Cancer Council

CANCER TYPE
fact sheet

Understanding
Soft Tissue Sarcoma

A guide for people affected by cancer

You may feel shocked and upset when told that you have soft tissue sarcoma. We hope this fact sheet will help you, your family and friends understand how this group of cancers are diagnosed and treated in adults.

What is soft tissue sarcoma?

Cancer happens when cells become abnormal and keep growing. Soft tissue sarcomas are a group of cancers. They start in areas that support, connect, surround and protect the body. This includes fat, muscles, tendons and ligaments, lymph vessels, blood vessels, nerves and deep skin tissue.

Soft tissue sarcomas often form a painless lump. The lump may become painful if it grows. But most lumps in the body are not cancer.

Soft tissue sarcomas can grow into nearby tissue or spread (metastasise) to other parts of the body.

Sarcoma that starts in the bones, also called primary bone cancer or Ewing sarcoma, may be diagnosed and treated differently to other soft tissue sarcomas.

- See our *Understanding Primary Bone Cancer* fact sheet for information about this type of sarcoma.

How common are soft tissue sarcomas?

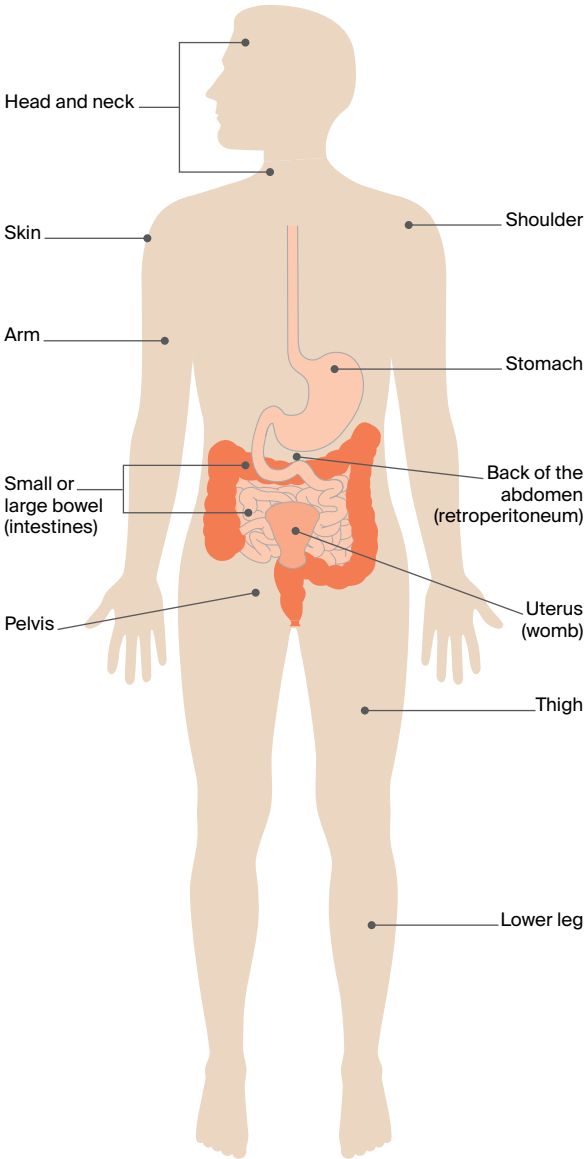
Soft tissue sarcomas are rare cancers. There are about 2,500 Australians diagnosed with a sarcoma each year, but this number is increasing.

Soft tissue sarcomas are more common in people over 55, but they can develop at any age.[1]

- For information about being diagnosed and coping with a rare type of cancer, see our *Understanding Rare and Less Common Cancers* fact sheet.

Where are soft tissue sarcomas found?

Soft tissue sarcoma can grow almost anywhere, but it's more common in the areas shown below.



