

# Understanding Multiple Myeloma

A guide for people with cancer, their families and friends.



*Building a  
Cancer Smart  
Community*

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## The Cancer Council New South Wales

The Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs.

This booklet is funded through the generosity of the people of NSW. To make a donation to help defeat cancer, visit the Cancer Council's website at [www.cancerCouncil.com.au](http://www.cancerCouncil.com.au) or phone 1300 780 113.

Before commencing any health treatment, always consult your doctor. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor's or health professional's advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

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# Introduction

This booklet has been prepared to help you understand more about multiple myeloma.

Many people feel understandably shocked and upset when told they have multiple myeloma. We hope this booklet will help you understand how this disease is diagnosed and treated. We also include information about support services.

We cannot advise you about the best treatment for you. You need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about questions you want to ask your doctors or other health practitioners.

You may like to pass this booklet to your family and friends for their information.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you.

Some medical terms that may be unfamiliar are explained in the glossary.

If you're reading this booklet for someone who doesn't understand English, tell them about the Cancer Council Helpline which is available in different languages (see page 46).



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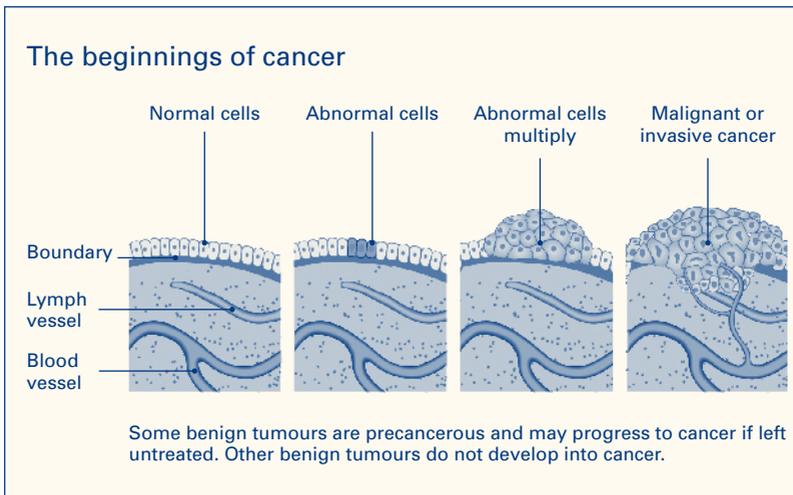
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# What is cancer?

Cancer is a disease of the body's cells, which are the body's basic building blocks. Our bodies constantly make new cells: to help us to grow, to replace worn-out cells, or to heal damaged cells after an injury.

Normally, cells grow and multiply in an orderly way, but sometimes something goes wrong with this process and cells grow in an uncontrolled way. This uncontrolled growth may result in abnormal blood cells, or a lump called a tumour.



A tumour can be benign (not cancer) or malignant (cancer). A benign tumour does not spread outside its normal boundary to other parts of the body. A malignant tumour is made up of cancer cells. If it hasn't invaded nearby tissue, it is known as a cancer in-situ (or carcinoma in-situ). If the tumour has invaded surrounding tissue, it is called invasive cancer. An invasive cancer that has not spread to other parts of the body is called primary cancer.

With cancers that affect the blood and bone marrow, abnormal cells multiply in such a way that they crowd the bone marrow and reduce its ability to make normal blood cells. Sometimes the abnormal cells also clump together to form a tumour.

If cells move away from the original (primary) cancer site and invade other organs and bones, they may continue to grow and form another tumour at that site. This is called a secondary cancer or metastasis.



# What is blood?

Multiple myeloma is a cancer affecting plasma cells, which are a type of white blood cell. To understand multiple myeloma, it is useful to know a little bit about blood and how it works.



Blood is pumped around your body to supply oxygen and nutrients to your tissues and take away waste products. It is made up of:

- red blood cells, which carry oxygen from your lungs to the rest of your body
- white blood cells, which fight infection
- platelets, which form clots to stop bleeding.



The different kinds of blood cells are made by the bone marrow, which is the spongy part in the centre of bones. The bone marrow contains stem cells, which are primitive blood cells that eventually develop into either red cells, white cells or platelets. When a stem cell has matured into one of these cell types, in most cases it is released into the bloodstream.

A type of white blood cell that normally remains in the bone marrow is called a plasma cell. Plasma cells form part of the immune system and help to fight infection by making a variety of special proteins called antibodies or immunoglobulins. These antibodies attack bacteria and viruses that have infected the body. In multiple myeloma, the plasma cells are affected.



# What is multiple myeloma?

Myeloma starts in the bone marrow. Because bone marrow is found in multiple areas of the body (e.g. in the spine, skull and pelvis), the disease is often called multiple myeloma.

In multiple myeloma, the DNA of plasma cells has been damaged, causing them to become malignant or cancerous. Instead of forming a lump or tumour, these abnormal plasma cells, which then become known as myeloma cells, divide and expand within the bone marrow.

When large numbers of abnormal plasma cells (myeloma cells) are made in the bone marrow, they crowd out the rest of the bone marrow so that it cannot make enough healthy blood cells. Myeloma also weakens the immune system and the level of normal antibodies is reduced.

The myeloma cells make only one kind of antibody, which is known as M-protein, monoclonal protein or paraprotein. This antibody is not like a normal antibody and has no useful function.

M-protein is detected in the blood of most people who have multiple myeloma. Part of this antibody can also be found in the urine of some patients, where it is called Bence Jones protein. If a large amount of this protein is present, it can damage the kidneys as it passes through them into the urine.

Myeloma produces substances that can cause soft, brittle bones (osteoporosis) or destroy areas of bone (lytic lesions). When bone is damaged like this, it is more likely to break or fracture, causing pain and restricting mobility. Damaged bones also release calcium into the blood and can cause hypercalcaemia (high levels of calcium in the blood). This can lead to drowsiness and renal (kidney) failure.

There are different types of myeloma, which are classified according to the type of M-protein present. There are also different stages of myeloma, which indicates the amount of myeloma present and can help determine a person's prognosis. For further information, see page 13.

## How common is it?

Multiple myeloma is not a common illness and represents 1% of cancer diagnoses in Australia. Based on figures from 2005, 428 people developed the illness in NSW in that year.

Myeloma usually occurs in people aged 60 and over. Only 20% of people diagnosed with myeloma are under 60, and it is very rare in people under 40. However, recent figures show myeloma is becoming more common in younger adults, but the reason for this is unclear. The disease is also becoming more prevalent in the elderly, which is partly explained by the ageing population.

## Causes of multiple myeloma

The cause of multiple myeloma is unknown. However, it is more common in older people, men and some racial groups (such as African-Americans). Certain chemicals (e.g. agricultural chemicals, dioxins), radiation and viruses (such as HIV) have been linked to an increased risk of myeloma and related diseases but they have not been proven to cause it. Research suggests that other contributing factors may include obesity and smoking.

