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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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 appropriate independent professional advice relevant to your specific situation and you may wish to discuss issues raised in this book with them.

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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. Publications from the Myeloma Foundation of Australia were used as source material.

If you’re reading this book for someone who doesn’t understand English, let them know that Cancer Council 13 11 20 can arrange telephone support in different languages. They can also call the Translating and Interpreting Service (TIS National) direct on 13 14 50.
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What is cancer?

Cancer is a disease of the cells, which are the body’s basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don’t grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

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**How cancer starts**

- **Normal cells**
- **Abnormal cells**
- **Abnormal cells multiply**
- **Malignant or invasive cancer**

Angiogenesis
The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (angiogenesis). If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis.

The process of spreading applies to solid tumours such as breast, prostate and bowel. As myeloma starts in the bone marrow, it doesn't follow the same process.
To understand myeloma, it is useful to know a little bit about blood and how it works.

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

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

The different kinds of blood cells are made by the bone marrow, which is the spongy part in the centre of bones. The bone marrow contains stem cells, which are early-stage blood cells that eventually develop into red blood cells, white blood cells or platelets. When stem cells have matured into one of these cell types, they are usually released into the bloodstream.

**Plasma cells**

A plasma cell is a type of white blood cell that is found in the bone marrow. These cells are part of the immune system and help to fight infection by making proteins called antibodies or immunoglobulins. Antibodies attack and kill bacteria and viruses that have infected the body.
A: Myeloma is a type of cancer that develops from plasma cells in the bone marrow.

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

The DNA of plasma cells becomes damaged and this causes the cells to become cancerous. These abnormal plasma cells, known as myeloma cells, divide and spread throughout the bone marrow. The myeloma cells crowd out the bone marrow, so there is not enough space to make enough normal blood cells.

The myeloma cells make an abnormal antibody, known as paraprotein, M-protein or monoclonal protein. This paraprotein reduces the production of normal antibodies and weakens the immune system.

Paraprotein is found in the blood of most people who have myeloma. Part of this antibody can also be found in the urine of some people with myeloma, where it is called Bence Jones protein. See page 8.

As myeloma starts in the bone marrow, it can damage the bones containing the marrow. This can cause several problems. For more information see Controlling symptoms on page 37.
Q: What are the different types?

A: Myeloma is classified according to the type of paraprotein produced by the myeloma cell. This is called immunoglobulin or antibody. The structure of each immunoglobulin (abbreviated to Ig) is made up of two heavy chains and two light chains.

There are five types of heavy chains – G, A, D, E and M – and two types of light chains, represented by the Greek letters kappa (κ) and lambda (λ). IgG is the most common, IgA is second most common, and IgM, IgD and IgE are rare.

- **Light chain myeloma** – About one in five (20%) people with myeloma produce light chains only. This is called the light chain or Bence Jones protein. The light chains show up in the urine and can be measured in the blood using a test called the serum free light chain assay.

- **Non-secretory myeloma** – In less than two out of 100 (2%) people with myeloma, little or no immunoglobulin is produced, making diagnosis more difficult. In most of these people, the serum free light chain assay can detect small amounts of light chains, but heavy chains are not present.

Aside from myeloma, plasma cells can cause other conditions. These non-cancerous conditions can develop into myeloma, but they don’t always do so. The most common plasma cell disorder is monoclonal gammopathy of undetermined significance.
Monoclonal gammopathy of undetermined significance (MGUS)

This occurs when there is raised abnormal protein, but no other features of myeloma. MGUS causes no symptoms, so it is not treated. One out of every 100 people (1%) diagnosed with MGUS every year will develop myeloma.

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. You may have:

- bone pain or a broken bone that has not been caused by an obvious injury
- frequent infections or an infection that is difficult 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
- heavy nosebleeds or easy bruising due to having fewer platelets
- feeling sick, drowsy or confused because of too much calcium in the blood (hypercalcaemia)
- abnormal blood counts as abnormal plasma cells may stop the bone marrow from making enough normal blood cells.

Less common symptoms of myeloma include weight loss or fever.
Q: **What causes myeloma?**
A: The causes of myeloma are unknown. Certain chemicals (e.g. dioxins), radiation and viruses (such as HIV) have been linked to an increased risk of myeloma and related diseases, but they have not been proven to cause it.

Myeloma is not hereditary, which means it does not run in families. It is rare for more than one person in a family to be affected.

Q: **How common is it?**
A: Myeloma is not a common disease. About 1500 people in Australia are diagnosed with the disease each year.

Myeloma usually occurs in people aged 60 and over. It is rare in people under 40. The disease is becoming more common in the elderly, which is partly explained by the ageing population. It is found more often in men than women.
Key points

- Myeloma, also known as multiple myeloma, develops from plasma cells, which are found in the bone marrow.

