Cancer Council

CANCER TYPE

Understanding
Myeloma

A guide for people with cancer, their families and friends

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Note to reader

Cancer Council NSW

Cancer Council stands by everyone living with cancer, protecting life's moments, for life. We support people affected by cancer when they need it most, speak out on behalf of the community on cancer issues, empower people to reduce their cancer risk, and find new ways to better detect and treat cancer. Together we are tackling cancer and leading NSW towards a cancer free future. To make a donation to help fund life-saving cancer research and support services, visit cancercouncil.com.au or phone 1300 780 113.

Cancer Council NSW acknowledges Traditional Custodians of Country and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.

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About this booklet

This booklet has been prepared to help you understand more about myeloma (sometimes called multiple myeloma), a type of blood cancer.

Many people feel 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, this information may answer some of your questions and help you think about what to ask your treatment team (see page 58 for a question checklist).

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 (see page 59). You may also like to pass this booklet to 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.[1, 3]

☎ If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit our website at cancercouncil.com.au.

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Key to icons

Icons are used throughout this booklet to indicate:

🔍 More information

! Alert

💬 Personal story

💡 Tips

Is this Cancer Council booklet helpful?
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SCAN ME

What is blood cancer?

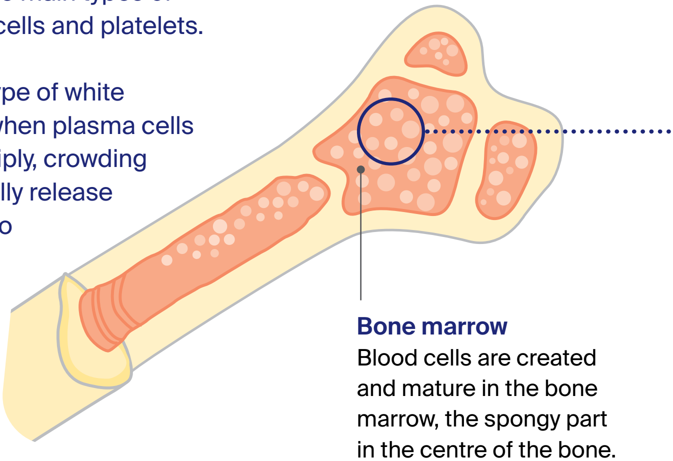
Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as breast cancer, the abnormal cells form a mass or lump called a tumour. However, myeloma is a blood cancer that starts in the bone marrow. Bone marrow is the spongy centre of the bone where blood cells are produced.

How myeloma starts

Bone marrow produces three main types of blood cells: red cells, white cells and platelets.

Plasma cells are a special type of white blood cell. Myeloma starts when plasma cells become abnormal and multiply, crowding the bone marrow. They usually release an antibody (paraprotein) into the blood.

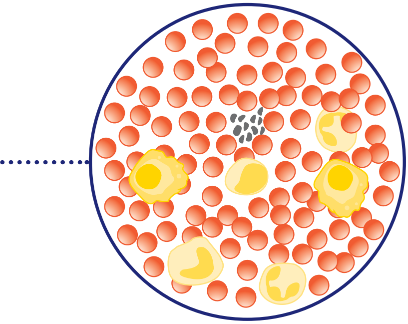


Bone marrow
Blood cells are created and mature in the bone marrow, the spongy part in the centre of the bone.

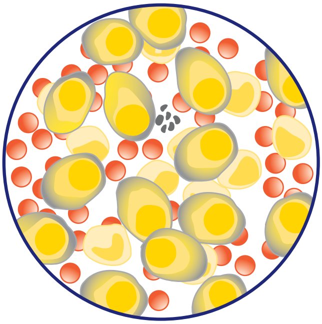
In myeloma, a type of white blood cell, called a plasma cell, changes and becomes abnormal. Healthy plasma cells make antibodies, called immunoglobulins, that protect us from infection.

Without treatment, the bone marrow keeps making more abnormal myeloma cells, leaving less room for normal healthy blood cells. This drop in healthy blood cells and antibodies weakens the immune system and can damage the kidneys. Myeloma can then spread to other parts of the body that contain bone marrow, such as the spine, skull, shoulders, ribs and pelvis.

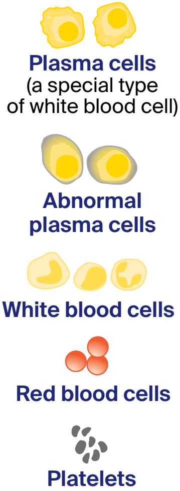
Most myeloma cells produce an abnormal antibody called paraprotein, which enters the bloodstream. Levels of paraprotein usually build up in the blood, and may be detected on a blood test.



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
In myeloma, bone marrow becomes crowded with abnormal plasma cells, leaving fewer normal white blood cells, red blood cells and platelets.

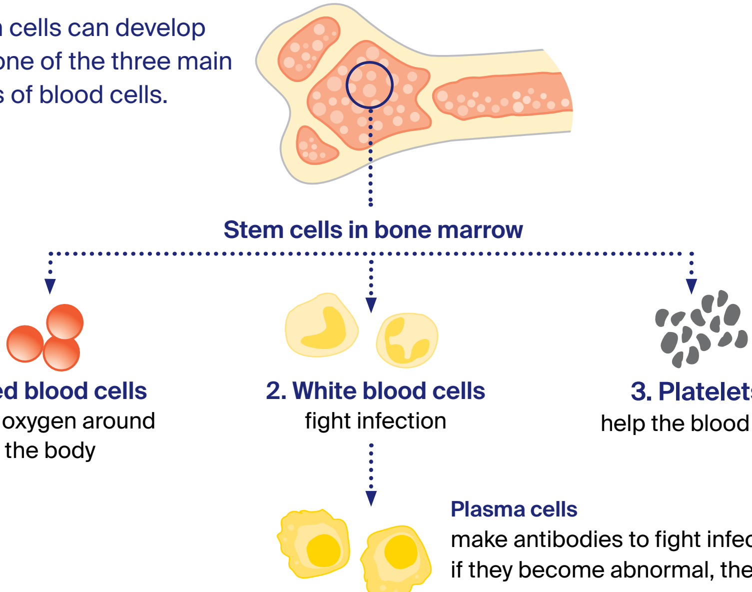


The blood

Blood is pumped around your body to provide oxygen and nutrients to your organs and tissues, and remove waste. It contains red blood cells, white blood cells and platelets – each with its own job to help the body function. All three types of blood cells live for a limited time and need to be continually replaced. Most are made in the bone marrow – the spongy 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, blood cells are usually released into the bloodstream to carry out their jobs.

Stem cells

Stem cells can develop into one of the three main types of blood cells.



Stem cells in bone marrow

1. Red blood cells
carry oxygen around the body

2. White blood cells
fight infection

3. Platelets
help the blood clot

Plasma cells
make antibodies to fight infection; if they become abnormal, they release the antibody paraprotein

Key questions

Q: What is myeloma?

A: Myeloma is blood cancer of the plasma cells that are made in the bone marrow. Because bone marrow is found throughout the body, myeloma can affect multiple areas at the same time, and the disease is often called multiple myeloma.