Myeloma is not hereditary, which means it does not run in families. It is rare for more than one person in a family to be affected. However, there is an increased risk for developing multiple myeloma among people who have a family history of other blood and lymphatic cancers.

## What are the symptoms?

Multiple myeloma can cause a range of symptoms because of its effects on the bones, bone marrow and kidneys.

The first signs of the disease are abnormal blood tests, osteoporosis, bone pain or a broken bone that has not been caused by an obvious injury.

The abnormal plasma cells may stop the bone marrow from making enough normal blood cells such as red cells, platelets and white cells. This results in irregular blood counts.

A low level of red blood cells, which causes a condition called anaemia, may cause you to become weak, tired and pale. Other symptoms include breathlessness or a racing heart. Platelets help the blood to clot, so having fewer platelets can cause bleeding problems such as heavy nosebleeds or easy bruising. If you don't have enough white blood cells and normal antibodies (immunoglobulins), you may get infections more often or more severely.

Other less common symptoms of myeloma are kidney failure and weight loss.

### Amyloidosis

Some people with multiple myeloma also have a condition called amyloidosis. This is a build-up in the body of a fibrous protein called amyloid tissue, which can sometimes affect the functioning of different organs. In many people the condition does not cause any symptoms.



# Diagnosis

## Diagnostic tests

A number of tests are needed to diagnose multiple myeloma. These include blood, urine and bone marrow tests, x-rays, CT scans and MRI scans. The tests may be uncomfortable, but they will enable your haematologist to determine the type of myeloma you have, how it is affecting you, and the best treatment plan for you.

### Blood and urine tests

The abnormal M-protein (or paraprotein) antibody is used as a marker for multiple myeloma. This means that you will have a blood test to look for any M-protein, as levels can be high in many cases. The blood test also determines the type of M-protein present. If you are diagnosed with myeloma, your levels of M-protein will be measured regularly to assess the ongoing activity of the cancerous cells and the effectiveness of treatments.

Blood tests can also show anaemia, kidney impairment and whether you have a high level of calcium in the blood.

A urine test will also be done to check for the Bence Jones protein made by the myeloma cells. About 30% of people with multiple myeloma produce enough Bence Jones protein to be measurable in the urine. For these people, a regular urine collection will be undertaken to monitor the myeloma and effectiveness of therapy.

Having M-protein in the blood or urine does not always mean you have multiple myeloma. Other conditions where M-protein is found include inflammatory diseases, chronic infection, and a condition called MGUS (Monoclonal Gammopathy of Undetermined Significance). A person with MGUS does not

have symptoms, other abnormal tests or other underlying disease. The majority of people with MGUS remain well for years, but some may develop myeloma or other related diseases. Your haematologist will be able to clarify this for you.

## X-rays

Bone x-rays, sometimes referred to as a skeletal survey, are needed to check for thinning and softening of the bones (osteoporosis). X-rays can also show up any areas where bone has been destroyed (lytic lesions).

## CT scan

A computerised tomography (CT) scan is a type of x-ray. It uses x-ray beams to take pictures of the inside of your body. While not always used for people with myeloma, sometimes a CT scan is needed to review a particular part of the body in more detail or to identify areas of bone damage that may not show up on a standard x-ray.

This painless test takes about 10-30 minutes. Sometimes a special contrast medium may be injected into a vein, probably in your arm, before the test. This will make the pictures clearer. However, if there is a risk of renal (kidney) impairment or allergy to the contrast medium, it will not be used.

For a few minutes, the contrast may make you feel hot all over. You will then lie flat on a table while the CT scanner, which is large and round like a doughnut, rotates around you. Most people are able to go home as soon as their scan is done.



## MRI

Magnetic resonance imaging (MRI) uses a powerful magnet linked to a computer to take detailed pictures of areas inside the body. These scans can help to show whether myeloma is present inside and outside the bone. The pictures are taken while you lie on a table that slides into a metal cylinder.

A special contrast may be injected into a vein to enhance the MRI pictures, as long as there is no risk of renal impairment or allergy. An MRI, like a CT scan, is painless.

You must tell the doctor if you have ever had an allergy to dyes or iodine, as this will affect whether contrast is used for a CT scan or MRI.

People who have a pacemaker or certain other metallic objects in their body cannot have an MRI, due to the effect of the magnet.

## Bone marrow biopsy

A bone marrow biopsy is required to allow the cells from the marrow to be examined. This biopsy is done with a local or general anaesthetic. A thin needle is used to remove a small piece of bone marrow from the pelvis, hip or breastbone.

## Cytogenetic tests

In these tests, chromosomes in the cells from bone marrow or blood samples are examined to help in the diagnosis and decide on treatment.

# Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis with your doctor, but it is not possible for any doctor to give you a 100% accurate prediction on the course of the illness. Test results, the rate and extent of tumour growth, how well you respond to treatment, and other factors such as age, fitness and your medical history are all important factors in assessing your prognosis.

Unfortunately, for most patients with multiple myeloma, the disease is not curable but it is increasingly treatable and can be controlled in most people. With this control, also called a plateau phase, people usually return to a state of good health. The good health may last for months or a few years. For some people, the disease can be controlled for much longer periods.

The typical course of this disease is multiple episodes of disease activity, followed by a plateau. If the disease comes back (relapses), further treatment will be needed, often with different forms of chemotherapy. This treatment may result in a further remission, although the chances of this are not quite as good as at the time of the original diagnosis.

The outlook for people with multiple myeloma continues to improve, with research investigating more effective treatments, such as less toxic medicines and better transplantation techniques.

Some people's prognosis may improve significantly with a bone marrow or blood stem cell transplant. However, this procedure is not suitable for everyone, with less than 5% of patients being eligible. See page 24 for more information.

## Which health professionals will I see?

Your GP will arrange the first tests to check out your symptoms. This can be a worrying and tiring time, especially if you need several tests.

If these tests do not rule out cancer, you will usually be referred to a haematologist, a doctor who specialises in diseases of the blood, the lymphatics and bone marrow. This specialist will investigate your symptoms, make a diagnosis, advise you about treatment options and prescribe treatment.

Other health professionals you may see include:

- radiation oncologist: prescribes and coordinates the course of radiotherapy
- nurses: give the course of treatment and support and assist you through all stages of your treatment
- dietitian: recommends the best eating plan to follow while you are in treatment and recovery
- social worker, physiotherapist and occupational therapist: help you to resume normal activities and link you to support services.



# Treatment

After the diagnosis, the most important decision is whether treatment is needed straight away. Early-stage myeloma, also called asymptomatic or smouldering myeloma, does not need to be treated, as early treatment has not been shown to be of any benefit. People with smouldering myeloma will need regular checkups, and treatment will be started if problems occur.