Types of soft tissue sarcomas

There are many different soft tissue sarcomas. The more common ones are listed here. Sarcomas are usually named after the type of cell where the cancer started, or the part of the body where they are found.

undifferentiated pleomorphic sarcoma (UPS)	mix of cells with different sizes and shapes
gastrointestinal stromal sarcoma (GIST)	from nerve cells in the stomach; treated differently to other soft tissue sarcomas
liposarcoma	from fat cells
leiomyosarcoma	from muscle tissues (e.g. in blood vessel walls or the uterus)
rhabdomyosarcoma	from muscle tissues; more common in children and young adults
angiosarcoma	from blood and lymph vessels
malignant peripheral nerve sheath tumour (MPNST)	from the cells that cover nerves; also called neurofibrosarcoma
fibrosarcoma and myxofibrosarcoma	from fibrous connective tissues
sarcomas in stromal tissue	from supporting tissues
Kaposi sarcoma	from skin cells; or may be in the lower legs
spindle cell sarcoma	made up of many spindle-shaped cells
synovial sarcoma	from connective tissues; often found in arms, legs, feet and around joints
pleomorphic dermal sarcoma (PDS)	most common on the surface of sun-damaged skin in older people
epithelioid hemangioendothelioma (EHE)	from cells in the walls of blood vessels

For more information about the different types of soft tissue sarcoma, visit the Australia and New Zealand Sarcoma Association (ANZSA) at sarcoma.org.au and Rare Cancers Australia at rarecancers.org.au.

What are the risk factors?

The cause of sarcoma is not always known. Factors that may increase your risk of certain types of soft tissue sarcomas include:

Radiation therapy – People who had radiation therapy (also called radiotherapy) have a slightly higher risk of sarcoma. But most people who have radiation therapy won't get soft tissue sarcoma.

Inherited conditions – Some rare conditions that run in families may increase your risk of sarcoma. These include neurofibromatosis (NF), Li-Fraumeni syndrome, retinoblastoma, tuberous sclerosis and Werner syndrome. Most people will know if one of these very rare conditions runs in their family.

Chemical exposure – Being exposed to vinyl chloride (used in making plastic), dioxins, and some high-dose herbicides (weedkillers) may increase your risk of sarcoma.

Lymphoedema – Swelling from a build-up of lymph fluid (lymphoedema), especially over a long period of time, may increase your risk of angiosarcoma.

Immunosuppression – People with a weak immune system, like those taking medicine after an organ transplant or for an autoimmune disease, are at a higher risk of Kaposi sarcoma.

What are the symptoms?

Soft tissue sarcomas often don't cause any symptoms at first. As they get bigger, you may notice a painless lump. It may become painful if it presses on sensitive areas, such as nerves or muscles.

Knowing whether something is a harmless lump or a soft tissue sarcoma is often difficult without proper testing. Some sarcomas are mistaken for a benign fatty lump (lipoma) or bruise (haematoma). Talk to your doctor if you notice a lump that doesn't go away or gets bigger over time.

Some less common sarcomas may cause skin changes, or tummy symptoms such as feeling sick, not being hungry, or blood in your poo.

Treatment at a specialist sarcoma unit

If your doctor thinks you may have sarcoma, you should be referred to a specialist sarcoma unit, including for a biopsy. These units provide expert care, and research shows they have better outcomes. Here you'll be treated by a multidisciplinary team (MDT) (see page 4). Find a list of sarcoma units and MDTs on the Australia and New Zealand Sarcoma Association (ANZSA) website at sarcoma.org.au. Rare Cancers Australia's directory, rarecancers.org.au, may also have useful contacts.

Diagnosis

Your doctor will ask about your medical history and do a physical examination to feel for a lump. They may also arrange tests or refer you to another specialist for testing. Common tests include:

- **CT (computerised tomography) scan** – This scan creates 3D pictures of the inside of your body. You may first have an injection of dye (called contrast) into a vein, to make the pictures clearer. Then, you lie still on a table that moves through a large, doughnut-shaped scanner. This is a painless scan and usually takes about 10 minutes, but the appointment may be longer if contrast is used.
- **MRI (magnetic resonance imaging) scan** – Like a CT, this scan creates 3D pictures of the inside of your body. You lie on a table that slides into a long metal tube, which is open at both ends. An MRI takes 30-90 minutes. Some people may feel anxious in the narrow space. You may or may not need an injection of contrast for this scan.
- **X-ray** – This painless test takes a few minutes and may be used to check your chest, lungs, abdomen or a limb. It gives less detail than other scans.
- **Ultrasound scan** – This scan creates pictures of the inside of your body. It's used to check lumps in the arm, leg, chest or abdomen. It's painless, uses no radiation, and is done with a handheld probe that moves over the skin.
- **PET (positron emission tomography) scan** – This scan helps show if sarcoma has spread to other parts of the body. You'll be injected with a small amount of harmless radioactive solution. You sit quietly for about 30–60 minutes so the solution can move through your body. The painless scan then takes about 30 minutes in a machine that is open at both ends. The radiation leaves your body after a couple of hours.