Myeloma begins when abnormal plasma cells, known as myeloma cells, start multiplying. Normal plasma cells make different types of antibodies to help the body fight infections. Abnormal plasma cells make an antibody known as paraprotein, monoclonal protein or M-protein.

Paraprotein is usually found in the blood of people who have myeloma (see page 13 for more information). However, low levels of paraprotein in the blood may also be a sign of smouldering myeloma (see page 20).

Because myeloma cells crowd the bone marrow, there is less space for normal blood cells to develop and keep you healthy. As a result, a lack of:

- normal plasma cells and other white blood cells makes infections more likely
- red blood cells (anaemia) can cause fatigue
- platelets can cause bleeding and bruising.

Myeloma may also cause growths on the bones called lesions. These can weaken bones and lead to breaks (fractures). This is often how myeloma is first discovered.

Q: How is it different to leukaemia?

A: Myeloma and leukaemia are both types of blood cancer, but they affect the body in different ways. Leukaemia is cancer of the white blood cells, which can be detected on a specific blood test. Myeloma is cancer of the plasma cells, which are found in the bone marrow and not usually detected in the blood.

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.

The most common symptoms of myeloma include:

- bone pain or an unusual broken bone (from a minor impact or not caused by an obvious injury)
- frequent infections or an infection that is hard to shake off
- fatigue or tiredness, shortness of breath or a racing heart, caused by a low level of red blood cells (anaemia)
- kidney problems, which may be caused by excess amounts of paraprotein produced by the myeloma cells. The symptoms of kidney problems may include frothy urine (wee or pee), passing too much or too little urine, nausea (feeling sick), weight loss or fluid retention (puffiness or swelling in the body)
- 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 these changes do not mean you definitely have myeloma. If you are worried or have ongoing symptoms, see your general practitioner (GP).

In rare cases, cancerous plasma cells form a tumour in the bone or tissue, called solitary or multiple solitary plasmacytoma. Unlike myeloma, solitary plasmacytoma produces few or no abnormal plasma cells in bone marrow. Because it is in one area, plasmacytoma is usually treated with radiation therapy. Some people later develop myeloma or another plasmacytoma.

Q: What are the risk factors?

A: DNA is in all cells and carries instructions for how cells work. Plasma cells become cancerous (myeloma) due to certain DNA changes, but it isn't always clear what causes these DNA changes.

Most cases of myeloma have no known cause, but things linked to an increased risk include:

- older age and being male (see *How common is myeloma?* below)
- exposure to certain toxic chemicals, including dioxins used in industry, benzenes, and some chemical herbicides
- being near high levels of radiation
- certain viruses (such as HIV)
- having monoclonal gammopathy of undetermined significance (MGUS, see page 20)
- being overweight (research has shown there may be a link)
- a close family member with myeloma (though it is not hereditary).

Q: How common is myeloma?

A: In Australia, about 2700 people are diagnosed with myeloma each year.[2] Myeloma accounts for almost 14% of blood cancers and less than 2% of all cancers. It is most common in people who are aged over 60. Myeloma can still affect younger people, but it is quite rare in people aged under 40. Myeloma is slightly more common in men than in women.

Q: Which health professionals will I see?

A: Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, such as a haematologist. In some regional areas, people may see a medical oncologist instead. The specialist will arrange further tests.

Health professionals you may see

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
haematologist	diagnoses and treats diseases of the bone marrow, blood and lymphatic system; prescribes chemotherapy and other drug therapies
radiation oncologist	treats cancer by prescribing and overseeing a course of radiation therapy
pathologist	examines cells and tissue samples to determine the type and extent of the myeloma
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
nurse	administers drugs and provides care, information and support throughout treatment

If myeloma is diagnosed, the specialist will consider treatment options (some myeloma may not need treatment). Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

pain management team (including pain specialist and nurses)	work together to treat pain, particularly if it is difficult to control
dietitian	helps with nutrition concerns and recommends changes to diet during treatment and recovery
social worker	links you to support services and helps you with emotional, practical and financial issues
physiotherapist	helps with restoring movement and mobility, and preventing further injury
occupational therapist	assists in adapting your living and working environment to help you resume usual activities after treatment
counsellor, psychologist	help you understand and manage your emotional response to diagnosis and treatment

Diagnosis

Myeloma is diagnosed with a combination of tests on samples of blood, urine and bone marrow. Blood tests, x-rays and other imaging scans are used to check for damage to bones and organs, such as your kidneys, caused by myeloma. The test results also help your doctor work out the type of myeloma you have and the best treatment for you.

Blood tests

You will usually have a full blood count along with other blood tests.

Serum analysis – There are two main blood tests that you are likely to have. Serum protein electrophoresis measures the level of paraprotein in your blood, while serum free light chain assay checks for a form of paraprotein known as free light chains (see opposite page).

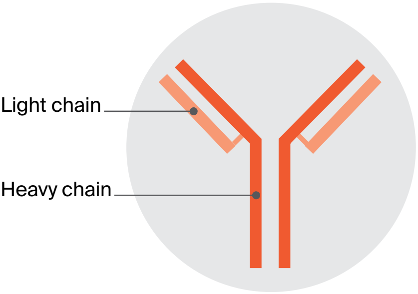
Other blood tests – These check for low red blood cells (anaemia), too much calcium in the blood (hypercalcaemia), inflammation, and how well your liver and kidneys are working.

Once myeloma has been diagnosed, further blood tests will help your doctor work out the stage (see pages 18–19). Levels of paraprotein or free light chains can indicate changes in the activity of the myeloma. Your paraprotein and/or serum free light chain levels will be monitored to see how well treatment is working and to check that the myeloma is stable when you aren't having treatment.

Blood tests are also an important way to check if the myeloma is changing your normal body function.

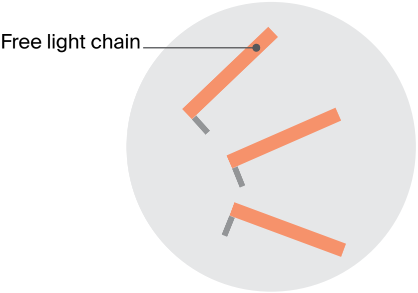
Understanding paraprotein

Myeloma cells produce an antibody 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 found in a urine test. Some people produce both intact paraprotein and free light chains.

Non-secretory myeloma

Although uncommon, some people with myeloma produce little or no paraprotein. This is called non-secretory myeloma. It makes diagnosis and monitoring myeloma more difficult.

Urine and specialised blood tests

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

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

Your doctor may also recommend that you have a specialised blood test called the serum free light chain assay (see *Blood tests,* page 12). This test may be done as well as, or instead of, a urine test, because the Bence Jones protein cannot be detected in a standard blood test.

Bone marrow aspiration and trephine biopsy

These tests are used to examine cells from the bone marrow. They look for an increased number of plasma cells as well as abnormal plasma cells. You will usually have 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. A trephine biopsy, sometimes done with a second needle, removes a small piece of bone with the marrow inside.

The bone marrow samples are sent to a laboratory to be looked at under a microscope. A medical specialist, called a pathologist, will check the number of plasma cells in the sample and look for any damage to the bone marrow caused by myeloma.

Throughout treatment there may be times when bone marrow and trephine biopsies are repeated so that your doctors can see how well the treatment is working.

