



# Understanding Myeloma

A guide for people with cancer,  
their families and friends

A blue circle containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving to the left and ending in a telephone handset icon.

Cancer  
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## **Understanding Myeloma**

A guide for people with cancer, their families and friends

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*Understanding Myeloma* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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Publications from the Myeloma Foundation of Australia were used as source material for previous editions of this title. We would also like to thank the health professionals and consumers who have worked on previous editions.

### **Note to reader**

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council NSW excludes all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

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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 beat cancer, visit [cancercouncil.com.au](http://cancercouncil.com.au) or phone 1300 780 113.



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# Introduction

This booklet has been prepared to help you understand more about myeloma. Myeloma is also called multiple myeloma.

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

We cannot give advice 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 other questions to ask your treatment team.

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

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by myeloma. It is based on clinical practice guidelines for myeloma.<sup>1</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer  
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# Contents

<b>What is blood cancer?</b> .....	<b>4</b>
<b>The blood</b> .....	<b>6</b>
<b>Key questions</b> .....	<b>8</b>
What is myeloma? .....	8
What are the symptoms? .....	9
What causes myeloma? .....	10
How common is it? .....	10
<b>Diagnosis</b> .....	<b>11</b>
Blood tests .....	11
Urine test .....	13
Bone marrow aspiration and trephine biopsy .....	13
Imaging and scans .....	15
Who needs treatment? .....	17
Staging myeloma.....	18
Prognosis.....	19
Which health professionals will I see?.....	20
<b>Making treatment decisions</b> .....	<b>23</b>
Talking with doctors .....	23
A second opinion .....	24
Taking part in a clinical trial .....	24
<b>Treatment</b> .....	<b>25</b>
Combination drug therapies.....	26
Stem cell transplant.....	31

Supportive treatment..... 34  
Palliative treatment..... 37

**Controlling symptoms..... 39**

Anaemia..... 39  
Infections..... 39  
Bone disease..... 41  
Kidney damage..... 41  
Excess calcium in the blood..... 42  
Thicker blood..... 43  
Pain..... 44  
Fatigue..... 45  
Nerve and muscle effects..... 46

**Looking after yourself..... 48**

Relationships with others..... 49  
Life between treatments..... 50  
When myeloma returns..... 52

**Seeking support..... 53**

Practical and financial help..... 53  
Talk to someone who's been there..... 53  
Myeloma Australia..... 54

**Caring for someone with cancer..... 56**

**Useful websites..... 57**

**Question checklist..... 58**

**Glossary..... 59**



# What is blood cancer?

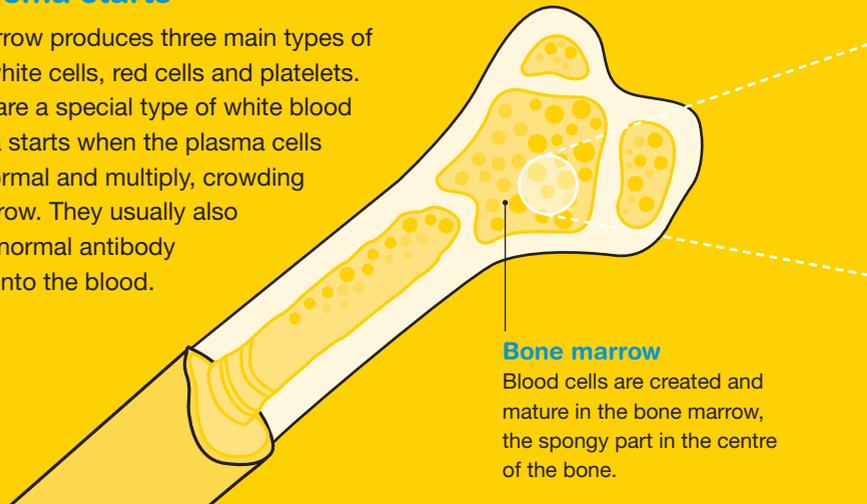
Cancer is a disease of the cells, which are the body's basic building blocks. Our bodies constantly make new cells to help us grow, to replace worn-out cells and to heal damaged cells after an injury. Normally cells grow and multiply in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause different kinds of cancer. Most cancers, such as breast cancer or bowel cancer, are solid cancers. In these, the abnormal cells form a lump called a tumour. Myeloma, however, is a blood cancer. It begins in the bone marrow, the spongy part in the centre of the bone where blood cells are produced.

In myeloma, a particular type of blood cell called a plasma cell is affected. The plasma cells grow abnormally and multiply in such

## How myeloma starts

The bone marrow produces three main types of blood cells: white cells, red cells and platelets. Plasma cells are a special type of white blood cell. Myeloma starts when the plasma cells become abnormal and multiply, crowding the bone marrow. They usually also release an abnormal antibody (paraprotein) into the blood.



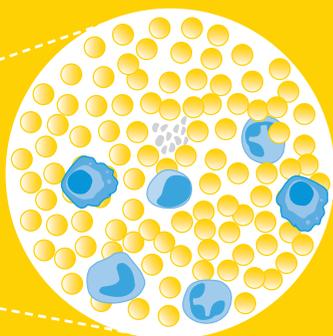
### Bone marrow

Blood cells are created and mature in the bone marrow, the spongy part in the centre of the bone.

a way that they crowd the bone marrow. These abnormal plasma cells are known as myeloma cells. The crowding can reduce the bone marrow's ability to produce normal levels of other blood cells, which affects the way that the rest of the body works.

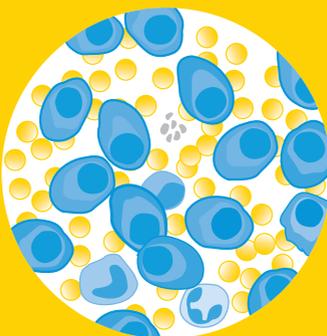
Usually, the myeloma cells produce an abnormal antibody called paraprotein that spills into the bloodstream, weakens the immune system and can damage the kidneys.

As myeloma progresses, paraprotein will build up in the blood. Without treatment, the bone marrow produces more myeloma cells and fewer normal blood cells, and the myeloma can spread to other parts of the body that contain bone marrow, such as the spine, skull, shoulders, ribs and pelvis.



#### Normal bone marrow

In healthy bone marrow, white blood cells (including plasma cells), red blood cells and platelets are kept in balance.



#### Bone marrow with myeloma

With myeloma, the bone marrow becomes crowded with abnormal plasma cells, so there are fewer normal white blood cells, red blood cells and platelets.



Plasma cells



Other white blood cells



Red blood cells



Platelets



# The blood

Blood is pumped around your body to provide oxygen and nutrients to your tissues, and to remove waste products. It is made up of three main types of blood cells, and these have specific functions:

Red blood cells	White blood cells	Platelets
		
carry oxygen around the body	fight infection	help the blood clot

All three types of blood cells live for a limited time and need to be continually replaced. Most are made in the bone marrow, which is the spongy part in the centre of the bones.

The bone marrow contains stem cells. These are unspecialised blood cells that develop into mature red or white blood cells or platelets. Once mature, the blood cells are usually released into the bloodstream to carry out their set functions.