Having a biopsy

A biopsy is the only way to accurately diagnose soft tissue sarcoma. It is important that the biopsy is done by a sarcoma specialist, or at a sarcoma unit.

A biopsy is done if a scan shows signs of sarcoma, or if your doctor feels a lump that may be a sarcoma. During a biopsy, a small sample of tissue or cells is taken and sent to a laboratory for testing.

The type of biopsy you have will depend on where the lump is, and how big it is.

Core needle biopsy – This is done under a local anaesthetic using an ultrasound or CT scan as a guide. A needle is inserted into the lump to take a sample. It uses a core needle, not a fine needle.

Surgical biopsy – This is usually done under a general anaesthetic (when you are asleep). The surgeon makes a small cut in the skin to remove a sample from the lump.

Staging sarcoma

Staging is the process doctors use to describe how far the cancer has grown, whether it has spread and the risk of it coming back. The stage is based on the below.

grade	describes how abnormal the cells look under a microscope. Most sarcomas are graded from 1 to 3 (low, intermediate, high). A higher grade means the sarcoma is likely to grow and spread more quickly
size	describes the size of the tumour from imaging scans and how far it may have spread (e.g. to the lungs)
location	describes where in the body the tumour is, for example, in a limb or the abdomen. Superficial sarcomas in or just under the skin have a lower risk. Deep sarcomas within muscles or areas such as the abdomen usually have a higher risk

Knowing the stage helps doctors plan the best treatment for you. How the stage is described may vary depending on the type of sarcoma and where in the body it is. Talk to your doctor about what the stage means and how if affects your treatment.

Sarcoma in young people

Children or teenagers can also get sarcoma. This fact sheet focuses on adults, because care for young people may be different. For support for young people, visit:

- Canteen, canteen.org.au
- ONTrac at Peter Mac, petermac.org/ontrac
- The Sydney Children's Hospitals Network, schn.health.nsw.gov.au.

Treatment

Because soft tissue sarcomas are a rare group of cancers, it's important to be referred to a specialist sarcoma unit or treated by a specialist sarcoma multidisciplinary team (MDT). See page 3.

The MDT usually includes a surgeon, radiologist (who interprets scans), radiation oncologist (for radiation therapy), medical oncologist (for drug therapies, such as chemotherapy), a pathologist or histopathologist (examines tissue under a microscope to make a diagnosis), genetic specialist (checks for inherited risk factors) and cancer nurse. Other health professionals may be a part of the MDT. You may also receive care from a dietitian, social worker, psychologist or counsellor, physiotherapist and occupational therapist.

The treatment recommended for you will depend on your test results; the type of sarcoma; where the cancer is; whether it has spread; and your age and general health.

The main treatments for sarcoma include surgery, radiation therapy and chemotherapy. Targeted therapy and immunotherapy are sometimes used to treat sarcoma. You may have one treatment or a combination of treatments.

Surgery

Surgery is the main treatment for most soft tissue sarcomas. The operation you have will depend on the sarcoma type, where it is in the body, the size, and whether it has spread.

Many sarcomas are in the arm or leg. Limb-sparing surgery is used to remove the tumour in one piece, along with some surrounding healthy tissue.

Having part or all of an arm or leg removed (called an amputation) is only done if there are no other options. For large sarcomas, a skin graft or skin flap will be used to cover the area where the tumour was removed.

If the sarcoma is in the chest or abdomen, you may have open surgery (uses a larger cut) or keyhole surgery (which uses several smaller cuts).

Your surgeon will explain the type of surgery needed and any risks. Check that your operation will be done by an experienced surgeon at a specialist sarcoma unit (see page 3). How long it takes to recover depends on the type of surgery and your general health, but most people stay in hospital for a few days. You'll be given medicine to control any pain.
▸ See our *Understanding Surgery* booklet.

If you need major surgery, it can help to talk to a social worker or counsellor. You may also find it helpful to talk to someone who has been through a similar experience. Peer support programs are available online, by phone or in person. Call Cancer Council 13 11 20 or see the organisations listed on page 7 to find support that suits you.

