

Primary bone cancer

For people with cancer,
their family and friends



This fact sheet is for people with primary bone cancer who would like to know more about their cancer and its treatment. It describes the types, causes and symptoms of primary bone cancer, as well as treatments and their possible side effects.

This does not replace talking to your doctors or nurses. However, we hope that it will help you make decisions with your doctor about your treatment.

Are you looking for information about cancer that has spread to the bones from another cancer site, such as the breast or prostate? Telephone the Cancer Council Helpline on **13 11 20**. The treatment and care for these sorts of bone cancers are different from treatment for a primary bone cancer.

What is bone cancer?

Bone cancer is a rare type of cancer that forms as a painful lump ('tumour') in bone. It is also known as bone sarcoma. When a bone cancer begins to grow, the cancer cells multiply and start to destroy the bone. The affected bone becomes weak and starts to cause problems.

The most common places where bone cancer develops are around the knee, the wrist, the shoulder and the pelvis.

There are over 30 types of bone cancers. The most common type is osteosarcoma, which is made up of millions of abnormal bone producing cells. Chondrosarcoma is a bone cancer that is made up of millions of abnormal cartilage cells. Ewing's sarcoma is another type of bone cancer.

Some types of bone cancer affect the soft tissues of the body. These are called soft tissue sarcomas: please contact the Cancer Council Helpline on **13 11 20** if you would like information about soft tissue sarcoma.

How common is bone cancer?

Bone cancer is rare. About 50 Victorians are diagnosed with some type of primary bone cancer each year (a rate of about 1 case per 100,000 people). Rates for males and females are very similar.

What causes bone cancer?

We don't know exactly what causes most bone cancer. There are several risk factors.

Age

Bone cancer commonly affects teenagers and young adults, and people over the age of 55. Bone cancer that develops later in life is usually linked to a prior disease of the bone, such as Paget's disease.

Radiotherapy treatment

There is a very small risk of bone cancer for people who have had radiotherapy. Radiotherapy sometimes affects bone in the treatment area. The risk is higher for people who had high doses of radiotherapy at a very young age. Most people who have had radiotherapy in the past will not develop a bone cancer.

Other medical conditions

Some people who have had Paget's disease of the bone, fibrous dysplasia or multiple enchondromas are at higher risk of bone cancer.

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Genetic factors

Most bone cancers are not caused by inheriting a faulty gene. However, some people inherit conditions that put them at higher risk, such as Li-Fraumeni syndrome. This condition runs in families and puts you at higher risk of several types of cancer, including bone cancer. People who have a strong family history of certain types of cancer are also at risk.

Children who have had a rare type of eye cancer called retinoblastoma are at a higher risk of osteosarcoma.

A small number of people develop bone cancer due to genetic changes that happen during their lifetime, rather than inheriting a faulty gene.

What are the symptoms of bone cancer?

The most common symptom of bone cancer is a painful swelling. Pain may not be constant. It may be much worse at night or during activity. Taking pain-relieving tablets may not help.

As the cancer grows over weeks or months the pain may get worse and become constant. The pain may cause problems with movement. For example, you may have a limp if the cancer is in the leg. Sometimes you may be able to feel a lump.

Most people who have pain and swelling do not have bone cancer. It is much more likely to be a less serious condition. However, if you have symptoms that stay for more than two weeks you should see your doctor.

How is bone cancer diagnosed?

If a bone cancer is suspected your doctor may recommend some tests, including blood tests, x-rays and scans. Depending on the test results, you may then be referred to a specialist centre.

You may need to have a biopsy. This is the only sure way to diagnose a bone cancer but the other tests are needed first to rule out other conditions. A biopsy means taking a sample of cells from the lump and examining them under a microscope. Your doctor will use a fine needle to do this. You will have local anaesthetic to numb the area before the needle is put into the lump.

A bone biopsy is a specialised procedure. It should only be carried out by a specialist who does them regularly. It is important that the biopsy is done properly in order to minimise the chance of the cancer spreading. It could also affect the type of treatment that you may be able to have.

Treatment of bone cancer

Your doctor will help you decide on the best treatment for your bone cancer, depending on:

- the type of bone cancer you have
- whether or not the cancer has spread (its stage)
- your age, fitness and general health
- what you want.

Treatment may include surgery, chemotherapy and radiotherapy. They may be given alone or in combination.

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Surgery

Surgery is the main treatment for most types of bone cancer. This usually means removing the cancer as well as some healthy tissue around the tumour. Doctors call this a 'wide local excision.' The healthy tissue is taken away to help decrease the risk of the cancer coming back in that area.