> After a biopsy, you may feel drowsy and have some bleeding and discomfort at the biopsy site. It is a good idea to have someone drive you home after this test.

Genetic tests

Each cell in the body contains chromosomes, which are threadlike structures that hold sets of instructions known as genes. Every kind of cancer, including blood cancer, changes the genes of the affected cells. These gene faults are not the same thing as genes passed through families. The fault is only in the myeloma cells.

Genetic tests, such as fluorescence in situ hybridisation (FISH) and next generation sequencing analysis, look for abnormal chromosomes or genes in the blood or bone marrow.

There may be changes in the structure of the chromosomes within myeloma cells. Sometimes part of the chromosome breaks off or goes missing (deletion), or reattaches to another chromosome (translocation).

This information is used by your medical team to help guide treatment choices. Some specific chromosomal abnormalities are related to a higher-risk myeloma. Talk to your doctor about whether these tests are likely to be of use in your situation.

Imaging scans

Your doctor will usually arrange imaging scans to check your bones. This may be done using a CT scan, x-rays or an MRI scan. Not all scans are available at all centres, and some scans may not be covered by Medicare. Speak to your doctor about any costs and availability.

CT scans and x-rays

A low-dose CT (computerised tomography) scan of the bones (also called a skeletal survey) is used to find any bone damage caused by the myeloma cells. For the CT scan, you lie flat on a table while the scanner takes detailed pictures of your body. The scan takes about 30 minutes.

Though less common, x-rays may be used instead of a CT scan. X-rays are usually taken of your head, spine, ribs, hips, legs and arms. Areas of bone damage, known as lytic lesions, show up as black shaded areas.

MRI scan

An MRI (magnetic resonance imaging) scan can find myeloma both inside and outside the bones. It uses magnetic fields and radio waves to take detailed cross-sectional pictures of the body. Let your doctor know if you have a pacemaker as the magnetic waves may interfere with it, though newer models do not have this problem.

For an MRI, you will lie on a table that slides into a large machine shaped like a cylinder. The scan may take 30–40 minutes. It is painless but can be noisy. You will be offered earplugs or headphones to listen to music. Some people feel anxious or claustrophobic in the cylinder. If you think you may feel distressed, let your medical team know before the appointment. You may be offered a mild sedative to help you relax.

Dye injection for CT or MRI

CT and MRI scans of organs sometimes involve the injection of a dye (contrast) into a vein, usually in your arm. This dye makes the pictures clearer. Before having scans, tell the person doing the scan that you are suspected of having myeloma, as this dye can damage the kidneys and may not be safe for you. Also, let the medical team know if you have any allergies, if you have had a reaction to contrast during previous scans, if you have diabetes or if you could be pregnant. Skeletal surveys usually don't need any contrast to be injected.

Other scans

In some cases, your doctor may arrange specialised scans, such as a PET–CT (positron emission tomography–computed tomography) or sestamibi (MIBI) scan. Both of these scans involve an injection of a small amount of a harmless radioactive substance, which shows up areas of healthy and abnormal tissue. This may help detect myeloma outside of the bone marrow. Most people with myeloma do not need to have these scans.

Staging myeloma

The tests described on pages 12–17 allow your doctor to work out how far the myeloma has progressed. Called staging, this is an indication of how much the myeloma has affected your body and how it is likely to respond to treatment.

Blood cancers are staged differently to solid tumours like breast or lung cancer. Doctors look at blood test results rather than at the size and spread of the cancer. If you have any difficulty understanding the stage of the myeloma, ask your doctor to explain it in simple terms.

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

The R-ISS divides myeloma into three stages. Stage 1 is the earliest stage and stage 3 is more advanced. The stages are based on the results of various blood tests that check:

- **levels of beta-2 microglobulin (B2M) –** a protein produced by myeloma cells that shows the extent of certain diseases
- **levels of albumin –** a protein produced by the liver that is a sign of overall health
- **levels of lactate dehydrogenase (LDH) –** an enzyme released into the blood when cells are damaged or destroyed
- **genetic information –** specific chromosomal abnormalities that identify people at risk of the disease progressing.

R-ISS staging system of myeloma

stage 1	• B2M is less than 3.5 mg/L • albumin level is 35 g/L or more • LDH levels are normal • genetic test results are considered not high risk
stage 2	• results higher than stage 1 but lower than stage 3
stage 3	• B2M is 5.5 mg/L or more, either LDH levels are high or genetic test results are considered high risk

Significant signs of myeloma

Doctors usually use the CRAB system to help identify people with myeloma who need to start treatment (see next page). The SLiM criteria were added as part of staging and have three specific signs known as biomarkers. When used together, the criteria are known as the SLiM–CRAB criteria.

CRAB criteria: myeloma-defining events	
C	calcium levels in the blood are raised
R	renal (kidney) damage
A	anaemia (low levels of red blood cells)
B	bone pain and damage (areas of damage known as lytic lesions and/or bone loss known as osteoporosis can weaken bones making them more likely to fracture)
SLiM criteria: biomarkers of malignancy	
S	60% or more abnormal plasma cells in the bone marrow (plasmacytosis)
Li	light chain ratio (a high level of free light chains in the blood)
M	MRI lesions (bone abnormalities found by MRI, CT or PET–CT of 5 mm or more in size)

When to start treatment

Test results will help your treatment team work out if, or when, you need to start any treatment.

Category	Test results	Need for treatment
monoclonal gammopathy of undetermined significance (MGUS)	• no SLiM–CRAB features • low level of paraprotein in blood or urine (less than 30 g/L) • low level of myeloma cells in the bone marrow (less than 10% clonal plasma cells)	• not cancer; needs active monitoring (see page 25) as it may progress to myeloma • only about 1% of people with MGUS develop myeloma
smouldering myeloma (asymptomatic myeloma)	• no SLiM–CRAB features • paraprotein in blood (more than 30 g/L) or urine (more than 500 mg), and/or • myeloma cells in the bone marrow (10–60% clonal plasma cells)	• usually doesn't need treatment straightaway • may progress to active myeloma, needs active monitoring (see page 25)
active myeloma (symptomatic myeloma)	• has SLiM–CRAB features • high level of paraprotein in blood or urine • one of the following: myeloma cells in the bone marrow (more than 60% clonal plasma cells); ratio of abnormal to normal light chains is less than 100; abnormal MRI with more than one (greater than 5 mm) focal lytic lesion (bone lesion)	• active myeloma requires treatment (see pages 25–38)

Prognosis

Prognosis means the expected outcome of a disease. It is not possible for any doctor to predict the exact course cancer will take, but your medical team can predict how the myeloma will respond to treatment based on several factors:

- your test results
- the type of myeloma you have, and its stage and rate of growth
- your age, fitness and medical history.

You will continue to have tests during treatment to check how well it's working.

The outlook for people with myeloma is improving all the time. Even though treatment can't cure myeloma, it can help control the disease (known as plateau phase or remission).

If the myeloma is under control, symptoms improve and 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 even longer periods.

When myeloma becomes active again it is called disease progression, or a relapse or recurrence. You will need to have further treatment when this happens (see pages 51–52).

> Living with myeloma may make you feel anxious. It can help to talk to a myeloma support nurse, or contact the hospital social worker or psychologist for support. You can also speak to other people who have myeloma (see page 54). Call Cancer Council on 13 11 20 for links to support.

