

Treating Soft Tissue Sarcoma - A Quick Guide



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This is a brief summary of the information on 'Treating soft tissue sarcoma' from CancerHelp UK. You will find more detailed information on the website.

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Stages of soft tissue sarcoma

The stage of a sarcoma tells the doctor how far it has spread. It is important because treatment is often decided according to the stage of a cancer. There are different ways of staging cancers. The two main ways are the TNM system and number systems. Grade is also taken into account when staging sarcomas.

'TNM' stands for Tumour, Node, Metastasis. This describes the size of the

tumour and whether it is near the body surface or deep in the tissue, whether there are lymph nodes with cancer cells in them and whether or not the cancer has spread.

The number stages of sarcoma are

- Stage 1A the tumour is low grade, small (5cm or less), superficial or deep with no sign of spread
- Stage 1B the tumour is low grade, large (more than 5cm) and superficial or deep with no sign of spread
- Stage 2A the tumour is medium or high grade, small, superficial or deep with no sign of spread
- Stage 2B the tumour is medium grade, large, superficial or deep with no sign of spread
- Stage 3 the tumour is high grade, large, superficial or deep and may have spread to lymph nodes
- Stage 4 the tumour can be any size and any grade, but has spread to another part of the body including lymph nodes

Recurrence means a soft tissue sarcoma has come back after it was first treated.



Statistics and outlook for soft tissue sarcoma

Outlook means your chances of getting better. Your doctor may call this your prognosis. With soft tissue sarcoma, the likely outcome depends on how advanced the cancer is when it is diagnosed (the stage).

On CancerHelp UK, we have some information on the factors that may affect your outcome. We don't yet have detailed information about the survival rates of the different types of soft tissue sarcoma. We are in the process of gathering statistics from our experts and from national centres and will make these available as soon as we can.

How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your cancer is unique. The same type of cancer can grow at different rates in different people. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

Types of treatment for soft tissue sarcoma

Surgery is the main treatment for most types of soft tissue sarcoma. It is most often used with radiotherapy. You may have chemotherapy before or after surgery for some types of sarcoma. Your doctor will plan your treatment taking into account the type of sarcoma you have, how far your cancer has grown or spread (the 'stage') your general health and fitness, and your age.

Treatment by stage

For small, localised sarcomas, surgery is the main treatment and may cure you. If your surgeon cannot completely remove the sarcoma and a wide border of healthy tissue, you are likely to have radiotherapy afterwards. This is to help stop the cancer coming back.

If you have a larger tumour that has not spread, you may have chemotherapy, or possibly radiotherapy, before surgery. This is designed to shrink the sarcoma so that you won't need as big an operation. This is only done with particular types of sarcoma such as rhabdomyosarcoma or Ewings. Some types do not respond so well and are less likely to shrink.

If your sarcoma has spread, you may still have surgery as this can help to relieve symptoms and control the cancer for longer. You may also have chemotherapy, radiotherapy or any combination of these three types of treatment. If your sarcoma has spread to the lungs and you have only a few small lung tumours, your surgeon may be able to remove them.

Surgery for soft tissue sarcoma

Types of sarcoma surgery

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Limb sparing surgery

If your tumour is in an arm or leg, your surgeon will want to do limb sparing surgery if at all possible. This means removing the cancer, but not the arm or leg.

Amputation

Sometimes the only possible treatment is to remove the limb or part of the limb in which the sarcoma is growing. You should have access to a specialist team of doctors, nurses and physiotherapists. They will help you before your operation and with your recovery and rehabilitation afterwards.

Plastic surgery

Sometimes the surgeon has to remove quite a lot of tissue. So you may need some plastic surgery to repair the area. This is done at the same time as your sarcoma operation. The exact operation you have will be unique to you. The aim will be to give you as natural looking a result as possible, and as much normal function as possible.

Having your operation for soft tissue sarcoma

Before your operation your doctor and anaesthetist will see you to explain what is going to happen, and to answer any questions you may have. Your nurse will teach you breathing and leg exercises to help prevent chest infections and blood clots.

After surgery

When you wake up, you will have several different tubes in place. You may have a drip to give you blood transfusions and fluids and one or more drains coming out near your wound. There may be a tube into your bladder (catheter) so that your urine output can be measured. You will also have a blood pressure cuff on your arm and a clip on your finger to measure your pulse and oxygen level.