- In myeloma, the DNA of plasma cells becomes damaged, causing the cells to become malignant or cancerous.

- Myeloma cells make an abnormal antibody called paraprotein. This reduces the production of normal antibodies and weakens the immune system.

- Myeloma is classified according to the type of paraprotein produced by the myeloma cell. This is called immunoglobulin or antibody.

- The immunoglobulin is made up of two heavy chains and two light chains.

- In about 20% of people, the abnormal plasma cells produce only the light chain parts of the paraprotein. This is called light chain myeloma.

- It is often through measuring the level of paraprotein in the blood that myeloma is diagnosed and monitored.

- More rarely, in less than 2% of people, the abnormal plasma cells produce no immunoglobulin making myeloma difficult to diagnose.

- Common symptoms include bone pain, bone fractures, tiredness, frequent infections, kidney damage and a high level of calcium in the blood.

- The exact cause of myeloma is not known, but certain chemicals are known to increase the risk. It is not hereditary.

- Myeloma accounts for 15% of blood cancers and 1% of cancers generally.
Diagnosis

Myeloma is diagnosed using information gathered from several tests. The test results help your haematologist determine the type of myeloma you have and the best treatment plan for you.

Blood and urine tests

**Blood tests** – A number of blood tests are used to diagnose myeloma. The main blood test is called serum electrophoresis and will measure the amount and type of paraprotein in your blood.

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.

You will also have a full blood count done, as well as other blood tests to check for anaemia, for too much calcium in the blood (hypercalcaemia), and how your kidneys are working.

**Urine test** – This will be done to check for the Bence Jones protein, which is made by the myeloma cells. You may have to collect your urine in a container over a 24 hour period.

About two-thirds of people with myeloma make enough Bence Jones protein to be measurable in the urine. These people will have regular urine tests to monitor the myeloma and how well treatment is working, although this test can usually be replaced by the serum free light chain assay (see page 8).
Imaging and scans
Your doctor may use one of these scans to see if you have myeloma and to monitor its effect on your bones.

X-rays
Bone x-rays, sometimes called a skeletal survey, are needed 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-ray beams to take pictures of the inside of your body. While not always used for people with myeloma, a CT scan may be used to see a particular part of the body in more detail or to look for areas of bone damage that may not show up on an x-ray.

Before the test, a special contrast medium may be injected into a vein, probably in your arm, to help make the pictures clearer. This may make you feel hot all over for a few minutes. If there is a risk of allergy to this contrast medium, it won’t be used.

You must let the person doing the CT scan know that you are suspected of having myeloma, as the contrast medium that is injected into your vein can affect the kidneys of myeloma patients.
You will lie on a table that moves in and out of the CT scanner, which is large and round like a doughnut. This painless test takes about 10–30 minutes. Most people are able to go home as soon as their scan is done.

**MRI scan**
A MRI (magnetic resonance imaging) scan can sometimes find myeloma in the bones and outside the bones. It uses a powerful magnet linked to a computer to take detailed pictures of areas inside the body.

You will lie on a table that slides into a metal cylinder. Some people find lying in the MRI scan cylinder noisy and confined. If you feel uncomfortable in confined spaces (claustrophobic), let your doctor or nurse know as they may be able to give you medication to help you feel more relaxed.

**FDG/PET scan**
A FDG/PET (fluoro-deoxyglucose positron emission tomography) scan involves a low-level injection of a radioactive drug, which shows up areas of healthy and abnormal tissue and can detect myeloma outside of the bone marrow. In Australia, this test is not commonly done for myeloma.

**Sestamibi scan**
This scanning technique uses a small amount of radioactive material (radiotracer) to help find myeloma deposits that may not be found by other imaging techniques. In Australia, this scan is not commonly done for myeloma.
**Bone marrow aspirate and trephine biopsy**

A biopsy is used to examine cells from the marrow.

A bone marrow aspirate and trephine biopsy is usually done with a local anaesthetic and a mild sedative. A thin needle is used to remove a sample of bone marrow – usually from the pelvic bone, but sometimes from the chest. While the needle is inside the bone, small pieces of bone and the marrow are removed. This gives the pathologist a better indication of the number of plasma cells present and the damage they have caused to the bone marrow.

After a biopsy you may feel a bit drowsy and have some bleeding from the biopsy site.

A biopsy may also be done at the start and end of each course of treatment to determine how you’re responding to treatment by comparing tissue samples.

**Cytogenetic tests**

Each cell in the body contains chromosomes, which are made up of genes. The 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 the normal cells of the body. Cytogenetic tests can examine the bone marrow biopsy for changes in the chromosomes, which may help to determine treatment and predict how the myeloma might respond.
Stages of myeloma

The results of the blood tests and various scans can help the doctor determine how far the cancer has spread. This is called staging.