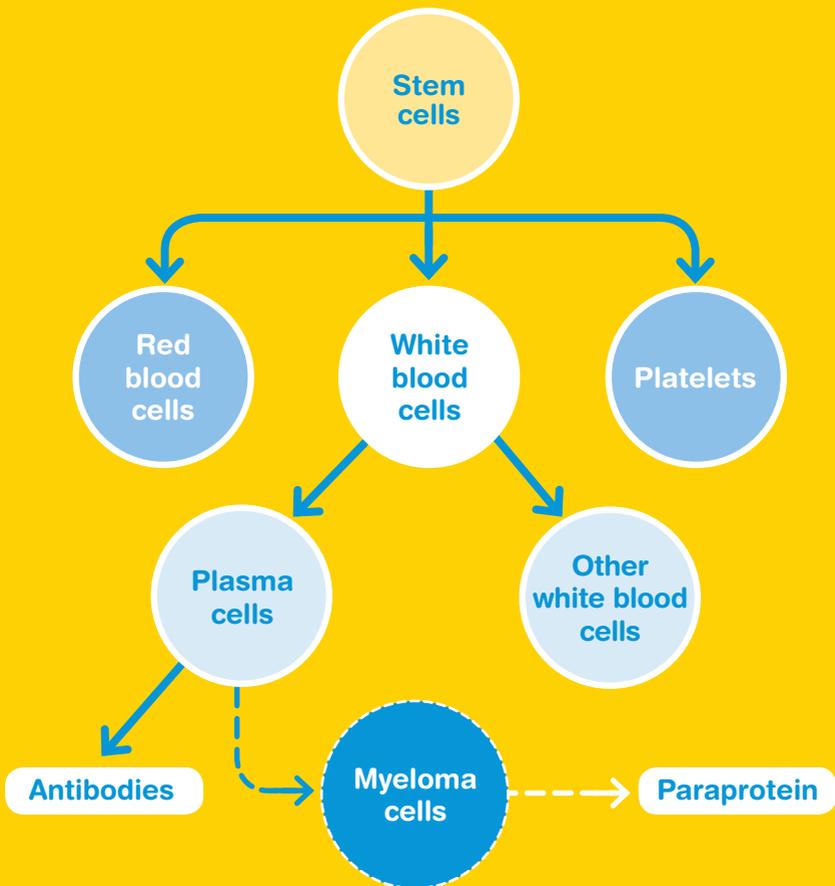
## Plasma cells

A plasma cell is a special type of white blood cell. Like other white blood cells, plasma cells develop in the bone marrow and form part of the immune system that protects the body from infection.

The role of a plasma cell is to make proteins called antibodies or immunoglobulins. Once released into the blood, these antibodies attack and kill bacteria and viruses that have infected the body.

## Blood cell production and myeloma

Stem cells turn into red or white blood cells or platelets. Plasma cells are one type of white blood cell. Normally they produce antibodies that are released into the blood to fight infection. Myeloma cells are abnormal plasma cells. They release an abnormal antibody called paraprotein.





## Key questions

### Q: What is myeloma?

**A:** Myeloma is a type of blood cancer that develops from plasma cells in the bone marrow. As bone marrow is found in multiple areas of the body, the disease is often called multiple myeloma.

Myeloma begins when abnormal plasma cells (myeloma cells) start multiplying rapidly. Normal plasma cells make a wide variety of antibodies that help the body fight infections, but myeloma cells make an abnormal antibody known as paraprotein, M-protein or monoclonal protein. Paraprotein is found in the blood of most people who have myeloma.

Without treatment, myeloma can affect your health in various ways. Because the myeloma cells crowd out the bone marrow, there is limited space for normal blood cells to develop. The lack of normal plasma cells and other white blood cells can make a person more prone to infections. A lack of red blood cells (anaemia) can cause fatigue, and a lack of platelets (thrombocytopenia) can cause bleeding and bruising.

Because myeloma starts in the bone marrow, it can spread to the bones, making them weak and thin (osteoporosis). As bones start to break down, they may release too much calcium into the blood (hypercalcaemia), which can lead to nausea, confusion and kidney damage. The paraprotein released into the blood by the myeloma cells can cause problems in the kidneys, and damage the nerves in the hands and feet (peripheral nerves). See *Controlling symptoms* on pages 39–47 for how these issues can be managed.



Cancerous plasma cells sometimes form a single tumour in the bone or tissue, rather than spreading throughout the bone marrow. Known as solitary plasmacytomas, these tumours are not common and make up only about 5% of plasma cell cancers.

## Q: What are the symptoms?

**A:** Myeloma can cause a range of symptoms because of its effect on the bones, bone marrow, blood, urine and kidneys. However, different people with myeloma can have different symptoms, and most will only have one or two symptoms.

The most common symptoms of myeloma are:

- bone pain or a broken bone that has not been caused by an obvious injury
- frequent infections or an infection that is hard to shake off
- tiredness, shortness of breath or a racing heart caused by a low level of red blood cells (anaemia)
- kidney problems caused by the excess amounts of paraprotein produced by the myeloma cells
- feeling sick, drowsy or confused because of too much calcium in the blood (hypercalcaemia)
- abnormal blood counts (because myeloma cells may stop the bone marrow from making enough normal blood cells).

Other conditions can cause these symptoms, so not everyone with these changes will have myeloma. However, if you are concerned or the symptoms are ongoing, see your general practitioner (GP) for a check-up.

## Q: What causes myeloma?

**A:** The causes of myeloma are unknown. We know that plasma cells become cancerous when there are certain changes in their DNA (the chemical instructions for the actions of the cells). However, we do not yet know what triggers those DNA changes.

Exposure to certain chemicals (e.g. dioxins used in industry), high levels of radiation (e.g. from working in a nuclear power plant) 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.

Myeloma is not considered to be hereditary (inherited) and there is little risk of passing it on to your children. It is rare for more than one person in a family to be affected by myeloma, although this does happen occasionally.

## Q: How common is it?

**A:** Myeloma is not a common disease. About 1500 people in Australia are diagnosed with the disease each year.<sup>2</sup> It accounts for 15% of blood cancers and 1% of all cancers generally.

Myeloma is rare in people under 40. The disease is being found more often in people over 60, which is partly explained by the ageing population. It is slightly more common in men than in women.



# Diagnosis

Myeloma is usually diagnosed when blood and urine tests show the presence of paraprotein, and bone marrow tests show an increased number of plasma cells. X-rays and sometimes other imaging scans are used to check for signs of myeloma in your bones.

The test results help your doctor determine the type of myeloma you have and the best treatment plan for you.

## Blood tests

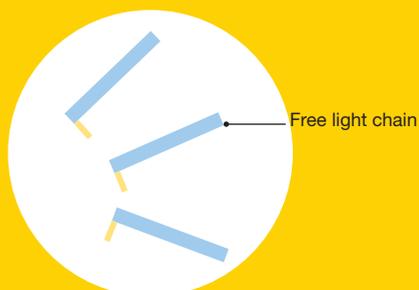
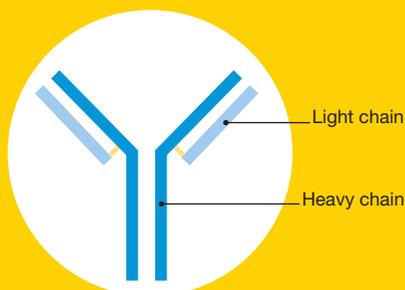
A number of blood tests are used to diagnose myeloma. The main blood test is called serum protein electrophoresis. This measures the level of paraprotein in your blood. Another blood test called the serum free light chain assay may be used to check for a form of paraprotein known as free light chains (see the *Understanding paraprotein* box on the next page).

You will also have a full blood count done, as well as other blood tests to check for too few red blood cells (anaemia), for too much calcium in the blood (hypercalcaemia), and how your kidneys are working. Once myeloma has been confirmed, further blood tests will help your doctor work out the stage of the disease (see pages 18–19).

Changes in the level of paraprotein may indicate changes in the activity of the myeloma. If you are diagnosed with myeloma, your paraprotein levels will be monitored to see how well treatment is working and to check that the myeloma is stable during periods that you are not having treatment.

## Understanding paraprotein

Myeloma cells release antibodies known as paraprotein. To make a diagnosis of myeloma, doctors will look for this paraprotein in the blood or urine. Once you have been diagnosed with myeloma, doctors will regularly check your paraprotein levels to monitor the disease.



### Intact paraprotein

Paraprotein is made up of smaller proteins that are usually linked together to form a pair of long chains (called heavy chains) and a pair of shorter chains (called light chains). Most people with myeloma release complete (intact) paraprotein made up of both heavy and light chains. Intact paraprotein can be detected in a blood test.

### Free light chains

About 1 in 5 people with myeloma do not produce intact paraprotein. They produce only the light chain parts. These light chain parts are known as free light chains when detected in a special blood test, and as the Bence Jones protein when detected in a urine test. Some people produce both intact paraprotein and free light chains.

### Non-secretory myeloma

In less than 1 out of 50 people with myeloma, little or no paraprotein is produced. This makes diagnosis more difficult.

## Urine test

A urine test may be used to check for the Bence Jones protein, which is the light chain part of paraprotein (see box opposite). About one-third of people with myeloma make enough Bence Jones protein for it to be measurable in the urine.

For this test, you may be asked to collect your urine in a container over a 24-hour period. If the Bence Jones protein shows up, your doctor may use regular urine tests to monitor the myeloma and check how well treatment is working.

The Bence Jones protein doesn't show up in standard blood tests, but it can be detected in a specialised blood test called the serum free light chain assay. Your doctor may recommend this test as well as or instead of the urine test.

