But most people who develop sarcoma don't have any risk factors. What we do know is that people with these conditions have a higher risk of developing a sarcoma:

- Having a disorder like Paget's disease or neurofibromatosis
- Having been exposed to high doses of radiation
- Lengthy exposure to some **chemicals** like arsenic
- Having certain cancer syndromes or genetic disorders in your family

Types of sarcoma

There are two main types of sarcoma: Those involving bone, and those involving soft tissues. This booklet will focus on **SoftTissue Sarcoma**.



There are more than 60 kinds of soft tissue sarcoma. They are organized into 9 main groups based on the type of cells in the tumor and where the tumor is found. Sometimes there are differences in how they are treated.

For more information you can visit the following website: http://bit.ly/SoftTissueSarcoma_CanadianCancerSociety

Diagnosis

Symptoms

Because sarcoma develops in your connective tissues, it can sometimes be hard to detect.

With Soft Tissue Sarcoma, some people may not have any symptoms. In some cases, you might notice a new lump. As the tumor grows, it can sometimes cause pain. In other cases, you might only notice symptoms if the tumor is pressing on organs, nerves or blood vessels in your body.

Tests for diagnosis

If your doctor thinks you have a sarcoma, you will need to have tests to confirm this. You will also need a general physical exam.
Usually, you will have 3 types of tests:

1) Blood tests

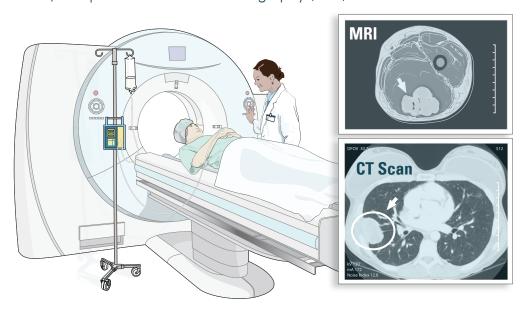
A sample of your blood is taken. The sample is sent to a laboratory for analysis. The results of the blood test will not indicate if you have sarcoma. But, they can sometimes show signs of illness or disease including cancer, for example:

- The number and quality of blood cells
- How well your organs are working



2) Imaging tests

Imaging tests take pictures of the inside of your body. These pictures help to see if there is a tumor. There are different machines that can take these pictures. They include: X-rays, computerized tomography (CT) scans, magnetic resonance imaging (MRI), whole body bone scans, and positron emission tomography (PET).



Here is what each test does:

An **X-ray** takes pictures of the bones in your body.

CT Scans use x-rays to take many pictures and put them together to make a 2D picture.

An **MRI** takes detailed pictures of the tissues in your body using magnetic beams. MRI is the best tool to show soft tissue sarcoma.

Bone Scans take very precise pictures of your bones. A chemical marker is injected before the scan.

PET scans also use a chemical marker to show areas in your body that use glucose for energy in way that is not normal. This can help to show where cancer cells are in the body.

3) A biopsy test

A **biopsy** takes out a small sample of tissue from a tumor to see if it is cancer. A biopsy is a very important step in managing sarcomas. After we have a tissue sample, a pathologist will look at it under a microscope. This is the best way to know if it is a sarcoma. A biopsy can also tell us if the cancer began in the place where the biopsy was done or if it started somewhere also in the body.

This information will help your healthcare team decide the best treatment for you.

A biopsy can be done in two different ways:

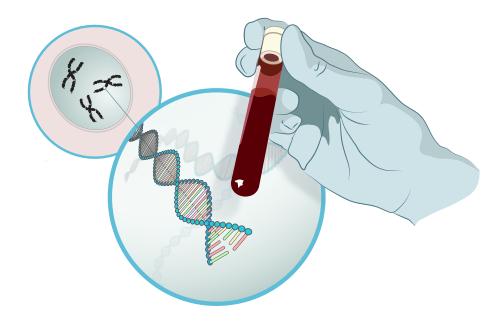
- 1. A needle biopsy, or
- 2. An open surgical biopsy



Your doctor will decide what type you need. Sometimes, you might have an ultrasound or CT scan at the same time as the biopsy. This helps to make sure that the biopsy is taken from the right place. This is called **image guidance**.