Staging the myeloma helps your health care team recommend what treatment is best for you.

The staging system for myeloma has been simplified. Doctors use the International Staging System (ISS), which divides myeloma into three stages based on the results of two blood tests. These blood tests are serum beta-2 microglobulin ($\beta_2$M) and serum albumin.

### International staging system

<table>
<thead>
<tr>
<th>Stage</th>
<th>Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage I</td>
<td>- serum beta-2 microglobulin is less than 3.5mg/L</td>
</tr>
<tr>
<td></td>
<td>- serum albumin is greater than or equal to 35g/dL</td>
</tr>
<tr>
<td>Stage II</td>
<td>- serum $\beta_2$M is less than 3.5mg/L but serum albumin is less than 3.5mg/dL OR</td>
</tr>
<tr>
<td></td>
<td>- serum $\beta_2$M is between 3.5–5.5 mg/L irrespective of serum albumin</td>
</tr>
<tr>
<td>Stage III</td>
<td>serum beta-2 microglobulin is greater than or equal to 5.5mg/L</td>
</tr>
</tbody>
</table>
Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor to predict the exact course of the disease.

Factors used to assess your prognosis include:
- test results
- the type of myeloma you have, its stage and its rate of growth
- how well you respond to treatment
- your age, fitness and medical history.

Treatment for myeloma can help control the disease, manage the symptoms and improve quality of life, but cannot cure it.

CRAB criteria

To help identify people with myeloma who need treatment, doctors often use the CRAB criteria. People without CRAB symptoms may not need treatment but will have active monitoring (see page 23).

<table>
<thead>
<tr>
<th>C</th>
<th>calcium elevation</th>
</tr>
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<tbody>
<tr>
<td>R</td>
<td>kidney (renal) damage</td>
</tr>
<tr>
<td>A</td>
<td>low levels of red blood cells (anaemia)</td>
</tr>
<tr>
<td>B</td>
<td>bone abnormalities/disease (lytic lesions or bone loss)</td>
</tr>
</tbody>
</table>
If the myeloma is under control (also called a plateau phase), people usually return to a state of good health. The good health may last for months or a few years.

For some people, the disease can be controlled for much longer periods. If the disease becomes active again (relapses), further treatment will be needed.

The outlook for people with myeloma is improving constantly, with research developing new treatments and finding ways to use existing treatments more effectively. You may be invited to join a clinical trial (see page 22).

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

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 will arrange further tests and advise you about treatment options.

You will probably be cared for by a multidisciplinary team of health professionals who specialise in different aspects of your treatment.
<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>haematologist</td>
<td>specialises in diagnosing and treating diseases of the blood, the lymphatics and bone marrow</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td>nurses</td>
<td>help administer chemotherapy and provide care, information and support throughout your treatment</td>
</tr>
<tr>
<td>pain management team</td>
<td>specialises in treating pain, particularly if it is difficult to control or severe</td>
</tr>
<tr>
<td>dietitian</td>
<td>recommends an eating plan to follow while you are in treatment and recovery</td>
</tr>
<tr>
<td>social worker</td>
<td>links you to support services and helps you with any emotional, physical or practical problems</td>
</tr>
<tr>
<td>physiotherapist</td>
<td>assists in restoring range of movement after surgery</td>
</tr>
<tr>
<td>occupational therapist</td>
<td>assists in adapting your living and working environment to help you resume usual activities</td>
</tr>
<tr>
<td>counsellor, psychologist and psychiatrist</td>
<td>provide emotional support and help manage anxiety and depression</td>
</tr>
</tbody>
</table>
Key points

• Several different types of tests are needed to diagnose myeloma.

• Tests can help your medical team decide on the best treatment plan and detect complications of the disease so they can be treated.

• Blood tests are used to measure the level of paraprotein present in the blood. Changes in paraprotein levels are an indication of changes in the activity of the myeloma.

• One of the first tests performed is often a bone x-ray (skeletal survey) as myeloma can thin or erode the bones.

• If a clearer picture of the bones is needed, you may have a CT or MRI scan.

• You may have a bone marrow aspirate and trephine biopsy to measure the amount of plasma cells in the bone marrow. This test may also be done at the beginning and end of each course of treatment.

• Staging indicates the amount of myeloma and helps doctors recommend treatment.

• The most recent staging system is the International Staging System. This takes into account beta-2 microglobulin ($\beta_2M$) and albumin.

• Doctors may also use other criteria to identify people who need treatment. The acronym CRAB summarises this criteria: C – calcium elevation R – kidney (renal) damage A – anaemia B – bone abnormalities.