Painkillers

You will almost certainly have pain for the first week or so after a major operation. It is important to tell your doctor or nurse as soon as you feel any pain. They need your help to find the right type and dose of painkiller for you.

After an amputation, some people feel pain in the limb that has been amputated. This is called phantom pain and you may need specific types of painkiller for it.

Getting up

This will seem impossible at first. Moving about helps you to get better, but you will need to start very gradually. If you have had limb sparing surgery, the limb will have to heal before you can use it very much. If you have an amputation, you will need an artificial limb. Artificial limbs are individually made to fit. The artificial limb fitter will visit



you before and after your operation to explain more about this.

What to ask your doctor about surgery for soft tissue sarcoma

- Do I need an operation?
- Which type of operation should I have and why?
- What are the risks and benefits of having this operation?
- Will the operation cure the cancer?
- What size is the margin of normal tissue that you remove around the cancer?
- What are the long-term effects of this operation?
- Will I need any more surgery in the future?
- When I wake up, will I be in intensive care?
- Will I have pain after this operation?
- How long will I have a drip after surgery?
- What are the possible complications of this type of operation?
- Will I need any other treatment as well as surgery?
- Is there any treatment I can have instead of surgery?
- What will happen if I don't have the operation?
- How long will it take me to get better?
- How can I help myself get over the operation?
- Who will help me learn to manage with my false limb?
- Where is the nearest limb centre to where I live?
- What will happen if the cancer comes back - Can I have more surgery or chemotherapy?

Radiotherapy for soft tissue sarcoma

Radiotherapy uses high energy waves to cure cancer. After surgery for soft tissue sarcoma, you may have radiotherapy to try to stop the sarcoma coming back. Radiotherapy can also be used to shrink cancers before surgery but this is not common. Radiotherapy can also be used to try to slow the growth of advanced sarcomas and relieve symptoms.

How you have radiotherapy

You are likely to have treatment once a day, Monday to Friday, with a rest at weekends. At your first visit, your doctor takes X-rays to help work out where to give the treatment. Marks will be made on your skin, which the radiographer will use to line up the radiotherapy machine. Each treatment only takes a few minutes. It does not hurt. Radiotherapy does not make you radioactive.

What are the side effects?

Radiotherapy usually causes tiredness, reddening or soreness of the skin in the treatment area, and hair loss (in the treatment area only but it may be permanent). If you have radiotherapy to your abdomen or pelvis, you may feel sick or have diarrhoea. Radiotherapy to the head and neck can cause a sore dry mouth.

Treatment to a joint can make it stiff. It is important to keep using the joint as normally as you can, to stop it stiffening up. Months or years after radiotherapy, some people develop swelling called lymphoedema. If you do get swelling in your hand or foot after radiotherapy to that limb, tell your specialist straight away.



There is more information in the radiotherapy section of CancerHelp UK.

Chemotherapy for soft tissue sarcoma

Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells.

Chemotherapy is usually given as a course of several cycles of treatment. Depending on the drugs you have, each treatment lasts from a few hours to a few days.

Treatments can be given weekly or every 2, 3 or 4 weeks, depending on the drugs and your treatment plan.

For soft tissue sarcoma, chemotherapy may be used

- Before surgery to try to shrink a cancer (neoadjuvant therapy)
- After surgery, to try to stop the cancer coming back (adjuvant therapy)
- To shrink the cancer after surgery if it was not possible to remove all of it
- To reduce or control symptoms in advanced sarcoma
- To slow the growth of an advanced sarcoma

You have nearly all chemotherapy for soft tissue sarcoma as injections into a vein, or through a drip. But a few come as tablets or capsules. How you have your chemotherapy will depend on the particular drug or combination of chemotherapy drugs your doctor prescribes.

There is more information in the chemotherapy section of CancerHelp UK.