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Molecular and Genomic Testing



DNA and **RNA** are molecules. They carry the genetic information of all living cells. They give instructions to the body about how to work. Changes or mutations in this genetic code can sometimes lead to diseases including cancer. Some types of sarcoma have specific types of mutations. The information from your tumor genetic code and other patients can help your doctor better understand your sarcoma. Testing your DNA or RNA can improve chances of finding a cure in the future.

Treatment

There are different ways to treat soft tissue sarcoma. Most people will need **surgery**, but you might not. You could have **radiotherapy**, **chemotherapy** or **targeted therapy** (See pages 28~32). These treatments can be used with or without surgery, and before or after surgery. Your treatment team will meet and discuss your situation. Then they will decide which treatment is best for your type of sarcoma based on:



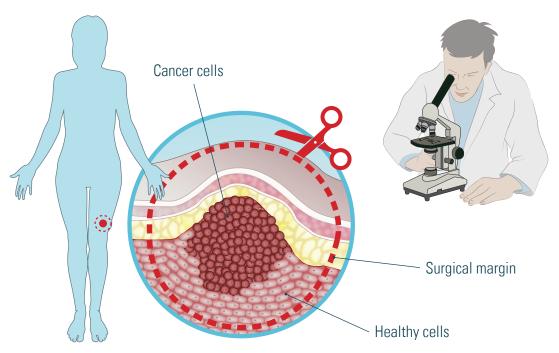
- **Location**: Where your cancer is located.
- Grade: The ability of the tumor cells to grow quickly. How different the tumor tissues look compared to normal tissues. Tumor cells are examined under a microscope to measure this.
- Stage: The size of the tumor and if it has spread to other places in your body. Imaging tests can help us measure this.

Surgery

For most people, the best way to treat sarcoma is to remove the tumor. For this reason, surgery will probably be part of your treatment plan.

If surgery is part of your plan, your treatment team will explain:

- What kind of surgery you will have
- How long it can take to get better
- What to expect right after the surgery and over the long term

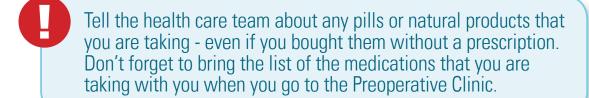


To make sure that the cancer is removed, surgeons will take out the tumor with a small amount of healthy tissue around the tumor. This is called a **surgical margin**. After the surgery, this tissue (the surgical margin) will be looked at under a microscope by the pathologist to see if there are any cancer cells in the margin. This will help the team decide the next step for treatment.

Preoperative testing

Your team will make an appointment for you at the Preoperative Clinic before the surgery. This is to make sure you are ready. During your Preoperative Clinic visit, you will:

- Meet with a nurse. Your nurse will tell you how to get ready for your surgery and explain what to expect while you are in the hospital.
- Meet with a doctor. The doctor will ask questions about your health and the medications that you are taking. Tell the doctor if you have medical problems. You might need to see another doctor (a specialist) before having surgery.



You might also need to:

- Have blood tests.
- Have an electrocardiogram (ECG) to check how your heart works.
- Stop taking some medications and natural products before surgery.
 During the appointment, the doctor will tell you which medications you should stop and which ones you should keep taking.

If you have any questions before surgery call the Pre-operative Clinic at: **514-934-1934, ext. 34916** (Monday to Friday from 7 a.m. to 3 p.m.)

See the general surgery preparation guide for the Glen site:

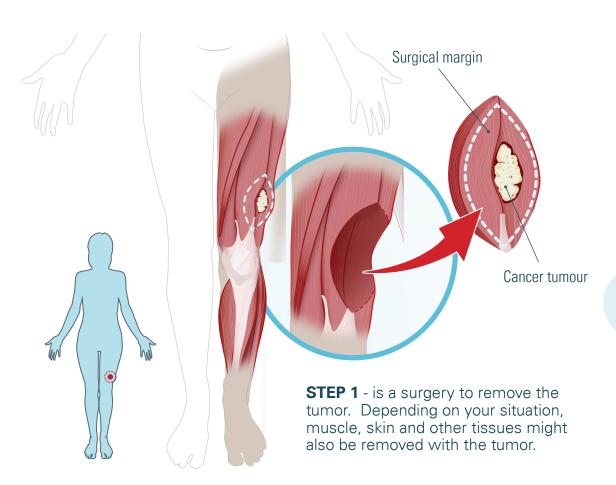
http://bit.ly/preparing-for-surgery-glen-site