## Bone marrow aspiration and trephine biopsy

This test is used to examine cells from the bone marrow. It is usually done with a local anaesthetic and a mild sedative.

For the bone marrow aspiration, a thin needle is used to remove a sample of fluid (aspirate) from the bone marrow – usually from the pelvic bone, but sometimes from the chest.

While the needle is inside the bone, small pieces of bone and marrow are also removed. This is the trephine biopsy. Sometimes it is done with a second needle instead.

The bone marrow samples are then sent to a laboratory for examination under a microscope and further testing. A medical specialist called a pathologist will check the number of plasma cells present and look for any damage to the bone marrow that has been caused by myeloma.

A bone marrow aspiration and trephine biopsy may also be done at the start and end of each course of treatment. By comparing samples, your doctor can see how well the treatment is working.



After a biopsy, you may feel a bit drowsy and have some bleeding and discomfort at the biopsy site.

## Cytogenetic tests

The bone marrow biopsy may be used for cytogenetic tests, which examine the structure and function of cells. Each cell in the body contains chromosomes, which are made up of genes. These genes control all activities of the cell.

In myeloma, there may be changes in the structure of the chromosomes within the myeloma cells, but not within the normal cells of the body.

Cytogenetic tests can check the cells in the bone marrow biopsy for changes in the chromosomes. These chromosomal changes may help to determine the most effective treatment and predict how the myeloma might respond.

## Imaging and scans

Your doctor will usually arrange for x-rays to check your bones, and may suggest other imaging scans, such as CT or MRI.

### X-rays

Bone x-rays, sometimes called a skeletal survey, are used to find any bone damage caused by the myeloma cells. X-rays are usually taken of your head, spine, ribs, hips, legs and arms. Areas of bone damage show up on x-ray film as black shaded areas and are known as lytic lesions.

### CT scan

A CT (computerised tomography) scan uses x-rays and a computer to make detailed pictures of the inside of your body. It can find bone damage that may not show up on a standard x-ray.

For a CT scan, you will lie flat on a table while the scanner, which is large and round like a doughnut, takes pictures. The scan takes about 30 minutes, and most people can go home straight after.

### MRI scan

An MRI (magnetic resonance imaging) scan can sometimes find myeloma in the bones and outside the bones. It uses magnetic waves to create detailed cross-sectional pictures of areas inside the body. You should let your medical team know if you have a pacemaker, as the magnetic waves can interfere with some pacemakers.

For an MRI, you will lie on an examination table inside a large metal tube that is open at both ends.

The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to your medical team. You may be given a mild sedative to help you relax, or you might be able to have a family member or friend in the room with you for support. You will usually be offered headphones or earplugs, and you may be able to bring along your favourite music to play. The MRI scan may take between 30 and 90 minutes.

## Other scans

In particular cases, your doctor may arrange specialised scans, such as an FDG-PET (fluoro-deoxyglucose positron emission tomography) or sestamibi scan. Both of these scans involve an injection of a small amount of a radioactive substance, which shows up areas of healthy and abnormal tissue and may help detect myeloma outside of the bone marrow. Most people with myeloma do not need these scans.

### Dye injection for CT or MRI

CT and MRI scans of organs sometimes involve the injection of a dye (contrast) into a vein, probably in your arm. This dye makes the pictures clearer. You must let the person doing the scan know that you are suspected of having myeloma, as this dye can damage the kidneys of people with myeloma and may not be safe for you. Also let the medical team know if you have had a reaction to iodine or dyes during a previous scan. Scans of bones usually do not need any contrast to be injected.

## Who needs treatment?

The test results will allow your doctor to determine whether you have myeloma or a pre-myeloma condition, and whether it needs treatment. The table below shows the main categories.

Category	Test results	Need for treatment
<b>Monoclonal gammopathy of undetermined significance (MGUS)</b>	<ul style="list-style-type: none"> <li>● low level of paraprotein in blood or urine</li> <li>● low level of myeloma cells in the bone marrow</li> <li>● no other significant signs of myeloma</li> </ul>	<ul style="list-style-type: none"> <li>● MGUS is not cancer. It isn't treated but needs active monitoring (see page 25).</li> <li>● One out of every 100 people diagnosed with MGUS develops myeloma each year.</li> </ul>
<b>Smouldering myeloma (asymptomatic myeloma)</b>	<ul style="list-style-type: none"> <li>● medium level of paraprotein in blood or urine and/or of myeloma cells in the bone marrow</li> <li>● no other significant signs of myeloma</li> </ul>	<ul style="list-style-type: none"> <li>● Smouldering myeloma does not usually need treatment. It may progress to active myeloma, so it needs active monitoring (see page 25).</li> </ul>
<b>Active myeloma (symptomatic myeloma)</b>	<ul style="list-style-type: none"> <li>● medium or high level of myeloma cells in the bone marrow, or the presence of myeloma cells in the bone or another part of the body</li> <li>● significant signs of myeloma (see next page)</li> </ul>	<ul style="list-style-type: none"> <li>● Active myeloma requires treatment (see pages 25–38).</li> </ul>

## Significant signs of myeloma

Doctors usually use the CRAB criteria of myeloma-defining events to identify people with myeloma who need to start treatment. The SLiM criteria are another set of signs (biomarkers) that may be used instead or as well. Together the criteria are known as the SLiM-CRAB criteria.

### CRAB criteria: myeloma-defining events

<b>C</b>	calcium elevation
<b>R</b>	renal (kidney) damage
<b>A</b>	anaemia (low levels of red blood cells)
<b>B</b>	bone abnormalities/disease (lytic lesions or bone loss)

### SLiM criteria: biomarkers of malignancy

<b>S</b>	significant plasmacytosis (a high level of myeloma cells in the bone marrow)
<b>Li</b>	light chain ratio (a high level of free light chains in the blood)
<b>M</b>	MRI lesions (more than one area of bone abnormality found by MRI – this is called a focal lesion and must be more than 5 mm in size)

## Staging myeloma

To work out the best treatment for you, your doctor will assign a stage to the myeloma. This is an indication of how much the myeloma has affected your body and how it is likely to respond to treatment.

The most commonly used staging system for myeloma is the Revised International Staging System (R-ISS).

The R-ISS divides myeloma into stages I, II and III based on the results of various blood tests that check:

- **levels of beta-2 microglobulin ( $\beta$ 2M)** – a protein produced by myeloma cells that indicates the extent of disease
- **levels of albumin** – a protein produced by the liver that indicates overall health
- **levels of lactate dehydrogenase (LDH)** – an enzyme released into the blood when cells are damaged or destroyed
- **genetic information** – may identify people at highest risk of the disease progressing.

## Prognosis

Prognosis means the expected outcome of a disease. It is not possible for any doctor to predict the exact course of the disease, but your medical team can predict how the myeloma will respond to treatment based on your test results; the type of myeloma you have and its stage and rate of growth; and your age, fitness and medical history. You will also have tests throughout your treatment that show how well the treatment is working.

The outlook for people with myeloma is improving constantly. Treatment cannot cure myeloma, but it can help control the disease, manage the symptoms and improve quality of life. If the myeloma is under control (also called a plateau phase), people usually return to a state of good health that may last for months or a few years. For some people, the disease can be controlled for much longer periods. When the disease becomes active again (recurrence or relapse), further treatment will be needed.

## Which health professionals will I see?

Often your GP (general practitioner) will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a haematologist, who is the key specialist for myeloma. (Occasionally in regional areas, people may see a medical oncologist instead.)

### MDT health professionals

<b>GP</b>	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
<b>haematologist*</b>	specialises in diagnosing and treating diseases of the blood and bone marrow
<b>radiation oncologist*</b>	prescribes and coordinates the course of radiotherapy
<b>pathologist*</b>	examines cells and tissues samples to try to determine the type and extent of the myeloma
<b>cancer care coordinator or clinical nurse consultant (CNC)</b>	coordinates your care, liaises with other members of the MDT, and supports you and your family throughout treatment
<b>nurses</b>	administer chemotherapy and other drugs, and provide care, information and support throughout your treatment

The haematologist arranges further tests and explains your treatment options. You will then be cared for by a range of health professionals who specialise in different aspects of your care. This is called a multidisciplinary team (MDT) and it may include some or all of the health professionals listed below.