• You will see a team of health professionals who care for you, 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 only offers 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 questions – see page 54 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 www.australiancancertrials.gov.au.
Treatment for myeloma depends on the type and stage of myeloma you have, as well as your general health. The aim is to try and 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** – Some people diagnosed with myeloma do not need treatment straightaway. Early-stage myeloma, also called asymptomatic or smouldering myeloma, develops very slowly, and research has shown that for most people, early treatment does not affect prognosis. However, this is still being researched.

People with early-stage myeloma need regular check-ups. This is called active monitoring. Treatment will start if symptoms occur.

**Treatments to control the myeloma** – This is often called initial or first-line treatment. It usually includes a combination of chemotherapy drugs, plus other drugs, such as thalidomide and steroids. A stem cell transplant may be suggested for some people. You will probably have treatment followed by periods of remission or stable disease (plateau) when no treatment is needed.

**Treatments for the symptoms and side effects caused by myeloma** – Common problems include bone disease, pain, tiredness, frequent infections, kidney damage and hypercalcaemia.

**Treatment if the disease comes back (relapse)** – You may be offered a different type of chemotherapy, stem cell transplant, steroids or other drugs to regain control of the disease.
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 pages 25–27).

Some people can have all their chemotherapy drugs as tablets. Others have the drugs injected into a vein (intravenously) or under the skin (subcutaneously). A hospital stay may be necessary 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.

To learn more about the different chemotherapy combinations for myeloma visit www.myeloma.org.au or the Cancer Institute NSW website at www.eviq.org.au.

Side effects

Some chemotherapy drugs can cause side effects, such as:

- feeling sick (nausea)
- fatigue
- a drop in your blood count
- a weakened immune system
- thinning or loss of hair from your body and head.
The side effects are temporary and there are ways to prevent or reduce them. Tell your doctor or nurse about any side effects you experience. Your doctor may prescribe a break in your treatment or change the kind of treatment you are having.

Some medications can affect how chemotherapy works in your body and may worsen side effects. Some vitamins and supplements can also interact with chemotherapy. Check with your treating doctor or pharmacist, and always let your doctor know of any medications, vitamins or supplements you are taking or planning on taking. For example, green tea and vitamin C should be avoided when having treatment with bortezomib (Velcade®).

For more information, see the Controlling symptoms chapter on pages 37–43. You can also call Cancer Council 13 11 20 to request a free copy of Understanding Chemotherapy or download it from www.cancercouncil.com.au.

**Thalidomide**

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

We now know thalidomide has anti-cancer properties that can be effective for myeloma. It belongs to a group of drugs called immunomodulatory agents (IMiDs). Thalidomide is thought to work by blocking the blood supply to cancerous cells and by stimulating the body’s immune system to attack myeloma cells.
Previously, thalidomide was only an option when other treatments had failed, but it is now used for newly diagnosed patients and also to maintain disease stability in some patients who have responded to therapy.

Thalidomide is given as a treatment either on its own, or more commonly, in combination with a steroid and a chemotherapy drug. It is taken as tablets, usually every day. Most people are also prescribed a blood thinner.

Some possible side effects of thalidomide include:
- drowsiness
- constipation
- rashes
- blood clots
- pain, numbness, tingling and muscle weakness in the hands and feet (peripheral neuropathy) – usually caused by prolonged use or a high dose.

For a copy of the Myeloma Foundation fact sheet on thalidomide call 1800 693 566 or download it from www.myeloma.org.au.

tips
- Take tablet in the evening, as it may make you feel drowsy.
- Maintain a high fibre diet with plenty of fluid. Use a laxative, if necessary.
- Let your doctor know if you get a rash or notice any tingling or numbness. Your doctor may be able to reduce the dose.
**Lenalidomide (Revlimid®)**

A new type of immunomodulator (IMiD) drug called lenalidomide (Revlimid®) works in a similar way to thalidomide. It is commonly used for people with relapsed myeloma. It is often given with a steroid drug, and taken daily as a tablet for three weeks followed by a weeks rest. The cycle is then repeated.

Lenalidomide may lower blood counts and increase your risk of developing blood clots. Many people are prescribed a blood thinner to prevent this.

This treatment does not seem to cause numbness or tingling in the hands and feet (peripheral neuropathy).

**Bortezomib (Velcade®)**

Bortezomib (Velcade®) is a type of drug called a proteasome inhibitor. This means it blocks the breakdown of protein within myeloma cells, causing them to stop growing and die. Your doctor will tell you if this treatment is suitable for you.

Bortezomib is given either as an injection under the skin (subcutaneously) or into a vein (intravenously). Injections are generally given once or twice a week for the first two weeks followed by a 10 day break. It is often given with a steroid and sometimes chemotherapy.