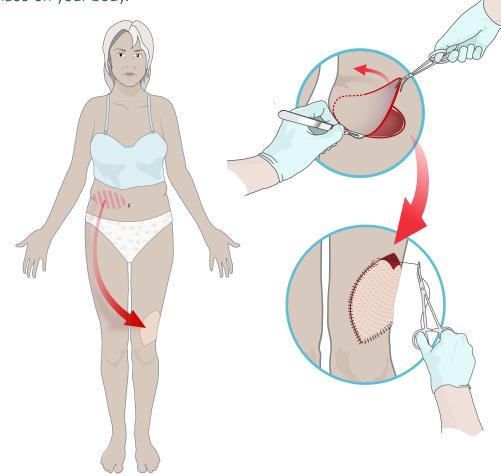
Types of Surgery

The type of surgery you have depends on the type of tumor, the size of the tumor and where it is found in the body. There are two main types of surgery: **Limb Salvage** or **Amputation**.

1. Limb Salvage Surgery (This has 2 steps)



STEP 2 - is called **Reconstructive Surgery**. You might need this type of surgery to help fill places where some tissues were removed. For example, if your surgeon had to remove some of your skin, you might need a skin graft. This is a layer of skin that is taken from another place on your body.



If some of your muscle was removed, you might also need a muscle flap. This is a piece of muscle that is taken from another place on your body to fill the place where the muscle was removed.

If your surgeon had to remove some of the tissues of your arm or leg (your limb), reconstructive surgery will help you use your arm or leg again. Most people (9 out of 10) will be able to function properly after this surgery. 2. Amputation surgery

Sometimes it is not safe to cut out the tumor in your limb. This might be because the tumor has affected important nerves or blood vessels in your limb. If this happens, your surgeon may suggest an amputation. An amputation means that the limb will be removed. This is not often necessary (about 1 in 20 people with sarcoma).

If you need an **amputation**, you will usually get a prosthesis to replace your arm or leg. Your team will also refer you to a rehabilitation center. This is so that you can regain your strength and learn how to adapt to your new prosthesis.



The rehab center:

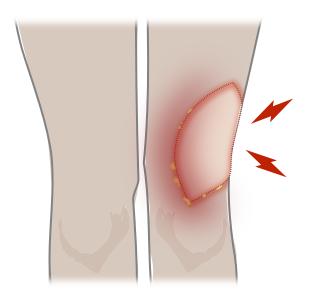
Rehabilitation Institute Gingras-Lindsay 514-340-2085

Possible risks of surgery

With any surgery, there is a chance of complications. This can happen during the surgery or afterwards.

Here are some complications you should know about:

Infection: This is one of the major risks in sarcoma surgery. Infection can happen more often in sarcoma surgery, especially limb salvage surgery. This is because large portions of muscle and other tissues are removed. This also happens because chemotherapy or radiotherapy treatments before surgery can weaken your body's immune system. Your team will give you antibiotics to help prevent infections but there is still a chance of infection (about 1 to 3 people out of 10).



- The incision (cut) is slow to heal or opens up again.
- Blood or fluid develops at the site of surgery.
- Bleeding too much.
- Needing to have a blood transfusion.
- Damage to nerves and blood vessels close to the tumor. This can lead to the limb getting numb or weak.

- Damage to nearby organs, especially if your tumor is in the belly or chest.
- Having chronic pain after surgery. This can happen if your surgeon has had to cut a nerve to remove the tumor.
- Phantom limb pain: after an amputation, it can feel like the limb is still there or that there is pain in the limb that was removed.

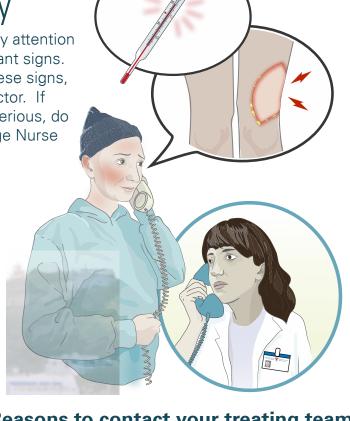
While you are in hospital, your surgical team will check on you regularly to make sure that you are recovering well, and that:



- fever and no significant pain.
- You are learning to adapt after surgery
- You are moving around safely.
- You are eating, drinking, and going to the bathroom normally (peeing and pooing).
- You have help to manage at home.