<b>pain management team (including pain specialist* and nurses)</b>	work together to treat pain, particularly if it is difficult to control or severe
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>social worker</b>	links you to support services and helps you with any emotional, physical or practical problems
<b>physiotherapist</b>	helps manage physical problems, such as bone or muscle weakness and pain
<b>occupational therapist</b>	assists in adapting your living and working environment to help you resume usual activities
<b>counsellor, psychologist</b>	provide emotional support and help manage anxiety and depression

\* Specialist doctor



## Key points

- Several types of tests are needed to diagnose myeloma.
- Tests help your medical team work out a treatment plan and detect complications of the disease so they can be treated.
- It is often through measuring the level of paraprotein in the blood that myeloma is diagnosed and monitored.
- A bone marrow aspiration and trephine biopsy measures the amount of myeloma cells in the bone marrow. This test may also be done at the beginning and end of each course of myeloma treatment.
- You are likely to have a bone x-ray (skeletal survey) to look for areas of bone damage (lytic lesions).
- If a clearer picture of the bones is needed, you may have a CT or MRI scan.
- The tests allow your doctor to classify the myeloma. MGUS is not cancer, but may progress to myeloma. Smouldering myeloma does not have symptoms. Both MGUS and smouldering myeloma need active monitoring. Myeloma that requires treatment is known as active myeloma or symptomatic myeloma.
- The SLiM-CRAB criteria are two sets of signs that help doctors decide when myeloma has become active and therefore requires treatment.
- You may be told the stage of the myeloma. This indicates how much the myeloma has affected your body and how likely it is to respond to the proposed treatment.
- If you are diagnosed with myeloma, you will be cared for by a team of health professionals, including a haematologist and nurses.



# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may 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.

If you are confused or want clarification, you can ask your doctor questions – see page 58 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

# Treatment

Treatment for myeloma is highly individual and depends on the type and stage of myeloma you have, as well as your general health. The aim is to try to get the myeloma under control. Treatment is often grouped into several categories. You will probably have a range of different treatments over time.

**Active monitoring** – People who have been diagnosed with monoclonal gammopathy of undetermined significance (MGUS) or smouldering myeloma (see page 17) usually do not need treatment straightaway. Most people with MGUS never develop active myeloma. In most cases of smouldering myeloma, early treatment does not offer any clear benefit.

If tests show you have MGUS or smouldering myeloma, you will need check-ups every 3–12 months. This is called active monitoring. Treatment will start if symptoms or other significant signs of myeloma (see page 18) occur.

**Treatment to control the myeloma** – This is often called initial or first-line treatment. It usually includes a combination of different drugs (see next page). A stem cell transplant may be suggested for some people. In between periods of treatment, you may have periods of remission or stable disease (plateau) when no treatment is needed.

**Treatment for the symptoms and side effects caused by myeloma** – Supportive treatment helps manage common problems associated with myeloma, such as tiredness, pain, bone disease, frequent infections, kidney damage and hypercalcaemia.

**Treatment to prevent the disease returning** – This is called maintenance or consolidation therapy and involves a longer, lower-dose course of thalidomide, steroids and/or other drugs. It is often used after a stem cell transplant and sometimes after other first-line treatment.

**Treatment when the disease comes back (recurrence)** – You may be offered a different type of chemotherapy, stem cell transplant, steroids or other drugs to regain control of the disease.

## Combination drug therapies

Most people with myeloma will be treated with a combination of two, three or more different drugs. Particular combinations work best for different types of myeloma, so your haematologist will aim to select the best one for you.

The combinations may include traditional chemotherapy drugs and steroids as well as newer therapies that are known as immunomodulators and proteasome inhibitors. To learn more about the different drug combinations for myeloma, visit [myeloma.org.au](http://myeloma.org.au) or [eviq.org.au](http://eviq.org.au).



Some over-the-counter medicines, vitamins and supplements can affect how chemotherapy and other cancer drugs work in your body and may worsen side effects. Always let your doctor know of any other substances you are taking or planning on taking.

## Chemotherapy

Chemotherapy is the treatment of cancer with anti-cancer drugs called cytotoxics. The aim of chemotherapy is to kill cancer cells while doing the least possible damage to healthy cells.

The most commonly used chemotherapy drugs for myeloma include melphalan, cyclophosphamide and doxorubicin. You may have chemotherapy in combination with other treatments, such as thalidomide, lenalidomide or bortezomib (see next two pages).

**How it is given** – Some people can have all their chemotherapy as tablets. Others have the drugs injected into a vein (intravenously) or under the skin (subcutaneously). A hospital stay may be needed for some treatments, but this stay is usually short. Your doctor will tell you about the drugs you are having and how long treatment will last.

**Side effects** – Some chemotherapy drugs can cause side effects, such as feeling sick (nausea), fatigue, loss of hair from the body and head, a drop in blood count, and a weakened immune system.

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

For more information, see the *Controlling symptoms* chapter on pages 39–47. You can also call Cancer Council 13 11 20 to request a free copy of *Understanding Chemotherapy*, or download a digital version from [cancercouncil.com.au](http://cancercouncil.com.au).

## New drug therapies

A range of new drug therapies for myeloma are continuing to emerge. These include new proteasome inhibitors such as carfilzomib, ixazomib and oprozomib, as well as monoclonal antibodies such as elotuzumab and daratumumab. Monoclonal antibodies are made in a laboratory, but behave like the natural antibodies that our bodies produce to fight infection and disease. They

target cancer cells and affect their growth or survival.

Until these new drugs are subsidised for myeloma on the Pharmaceutical Benefits Scheme (PBS), they will be very costly. If your doctor thinks these therapies are the most promising treatment for you, ask whether there are any clinical trials or compassionate access schemes that may be able to help.

## Immunomodulators

Immunomodulators work by blocking the blood supply to cancer cells and by stimulating the body's immune system to attack cancer cells. The most common immunomodulators used for myeloma are thalidomide, lenalidomide and pomalidomide.

Thalidomide is an old drug that has new uses. It was given to pregnant women 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 myeloma. Lenalidomide and pomalidomide are newer types of immunomodulators.

**How it is given** – An immunomodulator is most often given in combination with a steroid and a chemotherapy drug. It is taken as tablets, usually every day. Most people also take a blood thinner.

**Side effects** – Some possible side effects of immunomodulators include drowsiness, constipation, rashes, blood clots and a weakened immune system. Thalidomide or pomalidomide may also cause pain, numbness, tingling and muscle weakness in the hands and feet (peripheral neuropathy, see page 46). Peripheral neuropathy is not a typical side effect of lenalidomide.

## Proteasome inhibitors

Proteasome inhibitors block the breakdown of protein within myeloma cells, causing them to stop growing and die. The most commonly used proteasome inhibitor for myeloma is bortezomib, but new types are emerging (see box opposite).

**How it is given** – Bortezomib is given either as an injection under the skin (subcutaneously) or into a vein (intravenously). It is often given with a steroid and sometimes chemotherapy.

**Side effects** – Side effects may include fatigue, diarrhoea, fewer platelets, weakened immune system, and peripheral neuropathy.

## Steroids

Steroids (also known as corticosteroids) are hormonal substances made naturally in the body. They can also be made artificially and used as drugs. Steroids modify the immune system's responses, relieve swelling and inflammation, and actively kill myeloma cells.

**How they are given** – The typical steroids for myeloma are prednisolone and dexamethasone. These are usually given along with chemotherapy or other anti-myeloma drugs. Steroids are most often taken as tablets, but can also be given intravenously.

**Side effects** – Side effects vary depending on the dose and length of treatment. Common side effects include hyperactivity, difficulty sleeping, mood changes, energy changes, increased appetite, fluid retention, heartburn, and weight gain. Take steroids in the morning with food or milk. This will reduce the risk of sleeplessness at night and irritation to your stomach.

Some steroids can affect blood sugar levels, so people who have diabetes will need to monitor their blood sugars more often and may need to have their diabetes treatment adjusted. Discuss this with your GP and ask for a review of your diabetes. You can also call Diabetes Australia on 1300 136 588 to talk to a diabetes educator.

Steroid treatment is usually given in high doses, but for short periods only. If used for a long period, steroids may cause diabetes and contribute to thinning of the bones (osteoporosis).



Let your doctor know if you are finding it hard to cope with the side effects of steroids. The doctor may be able to adjust your dose. However, always consult your doctor if you want to reduce the dose or stop using steroids. Serious withdrawal effects can occur if changes to dosages are not managed.