Common side effects include fatigue, diarrhoea, low platelet counts and tingling in the hands and feet (peripheral neuropathy).
Corticosteroids (steroids)

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

The most commonly used corticosteroids include prednisolone and dexamethasone. These may be given on their own or, more commonly, along with chemotherapy or other anti-myeloma drugs. Corticosteroids are most often taken as tablets, but they can also be given intravenously.

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
- weight gain.

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

Bisphosphonates are a class of drugs that reduce bone pain and prevent further bone weakness or damage caused by myeloma cells. They also prevent a dangerous rise in blood calcium levels and improve wellbeing. They also block the activity of the cells that break down the bone.

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

Keep a symptom diary for a few weeks to help you identify side effects. You can also show the diary to your doctor or nurse.

Take steroids in the morning to reduce the risk of sleeplessness.

If it’s difficult to fall asleep, talk to your doctor or pharmacist about taking sleeping pills.

Adapt your activities around your steroid schedule.

Let your family know if you’re using steroids so they’re aware of changes to your mood and energy levels.

Ask your doctor for medication to help you manage the side effects. It may be possible to adjust the steroid dose if the effect on your mood is unmanageable.

Take steroids with food or milk to reduce irritation to your stomach. Your doctor may also prescribe medication to reduce the damage to your stomach.

If you want to reduce your dosage of steroids or stop using them, consult your doctors. Serious withdrawal effects can occur if changes to dosages are not managed.
Bisphosphonates may cause stomach upset. 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.

**tips**

- Have a dental check-up before you take bisphosphonates. Plan to have any invasive dental work done before your treatment starts.
- Talk to your haematologist if you need dental work while taking bisphosphonates – you may be able to have a break in your regime.
- Let your dentist know if you have been taking bisphosphonates.
- See your doctor if you experience mouth ulcers or jaw problems.

**Radiotherapy**

Radiotherapy uses x-rays to kill cancer cells or injure them so they cannot multiply. Treatment is carefully planned to destroy cancer cells while causing as little harm as possible to your normal tissue. Not all people with myeloma will need radiotherapy. The aim of radiotherapy treatment is to relieve some of the symptoms, such as bone pain.

You will lie under a machine that delivers x-ray beams 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.

To learn more, download the *Understanding Radiotherapy* booklet from www.cancercouncil.com.au or call 13 11 20 for a free copy.

**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) and causing symptoms such as blurred vision and decreased alertness.

Plasma exchange is a way of removing some of the extra proteins in the blood using a machine. A needle is placed into a vein in each arm. Blood is slowly removed from one arm and then passed through a separating machine. The healthy portion of the blood, plus new replacement plasma or albumin, is then put back in via the other arm. This process usually takes a few hours.
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 restore blood cell numbers.

This intensive treatment is being used more often 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 infection.

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 if 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, but occasionally they are taken from the bone marrow. Sometimes stem cells from another person are used (allogeneic transplant).

A general transplant process is described here, but the process for your individual transplant may be different because it varies from person to person. A transplant is done in several stages and the entire procedure, including recovery, may take many months.
Collecting the 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). Growth factor drugs are taken for about five 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.

Separating and storing the stem cells

Apheresis involves inserting a needle called a cannula into a vein in one arm to take blood from your body. The blood then passes through a machine called a cell separator, which spins it and removes the stem cells. Your blood is then returned to your body via another cannula placed in your other arm. This can take about 3–4 hours. Sometimes this process is repeated the next day. The stem cells are processed and frozen using liquid nitrogen (cryopreserved). Frozen stem cells can be stored for many years.

You will then have a rest period at home for about a month until the next stage of treatment, which usually requires a hospital stay of 3–4 weeks.

It takes a while to get over the fatigue, but I can honestly say that I feel more like the person I was pre-multiple myeloma thanks to the transplants. That is something I give thanks for every day. Vicki
Receiving the high-dose chemotherapy
High-dose chemotherapy, often referred to as conditioning therapy, is given through a vein. A Hickman catheter or central line is usually used, which is a long, flexible plastic tube.

In the week before the transplant, you will have high-dose chemotherapy, usually melphalan, to kill the myeloma cells and destroy your own blood-forming cells in the bone marrow. Before and after the melphalan is given, you will have large amounts of fluid through a drip to prevent dehydration and kidney damage. You may experience side effects, such as nausea, diarrhoea and mouth sores, from the chemotherapy. Your blood count will also be low, making you more at risk of infections.

Transplanting the stem cells
A day or so after high-dose chemotherapy, your frozen stem cells are thawed and returned to you via a vein. This takes about an hour, and you may have side effects, such as nausea and stomach cramps. These can be managed with medications.