The main forms of treatment are a combination of medication and radiotherapy (x-ray treatment). Some people are also able to have a bone marrow or stem cell transplant. The goal of treatment for most people is controlling the disease, improving well-being, and preventing complications of myeloma.

Treatment is highly individual and depends on the type and stage of myeloma present, as well as your general health.

Often, myeloma is treated with a combination of drugs such as melphalan and prednisone, or thalidomide and dexamethosone. Treatment is given intermittently over a period of many months.



# Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells. These drugs are called cytotoxics. Chemotherapy kills fast-growing cells such as cancer cells. Other cells that grow quickly can also be affected, such as the cells involved in hair growth and cells in the lining of the mouth. This can make your hair fall out or can cause mouth ulcers. The most commonly used chemotherapy drugs for multiple myeloma include melphalan and cyclophosphamide. Others are adriamycin, bis-chloronitrosourea (BCNU) and vincristine.

Some people can have all their chemotherapy drugs as tablets. Other people need to have drugs injected into a vein (intravenously) or under the skin (subcutaneously). A hospital

stay is sometimes necessary for some treatments but this stay is usually short. Your doctor will tell you about the drugs you are having and how long your treatment will last.

You can find out more about the different treatment combinations for multiple myeloma from the Cancer Institute NSW website. See [www.treatment.cancerinstitute.org.au](http://www.treatment.cancerinstitute.org.au).



## Side effects

Some chemotherapy drugs can cause side effects. They may include feeling sick, mouth sores, tiredness, drops in blood counts, and thinning or loss of hair from your body and head.

The side effects are temporary and there are ways to prevent or reduce them. Tell your doctor or nurse of any side effects you experience. They may prescribe a break in your treatment, or change the kind of treatment you are having.

Don't use aspirin or any other painkiller or medicine, unless your doctor says you can. These can affect how chemotherapy works in your body, and may sometimes worsen side effects. However, aspirin can be prescribed to prevent clots in veins associated with other medication, such as thalidomide and dexamethasone treatment.

For a copy of the Cancer Council's booklet *Understanding Chemotherapy* call 13 11 20, or download it from [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

### Contact your doctor or hospital urgently if any of these problems occur:

- fever over 38°C, chills or constant shivering
- sweating, especially at night
- burning feeling when urinating
- severe cough, sore throat, or if you feel very unwell
- vomiting that lasts more than 24 hours
- unusual bruising or bleeding, such as nose bleeds, blood in your urine, or black bowel motions
- tenderness, redness or swelling around the place where the injection goes in.

## Thalidomide and related drugs

Thalidomide is an old drug that has new uses. It was used in the 1950s as an anti-nausea drug but was banned because it caused severe birth defects.

We now know thalidomide has anti-cancer properties that can be effective for multiple myeloma. Thalidomide is thought to work by blocking the blood supply to cancerous cells and by altering the body's immune response to cancer. Previously, thalidomide was only available to people in whom other treatments had failed, but in some cases, it is now being used for newly diagnosed patients and also to maintain disease stability in some patients who have responded to therapy.

A new generation of thalidomide-like drugs have been developed and are being tested in clinical trials. One such drug is lenalidomide (Revlimid), which has shown promising results so far. Ask your doctor for more information.

Common side effects are drowsiness, rashes and constipation. With the new varieties of thalidomide-like drugs, venous thrombosis (blood clots in veins) and lowering of blood cell counts may occur. Prolonged use may cause peripheral neuropathy, which is a problem in nerve function leading to pain, numbness, tingling, swelling and muscle weakness in the hands and feet. It is important that you let your doctor know if you have any of these symptoms so they can be managed appropriately.

## Corticoid steroids

These include prednisone, prednisolone or dexamethasone. Corticoid steroids are drugs that are similar to a hormone produced by the adrenal glands in the body. These glands sit on top of the kidneys. Corticoid steroids can be commonly used to relieve swelling and inflammation. They have also been shown to act against myeloma cells.

Common side effects include hyperactivity, sleep disturbance, mood change, increased appetite, fluid retention and weight gain. If used for a prolonged period, corticoid steroids may cause the onset of diabetes and contribute to osteoporosis (thinning of the bones).

## Interferon alfa

Interferon alfa is used to treat certain cancers and viral infections. It is given as an injection under the skin several times a week and may be used after chemotherapy or a bone marrow transplant to prolong control of the disease.

## Bisphosphonates

Bisphosphonates are a new class of drugs that are useful in myeloma, and can be taken as tablets or injections.

Bisphosphonates have a number of roles. They:

- prevent and reduce complications of bone disease
- prevent a dangerous rise in blood calcium levels
- improve well-being and may help control of the disease.

A common side effect is stomach upset. An uncommon but severe side effect is osteonecrosis of the jaw (ONJ), which is a condition in which bone tissue dies, causing intense pain. You must tell your dentist if you are on bisphosphonates, as dental procedures should be avoided during treatment. You should also inform your doctor if you experience mouth ulcers, infection or jaw problems.

## Bortezomib

Bortezomib (Velcade) belongs to a class of drugs called proteasome inhibitors, which interfere with the key function of myeloma cells, causing them to die off. Bortezomib is available for people who have undergone initial treatment but the myeloma is still progressing. Ask your doctor if this treatment is an option for you.

Common side effects are fatigue, diarrhoea, low blood counts and peripheral neuropathy.

# Radiotherapy

Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. The x-rays are aimed at areas of myeloma cells using an external machine. The aim is to relieve some of the symptoms, such as bone pain. Not all people with myeloma will need radiotherapy.

Radiotherapy treatment is carefully planned to destroy cancer cells while causing as little harm as possible to your normal tissue. You will lie under a machine that delivers x-ray beams to the treatment area. Each treatment only takes a few minutes once started, but it can take one to three hours for the first appointment, to set up the machine, see the radiation oncologist and have tests. Radiotherapy may be given as a single dose, or as multiple smaller doses over several days or weeks.

You will probably have treatment for a few days each week for several weeks. Many people continue to work and live normally during the course of treatment, as usually you will visit the radiotherapy centre for each of your appointments, rather than staying overnight.

## Side effects

Radiotherapy can cause side effects, but most will go away in time and there are ways to reduce any discomfort. The most common side effect of radiotherapy is tiredness. Other side effects will depend on the part of the body being treated.

For more information, call the Cancer Helpline on 13 11 20 for a copy of the Cancer Council's booklet *Understanding Radiotherapy*, or download it from [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

# Plasma exchange

Plasma exchange is sometimes needed when the level of abnormal protein in the blood is very high, is interfering with blood circulation by making the blood thicker (hyperviscosity), or is damaging the body.

Plasma exchange involves the separation and removal of plasma (which contains the abnormal protein) from the blood. This is done by placing a needle into a vein in each arm. Blood is slowly removed from one arm and then passed through a separating machine. The healthy portion of the blood, plus new replacement plasma, is then put back in via the other arm. This usually takes a few hours.