Chemotherapy drugs for soft tissue sarcoma

The most commonly used chemotherapy drugs for soft tissue sarcomas are doxorubicin and ifosfamide. All chemotherapy drugs have side effects. The side effects you get will depend on which drugs you have, how much of the drugs you have and your own individual reaction. Common side effects of chemotherapy include

- A drop in your blood cell counts, causing an increased risk of infection, anaemia and sometimes bleeding problems (nosebleeds, heavy periods, a rash of dark red spots)
- Feeling or being sick
- Diarrhoea
- Tiredness
- Sore mouth
- Hair thinning or hair loss

What to ask your doctor about chemotherapy for soft tissue sarcoma

- Why are you recommending chemotherapy for me?
- What will the chemotherapy do for me?
- How will I have the chemotherapy?
- Can I have a central line or PICC line put in?
- Will I need a general anaesthetic to have a central line put in or can you use local anaesthetic cream (EMLA)?
- Who will look after the central line if I have one?
- What are the names of the drugs I'm going to have?
- What are the side effects?
- What can I do to reduce the side effects?
- How long will the treatment last?



- How often will I have to come to the hospital?
- Who should I contact if I'm worried about anything?
- Is it possible to get help with fares or transport to and from the hospital?
- Are there any long term effects of this treatment?
- Is there a clinical trial that is suitable for me?

Biological therapy for soft tissue sarcomas

Biological therapies are treatments that use natural substances from the body, or that change the way cells signal to each other. They can stimulate the body to attack or control the growth of cancer cells. There are many different types of biological therapy.

Glivec

Glivec (imatinib) is a type of biological therapy called a tyrosine kinase inhibitor. This means it blocks a chemical (an enzyme) that a cancer needs in order to grow. Glivec is used to treat a very particular type of soft tissue sarcoma, called a gastro-intestinal stromal tumour (GIST). It is a tablet. So you can have treatment at home. The most common side effects are tiredness (fatigue) and sickness. Some people also have water retention, causing swelling of the hands and feet and the area around the eyes. About half the people treated are sick or have diarrhoea. You may also have a rash or headaches.

Sunitinib

Sunitinib (also called Sutent) is another type of tyrosine kinase inhibitor. It has been approved in Europe for people with GIST whose disease does not respond to Glivec, or who have bad side effects. Side effects

reported with sunitinib include fatigue, diarrhoea, skin discolouration, sore mouth, taste changes, sore hands and feet, raised blood pressure and loss of appetite.

Follow up for soft tissue sarcoma

After your treatment has finished, your doctor will want you to have regular check ups. You may have blood tests, X-rays, and CT scans. You will not have all these tests at every visit to your specialist. But your doctor will examine you and ask how you are feeling and whether you have had any symptoms or are worried about anything.

Generally speaking, the routine follow up after treatment for soft tissue sarcoma is 3 monthly appointments for the first 2 years, 6 monthly appointments up to 5 years, and then yearly appointments up to 10 years. If you are worried or notice any new symptoms between appointments, you must let your doctor know as soon as possible. You don't have to wait until the next appointment.

Many people find their check ups quite worrying. They can bring all the worry about your cancer back to you. You may find it helpful to tell someone close to you how you are feeling. It is quite common nowadays for people to have counselling after cancer treatment. To find out more about counselling, look in the coping with cancer section of CancerHelp UK.

Soft tissue sarcoma research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that they are safe.



First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe are they tested in people, in clinical trials.

Researchers are looking into understanding sarcoma cells, chemotherapy, radiotherapy, and biological therapies.

What to ask your doctor about treating soft tissue sarcoma

- What can you tell me about the stage of my cancer?
- What type of treatment do I need?
- What written information can you give me about these treatments?
- Is there any choice of treatments?
- Will limb sparing surgery be possible for me?
- Will the operation cure the cancer?
- What are the risks and benefits of having this operation?
- How long will it take me to get better?
- How can I help myself get over the operation?
- What will happen if the cancer comes back? Can I have more surgery?
- Should I have any treatment before or after surgery?
- What are the risks and benefits of these treatments?
- What are the side effects?
- How can I help to reduce the side effects?
- Are there any long-term effects of this treatment?
- How often will I have to come to the hospital for treatment?
- Is there any transport available?
- Is it possible to have any help with the cost of fares to the hospital?
- Can I have a second opinion?
- Are there any experimental treatments or trials that might help me?
- Is there a counsellor here I could talk things through with?
- How often will you see me when my treatment is finished?
- How will you know if the cancer has come back?
- What should I do if I am worried between appointments?

More information

For more information about soft tissue sarcoma, visit our website <http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040** 9am till 5pm Monday to Friday

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