## Stem cell transplant

You may have a stem cell transplant, also known as high-dose therapy and stem cell rescue, to try to destroy remaining myeloma cells and increase the length of remission. In this treatment, high-dose chemotherapy destroys the bone marrow, including myeloma cells, but afterwards, transplanted blood-forming stem cells rescue the bone marrow and help to restore blood cell numbers.

This intensive treatment is often used for myeloma patients. However, it is not suitable for everyone as the high-dose chemotherapy that is given before the transplant can have a lot of side effects, such as serious infections or high blood sugars leading to diabetes.

To determine your suitability for a transplant, many factors will be considered, including your general health, age, the type of myeloma you have, how aggressive it is and how it responds to treatment. Your doctor will also consider whether the stem cell transplant is available at your hospital. You may need to be referred to another hospital.

Most people receive their own previously collected stem cells (autologous transplant). These are usually collected from the bloodstream via a process called apheresis (see next page) and then frozen until the transplant. Rarely, stem cells from another person are used (allogeneic transplant).

A transplant is done in several stages and the entire procedure, including recovery, can take months and may take up to a year.

## Stem cell transplant steps

A general autologous transplant process is described here, but the process varies from person to person. Detailed information is available from [leukaemia.org.au](http://leukaemia.org.au).

### 1 Collecting stem cells

- The first stage is to collect a supply of stem cells. If your own stem cells are used, you will usually be given a dose of chemotherapy followed by a special growth factor drug called granulocyte-colony stimulating factor (G-CSF). In some hospitals, you may just have the G-CSF without the chemotherapy.
- Growth factor drugs are taken for 5–10 days, and will help increase the number of stem cells in the bone marrow. This process of collecting stem cells is called mobilisation and takes several days.
- When enough stem cells have been made, they are collected via a process called apheresis.

### 2 Separating and storing stem cells

- Apheresis usually involves inserting a needle called a cannula into a vein in each arm. (People with weak veins may need a special line known as an apheresis catheter.) Blood is taken from your body through one of the cannulas and passed through a machine called a cell separator. The stem cells are removed and the rest of the blood is returned to your body through the other cannula.
- This process takes 3–4 hours and may need to be repeated the next day. The stem cells are processed and frozen using liquid nitrogen (cryopreserved).
- You will then have a rest period at home for about a month until the next stage of treatment.

### 3

## Receiving high-dose chemotherapy

- High-dose chemotherapy, often referred to as conditioning therapy, is given through a vein. A long, flexible plastic tube is usually used. This may be a peripherally inserted central catheter (PICC line), a Hickman catheter or a central line.
- In the week before the transplant, you'll have high-dose chemotherapy to kill the myeloma cells. This will also destroy the stem cells in the bone marrow. Before and after the chemotherapy is given, you will have fluids through a drip to prevent dehydration and kidney damage. You may experience side effects, such as nausea, diarrhoea and mouth sores, from the chemotherapy. Because your stem cells have been destroyed, your blood count will be low and you will be more at risk of infections.

### 4

## Transplanting stem cells and engraftment

- A day or so after high-dose chemotherapy, your frozen stem cells are thawed and returned to you via a cannula or via a PICC line, Hickman catheter or central line. This takes about an hour, and you may have side effects, such as nausea and stomach cramps. These can be managed with medication.
- Your stem cells will develop into new blood cells, allowing your bone marrow to recover. This is called engraftment and takes about 10–14 days.
- You will usually have a hospital stay of 1–4 weeks, depending on how soon you are well enough to go home.

## Side effects of stem cell transplant

Recovery time after a stem cell transplant varies depending on your situation. Talk to your doctor or nurse about what to expect during your recovery.

After the transplant, your blood count will be low. You may be more at risk of infections and need transfusions of blood products and intravenous antibiotics. You will be able to go home when your blood count has risen and your general health has improved. You will have regular follow-up care to check your blood counts and your progress.

Fatigue and diarrhoea are common side effects during engraftment. The diarrhoea usually stops by the time you go home, but the fatigue can be ongoing for months or even up to a year.

“ It takes a while to get over the fatigue, but I can honestly say that I feel more like the person I was pre-myeloma thanks to the transplants. That is something I give thanks for every day. ” *Vicki*

## Supportive treatment

You may be given some treatments that do not target the myeloma itself, but help to treat symptoms that have been caused by the myeloma. Antibiotics, antiviral drugs and steroids may be given to prevent infections. Blood thinners, such as aspirin, may be used to prevent blood clots.

Other supportive treatments may include bisphosphonates and radiotherapy for bone pain and damage, and plasma exchange for dangerous levels of paraprotein in the blood.

## **Bisphosphonates**

Bisphosphonates are a class of drugs that help to reduce bone pain and prevent further bone weakness or damage caused by myeloma cells. They also prevent a dangerous rise in the level of calcium in your blood. You will need regular blood tests to monitor your calcium levels and kidney function before you are given bisphosphonates.

**How they are given** – Several different types of bisphosphonates are used for myeloma. They may be given as a daily tablet or a monthly injection into a vein.

**Side effects** – Bisphosphonates can cause stomach upset. You may feel sick and/or have constipation or diarrhoea for a few days. An uncommon but severe side effect associated with prolonged bisphosphonate use is osteonecrosis of the jaw (ONJ). This condition causes bone tissue of the jaw to break down, causing pain. See your doctor if you experience mouth ulcers or jaw problems while taking bisphosphonates.

It is a good idea to visit your dentist for a check-up and try to have any invasive dental work done before you start taking bisphosphonates. If you need dental work during treatment, let your dentist know you have been taking bisphosphonates and ask your haematologist if you can have a break in your regime.

## Radiotherapy

Not all people with myeloma will need radiotherapy. When it is used, the aim is to relieve symptoms such as bone pain by reducing the number of myeloma cells in the bones.

Radiotherapy uses radiation, such as x-rays, to kill or injure cancer cells. Treatment is carefully planned to destroy the cancer cells while causing as little harm as possible to your normal tissue.

**How it is given** – You lie under a machine that delivers the radiation to areas with myeloma cells. Each treatment only takes a few minutes, but the first appointment can take 1–3 hours, which includes time setting up the machine, seeing the radiation oncologist and having tests. Radiotherapy may be given as a single dose, or as multiple smaller doses over several days or weeks. You will visit the radiotherapy centre for each of your radiotherapy treatments, rather than staying overnight.

**Side effects** – Radiotherapy can cause both immediate and delayed side effects. The most common side effect is tiredness. Other side effects will depend on the part of the body being treated. Most side effects will go away in time and there are ways to reduce any discomfort.



Cancer Council produces free booklets on radiotherapy, palliative care and advanced cancer. Call **13 11 20** for printed copies, or download digital versions from [cancercouncil.com.au](http://cancercouncil.com.au).

## Plasma exchange

Plasma exchange may be used if the level of paraprotein in the blood is very high and is interfering with blood circulation, making the blood thicker (hyperviscosity, see page 43) and causing symptoms such as blurred vision and decreased alertness.

**How it is given** – The process begins with a needle being placed into a vein in each arm. Blood is slowly removed from one arm and then passed through the machine, which separates it into each of the blood components. The plasma – the clear fluid part of the blood that contains much of the extra paraprotein – is removed and replaced with either donated plasma or a plasma substitute such as albumin (a blood protein). The blood is then mixed together again and returned to the body via the other arm. This process usually takes a few hours.

## Palliative treatment

In some cases of advanced myeloma, the medical team may talk to you about palliative treatment. Palliative treatment helps to improve quality of life by alleviating symptoms of cancer. It can be used at any stage of advanced cancer. As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include blood transfusions, radiotherapy, chemotherapy or other drug therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs.



## Key points

- Treatment for myeloma is highly individual and depends on the type and stage of myeloma you have. There is an increasing variety of different treatment combinations.
- While treatments can be very effective at controlling the myeloma, they do not cure the disease.
- Not everyone diagnosed with myeloma will need treatment straightaway to control the myeloma. It is common to wait until the myeloma is causing symptoms before starting treatment. In this case, you will have regular appointments to check for symptoms. This is called active monitoring.
- The treatment of myeloma can be grouped into several categories: active monitoring, first-line treatment (to control the myeloma), supportive treatment (for the symptoms and side effects caused by myeloma) and maintenance treatment (to prevent myeloma coming back).
- You may also have treatment when the disease comes back (recurrence or relapse).
- In most cases, the first treatment people receive is a combination of traditional chemotherapy drugs, steroids and another type of drug, such as thalidomide, lenalidomide or bortezomib.
- Some people will have a stem cell transplant to help destroy remaining myeloma cells and improve the length of remission.
- Stem cell transplants are not suitable for everyone. Talk to your doctor about your situation.
- Palliative treatment can help to ease the symptoms of advanced myeloma.