There are different types of surgery. Limb sparing surgery is the most common treatment. Amputation is less common.

Limb sparing surgery

This means taking out part or all of the bone in the arm or leg where the cancer is growing. The surgeon replaces the bone with a metal implant (prosthesis) or a bone graft. A graft means taking a piece of healthy bone from somewhere else in your body or from a 'bone bank'.

After this type of surgery you will work closely with a physiotherapist. They will plan an exercise program to help you get strength and function back in your limb.

After limb sparing surgery there will be some changes in the way the limb looks, feels or functions. But the aim is for your limb to return to as normal a state as possible. This can happen in about 85 out of every 100 people who have this type of surgery.

This complex surgery needs to be done by a surgeon with a lot of experience in treating bone cancer. This may mean that you have to travel to a treatment centre that has a team of experts. Good surgery will decrease the risk of the tumour cells spreading to nearby areas or other parts of the body.

Amputation

Sometimes 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 (amputation).

Amputation can be very distressing emotionally and physically. Most people will need a lot of support at this time. It could have a huge effect on you and the people who share your life.

After surgery you will have a carefully planned rehabilitation program. This will include seeing a specialist who makes false (prosthetic) limbs. You will also work very closely with a physiotherapist to help you become as independent and mobile as possible.

Psychological support is also very important. You may find it helps to speak with a social worker or counsellor or even someone else who has had the same operation. They may be able to offer advice on ways to cope and what to expect.

Surgery for cancer in other parts of the body

When possible, bone cancer in the pelvis is treated with a 'wide local excision'. Some people may need to have bone grafts to rebuild the pelvic bones.

Tumours in the lower jaw bone may mean that you will have all of your lower jaw taken out. Once healed, bones from other parts of the body can be used to replace the jaw bones.

If your cancer is in your spine or skull, wide local excision may not be possible.

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You may need to have a combination of treatments such as radiotherapy, cryotherapy (using freezing methods) and curettage. Curettage involves scooping out the tumour. Sometimes cryotherapy is used to kill off any remaining cells nearby. If you need these treatments your doctor will discuss them with you in detail.

Surgery for cancer that has spread

Bone cancer is one of the few cancers that may still be cured even if it has spread. This is usually only possible if the cancer has spread into the lungs. The bone secondaries in the lungs can be taken out with surgery. But it will depend on how many there are and where they are in the lung. Generally, if there are more than 15 lung secondaries it may not be possible. You may also have chemotherapy after surgery to help stop the cancer coming back.

Chemotherapy

Chemotherapy drugs are given to destroy cancer cells. Certain types of bone cancer respond well to this type of treatment. In recent years using chemotherapy alongside surgery has improved cure rates for bone cancer.

Chemotherapy is given:

- to reduce the size of the tumour before surgery, making it easier for the surgeon to remove
- after surgery, to help stop the cancer coming back
- to help stop the growth or control symptoms of an advanced cancer (palliative treatment).

Your treatment will depend on the type of bone cancer you have and the type of drugs you are prescribed. Your doctor will discuss this with you before you begin your treatment.

Chemotherapy is given as a course of several treatment cycles and you may have one or a combination of drugs. For example, one cycle commonly lasts three weeks. You may receive the drug over several hours or days as an inpatient or outpatient, and then let your body have a rest until the start of the next cycle. You may have between three and five cycles before surgery and then more after your surgery.

Chemotherapy for bone cancer can be given as an injection or a drip into a vein in your arm.

The doctor may recommend a 'central line' (Porta-cath, Hickman's line) or 'PICC line'. These are put in under local or general anaesthetic and stay in for the entire course of your treatment. Their main advantage is that the chemotherapy can be given safely through the line and you don't have to have lots of needles. You can also have your blood taken from this line without having a needle. If you have a central line, you will need to take good care of it. They need flushing and cleaning regularly to prevent any infection or blockage. A nurse will teach you before you go home or you may have a district nurse to help you take care of it. The line is taken out when treatment is finished.

Chemotherapy may cause unwanted side effects such as nausea and tiredness and

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your doctor will discuss these with you before treatment starts.

Cancer Council's booklet *Coping with Chemotherapy* discusses ways of managing side effects. Visit www.cancervic.org.au or telephone 13 11 20 for a copy.