Key points about diagnosing myeloma

What it is	Myeloma is a type of blood cancer that develops from plasma cells in the bone marrow.
Main tests	The main tests to diagnose myeloma are: • blood and urine tests to measure the level of paraprotein • bone marrow tests to measure the level of myeloma cells • genetic tests may sometimes be done on the bone marrow sample. These tests may also be done at the beginning and end of each course of treatment.
Other tests	• You are likely to have a bone CT or x-ray (usually a skeletal survey) to look for areas of bone damage (lytic lesions). • If a clearer picture of the bones is needed, you may have an MRI or PET-CT scan. • These tests let your doctor classify the myeloma. – MGUS is not cancer but may progress to myeloma. – Smouldering (asymptomatic) myeloma does not have symptoms. – Both MGUS and smouldering myeloma need active monitoring. – Active myeloma (also known as symptomatic myeloma) requires treatment. • The SLiM-CRAB criteria are two sets of signs that help doctors decide when myeloma has become active and requires treatment.
Staging	This shows how much the myeloma has affected your body and how likely it is to respond to the treatment you may have.

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, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a short time. Ask them to explain the options, and take what time you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 11) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 58 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

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

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.
▸ See our *Cancer Care and Your Rights* booklet.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.
▸ See our *Understanding Clinical Trials and Research* booklet.

Treatment

The treatment you have for myeloma depends on individual factors, such as the type and stage of the cancer, your symptoms and your general health. As myeloma usually can't be cured, the aim is to control it and then keep it under control for as long as possible.

Treatment options

Active monitoring – People who have been diagnosed with either monoclonal gammopathy of undetermined significance (MGUS) or smouldering myeloma (see page 20) don't usually need treatment straightaway. You will need check-ups every 3–12 months, depending on your level of risk. Your doctor will start treatment if you develop symptoms or other significant signs of myeloma.

It is estimated that about 5% of people aged 70 years and over have MGUS, but most will never develop active myeloma.

In most cases of smouldering myeloma, having treatment as soon as you are diagnosed does not offer any benefit. A small number of people with high-risk smouldering myeloma may benefit from early treatment. Talk to your doctor about what would be best for you.

Treatment to control active or symptomatic myeloma – This may be called induction, first-line or upfront treatment. It includes a combination of different medicines (see pages 27–31). A stem cell transplant may be suggested for some people (see pages 31–33). Active treatment is often followed by periods of stable disease (plateau phase or remission) when no maintenance therapy or treatment is needed.

Treatment for symptoms and side effects of myeloma – These help issues such as bone disease, pain, kidney damage, hypercalcaemia, frequent infections and fatigue (see pages 34–37 and 39–46).

Treatment to prevent the disease returning – This is called maintenance or consolidation therapy. It uses a longer, lower-dose course of an immunomodulator, such as lenalidomide, and steroids or other drugs. These are often used after a stem cell transplant and sometimes used after other first-line treatments (see pages 28–31).

Treatment when the disease comes back – You may be offered a different type of chemotherapy, a stem cell transplant, steroids or other drugs to regain control of the disease. Clinical trial treatments may also be available, so ask your doctor if they would benefit you.

Combining drug therapies

Most people with myeloma will be treated with a combination of two, three or more different drugs.

The combinations may include therapies called immunomodulators, proteasome inhibitors, monoclonal antibodies or immunotherapy (discussed on pages 28–31), as well as traditional chemotherapy drugs and steroids.

Combinations of drugs are used because each type of drug works differently to kill myeloma cells, and the combined effect helps treat as much of the disease as possible.

The choice of a particular drug combination will depend on things like the type of myeloma you have, your age and your kidney function. Your haematologist will select the most suitable combination and discuss this with you.

To learn more about the different drug combinations for myeloma, visit myeloma.org.au or eviq.org.au.

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, doxorubicin and cyclophosphamide.

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). You may need to stay in hospital while having some chemotherapy treatments, but this stay is usually short. Your doctor will tell you about the drugs you are having and how long treatment will last.

You may have chemotherapy in combination with other treatments, such as one of the immunomodulator drugs used for myeloma (see the next 2 pages).

Side effects – Some chemotherapy drugs can cause side effects, such as feeling sick (nausea), fatigue, hair loss, a drop in blood count, mouth sores, diarrhoea and a weakened immune system. In some cases, people may develop peripheral neuropathy (tingling in hands and feet, see page 46) after chemotherapy.

These side effects are temporary and there are ways to prevent or reduce them. Tell your doctor or nurse about any side effects that 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 *Managing symptoms and side effects* chapter, pages 39–47.

▸ See our *Understanding Chemotherapy* booklet.

Proteasome inhibitors

Proteasome inhibitors are chemotherapy drugs that block the breakdown of protein within myeloma cells, causing them to stop growing and die. Commonly used proteasome inhibitors for myeloma include bortezomib and carfilzomib. Other drugs may be accessed in certain circumstances.

How they are given – Bortezomib is given as an injection under the skin or into a vein. It is often used together with steroids and chemotherapy. Carfilzomib is given intravenously.

Side effects – Bortezomib and carfilzomib may cause fatigue, diarrhoea, nausea, constipation, low blood counts, infections and shingles. If you have unusual bruising or bleeding, pink urine, or nosebleeds, let your doctor know. Also tell them if you take aspirin, ibuprofen or naproxen. Peripheral neuropathy (see page 46) is common with bortezomib but rare with carfilzomib. Carfilzomib may cause high blood pressure or heart problems, or worsen pre-existing heart conditions.

Immunomodulators

Immunomodulator drugs work by blocking the growth signal for cancer cells and stimulating the body's immune system to attack the cancer. The most common immunomodulators for myeloma are thalidomide, lenalidomide and pomalidomide. Thalidomide is an old drug that 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 that thalidomide has anti-cancer properties that can be effective for myeloma. Lenalidomide and pomalidomide are newer types of immunomodulators.

How they are given – Immunomodulators are most often given in combination with a steroid and a chemotherapy drug. They are taken as tablets, usually every day or for a certain number of days each month. As some immunomodulator drugs increase the risk of blood clots, your doctor may advise you to take a blood thinner.

Side effects – Possible side effects of immunomodulators include drowsiness, constipation, nausea, diarrhoea, rashes, blood clots, low blood count and a weakened immune system.

Thalidomide may cause pain, numbness, tingling and muscle weakness in the hands and feet. This is called peripheral neuropathy (see page 46). It is not a typical side effect of lenalidomide or pomalidomide.

> It is very important that you do not get pregnant if you are taking immunomodulators. The fetus would develop serious abnormalities. Sperm is also affected, so men should not conceive a child or donate sperm. If you want to have children, talk to your doctor about fertility options before treatment starts.

Monoclonal antibodies

Monoclonal antibodies are made in a laboratory but behave like natural antibodies that fight infection and disease. They target cancer cells and interfere with how they grow and survive. Available drugs include daratumumab and elotuzumab (in combination with lenalidomide).

How they are given – Monoclonal antibodies are injected into a vein (intravenously) or under the skin (subcutaneously).

Side effects – As these drugs are often given as an injection, they may cause an allergic reaction. Other possible side effects include a fever, nausea, diarrhoea and low blood pressure.