After surgery

When you go home, pay attention to the following important signs. If you notice ANY of these signs, please contact your doctor. If your condition is very serious, do not wait. Call your Triage Nurse or Pivot Nurse.



Warning Signs: Reasons to contact your treating team:

- Your incision (cut) gets warm, red, and hard.
- You have a fever higher than 38 °C/100.4 °F.
- You see pus or liquid coming from your incision (cut).
- Your incision (cut) opens up.
- You are bleeding where you had the surgery.
- You have new, lasting pain.

- Your pain is getting worse and your pain medicine does not help.
- You have redness, swelling, warmth or pain in either leg.
- You cannot drink or keep liquids down (nausea or vomiting).
- You have trouble breathing.
- You pee a lot, have a burning feeling or pain when you pee, or need to pee badly.

Pain

You will have some pain for a few weeks after your surgery. This is normal but it will get better.

To relieve your pain, take acetaminophen (Tylenol®) and your anti-inflammatory. Add the stronger narcotic medication prescribed by your surgeon only if (Tylenol®) does not relieve your pain enough to make you comfortable.



If the pain medication causes burning or pain in your stomach, stop taking them. Call your surgeon's office to let them know.



If you have severe pain and your medication is not helping, call your surgeon or go to the emergency.

Pain medication can cause constipation. To help your bowels stay regular:

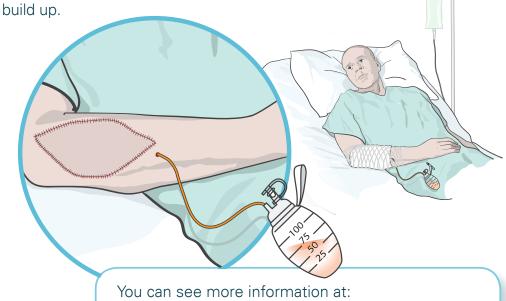
- Drink more liquids.
- Eat more whole grains, fruits and vegetables.
- Get regular exercise (a 20 minute walk is a good start).
- Take stool softeners if your doctor tells you to.

Incision Care and Drains:

You will go home with a special dressing (bandage) to cover your surgery incision (cut). The CLSC will schedule appointments with you to change the dressing.

You may have a drain (a Jackson Pratt) placed in the surgical area. This gets rid of extra fluid that can

This drain will most likely be removed before you go home, but sometimes it is left in place for a bit longer. If this is the case for you, the drain will be removed in the sarcoma clinic when you come back to see your doctor for follow-up.



muhcguides.com/module/jackson-pratt-drain

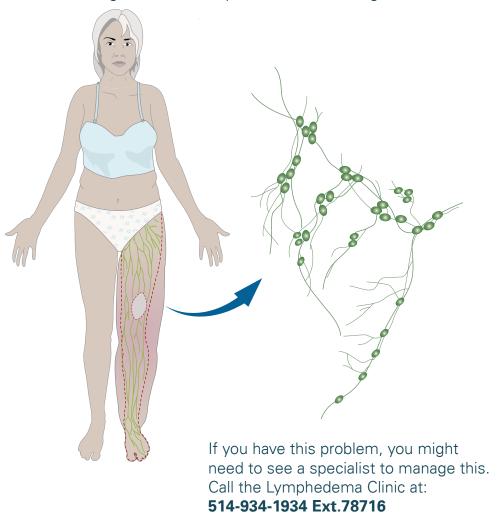
Activity

Your doctor will explain what kind of activities you are allowed to do.

A physiotherapist may meet with you before you leave the hospital to show you exercises to help you recover safely.

Lymphedema

If some of your lymph nodes were removed during surgery or damaged during radiotherapy, you might have some swelling in that part of your body. This is called lymphedema. Lymph nodes are part of the immune system in your body. They act like filters to help drain fluid and prevent infection. When lymph nodes are removed or damaged, it interrupts the flow of fluid. When fluid is not flowing well, it builds up and causes swelling.

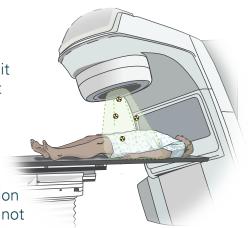


Radiotherapy

What is Radiotherapy?

Radiotherapy uses special X-rays to treat cancer. When radiation enters your body, it damages cancer cells so that they cannot make more cancer cells. The purpose of radiotherapy is to get enough radiation to reach the cancer cells but to not damage your healthy cells too much.