Radiotherapy

Radiotherapy uses high energy rays to destroy cancer cells. Radiotherapy aims to destroy the cancer cells as well as create a rind around the tumour. This may help to make surgery easier and safer. Sometimes chemotherapy is given as well as radiotherapy to help make the treatment more effective. Radiotherapy may be given before or after surgery. If it is given after surgery, the aim is to reduce the chance of the cancer cells regrowing.

Radiotherapy is usually given five days a week for five to six weeks. The treatment is only for a couple of minutes a day, but takes some time to get organised as you have to be in the same position every time you receive the treatment. Radiotherapy given in small doses minimises any side effects.

A course of radiotherapy needs to be carefully planned. During your first visit to the radiotherapy department you will need to lie under a large machine called a simulator. Your specialist will use this machine to calculate the correct dose and exact angles on your body for the radiation to target. This process ensures that the tumour receives the highest doses of radiation and the healthy tissue around it gets as little as possible.

Radiotherapy does not hurt but you do need to lie very still during the treatment. You can have radiotherapy as an outpatient. Some people are able to continue working throughout their treatment while others feel a little tired. Some people may have a skin reaction. Your treating team will discuss all these possibilities with you.

Cancer Council's booklet *Coping with Radiotherapy* discusses ways of managing side effects. Visit www.cancervic.org.au or telephone 13 11 20 for a copy.

Side effects of treatment

All treatments can have side effects. For example, chemotherapy may cause a drop in your blood cell count, increasing your risk of infection, anaemia and bleeding. Side effects are usually temporary but there may be some permanent side effects that can affect your future daily living. This may mean a change in the way a part of your body looks, feels or functions.

The type of side effects that you may have will depend on the type of treatment and where in your body the cancer is. Some people have very few side effects and others have more. Your medical team will discuss all possible side effects (long and short term) before your treatment begins. For further information about individual treatment side effects call the Cancer Council Helpline on **13 11 20**.

Making decisions about treatment

It can be difficult to know which treatment is best for you. It is very important that you speak with a bone cancer specialist team

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before making your decision. Ask them to give you a clear plan of your treatment options and any possible long and short-term side effects. Some people prefer to seek several opinions before feeling confident to go ahead with the treatment.

You may have to attend many appointments and it often helps to take someone with you. They will be able to listen, ask questions and remember what the doctor says. You can later discuss together your treatment options. It may also help to take a list of questions.

Questions for your doctor

If you have bone cancer there are many questions that you may wish to ask your specialist. Getting the answers may help you make the best decision for you about which treatment you choose. Here are a few suggestions.

- How will I know if I have bone cancer?
- What has caused my bone cancer?
- Are my family more at risk of bone cancer?
- If I need to have a bone biopsy, will I have it at a specialist centre?
- If I need to have treatment, where is the best centre for this type of cancer?
- Is it possible to have surgery to try to cure my bone cancer?
- If I can have surgery, which type will I need and why?
- What are the risks and long-term side effects of each type of surgery?
- Will I need to have any other type of treatment, such as radiotherapy or chemotherapy?

- How effective is radiotherapy and chemotherapy for my type of bone cancer?
- If my cancer has spread outside the bone, what treatment options are there for me?
- What support is available for someone who has bone cancer?

For more information contact the Cancer Council Helpline on **13 11 20** (cost of a local call). This is a confidential service staffed by cancer nurses. Information is available in languages other than English.

The cancer nurse can supply you with up-to-date information about your cancer and treatment. They can also link you with another person who has had your type of cancer through Cancer Connect. There is also Family Connect for your partner or carer. If you prefer you may also be linked in with your nearest Cancer Support Group.

The Cancer Council Helpline operates Monday to Friday from 8.30 am to 6 pm. All services are free.

Caring for someone with cancer

A carer is anyone, whether family or friend, who is helping to look after someone with cancer.

Caring for someone with cancer can be very stressful, particularly when it is someone you care about very much. The person with cancer may be distressed about their diagnosis, side effects from treatment and mood changes from the effects of drugs.

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Look after yourself during this time. Give yourself some time out, enjoy a cup of coffee with a friend, and share your worries and concerns with someone not involved. Make a list of 10 things you like to do and make sure that you do one each day.

Cancer Support Groups are usually open to patients and carers. A support group can offer the chance to share experiences and ways of coping.

A range of support services, such as home help, meals on wheels and visiting nurses, can help you cope with treatment at home. These are provided by local councils, the Royal District Nursing Service and the palliative care services.

Call the Cancer Council Helpline on **13 11 20** to:

- be linked with another carer by telephone
- speak with a cancer nurse for further support and information
- be sent a carers kit so that you can find out about financial assistance and other resources.

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