What is CAR T-cell immunotherapy?

At publication time (August 2024), CAR (chimeric antigen receptor) T-cell immunotherapy may be available to some people who have relapsed myeloma, or when other treatment has not worked. It may be available to some people with myeloma through clinical trials. Talk to your doctor about whether a clinical trial may be an option for you.

How it works – T-cells are part of the immune system and their job is to hunt down and attack abnormal cells in the body. For CAR T-cell immunotherapy, a blood sample is taken and T-cells are extracted from the blood. The T-cells are modified to target myeloma and then injected back into the body where they identify and attack myeloma cells.

Steroids

Steroids (sometimes called corticosteroids or glucocorticoids) are hormones made naturally in the body. They can also be made artificially and used as drugs. These drugs modify how the immune system reacts, relieve inflammation, and actively kill myeloma cells.

How they are given – The typical steroids used for myeloma are dexamethasone and prednisolone. These are usually given with chemotherapy or other anti-myeloma drugs. Steroids are most often taken as tablets but can also be given intravenously. They are usually given in high doses, but for short amounts of time.

Side effects – Common side effects include difficulty sleeping, mood changes, increased appetite, fluid retention, heartburn, infections and weight gain. Take steroids in the morning with food or milk to help with sleep problems or an upset stomach. Some steroids may cause diabetes if used for a long time. Stopping steroids suddenly can cause problems, so talk to your doctor if you want to change your dosage.

Stem cell transplant

You may be offered a stem cell transplant. This is when diseased blood cells are destroyed by high-dose chemotherapy and replaced with blood stem cells. This is also known as high-dose therapy and stem cell rescue. It aims to destroy as much remaining myeloma as possible and increase the length of the plateau phase (remission). Usually your own stem cells are used for this procedure, which is called an autologous transplant. If donor stem cells are used, it's an allogeneic transplant.

An autologous transplant is done in several stages. Before the process begins, you have induction treatment to put the myeloma into a plateau phase. The stem cells are then removed and frozen. Next, you have high-dose chemotherapy, followed by the return of your stem cells. See the next 2 pages for a detailed description of this process.

Although a stem cell transplant can help some people, it is not suitable for everyone. The high-dose chemotherapy that is given before the transplant can have a lot of side effects. To work out whether a stem cell transplant is suitable for you, your haematologist will consider your general health, age, the type of myeloma you have, how fast it is growing and how it responds to treatment. The risks and benefits will be discussed with you.

Stem cell transplants are available only at some hospitals, so you may need to be referred to another hospital. The entire procedure, including recovery, can take months or up to a year.

For an overview of what to expect at every stage of your cancer care, visit cancer.org.au/cancercareguides/multiple-myeloma. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Steps in an autologous stem cell transplant

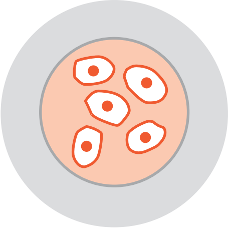
This is a general outline of a transplant using your own stem cells, but the process varies. Talk to your transplant team about what to expect.

1. Stem cells stimulated

The first step is to help the body make more stem cells. You'll usually have a dose of chemotherapy followed by injections of a growth factor drug called granulocyte-colony stimulating factor (G-CSF) for 5–10 days. You can often have these injections at home.

G-CSF helps the stem cells multiply and move out of the bone marrow into the blood. This process is called mobilisation and it takes several days. Blood tests will show whether your blood has made enough stem cells for collection.

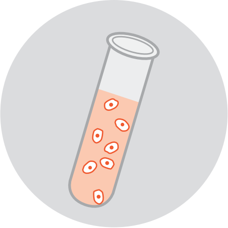
2. Stem cells collected



Stem cells are collected from your blood using a process called apheresis. You will have a needle called a cannula inserted into a vein in each arm, or you may need a special tube called a central line surgically inserted into your chest or neck.

During apheresis, blood is taken from your body, passed through a machine to remove the stem cells, and then returned to your body. This takes 3–4 hours and is usually done during a day visit to the hospital.

3. Stem cells preserved

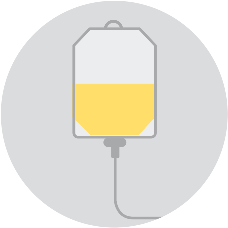


The stem cells are frozen using liquid nitrogen. This is known as cryopreservation.

You will have a rest period at home for about a month before the next step.

More detailed information about stem cell transplants is available from Myeloma Australia at myeloma.org.au.

4. High-dose chemotherapy



In the week before the transplant, you'll go to hospital for high-dose chemotherapy (sometimes called conditioning treatment) to kill any remaining myeloma cells. This will also destroy the stem cells in the bone marrow, making room for new stem cells to grow.

Side effects will be similar to those of standard chemotherapy but can be more intense. They may include nausea, diarrhoea, mouth sores, flu-like symptoms and high risk of infections (see page 27).

5. Stem cells transplanted

A day or so after you have high-dose chemotherapy, your frozen stem cells are thawed and put back into your body (reinfused) using an intravenous drip. This process is similar to a blood transfusion and takes about an hour.

You may have stomach cramps and feel sick (nauseous), which can be managed with medicines. You may also notice a "sweet corn" smell as the body flushes out the preservative used to freeze the stem cells.

6. Engraftment

Over the next couple of weeks, the new stem cells will develop into new blood cells, allowing your bone marrow to recover. This is called engraftment.

While the stem cells engraft, you're at risk of infection. In most cases, you will stay in hospital for 1–3 weeks until your blood counts have returned to safe levels and you're well enough to go home.

Once home, you'll need check-ups every week or so. Over time, you'll need check-ups less often.

Supportive treatment

You may have some treatments that do not target the myeloma itself, but help to treat symptoms caused by the myeloma. Antibiotics and antiviral drugs may be given to prevent infections, and blood-thinning tablets or injections may be used to prevent blood clots.

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

Bisphosphonates

Bisphosphonates are a group of drugs that help to strengthen the bones and reduce bone pain by preventing further bone weakness or damage caused by myeloma cells. They also help to control high calcium levels in the blood (hypercalcaemia, see page 42). You will need regular blood tests to monitor your calcium levels and kidney function before and while you are taking bisphosphonates.

How they are given – Several types of bisphosphonates are used for myeloma. They are usually given by an injection into the vein, but sometimes given by tablet.

Side effects – Bisphosphonates can cause stomach upset. You may feel sick, or you may also have constipation or diarrhoea for a few days.

An uncommon but severe side effect associated with long-term bisphosphonate use is osteonecrosis of the jaw or ONJ. This causes bone tissue in the jaw to break down, leading to pain and infection. It is important to see your dentist for a check-up and have any invasive dental work done before you start treatment. Keep up good dental hygiene by brushing and flossing twice daily, and see the dentist for yearly check-ups. If you need dental work during treatment, let your dentist know that you are taking bisphosphonates and ask your haematologist whether it's possible to have a break in treatment. If you have a tooth removed, you'll have a break from bisphosphonates for 1–3 months until your gum is healed. This is to prevent ONJ.