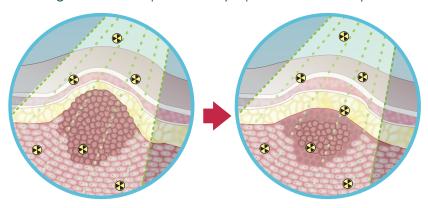
Patients get their treatment at the Radiation Oncology Clinic. This means that you will not stay in the hospital during your treatment.



When is it given?

Radiotherapy may be used in these situations:

- **Before surgery** or **after surgery** to kill any cancer cells that are in the margins and help prevent the sarcoma from coming back.
- **On its own** (without surgery or chemotherapy) to shrink the tumor, slow its growth or help relieve symptoms caused by the tumor.



Radiation tries to shrink the tumor. It can also slow down its growth and help relieve symptoms caused by the tumor.

What can I expect?

The side effects of radiation therapy are different from person to person. They can depend on things like: the area of the body being treated, the type of radiation, the amount of radiation, whether you are having chemotherapy at the same time and your general health.

Typical side effects of radiotherapy can include:

- During treatment, you may feel tired. It is important that you get the rest you need and that you eat well. For more information about nutrition and managing your energy, speak to a member of your treatment team.
- Skin redness during treatment (like a sunburn). If you have very sensitive skin, you may get blisters. These will not last.
- After treatment, your skin may darken (like a tan). This tan may stay.



You can also visit this website for more information:

http://bit.ly/muhcpatienteducation_radiotherapy

There may be other side effects. Your radiotherapy team will discuss these in more detail with you. Your radiation oncologist or resident will see you every week to check for side effects. The radiation oncologist might also prescribe medication to help with side effects or symptoms you may have.

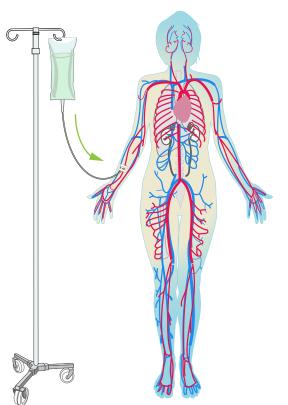


If a side effect or symptom appears between your weekly visits you should tell one of your team members

Chemotherapy

What is chemotherapy?

Chemotherapy uses anti-cancer drugs to kill sarcoma cells or slow down their growth. Chemotherapy usually involves several treatments given over time. These are called treatment cycles. Your oncologist will discuss this with you.





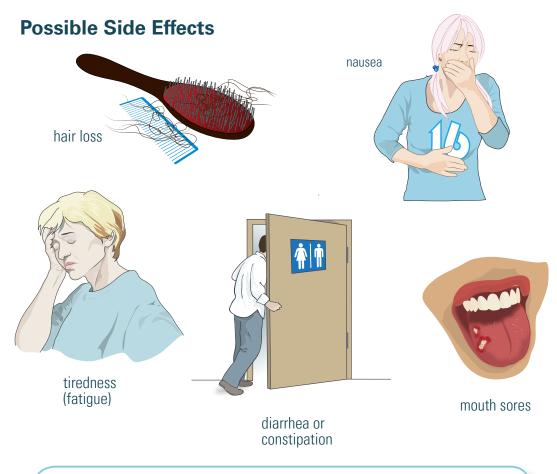
When is it given?

It may be given before surgery to:

- Treat cancer cells that may have spread in the body
- Help shrink the sarcoma to make it easier to remove during surgery. In soft tissue sarcoma, chemotherapy is used
 - When the tumor is difficult to remove with surgery,
 - ° If the tumor is large,
 - Or if the cancer has spread to different places in the body (we call this metastatic cancer).
- Sometimes, it is also given after surgery. This decreases the risk of the cancer coming back.
- Chemotherapy can also be given to lessen pain and other symptoms.

What can I expect?

Chemotherapy can be given as a liquid through an intravenous line (IV) into your blood or as a pill. Chemotherapy targets cells that grow fast like cancer cells. Chemotherapy also affects normal fast growing cells like hair cells, the cells in your mouth, intestines and blood cells. This is why you can have side effects like losing your hair, nausea, sores in your mouth, diarrhea, constipation and fatigue.