## Ian's story

Ian, a dentist, was diagnosed with multiple myeloma in 1999 at the age of 52. His story illustrates an individual experience with this disease, which affects people in many different ways.

“ About 16 years ago, I was diagnosed with Immune Thrombocytopaenic Purpura (ITP), which means a chronically low platelet count. After many unsuccessful treatments I now have weekly plasma infusions.

In 1999, my haematologist detected suspicious changes in my blood tests and ordered a bone marrow biopsy. This revealed the presence of abnormal plasma cells. The diagnosis was smouldering multiple myeloma. I did not have any bone lesions but was prescribed bisphosphonates to reduce the chance of developing osteoporosis. Aside from ongoing infusions for the ITP, I had no other treatment for five years.

In 2003, I developed carpal tunnel syndrome in both hands. Being a dentist, I needed full use of my hands, so I had surgery. I did not think that this could be connected to the myeloma, but a biopsy of material removed from my hands during surgery showed I had amyloidosis, a build-up of abnormal protein in the tissues that can cause problems with the way vital organs function. Amyloid tissue was also found in my heart walls.

My haematologist now recommended active treatment for the myeloma, so I had chemotherapy and then an autologous stem cell transplant in 2004. I was in hospital for a month. The first fortnight went well, but then the effects of the chemotherapy kicked in. I was vomiting, I had a very sore mouth and a chronically elevated temperature, my platelet count was seriously low and my hair fell out.

A few months later I was prescribed thalidomide to help control the myeloma. After nearly three years I ceased this treatment due to pain and cramping in the lower legs (known as peripheral neuropathy). I then changed to a very new drug, Revlimid, which – like most drugs – has side effects of its own.

I'm a fairly optimistic person and have always tried to fit my treatments into a regular, busy lifestyle, making the best of my situation. Last year we had a big party with friends and relatives for my 60th birthday.

The thing with multiple myeloma is that every patient is different. I've been lucky because I don't have bone lesions, but I do have amyloidosis. I have a loving wife and good medical advisers. My prognosis is better than it was originally thought to be with the onset of amyloidosis. I feel that I have been very fortunate and my condition has been well managed. ☺☺

## Bone marrow or stem cell transplant

A transplant of stem cells is an increasingly common treatment option for many myeloma patients. The goal of a transplant is to extend your life and improve your quality of life. It is not suitable for everyone with myeloma because there are risks – such as infection and excessive bleeding – associated with the high-dose chemotherapy that is given before the transplant.

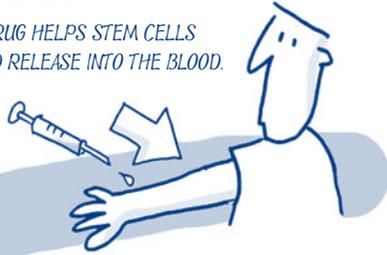
To determine your suitability for a transplant, many factors will be considered, including your age and general health, the type of myeloma you have, how aggressive it is and how it responds to treatment. For more information, ask your doctor.

The general transplant process is detailed over the page, but your health care team will explain the procedures for your individual transplant because they vary from person to person. There are several stages of treatment and the entire process, including recovery, may take many months.

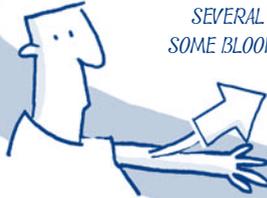
Stem cells are early-stage cells from which other cells develop. They are found in the bone marrow. A very small number are also found in the blood (where they are called peripheral stem cells). High doses of chemotherapy destroy the bone marrow, including the myeloma cells, but afterwards, transplanted blood-forming stem cells rescue the bone marrow and help restore blood cell numbers to normal. The doctor may use stem cells from another person (allogeneic transplant) or, more commonly, your own (autologous transplant). If your own stem cells are used, they are usually collected from the bloodstream, but occasionally they are taken from the bone marrow.

## RECYCLING STEM CELLS

FIRST, A DRUG HELPS STEM CELLS  
MULTIPLY AND RELEASE INTO THE BLOOD.



SEVERAL DAYS LATER,  
SOME BLOOD IS TAKEN OUT.



THE STEM CELLS ARE  
SEPARATED, PROCESSED  
AND FROZEN. YOUR  
OTHER BLOOD CELLS ARE  
RETURNED TO YOU.



A MONTH ON... AFTER CHEMO,  
THE STEM CELLS ARE THAWED  
AND PUT BACK.



*THIS IS A SIMPLE OVERVIEW OF THE TRANSPLANT PROCESS. YOUR CASE MAY BE DIFFERENT.*

## Collecting the stem cells

The first stage is to collect a supply of blood-forming stem cells. If your own stem cells are collected from your blood, you will be given a small injection under the skin of a special drug called granulocyte-colony stimulating factor (G-CSF), which helps the stem cells multiply quickly and move into the blood. This process is called mobilisation and takes a number of days. When enough stem cells have been made, they will be collected from a vein with a needle or small tube.

## Separating and storing the stem cells

The next stage is to separate the stem cells from your other blood cells by pumping the blood through a cell-separating device called an apheresis machine. This usually takes about four hours. Once separated, your other blood cells are returned to you. The stem cells are then processed and frozen using liquid nitrogen (cryopreserved). These stem cells can be stored for many years.

You will then have a rest period at home for around a month before the next stage of treatment, which usually requires a stay in hospital for a few weeks.

## Chemotherapy

In the week before the transplant, you will receive high-dose chemotherapy – usually melphalan – which kills the myeloma cells. It will also kill off your own blood-forming cells in the bone marrow. You may experience side effects, such as nausea and mouth sores, from the chemotherapy. Your blood count will also be low, making you more at risk of infections.

## Transplanting the stem cells

A day or so after chemotherapy, the stem cells are thawed and returned to you through an injection or intravenous drip (via the veins). This takes around an hour and you may have side effects such as nausea or abdominal cramps.

## Recovery

After the transplant, your blood count will be low and you may also experience some side effects from the chemotherapy. You will also be more at risk of infections. However, over the next couple of weeks, your stem cells will develop into new blood cells, allowing your bone marrow to recover.

When your blood count has risen and your general health improves, you will be able to return home. You will then need to return as an outpatient for regular follow-up care to check your blood counts and your progress.

The time it takes to recover varies depending on your situation, and at times it can be challenging. Your nurse will be able to discuss with you what you might expect during your convalescence.

You can also talk to someone from the Cancer Council Helpline (13 11 20) or the Myeloma Foundation of Australia Support Line. Details are on page 45.

The Bone Marrow Transplant Network NSW has a useful resource for transplant patients and families, available from [www.bmtnsw.com.au](http://www.bmtnsw.com.au). If your friends and family are wondering whether they can help you or another person in a similar situation, they might consider donating their own bone marrow. See page 47 for more information.