Engraftment
Over the next couple of weeks, 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.

**tip**
Recovery time varies depending on your situation. Talk to your doctor or nurse about what to expect during your recovery.
Side effects

After the transplant your blood count will be low, and you may be more at risk of infections and need transfusions of blood products and intravenous antibiotics. Fatigue and diarrhoea are also common side effects during the engraftment phase. The diarrhoea usually stops by the time you go home, but the fatigue can be ongoing for several months or even up to a year.

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.

Palliative treatment

Palliative treatment helps to improve people’s quality of life by alleviating symptoms of cancer – it is not just about end-of-life care. Often treatment is concerned with pain relief, but it can also involve the management of other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other medication.

For more information about palliative care and advanced cancer, call the Helpline or go to www.cancercouncil.com.au.
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. This is called active monitoring.

- The treatment of myeloma can be grouped into several categories: active monitoring, treatments to control the myeloma and treatments for the symptoms and side effects caused by myeloma.

- You may also have treatment if the disease comes back (relapses).

- Most often, the first treatment people receive includes a combination of chemotherapy drugs, steroids and a drug, such as thalidomide, lenalidomide or bortezomib.

- Some people may have a stem cell transplant to help destroy remaining myeloma cells and improve the length of remission.

- Not everyone is suitable for a stem cell transplant. Talk to your doctor about your situation.

- Some people may be offered palliative treatment. This is given to ease the symptoms of myeloma without trying to cure the disease.
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 the paraprotein in the blood or urine. Some of the treatments described in the previous chapter will manage these symptoms.

**Anaemia**

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

Anaemia may develop for several reasons. Sometimes it develops because of the chemotherapy itself. If this happens, your doctor may suggest that you have 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**

Frequent infections are a common problem with myeloma. If you develop symptoms of an infection (see next page), contact your doctor immediately.

If your white blood cell count falls very low, antibiotics may help prevent infections. There are also drugs called growth factors that can stimulate the body to make more white blood cells.
Taking care with infections

Myeloma, high dose steroids and treatments such as bortezomib, lenalidomide, thalidomide and chemotherapy can weaken your immune system. 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 and willing to do so. You should also ask family or friends with a cold or the flu to wait until they are well before visiting. Of course, this is not practical for people you live with, so use your common sense and try to avoid close contact until they are well.

Contact your doctor or go to the nearest hospital Emergency department immediately if you experience:

- a fever over 38°C (keep a thermometer handy to check your temperature)
- chills or constant shivering
- sweating, especially at night
- burning or stinging when urinating
- a severe cough or sore throat
- vomiting that lasts more than a few hours
- severe abdominal pain, constipation or diarrhoea
- unusual bruising or bleeding, such as nosebleeds, blood in your urine or black bowel motions
- tenderness, redness or swelling around an injection site
- prolonged faintness and a rapid heartbeat
- feeling unwell suddenly, even without a raised temperature.
**Bone disease**
This is one of the most common complications of myeloma.

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 29.

**Pain**
Pain is the most common symptom at diagnosis for people with myeloma. It is often related to bone disease.

Regular reviews by pain management specialists will help keep your pain under control. It’s better to take medication regularly, rather than waiting for the pain to occur.

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 (vertebral body), because it has collapsed.
Complementary therapies, such as relaxation and meditation, can work well when used with pain medication.

Free pain-related resources are available from Cancer Council and the Myeloma Foundation. Call 13 11 20 for a free copy of Cancer Council’s CD *Relaxation for People with Cancer* and the publications *Overcoming Cancer Pain* and *Understanding Complementary Therapies*. You can also visit www.myeloma.org.au to download the *Pain and Myeloma* information sheet.

**Fatigue**

Fatigue, or feeling very tired and lacking the energy to do day-to-day things, is very common in people with myeloma. It can be caused by the cancer itself, and the physical and emotional effects of diagnosis and treatment. Fatigue is different from normal tiredness because it often doesn’t go away with rest or sleep.

Sometimes people don’t tell their doctor about fatigue because they think nothing can be done about it. However, your treatment team may have suggestions to help. Keeping active or some planned exercise can minimise fatigue. You may also want to download the Myeloma Foundation’s *Fatigue and Myeloma* information sheet from their website.

“I think what is shocking for many of us is just how long the fatigue can last. My husband finished treatment a year ago and still feels very tired at times.”

*Lori, carer*
**Kidney damage**

Kidney problems can develop in people with myeloma for a variety of reasons. The abnormal protein produced by myeloma cells can damage the kidneys. This is particularly common with the Bence Jones protein.