Radiation therapy

This treatment uses a controlled dose of radiation to kill or damage cancer cells. The radiation is usually in the form of x-ray beams. Radiation therapy can be given before or after surgery to treat the sarcoma and surrounding area and reduce the risk of the cancer coming back.

Radiation therapy may also be used:

- if surgery isn't possible because the sarcoma is in a hard-to-reach area
- on its own or at the same time as chemotherapy (called chemoradiation)
- in rare cases, internally (called brachytherapy) by placing the radioactive material near the tumour
- to kill any remaining cancer cells after treatment.

Radiation therapy needs to be carefully planned during your first appointment with a radiation oncologist. You'll have a CT scan to map the area

and help work out the radiation treatment plan. A radiation therapist will then deliver the radiation therapy. The number of treatments and how long you have radiation varies from person to person.

The treatment is done at a hospital or treatment centre on weekdays. Radiation therapy doesn't hurt and you can go home afterwards.

Radiation therapy often causes general side effects (e.g. fatigue, nausea), as well as side effects specific to the area being treated (e.g. sore skin on the arm). These side effects may not always happen straightaway. Many people feel very tired after radiation therapy, while others are able to continue working or doing their usual activities.

▸ See our *Understanding Radiation Therapy* booklet.

Chemotherapy

Chemotherapy (also called "chemo") uses drugs to kill or slow the growth of cancer cells. It may be used before surgery to help shrink the sarcoma and make it easier to remove. It's also commonly used after surgery or other treatments to reduce the risk of sarcoma spreading or coming back.

The chemotherapy drugs used will depend on your general health and the type of sarcoma you have. You may have one drug or a combination of drugs.

Chemotherapy is usually given through a drip into a vein (intravenously). This may take a few hours during a day visit to the hospital or treatment centre. Occasionally you may need to stay in hospital for a few days while having chemotherapy. It may sometimes be given as tablets you take at home.

Treatment is given in cycles. For example, you may have one dose of chemotherapy every 3 weeks, over 6 months. How often, and for how long you have treatment will depend on the type of chemotherapy drugs used and your health.

▸ See our *Understanding Chemotherapy* booklet.

For an overview of what to expect during your cancer care, visit cancer.org.au/cancercareguides/sarcoma. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Should I join a clinical trial?

Your doctor may suggest you take part in a clinical trial. Clinical trials test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you'll be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

▸ See our *Understanding Clinical Trials and Research* booklet and website information.

Targeted therapy

Targeted therapy is a drug treatment that targets specific features of cancer cells to stop the cancer growing and spreading. Drugs are given as tablets or intravenously. They travel through the body like chemotherapy, but they work in a more focused way.

Targeted therapy may help slow the growth of some sarcomas. It's mostly used for rare types of sarcoma, or when sarcoma is advanced, has spread or has come back.

Your doctor may suggest you have genomic tests to look for specific changes in the cancer cells. This helps to show whether targeted therapy is likely to work for you.

▸ See our *Understanding Targeted Therapy* fact sheet for information about these tests.

Immunotherapy

Immunotherapy is a treatment that uses your body's own immune system to fight cancer. It's only used for some types of sarcoma and usually as part of a clinical trial. Your doctor will tell you if immunotherapy is suitable or available for you.

There are different types of immunotherapy. Checkpoint inhibitors help the immune system to recognise and attack cancer cells. Other types of immunotherapy stimulate the immune system to help it work better against cancer. Your doctor will explain whether immunotherapy is recommended for you.

▸ See our *Understanding Immunotherapy* fact sheet.

Side effects of treatment

The side effects you have will depend on the type of treatment, the medicines used, the dose and how long your treatment lasts. For example, different chemotherapy drugs may cause different side effects. And people can react to the same treatment in different ways. Some people have very few side effects, while others have more.

Most side effects are temporary, but some can be permanent. Some don't start until months or years after treatment ends. These are called late effects. Before you start treatment, ask your treatment team about what side effects to expect.

There are common side effects and others that are less common. For ways to manage them, see our booklets and fact sheets on surgery, radiation therapy, chemotherapy, immunotherapy, targeted therapy, fatigue and heart health.

Some cancer treatments may affect your ability to have children (fertility). Ask your doctor if your cancer treatments could affect your fertility now or in the future.

▸ See our *Fertility and Cancer* booklet.