## Ongoing checkups

Whether you have treatment or not for multiple myeloma, you will need regular checkups to keep an eye on your health. Your doctor will decide how often you need checkups because everyone is different. Checkups will become less frequent if your condition has stabilised or you have no further problems.

Blood tests, urine tests, x-rays, scans and sometimes bone marrow biopsies may be used to check your health.

If you notice any symptoms, tell your doctor as soon as they appear. Don't wait until your next appointment.

# Making treatment decisions



Sometimes it is difficult to decide on the right treatment. You may feel that everything is happening so fast that you don't have time to think things through, but there is usually time for you to consider what kind of treatment you want.

Waiting for test results and for treatment to begin can be difficult. While some people feel overwhelmed with information, others feel they don't have enough. You need to make sure you understand enough about your illness, the treatment and side effects to make your own decisions.

If you are offered a choice of treatments, you will need to weigh the advantages and disadvantages of each treatment. If only one type of treatment is recommended, ask your doctor to explain why other choices have not been offered.

Some people with more advanced cancer will choose treatment, even if it only offers a small chance of cure. Others want to make sure the benefits of treatment outweigh any side effects. Still others will choose the treatment they believe offers them the best quality of life. Some people may choose to have symptoms managed to optimise their physical and emotional well-being.

You always have the right to find out what a suggested treatment means for you, and the right to accept or refuse it.

## Decision-making steps

1. Take the time to consider all treatment options.
2. Weigh up the advantages and disadvantages of each treatment.
3. Consider how important each side effect is to you – particularly those that affect your lifestyle. If you have a partner, discuss the side effects with them.
4. If only one type of treatment is recommended, ask your doctor if other treatment choices are available.
5. Find out more about the treatment choices offered to you – speak to your doctor, get a second opinion, look at the recommended Internet sites on page 48, talk to your family and friends and to other people who have received these treatments.
6. If you are not happy with the information you are given – or how it is given – tell the doctor about your concerns, or seek a second opinion.

## Talking with doctors

When your doctor first tells you that you have cancer, it is very stressful and you may not remember very much. It is often difficult to take everything in, so you may want to see the doctor a few times before deciding on treatment. Your doctor may use medical terms you don't understand; it's okay to ask your doctor to explain something again. You can also check a word's meaning in the glossary at the end of this booklet.

Before you see the doctor, it may help to write down your questions – see the list of suggested questions on page 49. Taking notes during the session or recording the discussion can also help. Many people like to have a family member or friend go with them, to take part in the discussion, take notes or simply listen.



I took a friend with me for support to the second appointment. It was like a dream where I just said 'yes, yes, yes', and luckily my friend wrote down all the information.

## Talking with others

Once you have discussed treatment options with your doctor, you may want to talk them over with family or friends, nursing staff, the hospital social worker or chaplain, your own religious or spiritual adviser, a cancer support group or the Cancer Council Helpline on 13 11 20. Talking it over can help sort out the right course of action for you.

If you talk to other people who have had myeloma, remember there are several different types of myeloma and the best treatment for one person may not be the best treatment for another.

## A second opinion

You may want to get a second opinion from another specialist. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this.

A second opinion can be a valuable part of your decision-making process. It can confirm or clarify your doctor's recommended treatment plan and reassure you that you have explored all of your options. A second specialist can also answer any questions you may still have.

Your original specialist or family doctor can refer you to another specialist and you can ask for your initial results to be sent to the second-opinion doctor.

You may later decide you would prefer to be treated by the doctor who provided the second opinion, and this is your right.

You can ask for a second opinion even if you have already started treatment or still want to be treated by your first doctor.

## Taking part in a clinical trial

Your doctor may suggest you consider taking part in a clinical trial. Doctors conduct clinical trials to test new or modified treatments and see if they are better than current treatments.

Before deciding whether or not to join a trial, you may wish to ask your doctor:

- What treatments are being tested and why?
- What tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if problems occur while I am in the trial?
- Has an independent ethics committee approved the trial?

If you are unsure about joining the trial, ask for a second opinion from an independent specialist.

If you decide to join a randomised clinical trial, you will be given either the best existing treatment or a promising new treatment. You will be chosen at random to receive one treatment or the other.

Being in a trial gives you important rights. You have the right to withdraw at any time. Doing so will not jeopardise your treatment for cancer.

For more information about clinical trials – and how to find a trial that may be suitable for you – call the Helpline for a free copy of *Understanding Clinical Trials*.

It is always your decision to take part in a clinical trial. If you don't want to take part in the trial, your doctor will provide the best current treatment choices for you.



# Looking after yourself

When you find out you have cancer and while you are undergoing treatment, your body is put through a great deal of physical and emotional strain. It is crucial that you take steps to enhance your well-being at this time to help you adapt to the stress that you are facing. Nurturing your body and mind by eating nourishing food, doing some enjoyable physical activity, and taking some time out to relax can help you to feel more balanced and improve your vitality.

## Healthy eating

Eating nutritious food will help you keep as well as possible and cope with the cancer and treatment side effects. Depending on your treatment, you may have special dietary needs.

A dietitian can help to plan the best foods for your situation – ones that you find tempting, easy to eat and nutritious. Some people take vitamin and mineral supplements to boost their nutritional intake. Discuss your needs with your dietitian and let your doctor know if you are taking any supplements, as high doses may interfere with other medications you are on.

The Cancer Council Helpline can send you information on nutrition during and after cancer treatment. Call the Helpline for free copies of *Food and Cancer* and *After Your Cancer Treatment: a guide for eating well and being active*.

## Being active

You will probably find it helpful to stay active and to exercise regularly if you can. Physical activity – even if gentle or for a short duration – helps to improve circulation, reduce tiredness, decrease joint or muscle pain, and elevate mood. The amount and type of exercise you do will depend on what you are used to, how well you feel and what your doctor advises.

Start by making small changes to your daily activities, such as walking to the shops. Even gardening can be beneficial. If you want to do more vigorous exercise or weight-bearing exercise, ask your doctor what is best for you, as you may have fragile bones because of the myeloma.

### Relaxation techniques

Some people find relaxation or meditation helps them feel better by releasing tension and anxiety. Often, relaxation exercises can also help reduce pain and increase energy levels. The hospital social worker or nurse will know whether the hospital or a community health centre runs any programs.

You may also enjoy exploring relaxation techniques in the comfort of your own home using audiovisual material such as CDs or DVDs. Contact your local library or the Cancer Council Library to access these resources.

# Complementary therapies

Many people use complementary therapies to help enhance their general well-being and to cope better with problems such as pain, anxiety and stress. Some people find that these therapies increase their sense of control over what is happening to them. There are many types of complementary therapies, such as nutrition, yoga, art therapy, relaxation, hypnotherapy, acupuncture and massage.