For more information on side effects and how to manage them, visit: **muhcguides.com/module/chemotherapy**

Targeted Therapy and Immunotherapy

Some types of sarcoma can be treated by special cancer medications. These medications include targeted therapy (like SutentTM and VotrientTM) and immunotherapy. **Targeted therapy** is a type of medication that targets one step in the process that cancer cells use to grow. This type of therapy can shrink the tumor or slow its growth. **Immunotherapy** is a type of medication that can make your body's immune system more active so that it fights cancer cells.

Side Effects

Some of the common side effects are:

Immunotherapy:

Symptoms of a flu (nausea, chills, aching muscles)

Changes in how your liver functions

• Thinning hair

Changes in thyroid function

Diarrhea, sometimes severe

Feeling tired

Targeted Therapy:

- A rash on your skin
- Pain in your muscles or joints
- Headache
- Feeling tired
- Nausea and vomiting
- Fever
- Changes in thyroid function



Surveillance

After you have completed your treatments, your doctor will continue to see you for follow-up. You will be seen more often at first but then less often over time. This is the usual schedule:

The first 2 years you will be seen every 3 months.

In the next 2-5 years, you will be seen every 6 months.

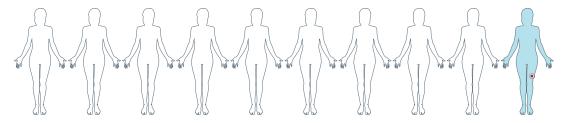
After 5 years, you will be seen every year for 5 more years. During your follow-up visits, tests will be ordered to check that the tumor has not come back.



Local recurrence:

It is possible that your sarcoma will return where it first happened. Here are some factors that might affect the chances that this will happen.

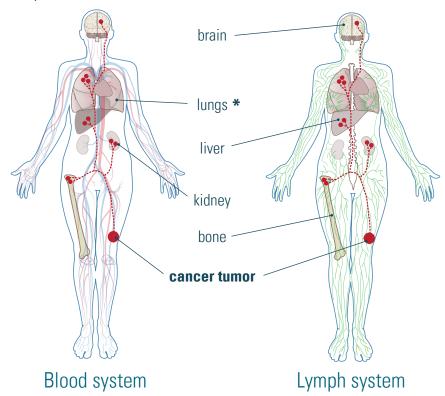
- The grade of the tumor
- The surgical margin results
- The first location of the tumor
- If the tumor has come back before



About 1 out of 10 patients will have their sarcoma come back in the same place where their cancer was found.

Metastasis:

When sarcoma spreads from where it was first found to other parts of the body, we call this metastasis. The lungs are the most common place sarcoma spreads to.



Research shows that when you are first diagnosed with sarcoma, the process of spreading may have already started but is too small to be seen. In order to see if your sarcoma has spread and offer treatment as early as possible, your sarcoma team will check you regularly. They will use different imaging tests. These imaging tests can include a chest CT-scan, whole body bone scan, or PET scan.



It is important to do these tests as soon as you are diagnosed, while you are waiting for surgery and after your surgery.

Fertility

Fertility is a person's ability to create new life. In women, this is the ability to become pregnant. In men, this is related to the ability to make sperm.

Some chemotherapy and radiotherapy treatments can affect fertility. These effects are sometimes permanent. There are options available to help you keep your ability to have a child in the future.

For more information on these options, speak with your healthcare team.



You can also find more information about the options here:

http://bit.ly/muhcpatienteducation_FertilityOptions

Commonly asked questions

If I have sarcoma, will my children get sarcoma?

Sarcoma is not a genetic change that is passed on to children or inherited. Sarcoma is sometimes due to a genetic change (mutation) in the tumor's cells. In most cases, we don't know what causes sarcoma.

Does an injury cause a sarcoma?

If you have a limb sarcoma, you might remember having had a serious injury to that limb. Even so, there is no evidence that an injury can cause a sarcoma.

How long does it take to recover function of my limb?

Most of your recovery will happen in the first 6 months after your surgery. Your recovery may depend on the treatments you receive and if you had any complications. After one year, you will likely be at your new baseline function level.

When should I expect to go back to work?

Patients are usually back to work in 6 months. Your return to work depends a lot on the actual tumor, your treatment and the type of job you have. Since the function of your limb does not usually change after 1 year, if you are unable to return to work after one year, you may need to consider a different type of job that does not rely so much on your limb.

What is the risk of the tumor coming back around the same spot?

When radiotherapy is used, less than 10% of people will have the tumor come back in the same spot. (This means that out of 10 people, only 1 person will have the tumor come back).