Other complications of myeloma, such as dehydration and hypercalcaemia, as well as some of the drugs used to treat myeloma and its symptoms, can also cause kidney damage.

There are many ways to treat kidney damage in people with myeloma depending on the cause. In many cases, the damage is temporary and your 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 (hypercalcaemia)**

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.

**Tips**

- Avoid using pain-killers that contain a non-steroidal anti-inflammatory drug (NSAIDs).
- Drink plenty of water. Aim for 2½ litres every day.
- Treat any infections promptly.
This 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 but may also require treatment in hospital, such as intravenous fluids, steroids and bisphosphonates. Treatment of the myeloma will often help to control the high calcium.

**Brigita’s story**

I was diagnosed with myeloma in late 2003. My doctor prescribed nine chemotherapy cycles, leading up to a stem cell transplant in late 2004. 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.

I’ve also had thalidomide and steroid treatment to reduce the cancer. I had various doses and lots of side effects, but the most difficult thing was that I became very susceptible to infections. Some were serious, and I was admitted to hospital.

Luckily, treatment hasn’t damaged my kidneys. However, I’ve had other side effects. At times, I’ve been so fatigued that my brain can’t seem to think, but on these days, I just take it easy and wait until I feel less dopey. Sometimes a small scrape on my skin turns into a serious infection.

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 something like an infection coming on, I’ve learnt to see my doctor straightaway.
Key points

• Myeloma can affect the body in several ways.

• Not everyone will experience all these symptoms and there are ways to treat them.

• Frequent infections is a common problem with myeloma. Keep an eye out for signs of infection, such as a temperature over 38°C, chills or redness around an injection site. Contact your doctor immediately if you develop any signs of infection.

• Bone disease is one of the most common complications of myeloma. It is usually treated with bisphosphonates.

• 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. Fatigue has many causes, including anaemia. It can be treated with blood transfusions. Ask your doctor about other ways to manage your tiredness.

• Kidney problems can develop in people with myeloma. Drinking plenty of water every day can help prevent kidney damage. In many cases the kidneys recover, but if the problem is permanent, you may need dialysis.

• If you use pain-killers, let the pharmacist know that you need to avoid non-steroidal anti-inflammatory drugs (NSAIDs).

• Excess calcium in the blood (hypercalcaemia) can start to break down some of the bone cells.
Cancer can cause physical and emotional strain. It’s important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food 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** – These 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 or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.
**Relationships with others**

Having cancer can affect your relationships. 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, particularly if taking the drugs thalidomide or lenalidamide. 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 for free copies of Sexuality, Intimacy and Cancer and Fertility and Cancer, or download the booklets from the website.
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 page 49).

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 has information about coping with depression and anxiety. Go to www.beyondblue.org.au or call 1300 224 636 to order a fact sheet.

After treatment: follow-up
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
**If myeloma returns**

If 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 relapse 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 relapsed, and as 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:
- thalidomide-based combination, if not already used as initial treatment
- bortezomib (Velcade®)-based combination
- lenalidomide (Revlimid®)-based combination
- trying a different chemotherapy combination
- undergoing another high-dose therapy and stem cell transplantation
- participating in a clinical trial to access new drugs being developed and tested.

*New treatments are being developed all the time so it’s hard to know what options will be available when a person relapses.*
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 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 offers free legal and financial services in some states and territories 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.
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 even more open and honest in these support settings because they aren’t trying to protect their loved ones.

**Types of support**
There are many ways to connect with others for mutual support and to share information. This includes:

- **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 www.cancerconnections.com.au.

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

> 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
The Myeloma Foundation of 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 the Myeloma Foundation of Australia Myeloma Support Line on 1800 693 566. The Support Line is available 9am to 5pm Monday to Friday, and a myeloma support nurse will answer your call in confidence.

**Support groups**

Find details of myeloma-specific support groups for those affected by the disease by searching the Myeloma Foundation website or calling the support nurses. A telephone support group is available 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 www.myeloma.org.au or by calling 1800 693 566.
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 Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information and resources.

You can also call Cancer Council Helpline 13 11 20 to find out more about carers’ services and to get a copy of the Caring for Someone with Cancer booklet.
The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

**Australian**

beyondblue.................................................... [www.beyondblue.org.au](http://www.beyondblue.org.au)

**Blood cancer specific websites**

Arrow Bone Marrow Transplant Foundation.......... [www.arrow.org.au](http://www.arrow.org.au)
Australian Bone Marrow Donor Registry............... [www.abmdr.org.au](http://www.abmdr.org.au)
Leukaemia Foundation.................................... [www.leukaemia.org.au](http://www.leukaemia.org.au)
Myeloma Foundation of Australia....................... [www.myeloma.org.au](http://www.myeloma.org.au)

**International**

American Cancer Society................................ [www.cancer.org](http://www.cancer.org)
International Myeloma Foundation.................... [http://myeloma.org](http://myeloma.org)
Macmillan Cancer Support............................... [www.macmillan.org.uk](http://www.macmillan.org.uk)
Multiple Myeloma Research Foundation............. [www.themmrf.org](http://www.themmrf.org)
Myeloma UK................................................ [www.myeloma.org.uk](http://www.myeloma.org.uk)
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?
- How far has the cancer spread? How fast is it growing?
- 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 this type of cancer 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?
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 cells are taken from one person and given to another.

amyloidosis
Abnormal deposits of protein called amyloid tissue that can impair the way some organs work.