There have been no studies to prove the benefits of complementary therapies for people specifically with multiple myeloma, however some studies have shown benefits for people with cancer in general. It is therefore very important to tell your doctor if you are using – or planning to use – any complementary therapies, as some may pose a safety risk. For example, some herbs and nutritional supplements may interact with your medication, and therapies such as massage and acupuncture may not be appropriate or may need to be modified if you have lowered immunity, low platelets or fragile bones.

For further information, talk to your haematologist or call the Cancer Council Helpline for a copy of its latest publication on complementary therapies.





# Life after treatment

There are many types of treatment for myeloma. You may have some treatments over weeks or months, such as radiotherapy, chemotherapy or a stem cell transplant. Other treatments – such as medications – will be ongoing for months or years. While the goal of treatment is improvement of symptoms or a remission of the disease, often the treatments put the body under a lot of initial strain.

After you have had a course of treatment, you will probably find that it is helpful to give yourself time to recover. Not only may you have to adjust to physical and emotional changes, you need time to get your strength back. If you're responsible for the house, you'll need some help for a while. If you work, you'll need to ease back into it slowly.

You might have to remind your family and friends that you won't be fit enough to do all your usual activities for a while. Eventually people are able to re-establish a daily routine, but it will be at their own pace. It may take some time to balance the need for regular checkups with resuming day-to-day activities and making plans for the future. Talking to someone who has had some of the same treatments as you for multiple myeloma may help you deal with this uncertainty. For more information see page 44.

## Will myeloma affect me in the future?

For most people with multiple myeloma, the typical course of the disease is a number of episodes of disease activity, followed by a plateau when you experience good health for months or years. Although treatment options have improved and many people may go into remission, particularly after a bone marrow or blood stem cell transplant, it is still likely that at some stage in the future you will have symptoms again.

Fear of multiple myeloma returning or worsening can feel like a shadow on your life. It might help to talk to your doctor and ask about what to expect in the future. This might reassure you, but if you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation for things that previously gave you pleasure, let your doctor know. You might be clinically depressed and there are ways this condition can be helped.

## Strengthening your relationships

The strong emotions you experience as a result of cancer may affect your relationships with people close to you. Your experiences can cause you to develop a new outlook on your values, priorities and life in general. It may help to share those thoughts and feelings with your family, friends and work colleagues.

It may be uncomfortable to talk about your feelings; take your time and approach others when you are ready. You may feel relieved when you have talked to them. People usually appreciate insight into how you are feeling and guidance on how they can best support you during and after treatment. This open and honest approach can strengthen your relationships.

While you are giving yourself time to adjust to your diagnosis, your treatment and your life after treatment, remember to do the same for your friends and family. Everyone will react in a different way – by putting on a happy face, playing down your or their anxiety, or even ignoring you. They are also coming to terms with the situation in their own way. If someone's behaviour upsets you, it will probably help to have a discussion about how you both feel.

## Changing body image

Cancer treatment can change the way you feel about yourself (your self-esteem). You may feel less confident about who you are and what you can do. This is more common if your body has changed physically, but even if it has not, you may still be affected by lowered self-esteem.

Give yourself time to adapt to these changes and try not to focus solely on the parts of you that have changed. Seeing yourself as a whole person (your body, mind and personality)

Look Good...Feel Better is a program that helps people restore their self-esteem by managing appearance-related side effects. Call 1800 650 960 or visit [www.lgfb.org.au](http://www.lgfb.org.au).

can help to increase your self-esteem. You may eventually adjust to and come to accept any physical changes.

For practical suggestions about hair loss, weight changes and other physical changes, call the Helpline.

## Sexuality, intimacy and cancer

The role that sexuality and intimacy play in people's lives is ever changing and depends on one's age, environment, health, relationships, culture, beliefs and interest. As individuals, people not only have different ways of expressing and defining sexuality and intimacy, but they also place their own importance on these needs.

Having cancer can affect your sexuality in both physical and emotional ways. The impact of these changes depends on many factors, such as your treatment and its side effects, the way you and your partner communicate, and your self-confidence. Knowing the potential challenges, such as a change in libido, and addressing them if they affect you personally will help you overcome or adjust to these changes.

Sexual intercourse may not always be possible, but closeness and sharing are vital to a healthy relationship.

More information about sexuality for men and women is available. Call 13 11 20 for a copy of the Cancer Council's sexuality booklets.



YOU CAN STILL MAKE MUSIC ...  
TO THE BEAT OF A DIFFERENT DRUM



# Seeking support

When you are first diagnosed with cancer, it is normal to experience a range of emotions, such as fear, sadness, depression, anger or frustration. If anxiety or depression is ongoing or severe, tell your doctor about it as counselling or medication can help.

It may help to talk about your feelings with others. Your partner, family members and friends are a good source of support or you might prefer to talk to:

- members of your treatment team
- a hospital counsellor, social worker or psychologist
- your religious or spiritual adviser
- a support group – see page 44
- the Cancer Council Helpline.

If you have children, the prospect of telling them you have multiple myeloma can be frightening and unsettling. The

Cancer Council booklet *When a Parent Has Cancer: how to talk to your kids* can help you prepare for this difficult conversation.

You may find that your friends and family don't know what to say to you. In time, you may feel able to approach your friends directly and tell them what you need. Some people prefer to ask a family member or a friend to talk with others and coordinate any offers of help.



Some people may feel so uncomfortable that they avoid you. They may expect you to ‘lead the way’ and tell them what you need. This can be difficult to handle and can make you feel lonely.

The Cancer Council’s booklet *Emotions and Cancer* may help at this stressful time. Ring 13 11 20 for a copy or download it from the Cancer Council’s website, [www.cancercouncil.com.au](http://www.cancercouncil.com.au).

## Practical and financial help

A serious illness often causes practical and financial difficulties. You don’t need to face these alone.

Many services are available to help:

- Financial assistance, through benefits and pensions, can help pay for the cost of prescription medicines and for travel to medical appointments.
- Meals on Wheels, home care services, aids and appliances can make life easier.

To find out more, contact the hospital social worker, occupational therapist or physiotherapist, or the Cancer Council Helpline.

## Understanding Cancer program

If you want to find out more about cancer and how to cope with it, you may find the Cancer Council's Understanding Cancer program helpful. The program offers practical information and discussions about many of the issues people experience after a diagnosis of cancer. Topics covered include: what cancer is, cancer symptoms and side effects, treatment, palliative care, diet, exercise and complementary therapies. Courses are held frequently at hospitals and community organisations throughout NSW. Call the Helpline to find out more.

## Talk to someone who's been there

Getting in touch with other people who have been through a similar experience to you can be very beneficial. There are many ways you can get in contact with others for mutual support and to share information.

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

“Being able to talk with someone who has experienced cancer... I can be completely honest with my feelings and fears.”