If the cancer comes backs or spreads, what will happen?

We can offer different treatments depending on whether the sarcoma comes back in the same place or if it has spread to another part of your body (metastasis). These treatments could include more surgery, chemotherapy, or radiation.

What are my chances of dying from my soft tissue sarcoma?

This is difficult to predict. We believe that it depends on these factors: the size of the tumor, if it is under the skin or deep in muscle, how close to normal the tumor looks under a microscope (the grade) and the surgical margins. Between 50 and 90% of soft tissue sarcomas are cured. This means that out of 10 people, between 5 to 9 people will be cured.



Living with sarcoma

Your treatment team, your friends and family and even support groups can be a big help during and after diagnosis. We know that this can be a stressful time for you. It might take a while to get used to all these changes. Try to do things that you enjoy. Try not to do too much if you notice that you are feeling tired. Here are people who can help and who you can talk to:



Treatment team

Follow your team's recommendations. Review this booklet. Speak with your team if you have questions or concerns. Sometimes it helps to write down your questions or to have a friend or family member with you during your appointments.

Tell your team if you have side effects, difficulty getting to appointments or other concerns.

The treatment team pivot nurse and social worker can help you get the support you need. They can guide you through your treatment.

Physical and occupational therapists

They can help you regain your strength, improve your movement and help you get back to normal. If you have a prosthetic device, they will teach you how to use it.

Support groups

Many patients with cancer will get support from other people who are going through the same kind of things (whether it is surgery, radiotherapy, chemotherapy or something else). Support groups can give you useful tips for day-to-day living. Although they might not offer the same kind of medical advice as a health professional, they can offer support, suggest useful tips, encourage you to talk to your doctor and recommend what questions to ask your sarcoma team. Also, sometimes just talking to people who have the same kind of cancer can help.

Cedars Cancer Support

Free, bilingual support groups are available. You can register for a support group by calling (514) 934-1934 ext. 35297 or 31666

Supportive care team

You may have to see a team of specialists to help manage symptoms caused by your cancer or cancer treatments. They have experience managing pain, chronic fatigue and extreme weight-loss.

Psychosocial Oncology Program

This is a team of experts who can offer professional counselling to you and your family members. If you need their help or would like to know more, call (514) 934-1934 ext. 44816.

Friends and family

Accept help from your family and friends. There is plenty that they can do. They can help by offering to make you meals, do your groceries, or drive you to appointments.



Resources



Can Support/Faire Face cansupport.rvh@muhc.mcgill.ca

Cedars Cancer Institute www.cedars.ca

Canadian Cancer Society www.cancer.ca

Fondation Quebecoise du Cancer www.fqc.qc.ca

The War Amps www.waramps.ca

O.M.P.A.C. (Organization Montrealaise des Personnes Atteintes du cancer) www.ompac.org

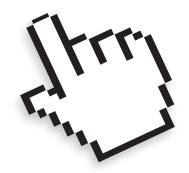
Sarcoma Alliance www.sarcomaalliance.org

Hope & Cope www.hope.jgh.mcgill.ca

National Cancer Institute www.cancer.gov

American Cancer Society www.cancer.org

Liddy Shriver Sarcoma www.sarcomahelp.org/about.html

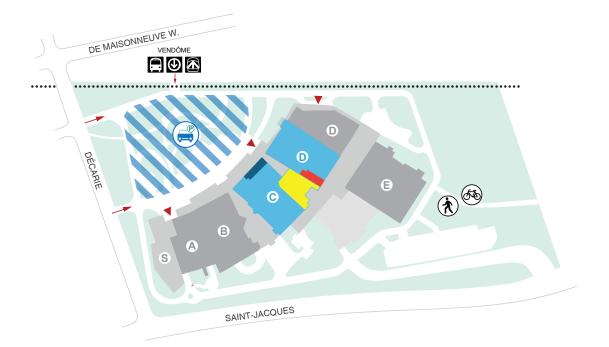


Notes



Office d'éducation des patients Patient Education Office

Glen site: 1001 Décarie Blvd. Montreal, QC H4A 3J1



- **A + B** Montreal Children's Hospital
- C + D Royal Victoria Hospital
 - **D** Montreal Chest institute
 - **D** Cedars Cancer Centre
- **E** MUHC Research Institute
- S Shriners Hospitals for Children
- Main Entrances
- Underground Parking (patients and visitors)