Radiation therapy

Radiation therapy (also sometimes called radiotherapy) uses a controlled dose of radiation to kill or injure cancer cells. The radiation is usually in the form of focused x-ray beams. Treatment is carefully planned to destroy the cancer cells while causing as little harm as possible to normal tissue.

Not all people with myeloma will need radiation therapy. It is used to relieve symptoms, such as bone pain, or to prevent bones from breaking by reducing the number of myeloma cells in the bones.

How it is given – You will lie under a machine that delivers the radiation to areas with myeloma cells. Each treatment takes only a few minutes, but the first appointment, known as planning or simulation, can take 1–3 hours. Radiation therapy may be given as a single dose, or as multiple doses over several days or weeks. You will visit the radiation therapy centre for each of your radiation treatments, rather than staying overnight.

Side effects – Radiation therapy 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 of these side effects go away within days to weeks of treatment finishing. Tell your radiation oncology team about any side effects you may have.
▸ See our *Understanding Radiation Therapy* booklet.

Immunoglobulin replacement therapy

Most people with myeloma have low levels of normal antibodies, which means they are more likely to get infections. You may have a process called immunoglobulin replacement therapy (IRT) to boost your antibody levels and protect you against infections. Whether you need this therapy will depend on if you have had repeated infections and also on the level of any remaining normal antibodies in your blood.

How it is given – Immunoglobulin is produced from blood donor plasma and can be injected into a vein (intravenously) or under the skin (subcutaneously). When delivered intravenously, each treatment takes 2–4 hours and most people receive one dose a month. When given subcutaneously, it takes about 30 minutes and is delivered by a pump or a slow injection. It's often possible to give yourself subcutaneous treatment at home, once you have been shown how to do so.

Side effects – Side effects are uncommon but may include a headache, low-grade fever, nausea, diarrhoea or reaction at the injection site. Side effects are more common with the first treatment and are temporary.

Plasma exchange

If the level of paraprotein in the blood is very high, it makes the blood thicker and slower to circulate (see page 43). This causes symptoms such as blurred vision and confusion, but a plasma exchange may help. The plasma is the clear fluid that carries blood cells around the body and contains much of the extra paraprotein.

How it is given – A needle is placed into a vein in each arm. Blood is removed from one arm and passed through a machine that separates it into each of the blood components. The plasma is removed and replaced with plasma from a donor, or a plasma substitute such as albumin (a blood protein). The blood is then returned to the body via the other arm. The process usually takes a few hours and is not painful.

Side effects – Sometimes people can feel faint or light-headed, so eat normally before the treatment. Blood pressure may fluctuate, so before treatment tell your treatment team if you are on any medication.

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 cancer symptoms. 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, radiation therapy, chemotherapy or other drug therapies. Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, cultural, social and spiritual needs.

▸ See our *Understanding Palliative Care* booklet and listen to our podcast *The Thing About Advanced Cancer*.

New drug therapies

New drug therapies are being developed all the time, including antibody drug conjugates, BCL2 inhibitors, and selective inhibitors of nuclear exports (SINE). At the time of publication (August 2024), the Pharmaceutical Benefits Scheme (PBS) only covers the cost of some newer drugs for myeloma (e.g. the SINE drug Selinexor). If your doctor thinks there is a promising treatment for you, ask about clinical trials or compassionate access schemes that may help with costs.

Key points about treating myeloma

Main treatments	Treatment for myeloma is highly individual and depends on the type and stage of myeloma. You may have: • active monitoring – not everyone diagnosed with myeloma needs treatment straightaway. 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 • first-line treatment to control the myeloma – this is usually a combination of chemotherapy drugs, steroids and another type of drug, such as thalidomide, lenalidomide or bortezomib • supportive treatment for symptoms and side effects – this may include bisphosphonates, radiation therapy, immunoglobulin replacement therapy and plasma exchange • maintenance treatment to prevent the myeloma coming back – this may include immunomodulators, steroids or other drugs.
Other treatments	• While not suitable for everyone, some people will have a stem cell transplant to help destroy any remaining myeloma cells and improve the length of the plateau phase (remission). • Palliative treatment can help to ease the symptoms of advanced myeloma.

Managing symptoms and side effects

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 paraprotein in the blood or urine. This chapter discusses how to manage these symptoms. Your health care team may call these supportive treatments.

Bone disease

Bone disease is one of the most common side effects experienced by people with myeloma. The myeloma cells release chemicals that damage the cells that normally repair damaged bone. When this happens, bone breaks down faster than it can be repaired, causing bone pain, bone damage (lytic lesions), or even fractures. The middle or lower back, the rib cage and the hips are the most frequently affected areas.

The rapid breakdown of bone can lead to an increase in blood calcium levels (hypercalcaemia). For more information, see page 42. 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 (see page 34).

> *“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

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 or palliative care specialists will help keep pain under control. It's better to take pain medicine regularly, rather than waiting until you feel pain.

Some people may need further treatment to manage pain. This may include localised radiation therapy or other procedures.

Tips for managing pain

- Tell your treatment team if you are experiencing pain – don't wait for them to ask.
- Complementary therapies, such as relaxation and meditation, sometimes work well when used along with pain medicine.
- Talk to a psychologist about cognitive behaviour therapy (CBT). This approach aims to change how you feel pain by changing your thoughts.
- Visit Myeloma Australia at myeloma.org.au/resources to download the *Pain and Myeloma* information sheet.
- Listen to our *Finding Calm During Cancer* podcast series and the "Managing Cancer Pain" episode in our *The Thing About Cancer* podcast available from cancercouncil.com.au/podcasts.
- Read our *Understanding Cancer Pain* and *Understanding Complementary Therapies* booklets. You can find the booklets at cancercouncil.com.au.

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, or by the physical and emotional side 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

- Try to keep as active as possible. See Cancer Council’s *Exercise for People Living with Cancer* booklet.
- Plan your activities for the time of day when you tend to feel most energetic.
- If you’re having trouble sleeping, try some relaxation and meditation exercises. Call Cancer Council 13 11 20 for resources that may help.
- Fatigue is common during cancer treatment, but it can also be a symptom of depression (see page 50).
- Download Myeloma Australia’s information sheet on fatigue from myeloma.org.au/resources.
- Listen to our “Managing Cancer Fatigue” podcast episode available at cancercouncil.com.au/podcasts.
- Find more information in the *Understanding Fatigue and Cancer* fact sheet available at cancercouncil.com.au.

Kidney damage

Kidney problems can develop in people with myeloma for several reasons. The paraprotein produced by myeloma cells can cause blockages or inflammation and damage the kidneys. This is common with the Bence Jones protein (see page 14). Other complications of myeloma, such as dehydration, infection and hypercalcaemia, can also damage the kidneys, as can some of the drugs used to treat myeloma and its symptoms.

People with myeloma should try to drink enough fluids. Along with water, try tea, coffee, juice and milk. Ask your doctor whether you should also avoid pain medicines containing a non-steroidal anti-inflammatory drug (NSAID), because these can also damage the kidneys. It is important to treat any infections quickly (see pages 44–45) to limit further stress on the kidneys. Also ask your doctor if you should avoid contrast dye during CT or MRI scans.

The treatment for kidney damage in people with myeloma will depend on the cause. Your doctor may decide to change your treatment. Often, damage is temporary and the kidneys can recover. In some people, kidney problems are permanent and require dialysis. This is a way of filtering the blood using a machine.