Support services are available for patients, carers and family members. They include:

- face-to-face support groups, which are often held in community centres or hospitals
- tumour- or situation-specific telephone support groups, which are facilitated by trained counsellors
- online discussion forums where people can connect with each other any time
- Cancer Council Connect, a program that matches you with a volunteer who has been through a similar cancer experience, and who understands how you're feeling.

Ask your nurse or social worker to tell you about support groups in your area. Call the Helpline on 13 11 20 to find out how you can connect with others and go to our website, [www.cancercouncil.com.au](http://www.cancercouncil.com.au), to access the Cancer Services Directory or join an online discussion.

The Myeloma Foundation of Australia has specialist myeloma support nurses who can answer your questions on the phone or by email. The organisation also runs support groups, seminars and workshops. Phone 1800 051 532 (Monday and Tuesday) or 1800 444 996 (Thursday and Friday). See also [www.myeloma.org.au](http://www.myeloma.org.au), or email [info@myeloma.org.au](mailto:info@myeloma.org.au).

# The Cancer Council Helpline 13 11 20

## Monday to Friday 9am to 5pm

The Cancer Council Helpline is a service of the Cancer Council NSW. There is no charge for this service except for the cost of a local call. The Cancer Council Helpline is a telephone information and support service for people affected by cancer. You can talk about your concerns and needs confidentially with specialised oncology health professionals. They can send you written information and put you in touch with appropriate services in your own area. If calling outside business hours, you can leave a message on an answering machine and your call will be returned the next business day.

You can call the Cancer Council Helpline, Monday to Friday, 9am to 5pm, for the cost of a local call.

<b>Cancer Council Helpline</b> .....	<b>13 11 20</b>
Cantonese and Mandarin .....	1300 300 935
Greek .....	1300 301 449
Italian .....	1300 301 431
Arabic .....	1300 301 625
Tele-typewriter (TTY) for deaf or hearing-impaired people .....	(02) 9334 1865



## Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be very stressful, especially when the person you are looking after is someone you love very much. Look after yourself during this time. Give yourself some time out, and share your worries and concerns with somebody neutral such as a counsellor or your doctor.

Many cancer support groups are open to carers as well as people with cancer. A support group can offer a valuable opportunity to share experiences and ways of coping.

There are several support services that can help you in your caring role, such as Home Help, Meals on Wheels or visiting nurses. There are also many organisations and groups that can provide you with information and support, such as Carers NSW. Phone 1800 242 636 to talk about your needs, or visit [www.carersnsw.asn.au](http://www.carersnsw.asn.au).

Call the Cancer Council Helpline to find out more about different services or to obtain a free copy of the *Caring for Someone with Cancer* booklet.

## Bone marrow donations

One way people can offer indirect support to someone with multiple myeloma is by considering becoming a bone marrow donor. Because of the difficulty of finding a match between donors and recipients, allogeneic bone marrow transplants from unrelated people is rare. Currently, each year only around one out of 1,000 potential donors in Australia is able to give their bone marrow. However, the more donors who are on the registry, the better the chance that a patient will have the opportunity to receive a bone marrow transplant. For more information see the Australian Bone Marrow Donor Registry website, [www.abmdr.org.au](http://www.abmdr.org.au).

## Information on the Internet

The Internet can be a useful source of information, although not all websites are reliable. The websites listed below are good sources of reliable information.

### Australian

The Cancer Council NSW ..... [www.cancercouncil.com.au](http://www.cancercouncil.com.au)

The Cancer Council Australia ..... [www.cancer.org.au](http://www.cancer.org.au)

The Cancer Institute NSW ..... [www.cancerinstitute.org.au](http://www.cancerinstitute.org.au)

Myeloma Foundation of Australia ..... [www.myeloma.org.au](http://www.myeloma.org.au)

Arrow Bone Marrow  
Transplant Foundation ..... [www.arrow.org.au](http://www.arrow.org.au)

Bone Marrow  
Transplant Network NSW ..... [www.bmtnsw.com.au](http://www.bmtnsw.com.au)

Australian Bone Marrow Donor Registry ..... [www.abmdr.org.au](http://www.abmdr.org.au)

Australian Red Cross Blood Service ... [www.donateblood.com.au](http://www.donateblood.com.au)

The Leukaemia Foundation ..... [www.leukaemia.com](http://www.leukaemia.com)

### International

Myeloma UK ..... [www.myelomaonline.org.uk](http://www.myelomaonline.org.uk)

Multiple Myeloma  
Research Foundation ..... [www.multiplemyeloma.org](http://www.multiplemyeloma.org)

International Myeloma Foundation ..... [www.myeloma.org](http://www.myeloma.org)

Macmillan Cancerbackup ..... [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

American Cancer Society ..... [www.cancer.org](http://www.cancer.org)

Canadian Cancer Society ..... [www.cancer.ca](http://www.cancer.ca)



# Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your illness and treatment. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

- 1 What kind of multiple myeloma do I have?
- 2 What is the stage and what does that mean?
- 3 What tests do I need?
- 4 What treatment do you recommend and why?
- 5 Are there alternative treatments available?
- 6 What are the risks and side effects of each treatment?
- 7 What side effects should I report?
- 8 How long will treatment last?
- 9 What happens if I do nothing?
- 10 Will the treatment affect my sex life and fertility?
- 11 What happens if the multiple myeloma comes back?



# Glossary

## **adjuvant therapy**

A treatment used to assist your main treatment.

## **allogeneic bone marrow transplant**

A transplant that uses stem cells donated by another person.

## **amyloidosis**

A build-up of thick fibrous tissue called amyloid tissue that can impair the way some organs work. Some people with myeloma also have amyloidosis.

## **anaemia**

A drop in the number of red blood cells in your body. Anaemia decreases the amount of oxygen in the body. This may cause tiredness and fatigue, breathlessness, paleness and poor resistance to infection.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs only a part of the body. A general anaesthetic puts a person to sleep for a period of time.

## **antibody**

Part of the body's immune system. Antibodies are proteins made by the blood in response to an invader (antigen) in the body. They help protect against viruses, bacteria and other foreign substances.

## **autologous bone marrow transplant**

A transplant that uses the patient's own blood stem cells.

**Bence Jones protein**

The name for the myeloma protein found in the urine.

**benign**

Not cancer. Not malignant.

**biopsy**

The removal of a small sample of tissue from the body, for examination under a microscope, to diagnose a disease.

**bisphosphonate**

A type of drug that protects against bone breakdown.

**bone marrow**

The soft spongy material inside bones. Bone marrow contains stem cells that produce red blood cells, white blood cells and platelets.

**bone marrow biopsy**

The removal of a small amount of bone marrow with a needle for examination under a microscope.

**bone marrow transplant**

A procedure to replace bone marrow with healthy bone marrow stem cells after intensive treatment destroys the myeloma and the remaining stem cells in the bone marrow.