# Controlling symptoms

Myeloma and its different treatments may cause symptoms and side effects. Most of these issues are caused by the build-up of myeloma cells in the bone marrow and the presence of paraprotein in the blood or urine. Some of the treatments described in the previous chapter will help manage these symptoms.

## Anaemia

Anaemia means you have a low red blood cell count. You may look pale, feel weak and tired, and be breathless. It is common to have anaemia when myeloma is diagnosed, but this will normally get better when treatment begins to control the myeloma.

Sometimes anaemia develops because of the chemotherapy itself. If this happens, your doctor may suggest a blood transfusion to increase your red blood cell count. The blood will be given to you through a catheter inserted into a vein in your arm.

## Infections

Myeloma, high-dose steroids and treatments such as bortezomib, lenalidomide, thalidomide and chemotherapy can weaken your immune system and leave you prone to infections. Call your doctor straightaway if you have symptoms of an infection (see next page).

If your white blood cell count falls very low, antibiotics may help prevent infections, while drugs called growth factors can stimulate the production of white blood cells. If you have repeated infections, you may be given intravenous immunoglobulins (antibodies).

## Taking care with infections

Some chemotherapy and other drugs, as well as the myeloma itself, can cause a low count of normal, healthy white blood cells (neutropenia). Colds and flu may be easier to catch and harder to shake off, and scratches and cuts may get infected easily.

You may want to ask people close to you to have a flu shot, if they are able to do so. You can also ask family and friends to wait until they are well before visiting. Of course, this is not practical for people you live with, so try to minimise close contact while they are unwell.

Good food hygiene is important for everyone. If the myeloma or its treatment has caused neutropenia, however, you will be more susceptible to foodborne illness and will have to be especially cautious about food poisoning. Extra care needs to be taken when preparing and storing food.

Your treatment team may advise you to avoid cold meats, undercooked foods, raw eggs, prepackaged salads, pâté, some types of seafood and certain cheeses.

Talk to a dietitian about any special food handling requirements that may apply to your stage of treatment.

Contact your doctor/hospital immediately if you experience:

- fever over 38°C
- chills or constant shivering
- sweating, especially at night
- burning or stinging when urinating
- severe cough
- sore throat
- vomiting that lasts more than a few hours
- severe constipation, diarrhoea or abdominal pain
- unusual bleeding or bruising
- prolonged faintness and a rapid heartbeat
- any sudden deterioration in your health.

## Bone disease

Bone disease is one of the most common complications experienced by people with myeloma. The myeloma cells release chemicals that damage the cells in your body that normally repair damaged bone. When this happens, the bone is broken down faster than it can be repaired, causing bone pain, bone lesions or even fractures. The rapid breakdown of bone can lead to an increase in blood calcium levels (hypercalcaemia). The middle or lower back, the rib cage and the hips are the most frequently affected areas.

A group of drugs called bisphosphonates are used to treat bone disease. They help to control hypercalcaemia, manage existing bone disease and slow down any further bone destruction. For more information on bisphosphonates, see page 35.

🗨️ Increasingly, those of us with myeloma are living longer and with a better quality of life – so much so that research is now needing to be done on longer-term effects of the cancer and its treatments. This is almost a nice ‘problem’ to have! 🗨️ *Brigita*

## Kidney damage

Kidney problems can develop in people with myeloma for various reasons. The paraprotein produced by myeloma cells can damage the kidneys. This is particularly common with the Bence Jones protein (see page 12). Other complications of myeloma, such as

dehydration and hypercalcaemia, can also damage the kidneys, as can some of the drugs used to treat myeloma and its symptoms.

People with myeloma should drink plenty of water and also ask their doctor if they need to avoid using painkillers that contain a non-steroidal anti-inflammatory drug (NSAID). It is important to treat any infections promptly (see page 40) to avoid further stress on the kidneys.

The treatment for kidney damage in people with myeloma will depend on the cause. In many cases, the damage is temporary and the kidneys can recover. In a small number of people, the kidney problems are permanent and require dialysis. This is a way of filtering the blood using a machine.

## **Excess calcium in the blood**

The myeloma cells in the bones can sometimes start to break down some of the bone cells, which release calcium into the blood. This condition is called hypercalcaemia. It can cause symptoms such as tiredness, nausea, constipation, thirst, irritability and confusion. In some people, hypercalcaemia is discovered during a blood test before any symptoms develop.

People with hypercalcaemia need to drink more fluids. However, they might also require treatment in hospital, which may include intravenous fluids, steroids and bisphosphonates. Treatment of the myeloma itself will often help to control the high calcium levels in the blood.

## Thicker blood

Occasionally, the myeloma cells release so much paraprotein into the blood that the blood becomes thick and starts to circulate more slowly. This is known as hyperviscosity.

The thickened blood may block small blood vessels in the brain, and this can lead to blurred vision, confusion, headaches and dizziness. It can also cause stroke-like symptoms such as slurred speech and weakness on one side of the body. A process called plasma exchange (see page 37) can quickly remove the excess paraprotein from the blood.

### Brigita's story

When I was diagnosed with myeloma, my doctor prescribed nine chemotherapy cycles, leading up to a stem cell transplant about a year later. I've also had thalidomide and steroid treatment.

After I had the transplant, I was feeling good, but looking back at photos, I think it affected me more than I realised at the time.

Luckily, all the treatment hasn't damaged my kidneys, but I have

had other side effects. At times, I've been so fatigued that my brain can't seem to think, but I just wait until I feel less dopey. I also became very susceptible to infections. A small scrape can quickly become serious.

I'm still figuring it out. Some things are caused by ageing, some things are the cancer, and some things are the drugs. But when I feel like an infection is coming on, I've learnt to see my doctor straightaway.



## Pain

Pain is the most common symptom at diagnosis for people with myeloma. It is often related to bone damage that has been caused by the disease.

Regular reviews by pain management specialists will help keep your pain under control. It's better to take pain medicine regularly as prescribed, rather than waiting until you feel the pain.

Some people may need further treatment to manage the pain. This may include localised radiotherapy or, in some specific cases, vertebroplasty. This is when medical-grade cement is injected into the spine because it has collapsed.



### Tips for managing pain

- Complementary therapies, such as relaxation and meditation, sometimes work well when used along with pain medicine.
- Talk to a psychologist about cognitive behavioural therapy (CBT). This approach aims to change how you feel pain by changing your thoughts.
- Call **13 11 20** and ask for our free relaxation CD and the booklets *Overcoming Cancer Pain* and *Understanding Complementary Therapies*, or download the booklets from [cancercouncil.com.au](http://cancercouncil.com.au).
- Visit Myeloma Australia at [myeloma.org.au](http://myeloma.org.au) to download the *Pain and Myeloma* information sheet.
- Tell your treatment team if you are experiencing pain – don't wait for them to ask.

## Fatigue

Feeling very tired and lacking the energy to do day-to-day things is known as fatigue. It is different from normal tiredness because it often doesn't go away with rest or sleep.

Fatigue is very common in people with myeloma and may last for weeks or months after treatment ends. It can be caused by the cancer itself, and by the physical and emotional effects of diagnosis and treatment.

Sometimes people don't tell their doctor about fatigue because they think nothing can be done about it. However, your treatment team may be able to suggest strategies to manage the fatigue.



### Tips for managing fatigue

- Rest when you need to, but balance this with regular exercise. Keeping active can minimise treatment-related fatigue. See Cancer Council's *Exercise for People Living with Cancer* booklet.
- Plan activities for the time of day when you tend to feel most energetic.
- If you are tired because you are having trouble sleeping, try some relaxation and meditation exercises. Call Cancer Council **13 11 20** for resources that may help.
- Fatigue is a common side effect of cancer treatment, but it can also be a symptom of depression (see pages 50–51).
- Download Myeloma Australia's information sheet *Fatigue and Myeloma* from [myeloma.org.au](http://myeloma.org.au).