High calcium levels in the blood

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

People with hypercalcaemia need to drink extra fluids. However, they might also need to have 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 building up 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 syndrome.

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 36) can quickly remove the excess paraprotein from the blood and improve 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 treatment itself. If anaemia is causing significant symptoms, 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.

Brigita's story

When I was diagnosed with myeloma, my doctor prescribed 9 chemotherapy cycles leading up to a stem cell transplant 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... Luckily, all the treatment hasn't damaged my kidneys, but I have other side effects. At times, I've been so fatigued 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... when I feel like an infection is coming on, I've learnt to see my doctor straightaway.

Infections

Many of the active drug therapies, such as high-dose steroids, and treatments such as immunomodulators, proteasome inhibitors and chemotherapy, can weaken your immune system. This makes you more likely to get infections and less able to fight them.

You may be given antibiotics or antiviral drugs to prevent infections and help avoid illness. It is advised you keep vaccinations up to date (ask your doctor which vaccines are safe for you).

If your white blood cell count falls very low, it's important to treat infections with appropriate antibiotics immediately. You may also be given a course of the special growth factor drug G-CSF and, if you have repeated infections, intravenous immunoglobulins (antibodies).

Taking care with infections

Ways to reduce your risk

To prevent the spread of infection:

- check with your doctor about having COVID-19, flu and pneumococcal vaccines
- ask people close to you to consider having COVID-19 and flu vaccines
- ask family and friends with COVID-19, cold, flu or other contagious infection (e.g. chickenpox, measles or a cold sore) to wait until they are well before visiting
- as far as practical, avoid close contact with people you live with if they are unwell
- try to avoid crowded places, such as shopping centres or public transport in peak hour
- wash your hands thoroughly with soap and water before preparing food, eating and after using the toilet
- prepare and store food properly to avoid foodborne illness and food poisoning
- eat freshly cooked foods; avoid raw fish (sushi), undercooked meat, raw eggs, seafood, soft cheeses and pre-made salads; wash fruits and vegetables well before eating.

When to seek medical help

Contact your doctor or nurse or go to the nearest emergency department immediately if you have any of these symptoms:

- a temperature of 38°C or higher
- chills or shivering
- sweating, especially at night
- burning or stinging when peeing
- a severe cough or sore throat
- shortness of breath
- vomiting that lasts more than a few hours
- severe abdominal pain, constipation or diarrhoea
- unusual bleeding or bruising, such as nosebleeds, blood in your urine or black bowel motions (poo)
- sores in your mouth or around your gums
- redness at a wound site or any cuts
- prolonged faintness or dizziness and a rapid heartbeat
- any sudden deterioration in your health.

Nerve and muscle effects

Many people with myeloma develop tingling ("pins and needles"), pain or numbness 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.

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 as you are more likely to fall if your feet are numb, if you have tingling or if 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 or soak your hands and feet in warm water.
- Wear comfortable and properly fitting shoes. Tight shoes can make the tingling worse, while loose shoes may make you more likely to stumble.
- If your symptoms are severe, talk to your doctor about whether you can take any medicines that may offer relief.
- Read our *Understanding Peripheral Neuropathy and Cancer* fact sheet available at cancercouncil.com.au, or visit Myeloma Australia at myeloma.org.au to read the *Managing Peripheral Neuropathy* booklet.

Key points about symptoms and side effects

Common symptoms and side effects

- Bone disease – This is usually treated with drugs called bisphosphonates.
- Pain – This is often linked to bone damage that has been caused by the disease.
- Extreme tiredness and lack of energy (fatigue) – This is a common side effect that may last for weeks or months.
- Kidney problems – The kidneys usually recover, but if the damage is permanent, you may need to have dialysis.
- Excess calcium in the blood (hypercalcaemia) – This can cause symptoms such as tiredness, nausea, constipation, bone pain and confusion.
- Thicker blood – This can be caused by paraprotein being released into the blood.
- Anaemia – The myeloma itself and chemotherapy treatment can both lead to low levels of red blood cells (anaemia).
- Frequent infections – Contact your doctor or hospital immediately if you develop a temperature of 38°C or higher, or have other signs of infection.
- Peripheral neuropathy – Symptoms include tingling, pain, and numbness of fingers and toes and muscle weakness in the legs.

Managing symptoms and side effects

Talk to your treatment team about any symptoms or side effects that you have. They may be able to suggest strategies or adjust your treatment.

Looking after yourself

Myeloma can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit cancercouncil.com.au.

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.
▸ See our *Nutrition for People Living with Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.
▸ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.
▸ See our *Understanding Complementary Therapies* booklet.

> Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the myeloma and can be harmful. Cancer Council does not recommend the use of alternative therapies as a myeloma treatment.

Work and money – Myeloma can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▸ See our *Cancer and Your Finances* and *Cancer, Work and You* booklets.

Relationships – Having myeloma can affect your relationships with family, friends and colleagues in different ways. Myeloma is stressful, tiring and upsetting, and this may strain relationships. The experience of having myeloma may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

▸ See our *Emotions and Cancer* booklet.

Sexuality – Myeloma 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.

▸ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▸ See our *Fertility and Cancer* booklet.

Life after treatment

For most people, the myeloma experience doesn't end on the last day of treatment. Life after myeloma treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the myeloma is coming back.

Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have myeloma, and provide you with information about the emotional and practical aspects of living well after myeloma treatment.
▸ See our *Living Well After Cancer* booklet.

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 myeloma.

Talk to your GP, because counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline 13 11 14 or visit lifeline.org.au.

Follow-up appointments

You will need regular check-ups, even if you don't have any treatment for myeloma. Blood tests, urine tests, and bone marrow biopsies will be used to check your health. Sometimes x-rays and scans such as PET-CT or MRI may also be used. Your doctor may check the levels of antibodies and proteins in the blood and urine.

This is a good chance to discuss how you're feeling and mention any new symptoms or concerns you may have. When a follow-up appointment or test is approaching, many people find that they think more about the myeloma and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Check-ups will become less frequent if your condition has stabilised or you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

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

What if the myeloma returns?

For many people, myeloma does come back after treatment, which is known as disease progression or relapse. This is why it's important to have regular check-ups.

You and your doctor will need to discuss what treatment is needed to try to regain control of the disease (see next page).

While options for managing disease progression 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. The disease characteristics and how you feel about treatment 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 for resistant disease may include:

- taking a different combination of drugs
- treatment with a different class of drugs
- having another stem cell transplant
- participating in a clinical trial to access new drugs being developed and tested, such as CAR T-cell or bispecific immunotherapy.

New treatments are being developed all the time, so if the myeloma comes back, talk to your doctor about what treatment options are available.

Seeking support

A myeloma diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Myeloma also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the myeloma experience, including:
- information about myeloma and its treatment
- access to benefits and programs to ease the financial impact of myeloma treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

> *“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

Support from 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 professionals through its specialist myeloma support nurses.

Myeloma specialist support nurses – If you are a person living with myeloma, a carer, family member or friend, and you need support or information about any aspect of myeloma and its treatment, you can talk to a specialist myeloma nurse. Visit myeloma.org.au to book a time for a nurse to call you. If you prefer, you can call Myeloma Australia for free on 1800 MYELOMA (1800 693 566) Monday to Friday 9am–5pm (AEST) to book a time for a nurse to call you.