**chemotherapy**

The use of cytotoxic drugs, which kill or slow cell growth, to treat cancer.

**clinical trial**

A research study that tests new and better ways of improving health in people.

## **corticoid steroids**

A class of drugs that are mostly used to reduce inflammation, and have been found to be effective in treating myeloma.

## **CT (computerised tomography) scan**

A technique that uses x-rays to build a picture of the body.

## **diagnosis**

The identification and naming of a person's disease.

## **erythrocytes**

Red blood cells. These cells carry oxygen from the lungs to the rest of the body.

## **haematologist**

A doctor who specialises in treating diseases (including cancer) of the blood, bone marrow and lymphatic system. He or she also performs bone marrow or peripheral blood stem cell transplants.

## **interferon**

A substance that occurs naturally in the body and enhances the immune system's fight against viruses. Interferon is manufactured for use as a medication, and has shown anti-tumour activity against some uncommon cancers.

## **leucocytes**

White blood cells. These cells fight infection.

## **lymphocyte**

A type of white blood cell that helps fight infection.

## **lytic lesions**

Areas where bone has been destroyed.

**malignant**

Cancer. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

**M-brand**

A paraprotein, which is a substance produced when plasma cells multiply abnormally.

**MGUS**

Some people have a blood test result that may indicate multiple myeloma, but they don't have the disease. This is called MGUS, which stands for monoclonal gammopathy of uncertain significance. People who have MGUS do not have any other signs of multiple myeloma. They will need regular checkups in case they develop it in the future.

**nausea**

Feeling sick or wanting to be sick.

**oncologist**

A doctor who specialises in the study and treatment of cancer.

**osteoporosis**

A decrease in bone mass causing bones to become fragile. This makes them brittle and liable to break.

**palliative care**

Treatment that aims to promote comfort, relieve symptoms and maximise quality of life, when cure is no longer possible.

**pathologist**

A person who studies diseases to understand their nature and cause.

## **peripheral blood stem cell transplant**

The replacement of stem cells in the bone marrow after high-dose chemotherapy with healthy stem cells that have been collected from the blood.

## **plasma**

The clear fluid part of the blood that carries blood cells.

## **plasma cells**

A type of white blood cell that stays mostly in the bone marrow. Plasma cells make antibodies. Multiple myeloma is a cancer of the plasma cells.

## **plateau**

A prolonged period of stable disease, where the disease is present but well controlled.

## **platelets**

Also called thrombocytes. One of three types of cells found in the blood. These help the blood to clot and stop bleeding.

## **prognosis**

The likely outcome of a person's disease.

## **radiation oncologist**

A doctor who specialises in treating cancer with radiotherapy.

## **radiotherapy**

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply.

## **red blood cells**

Also called erythrocytes. One of three types of cells found in the blood. They carry oxygen around the body.

**relapse**

The return of a disease after a period of improvement.

**remission**

When the symptoms and signs of the cancer reduce or disappear. A partial remission is when there has been a significant improvement in the cancer. A complete remission is when there is no evidence of active disease. This does not necessarily mean that the cancer is cured.

**side effects**

Unintended or unwanted effects of a drug or treatment.

**smouldering multiple myeloma**

Early disease that does not cause any problems and does not need treatment. Patients have some signs of myeloma, but no evidence of active bone destruction or any other features of active myeloma.

**spleen**

An organ located on the left side of the abdomen under your ribs. It is part of the lymphatic system.

**stage**

The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

**stem cells**

Early-stage cells from which other cells develop.

**white blood cells**

Also called leucocytes. One of three types of cells found in the blood. They help fight infection. Types of white blood cells include neutrophils, lymphocytes and monocytes.



# How you can help

At the Cancer Council NSW we're dedicated to defeating cancer. As well as funding more cancer research than any other charity in the state, we advocate for the highest quality of care for cancer patients and their families, and create cancer-smart communities by empowering people with knowledge about cancer, its prevention and early detection. We also offer direct financial assistance for those people in hardship as a result of having cancer. These achievements would not be possible without community support, great and small.

**Join a Cancer Council event:** join one of our community fundraising events like Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

**Make a donation:** any donation whether large or small will make a meaningful contribution to our fight to defeat cancer.

**Buy your sun protection products from our website or our retail stores:** every purchase helps you prevent cancer and contributes financially to our work.

**Help us speak out and create a cancer-smart community:** the Cancer Council is a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us defeat cancer by living and promoting a cancer-smart lifestyle.

To find out more about how you or your family and friends can help, please call 1300 780 113.



# Regional offices

## **Central Coast Region**

127 Erina Street  
Gosford NSW 2250  
Ph: (02) 4325 5444  
Fax: (02) 4325 5688

## **Far North Coast Region**

101-103 Main Street  
Alstonville NSW 2477  
Ph: (02) 6627 0300  
Fax: (02) 6628 8659

## **Hunter Region**

22 Lambton Road  
Broadmeadow NSW 2292  
Ph: (02) 4961 0988  
Fax: (02) 4961 0955

## **Mid North Coast Region**

121 High Street  
Coffs Harbour NSW 2450  
Ph: (02) 6651 5732  
Fax: (02) 6652 1530

## **North West Region**

Shop 2  
218 Peel Street  
Tamworth NSW 2340  
Ph: (02) 6766 1164  
Fax: (02) 6766 7053

## **South West Region**

1/37 Tompson Street  
Wagga Wagga NSW 2650  
Ph: (02) 6937 2600  
Fax: (02) 6921 3680

## **Southern Region**

1 Lowden Square  
Wollongong NSW 2500  
Ph: (02) 4225 3660  
Fax: (02) 4225 1700

## **Sydney Metropolitan Region and Head Office**

153 Dowling Street  
Woolloomooloo NSW 2011  
(PO Box 572)  
Kings Cross NSW 1340  
Ph: (02) 9334 1900  
Fax: (02) 9334 1739

## **Western Sydney Region**

43 Hunter Street  
Parramatta NSW 2150  
Ph: (02) 9687 1399  
Fax: (02) 9687 1118

## **Western Region**

84 Byng Street  
Orange NSW 2800  
Ph: (02) 6361 1333  
Fax: (02) 6361 1863

# Cancer Council Helpline 13 11 20

For support and information on cancer and cancer-related issues, call the Cancer Council Helpline. This is a free and confidential service.

Cancer Council Helpline ..... 13 11 20 (cost of a local call)  
TTY ..... (02) 9334 1865 for deaf and hearing-impaired  
Cantonese and Mandarin ..... 1300 300 935  
Greek ..... 1300 301 449  
Italian ..... 1300 301 431  
Arabic ..... 1300 301 625

For further information and details please visit our website:

[www.cancercouncil.com.au](http://www.cancercouncil.com.au)



*Building a  
Cancer Smart  
Community*