## Nerve and muscle effects

Many people with myeloma develop tingling (‘pins and needles’), pain or loss of sensation in the fingers and/or toes, and muscle weakness in the legs. This is called peripheral neuropathy because it involves the nerves of the peripheral nervous system (the nerves outside the brain and spinal cord).

Peripheral neuropathy may be caused by the myeloma itself. The paraprotein produced by myeloma cells can travel through the bloodstream, build up in nerve tissue, and damage the nerve cells. Some myeloma treatments, such as thalidomide and bortezomib, can also damage the nerve cells. Always tell your doctor if you have tingling or numbness, as your treatment may need to be adjusted.



### Tips for managing peripheral neuropathy

- Take care when moving around – you may be more prone to trip and fall if your feet are numb or your legs are weak.
- Keep your hands and feet warm to help the blood circulate. Gloves and warm socks can help when it’s cold.
- Soak your hands and feet in warm water to relieve the symptoms.
- Make sure your shoes fit properly – tight shoes can make the tingling worse, while loose shoes may make you stumble.
- Use your elbow to check water temperature so you don’t scald yourself.
- If your symptoms are severe, talk to your doctor about whether you can take any medicines that offer relief.



## Key points

- Myeloma can affect the body in several ways. Not everyone will experience all these symptoms and there are ways to treat them.
- The myeloma itself and chemotherapy can both lead to low levels of red blood cells (anaemia). Anaemia can be treated with blood transfusions.
- Frequent infections are common with myeloma. Contact your doctor or hospital immediately if you develop signs of infection.
- Myeloma often leads to bone disease, which is usually treated with drugs called bisphosphonates.
- Kidney problems can develop in people with myeloma. The kidneys usually recover, but if the problem is permanent, you may need dialysis.
- When bone cells start to break down, they can release excess calcium in the blood (hypercalcaemia). This can cause symptoms such as tiredness and nausea.
- When myeloma cells release paraprotein into the blood, the blood can become thicker and nerve cells may be damaged.
- Pain is the most common symptom for people with myeloma at the time of diagnosis. This is often linked to bone disease.
- Extreme tiredness and lack of energy (fatigue) is a common side effect and may last for weeks or months.
- Talk to your treatment team about any symptoms or side effects you have. They may be able to suggest strategies or adjust your treatment.



# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to try to look after your wellbeing.

**Nutrition** – Eating well can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – Complementary therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe. Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful.

For more information about complementary and alternative therapies, call 13 11 20 and ask for a free copy of the *Understanding Complementary Therapies* booklet or visit [cancercouncil.com.au](http://cancercouncil.com.au).

## Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you will be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call **13 11 20** or visit [cancercouncil.com.au](http://cancercouncil.com.au) for free copies of *Sexuality, Intimacy and Cancer* and *Fertility and Cancer*.



## Life between treatments

You may be surprised to find out that life between cancer treatments can present its own challenges. You will need time to get used to the changes.

You may have mixed emotions. During treatment, you may have been busy with appointments and focused on treatment, but between treatments you may feel anxious rather than secure.

Some people say that after a myeloma diagnosis they have changed priorities and see life with a new clarity. For example, you may decide to travel, spend more time with family or do volunteer work. Many people say they don't necessarily return to 'normal life' as it was before cancer. Instead, it takes some time to establish a 'new normal'.

Different people find different approaches help them. You might find it helpful to:

- take time to adjust to physical and emotional changes
- re-establish a new daily routine at your own pace
- maintain a healthy diet and lifestyle
- schedule regular check-ups with your doctor
- tell your family and friends how they can support you
- talk to someone else who has had cancer (see pages 53–55).

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer. Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Visit their website at [beyondblue.org.au](http://beyondblue.org.au) or call 1300 224 636 to order a fact sheet.

## Follow-up appointments

Whether or not you have treatment for myeloma, you will need regular check-ups to keep an eye on your health. Your doctor will decide how often you need check-ups because everyone is different. Check-ups 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. Your doctor may note the levels of antibodies and proteins in the blood and urine.

If you notice any symptoms between appointments, tell your doctor as soon as possible. You don't have to wait until the next scheduled appointment.

“ I've had many appointments with my doctors, mostly to manage pain caused by the myeloma. My doctors also monitor my bone lesions. ” *Sam*

## When myeloma returns

When myeloma returns, you and your doctor will need to consider what treatment is needed to try to regain control of the disease. While options for managing recurrence may have been considered in the initial treatment plan, many doctors like to discuss all the options again. This is because the risks and benefits of treatment are not as clear in people whose myeloma has recurred, and your views and the disease characteristics may have changed.

In some people, the original treatment can be repeated successfully, especially if the initial response to the treatment was good. In other people, the myeloma may not respond to the treatment that was used previously. This is called resistant or refractory disease.

Treatment options may include:

- taking the same or a different combination of drugs (see pages 26–30)
- having another stem cell transplant (see pages 31–34)
- participating in a clinical trial to access new drugs being developed and tested (see page 24).



New treatments are being developed all the time so it's hard to know what options will be available when myeloma recurs.



# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help you deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council NSW offers free legal and financial advice for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience. In a support

group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be open and honest because they aren't trying to protect loved ones.

## Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as [cancerconnections.com.au](http://cancerconnections.com.au).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

## Myeloma Australia

Myeloma Australia is a national not-for-profit organisation dedicated to providing information and support for people affected by myeloma. It aims to:

- raise awareness of the disease in the community
- promote research
- advocate to governments for more generous support for the myeloma community
- support patients, carers and health care professionals through its specialist myeloma support nurses.

## Myeloma support nurses

If you would like to talk to someone about any aspect of myeloma, its treatment and management, call Myeloma Australia's toll free Support Line on 1800 MYELOMA (1800 693 566). The Support Line is available during business hours Monday to Friday, and a myeloma support nurse will answer your call in confidence.

## Support groups

Find details of myeloma-specific support groups for people affected by the disease by searching Myeloma Australia's website or calling the support nurses. In NSW, a telephone support group is available through Cancer Council 13 11 20 for those unable to access a group in person.

## Information resources

A comprehensive range of information resources, including booklets and fact sheets on many aspects of myeloma, its treatments and supportive care issues, are available to download from [myeloma.org.au](http://myeloma.org.au) or by calling 1800 693 566.

🗨️ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. 🗨️ *Sam*



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – 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 and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit the website at [carergateway.gov.au](http://carergateway.gov.au) or call 1800 422 737. Carers NSW is a state-wide organisation specifically for carers. Visit [carersnsw.org.au](http://carersnsw.org.au) or phone 1800 242 636 for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet, or visit [cancercouncil.com.au](http://cancercouncil.com.au) to download a digital version of the booklet.

“It was very hard work, but I found that caring for my mother at home was one of the best things I could have done for her in her greatest time of need.”  Janice



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

## Australian

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Cancer Council NSW .....	<a href="http://cancercouncil.com.au">cancercouncil.com.au</a>
Cancer Council Australia.....	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Institute NSW .....	<a href="http://cancerinstitute.org.au">cancerinstitute.org.au</a>
Cancer Australia .....	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway.....	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Carers NSW .....	<a href="http://carersnsw.org.au">carersnsw.org.au</a>
healthdirect.....	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>

## Blood cancer specific websites

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Arrow Bone Marrow Transplant Foundation.....	<a href="http://arrow.org.au">arrow.org.au</a>
Australian Bone Marrow Donor Registry .....	<a href="http://abmdr.org.au">abmdr.org.au</a>
Leukaemia Foundation.....	<a href="http://leukaemia.org.au">leukaemia.org.au</a>
Myeloma Australia .....	<a href="http://myeloma.org.au">myeloma.org.au</a>

## International

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American Cancer Society.....	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK.....	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
International Myeloma Foundation.....	<a href="http://myeloma.org">myeloma.org</a>
Macmillan Cancer Support (UK).....	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
Multiple Myeloma Research Foundation (US).....	<a href="http://themmr.org">themmr.org</a>
Myeloma UK .....	<a href="http://myeloma.org.uk">myeloma.org.uk</a>
National Cancer Institute (US).....	<a href="http://cancer.gov">cancer.gov</a>



# Question checklist

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

- What type of myeloma do I have?
- What tests do I need?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for myeloma available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?



# Glossary

## **active monitoring**

Regular check-ups to test for signs or symptoms of a disease. Used for monoclonal gammopathy of undetermined significance (MGUS) and smouldering myeloma.