Follow-up appointments

You'll have regular appointments for at least 5 years to check that the sarcoma hasn't come back. These appointments may include scans (such as MRI, CT and/or PET – see page 3) and physical examinations. At first, it's common to have scans of the affected area regularly. You may also have a chest CT or x-ray, as the lungs are the most common place for sarcoma to spread to.

Tell your doctor if you notice a lump, swelling or any health problems between appointments. Some cancer centres give you a survivorship care plan. This outlines times for appointments and follow-up tests, symptoms and long-term side effects to look out for, support for medical or emotional problems, and tips for staying healthy. If you don't have a survivorship care plan, ask your specialist for a written summary of your cancer treatment, and give a copy to your GP and other doctors.

▸ See our *Living Well After Cancer* booklet.

Making decisions about treatment

Find out more

It can be hard to know which treatment is best for you. It's important to talk to a sarcoma specialist team before making decisions. Ask them to explain your treatment options, the side effects and long-term impacts, and any costs involved. If you're confused or want to check anything, ask for more information. This can help you make a decision you're comfortable with.

Seek a second opinion

Some people talk to several specialists before deciding on treatment. Getting a second opinion can help you feel more confident in your decision and reassure you that you have explored all your options. Specialists are used to people doing this. You can still be treated by the first specialist, even if you get a second opinion. See page 3 for where to find a sarcoma specialist.

Get support

You may have a lot of appointments. If you can, take a family member or friend with you. They can listen, ask questions and help you remember what the doctor said. Bring a list of questions (see page 7), take notes or ask if you can record the discussion.

▸ See our *Making Treatment Decisions* podcast episode and our *Cancer Care and Your Rights* booklet.

If the cancer comes back

Sometimes soft tissue sarcomas come back after treatment, which is called a recurrence. This is why regular follow-up appointments are important – they help find the cancer early if it does return.

If sarcoma does come back, treatment will depend on where the cancer is, the type of sarcoma, and what treatment you've already had. Options may include surgery, chemotherapy, immunotherapy, radiation therapy, targeted therapy or treatment as part of a clinical trial.

▸ See our *Living with Advanced Cancer* booklet.

If you need to travel away from home for treatment, you may be able to get help with transport or accommodation costs. Ask your hospital social worker or call Cancer Council 13 11 20 to find out more.

Questions to ask your doctor

Asking your doctor questions will help you to make an informed choice. You may want to include some of the suggested questions below in a list to ask at your appointment.

- What type of soft tissue sarcoma do I have? Has it spread?
- Have you treated this type of sarcoma before?
- Have you discussed my case at a specialised sarcoma multidisciplinary team (MDT) meeting?
- Will I have treatment in a specialist sarcoma unit?
- What tests will I need to have?
- What treatment do you recommend for me?
- Are there any clinical trials I should join?
- Is it possible to have surgery? If so, what type?
- Will I need to have radiation therapy, chemotherapy or other treatments?
- How well do the suggested treatments work for this type of sarcoma?
- What are the possible risks and side effects of my treatment? How will they be managed?
- Are there any costs not covered by Medicare or private health insurance?
- How will we know if the treatment is working?
- Is my family at higher risk of soft tissue sarcoma? Should I have any genomic testing?

Where to get help and information

Call Cancer Council 13 11 20 for more information. Our experienced health professionals can listen to your concerns and put you in touch with services. You can also visit your local Cancer Council website.

ACT	**actcancer.org**
NSW	**cancercouncil.com.au**
NT	**cancer.org.au/nt**
QLD	**cancerqld.org.au**
SA	**cancersa.org.au**
TAS	**cancer.org.au/tas**
VIC	**cancervic.org.au**
WA	**cancerwa.asn.au**
Australia	**cancer.org.au**

Other useful websites

Australia and New Zealand Sarcoma Association (ANZSA)	**sarcoma.org.au**
Cancer Australia	**canceraustralia.gov.au**
Rare Cancers Australia	**rarecancers.org.au** 1800 257 600
Sarcoma Alliance (US)	**sarcomaalliance.org**
Sarcoma Patient Advocacy Global Network (SPAGN)	**sarcoma-patients.org**
Sarcoma UK	**sarcoma.org.uk**

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Note to reader
Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

Reference

1. Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: *Soft tissue sarcomas*. AIHW, Canberra, 2018. Viewed 3 April 2025.

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Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.

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