



## What to expect during each stage of treatment and beyond

### Sarcoma cancer support

For information about bone or soft tissue sarcomas or where to go for support call the Cancer Council on **13 11 20**. Qualified cancer nurses can answer your questions about the effects of cancer, explain what will happen during treatment or link you to support

groups and other community resources.

If you need an interpreter, call TIS (the Translating and Interpreting Service) on 13 14 50.

For support and advice for carers, call the Carers Association on 1800 242 636.

## 1. Initial investigations and referral

The first point of medical contact may be your general practitioner (GP) or a doctor in an emergency department. The doctor will assess your symptoms (for example, a lump or a painful swelling), conduct a physical examination and arrange tests.

### Tests you may have:

#### Blood tests

To check your overall health, how your blood cells, liver and kidneys are working.

#### Magnetic resonance imaging (MRI) scan

Magnetic fields and radio waves are used to take pictures of the inside the body.

#### Computed tomography (CT) scan

Computer technology and x-rays are used to create detailed images of the body.

Your GP should also discuss your needs (including physical, psychological, social and information needs) and recommend sources of reliable information and support.

If sarcoma is suspected, you must be referred promptly to a sarcoma specialist for further testing. Your GP will provide the specialist with information about your medical history, whether there is a history of cancer in your family, and results of the initial tests.

**It can be helpful to bring a family member or friend with you to your appointments.**

## 2. Diagnosis and staging

Your specialist will discuss your test results with you and what further tests are required. This is to find out whether cancer is present and, if it is, its stage of progression. Your specialist should arrange a biopsy.

#### CT guided biopsy

This is the most common method of biopsy for a soft tissue or bone tumour. A sample of cells will be taken from the lump using a needle with local anaesthetic to numb the area. CT scan is used to guide the biopsy needle. Biopsies for bone and soft tissue cancers are specialised procedures and should

only be carried out by a specialist who does them regularly. An expert pathologist will then look at the sample of cells under a microscope and determine the exact diagnosis. This may involve special testing of the cells and usually takes several days, sometimes longer.

**It can be helpful to contact cancer peer support groups and support groups for carers.**

## 3. Treatment

The term sarcoma describes over fifty different types of cancer, each of which may be treated differently. To ensure you receive the best care, your specialist will arrange for a team of health professionals to plan your treatment based on your preferences and needs. Your specialist will tell you when the team will be discussing your case.

Your team will plan your ongoing care, and should discuss the different treatment options with you including the likely outcomes, possible side effects and the risks and benefits. If appropriate, your team should also discuss the option of fertility preservation. You may be referred to a fertility service to help you evaluate your options.

Let your team know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment.

### Treatment options:

Treatment for bone sarcoma and soft tissue sarcoma may include surgery, chemotherapy and radiotherapy in a range of combinations.

**Surgery** is the most common treatment for most types of sarcoma. The type of surgery used will depend on where the cancer is and its size. It is important that this surgery is performed by a surgeon who is very experienced in surgery on sarcoma and performs several of these operations every year.

**Reconstructive surgery** aims to restore function and appearance to the affected area after surgical removal of bone or tissue. When this involves the limb, the preference is for reconstruction (limb salvage surgery). Reconstruction can involve replacing bone, soft tissue, or function of muscles and nerves.

### 3. Treatment cont'd

#### Limb ablative surgery (amputation)

Occasionally it is not possible to remove all of the cancer without badly affecting the arm or leg. The doctor may advise that the only effective treatment will be to remove the limb.

**Radiation therapy** (also called radiotherapy) may be given to you before or after surgery and is most often used for soft tissue sarcomas.

**Chemotherapy** may be given to you either before surgery to try and shrink the cancer, or after surgery to stop it coming back. It is most often used for bone sarcomas.

Your doctor may also suggest you consider taking part in a clinical trial using newer or experimental therapies.

For more information about treatment and treatment side effects ask your doctor or **visit** [www.cancer.org.au/about-cancer/treatment](http://www.cancer.org.au/about-cancer/treatment)

Your specialist should discuss your needs with you during and after treatment (including physical, psychological, social and information needs) and may refer you to another service or health professional for different aspects of your care.

### 4. After treatment

During treatment, a rehabilitation program may be developed for you. If you had an amputation, this will include seeing a specialist who makes false (prosthetic) limbs. A physiotherapist will help you become as independent and mobile as possible.

After treatment is completed, your specialist team will see you regularly for follow-up appointments. During these visits your specialist will arrange tests to watch for signs of cancer recurrence or treatment side effects and support your return to health.

Your doctor should provide you with a treatment summary that details the care you received, including:

- diagnostic tests performed and their results
- types of treatment used and when they were performed
- treatment plans from other health professionals
- supportive care services provided to you
- contact information for key care providers.

You and your GP will receive a follow-up care plan that tells you:

- the type of follow-up that is best for you
- ways to manage any side effects of treatment, should they occur
- how to get specialist medical help quickly if you think the cancer has returned or got worse.

Your doctor should:

- discuss your needs with you and refer you to appropriate health professionals and/or community organisations, if support is required
- provide information on the signs and symptoms to look out for that might mean a return of the cancer
- provide information on healthy living.

Sarcoma can come back after treatment. This is why it is important that you have regular check-ups.

### 5. Living with cancer

**Side effects:** Some people experience side effects (for example, tiredness) that continue beyond the end of treatment. Side effects sometimes might not begin until months after treatment has finished.

For more information about side effects ask your doctor or **visit** [www.cancervic.org.au/about-cancer/survivors/long-term-side-effects](http://www.cancervic.org.au/about-cancer/survivors/long-term-side-effects)

**Advance care plan:** Your doctor may discuss with you the option of developing an advance care plan. An advance care plan is a

formal way of setting out your wishes for future medical care.

For more information about advance care planning ask your doctor or **visit** [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)

**Palliative care:** This type of treatment will be used at different stages to help you with pain relief, to reduce symptoms or to help improve your quality of life.

For more information about palliative care ask your doctor or **visit** [www.palliativecare.org.au](http://www.palliativecare.org.au)

### 6. Questions of cost

There can be cost implications at each stage of the cancer care pathway, including costs of treatment, accommodation and travel. There can be substantial out-of-pocket costs if you are having treatment in a private health service, even if you have private health insurance. You can discuss these costs with your doctor and/or private health insurer for each type of treatment you may have. If you are experiencing financial difficulties due to your cancer

treatment you can contact the social worker at your local hospital.

For more information about cost of treatment ask your doctor or **visit** [www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment](http://www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment)

For more about accommodation and travel costs ask your doctor or **visit** [www.cancercouncil.com.au/get-support/practical-support-services](http://www.cancercouncil.com.au/get-support/practical-support-services)