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. A local anaesthetic numbs a 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 the blood in response to an invader (antigen) in the body. They help protect against viruses, bacteria and other substances.

asymptomatic myeloma
See smouldering myeloma.

autologous stem cell transplant
A transplant where bone marrow stem cells are taken from a person’s body and given back following high-dose chemotherapy.

Bence Jones protein
The name of a protein found in the urine. The protein is associated with myeloma.

benign
Not cancer. Not malignant.

beta-2 microglobulin (β₂M)
A small protein found in the blood. High levels occur in people with active myeloma.

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

bisphosphonate
A type of drug that protects against bone breakdown.

blood
A watery body fluid that flows through the circulatory system. Blood comprises plasma, red blood cells, 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 that produces red blood cells, white blood cells and platelets.

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

central line
A type of thin plastic tube inserted into a vein.

chemotherapy
The use of cytotoxic drugs to treat
cancer cells by killing cancer cells or slowing their growth.

**clinical trial**
A research study that tests new and better ways of improving people’s health.

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

**CT scan**
A computerised tomography scan. This type of scan uses x-rays to create a picture of the body.

**engraftment**
The process by which the transplant stem cells develop into new blood cells.

**granulocyte-colony stimulating factor (G-CSF)**
A growth factor used to stimulate the growth of stem cells before collection 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.

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

**hypercalcaemia**
Higher than normal levels of calcium in the blood.

**immunoglobulin (Ig)**
A protein that is produced by plasma cells. There are five main types: IgA, IgD, IgE, IgG and IgM. They are also known as antibodies.

**light chain**
One of the short protein chains that make up an immunoglobulin. Often referred to as Bence Jones protein when found in the urine.

**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.

**M-band**
See paraprotein.

**monoclonal gammopathy of undetermined significance (MGUS)**
A benign condition that affects the plasma. This condition may increase the risk of developing cancers of the blood such as myeloma.

**myeloma**
Cancer of the plasma cells.

**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.

**osteoarthritis**
A decrease in bone mass causing bones to become fragile or brittle.

**palliative treatment**
Medical treatment to help a patient manage pain and other physical and emotional symptoms of cancer.

**paraprotein**
A substance produced when plasma cells multiply abnormally. Also called M-protein or monoclonal protein.

**pathologist**
A specialist who studies diseases to understand their nature and cause, and interprets the results of tests (such as biopsy or blood count).

**plasma cells**
A type of white blood cell that produces antibodies.

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

**platelets**
One of three 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.

**radiation oncologist**
A doctor who specialises in treating cancer with radiotherapy.

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

**red blood cells**
One of three 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**
The return of a disease after a period of improvement.

**remission**
When the symptoms and signs of the cancer reduce or disappear. A partial remission is when there has been a significant improvement in the cancer. A complete remission is when there is no evidence of active disease.

**serum free light chain assay**
A test that can detect free light chains in the blood serum.

**side effects**
Unintended effects of a drug or treatment.

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

**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 cell transplant**
The replacement of stem cells in the bone marrow after high-dose chemotherapy with healthy stem cells, which have been collected from the blood.

**stem cells**
Early-stage cells from which mature cells develop. Stem cells are found in the bone marrow.

**trephine biopsy**
The removal of a bone tissue sample using a needle.

**white blood cells**
One of three types of cells found in the blood. They help fight infection. Types of white blood cells include neutrophils, lymphocytes and monocytes.
How you can help

At 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 Helpline is a telephone information service provided by Cancer Council NSW for people affected by cancer.

For the cost of a local call (except from mobiles), you can talk confidentially with oncology health professionals about any concerns. Helpline consultants can send you information and put you in touch with services in your area. If you need information in a language other than English, an interpreting service is available.

You can call the Helpline, Monday to Friday, 9am to 5pm.

If you have difficulty communicating over the phone, contact the National Relay Service (www.relayservice.com.au) to help you communicate with a Cancer Council Helpline consultant.

For more information, go to www.cancercouncil.com.au.

### Regional offices

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