## **active myeloma**

Myeloma that requires treatment because it is causing symptoms or because test results indicate a high risk of the disease progressing. Also known as symptomatic myeloma.

## **albumin**

A major protein found in the blood. The protein level can provide some indication of overall health and nutritional status.

## **allogeneic stem cell transplant**

A transplant where the stem cells are taken from one person and given to another.

## **anaemia**

A drop in the number or quality of red blood cells in the body.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local anaesthetic numbs a particular part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

## **antibody**

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

cells make an abnormal antibody called paraprotein.

## **antigen**

Any substance that causes the body's immune system to respond. This response often involves making antibodies.

## **apheresis**

When blood is removed from the body and passed through a machine to separate a component such as stem cells. The remainder of the blood is then returned to the body. Apheresis is one of the key steps in a stem cell transplant.

## **asymptomatic myeloma**

See smouldering myeloma.

## **autologous stem cell transplant**

A transplant where bone marrow stem cells are taken from a person's body and then given back following a course of high-dose chemotherapy.

## **Bence Jones protein**

The name of a light chain protein found in the urine of some people with myeloma. For these people, urine tests may be used to help diagnose and monitor the disease.

## **benign**

Not cancer or malignant.

## **beta-2 microglobulin ( $\beta$ 2M)**

A small protein found in the blood. High levels occur in people with active myeloma.

## **biopsy**

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

**bisphosphonate**

A type of drug that protects against bone breakdown.

**blood**

The watery fluid that flows through the circulatory system. Blood contains red and white blood cells and platelets.

**blood count**

A test that counts the number of red blood cells, white blood cells and platelets in the blood.

**bone marrow**

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

**bone marrow aspiration**

The removal of a small amount of bone marrow liquid (aspirate) with a needle for examination under a microscope.

**central line**

A type of thin plastic tube inserted into a vein.

**chemotherapy**

The use of anti-cancer drugs to treat cancer by killing cancer cells or slowing their growth.

**clinical trial**

A research study that tests new and better treatments to improve people's health.

**corticosteroids**

See steroids.

**CRAB criteria**

A set of myeloma-defining events used to help identify people who need treatment. The letters stand for the events: C = calcium elevation;

R = renal damage; A = anaemia; B = bone abnormalities. Often combined with the SLiM criteria to form the SLiM-CRAB criteria.

**CT scan**

Computerised tomography scan. This scan uses x-rays and a computer to create a detailed, cross-sectional picture of an area inside the body.

**cytogenetic test**

A test that examines whether cells have an abnormality in their chromosomes.

**engraftment**

The process by which transplanted stem cells develop into new blood cells.

**free light chains**

See light chains.

**granulocyte-colony stimulating factor (G-CSF)**

A growth factor used to stimulate the growth of stem cells before collection for a transplant, or to boost white blood cells if they are low in numbers.

**growth factor**

A protein that stimulates the development and growth of cells.

**haematologist**

A doctor who specialises in the study and treatment of diseases of the blood, bone marrow and lymphatic system.

**heavy chains**

Long chains of proteins in an antibody.

**Hickman line**

A type of central line inserted into a vein in the chest.

**high-risk myeloma**

See active myeloma.

**hypercalcaemia**

Higher than normal levels of calcium in the blood.

**hyperviscosity**

A syndrome triggered when blood thickens and starts to circulate more slowly. Symptoms include blurred vision, confusion, headaches and dizziness. Hyperviscosity sometimes occurs when myeloma cells release large amounts of paraprotein into the blood.

**immunoglobulin**

See antibody.

**immunomodulators**

Drugs that interact with the immune system to attack cancer cells in a number of different ways. Thalidomide, lenalidomide and pomalidomide are immunomodulators that are used in the treatment of myeloma.

**light chains**

Short chains of proteins in an antibody. Often referred to as Bence Jones protein when found in the urine of people with myeloma, or as free light chains when found in their blood.

**lymphocyte**

A type of white blood cell that helps fight infection.

**lytic lesions**

Areas where bone has been damaged.

**malignant**

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

**monoclonal gammopathy of undetermined significance (MGUS)**

A benign condition that affects plasma cells in the blood. This condition may increase the risk of developing cancers of the blood such as myeloma.

**M-protein**

See paraprotein.

**myeloma**

Cancer of the plasma cells. Also called multiple myeloma.

**oncologist**

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

**osteonecrosis of the jaw**

A condition in which bone tissue of the jaw breaks down, causing pain.

**osteoporosis**

Thinning and weakening of the bones that can lead to pain and fractures.

**palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other symptoms of cancer. It is an important part of palliative care.

**paraprotein**

A substance produced when plasma cells become cancerous and multiply abnormally. Also called monoclonal protein or M-protein.

**pathologist**

A specialist doctor who interprets the results of blood tests and biopsies.

**peripheral neuropathy**

Weakness, numbness, tingling or pain, usually in the hands and feet, caused by damage to the nerves located away from the brain and spinal cord (peripheral nerves). Myeloma or some treatments can damage these nerves.

**plasma**

The clear fluid part of the blood that carries red blood cells, white blood cells and platelets.

**plasma cells**

A type of white blood cell that stays mostly in the bone marrow. Plasma cells make antibodies.

**plasma exchange**

When the plasma portion of the blood is removed and replaced with donated plasma or a plasma substitute. Plasma exchange may be used if high levels of paraprotein are causing hyperviscosity.

**plateau**

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

**platelets**

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

**prognosis**

The predicted outcome of a person's disease.

**proteasome inhibitors**

Drugs that block the breakdown of protein within cancer cells, causing them to stop growing and die.

**radiation oncologist**

A doctor who specialises in treating cancer with radiotherapy.

**radiotherapy**

The use of radiation, such as x-rays, gamma rays, electron beams or protons, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

**recurrence**

The return of a disease after a period of improvement (remission).

**red blood cells**

One of the three main types of cells found in the blood. They carry oxygen around the body.

**refractory disease**

Disease that does not respond to treatment. Also called resistant disease.

**relapse**

See recurrence.

**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.

**serum free light chain assay**

A test that can detect free light chains in the blood, which can be a sign of myeloma.

**side effect**

Unintended effect of a drug or treatment.

**SLiM criteria**

A set of signs of myeloma (biomarkers of malignancy) used to help identify people who need treatment. The letters stand for the biomarkers:

S = significant plasmacytosis (myeloma cells in bone marrow); Li = light chain ratio; M = MRI lesions (bone abnormalities found by MRI). Often combined with the CRAB criteria to form the SLiM-CRAB criteria.

### **smouldering myeloma**

Early myeloma that does not cause the person any problems and does not need treatment. Also called asymptomatic myeloma.

### **solitary plasmacytoma**

A single tumour formed in the bone or tissue by cancerous plasma cells.

### **spleen**

An organ in the lymphatic system located on the left side of the abdomen under the ribs. It produces lymphocytes, filters the blood, stores blood cells, and destroys old blood cells.

### **stage**

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

### **stem cells**

Unspecialised cells from which mature blood cells develop. Stem cells are found in the bone marrow.

### **stem cell transplant**

A treatment in which diseased blood cells are destroyed by high-dose

chemotherapy, then replaced by healthy stem cells. Stem cells are collected from the blood of the patient or a donor beforehand.

### **steroids**

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

### **symptomatic myeloma**

See active myeloma.

### **trephine biopsy**

The removal of a bone tissue sample using a needle.

### **white blood cells**

One of the three main types of cells found in the blood. They help fight infection. Types of white blood cells include neutrophils, lymphocytes and monocytes. Plasma cells are a type of lymphocyte.

### **Can't find a word here?**

For more cancer-related words, visit:

- [cancerCouncil.com.au/words](http://cancerCouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## **References**

1. H Quach & M Prince on behalf of Medical Scientific Advisory Group (MSAG) to the Myeloma Foundation of Australia (MFA), *Clinical Practice Guideline: Multiple Myeloma*, Myeloma Australia, V.3, updated August 2015.
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Multiple myeloma*, AIHW, Canberra, 2016.



# How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as 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 gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**



**If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.**  
[www.relayservice.gov.au](http://www.relayservice.gov.au)

Produced in collaboration with:



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

For further information and details, visit our website, [cancercouncil.com.au](http://cancercouncil.com.au).

*This booklet is funded through the generosity of the people of NSW.*