Support groups – Find a myeloma support group, or carer support group, by searching the Information and Support Groups section of Myeloma Australia's website at myeloma.org.au, or call 1800 693 566.

In NSW, a telephone support group is available through Cancer Council for those unable to attend a group in person. To find out more, call 13 11 20 or visit cancercouncil.com.au.

Information resources – You can find more information and download a comprehensive range of resources, including booklets, fact sheets and seminars on many aspects of myeloma, its treatments and supportive care issues, from myeloma.org.au/resources.

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20

Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Legal and financial support

If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Council 13 11 20.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit cancercouncil.com.au/OC.

Information resources

Cancer Council produces booklets and fact sheets on more than 40 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Practical help

Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council NSW	**cancercouncil.com.au**
Cancer Council Online Community	**cancercouncil.com.au/OC**
Cancer Council podcasts	**cancercouncil.com.au/podcasts**
Guides to Best Cancer Care	**cancer.org.au/cancercareguides**
Australian Bone Marrow Donor Registry	**abmdr.org.au**
Cancer Institute NSW	**cancer.nsw.gov.au**
Carer Gateway	**carergateway.gov.au**
Carers NSW	**carersnsw.org.au**
Department of Health and Aged Care	**health.gov.au**
eviQ Cancer Treatments Online	**eviq.org.au**
Healthdirect Australia	**healthdirect.gov.au**
Leukaemia Foundation	**leukaemia.org.au**
Myeloma Australia	**myeloma.org.au**
Services Australia (Medicare, Centrelink)	**servicesaustralia.gov.au**

International

American Cancer Society	**cancer.org**
Cancer Research UK	**cancerresearchuk.org**
International Myeloma Foundation	**myeloma.org**
Macmillan Cancer Support (UK)	**macmillan.org.uk**
Multiple Myeloma Research Foundation (US)	**themmrf.org**
Myeloma UK	**myeloma.org.uk**

Caring for someone with myeloma

You may be reading this booklet because you are caring for someone with myeloma. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Association – Carers NSW provides information and support for carers. Call 02 9280 4744 or visit carersnsw.org.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit cancercouncil.com.au to find out more about carers' services.
▸ See our *Caring for Someone with Cancer* booklet.

Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of myeloma do I have? What stage and category is it?
- What tests do I need?
- Has the myeloma spread? How fast is it growing?
- Does it need treatment now or do you recommend active monitoring?
- If you recommend active monitoring, how often will I need check-ups?
- Are the latest tests and treatments for myeloma available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of myeloma?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? Can I work, drive and do my normal activities?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

After treatment

- How often will I need check-ups after treatment?
- If the myeloma returns, how will I know? What treatments could I have?

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 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 provides some indication of overall health and nutritional status.

allogeneic stem cell transplant
A process that involves taking stem cells from one person and giving them to another.

anaemia
A reduction 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 and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

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

antigen
Any substance that causes the immune system to respond, often prompting plasma cells to make antibodies.

apheresis
A procedure where 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. It is a key step in a stem cell transplant.

asymptomatic myeloma
See smouldering myeloma.

autologous stem cell transplant
A process that involves taking stem cells from a person's own body and then giving them back following 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 can be used to help diagnose and monitor the disease.

beta-2 microglobulin (B2M)
A 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 a disease.

bisphosphonate
A type of drug that slows down or prevents 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. Bone marrow produces stem cells that become 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.

calcium
A mineral found mainly in the hard part of bones, where it is stored.

cannula
A small plastic tube inserted into a vein or narrow opening in the body so that fluids can be introduced or removed.

central line
A special tube surgically inserted into your neck or chest, used for direct access to a vein.

chemotherapy
A cancer treatment that uses drugs to kill cancer cells or slow their growth.

chromosome
A threadlike structure found in all body cells (except red blood cells). Chromosomes are made up of strings of proteins called genes.

clinical trial
A study that tests new approaches to prevention, screening or treatment.

corticosteroids
See steroids.

CRAB criteria
A set of myeloma-defining events used to help identify people who need treatment. The letters stand for: 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 to create a detailed, cross-sectional picture of the body.

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

disease progression
When tests show that the myeloma is increasing and needs active treatment. This is also known as relapse or recurrence.

DNA
A tiny molecule in every cell of the body that carries instructions for how that cell behaves and functions.

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

fluorescence in situ hybridisation (FISH)
A test used to look for abnormal chromosomes in myeloma cells.

free light chains
See light chains.

genetic tests
Genetic tests aim to detect gene changes that are more commonly seen in certain types of cancer.

granulocyte-colony stimulating factor (G-CSF)
A growth factor drug used to help the body make more stem cells so that they can be collected for a transplant, or to increase the number of white blood cells if they are low. Given either as an injection or through a drip.

growth factor
A protein that stimulates the development and growth of cells.

haematologist
A doctor who specialises in studying and treating diseases of the blood, bone marrow and lymphatic system.

heavy chains
Long chains of proteins in an antibody such as paraprotein.

hypercalcaemia
Higher than normal levels of calcium in the blood.

hyperviscosity
A syndrome triggered when blood thickens and starts to circulate more slowly. May occur if myeloma cells release large amounts of paraprotein into the blood.

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immunoglobulin
A protein that is produced by plasma cells and fights infections. Also called antibodies.

immunoglobulin replacement therapy (IRT)
A treatment often given to boost your antibody levels if you have repeated infections.

immunomodulators
Drugs that interact with the immune system to attack cancer cells in a number of different ways.

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

lymphocyte
A type of white blood cell that helps fight infection. Lymphocytes destroy bacteria, viruses and other harmful substances.

lytic lesions
Areas where bone has been damaged.

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maintenance therapy
Treatment given for months or years after initial treatment to prevent cancer returning.

medical oncologist
A doctor who specialises in treating cancer with drug therapies.

monoclonal antibodies
A group of targeted therapy drugs that lock onto a specific protein on the surface of cancer cells and interfere with the cells' growth or survival.

monoclonal gammopathy of undetermined significance (MGUS)
A benign condition in which low levels of paraprotein are present in the blood. May increase the risk of developing myeloma.

M-protein
See paraprotein.

myeloma
Cancer of the plasma cells. Also called multiple myeloma.

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osteonecrosis of the jaw (ONJ)
A condition in which bone tissue of the jaw breaks down, causing pain.

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

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palliative treatment
Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms. Treatment may include radiation therapy, chemotherapy or other therapies. It is an important part of palliative care.

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

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

peripheral neuropathy
Damage to the nerves that are located away from the brain and spinal cord. This causes weakness, numbness, tingling or pain, usually in the hands and feet.

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.

plateau phase
A period of time when myeloma is stable. Also called remission.

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

prognosis
The expected outcome of a person's disease.

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

radiation oncologist
A doctor who specialises in treating cancer with radiation therapy.

radiation therapy
The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply and spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

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 disease progression.

remission
See plateau phase.

serum free light chain assay
A test that can detect free light chains in the blood. These can be a sign of myeloma.

SLiM criteria
A set of signs of myeloma 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. May progress to active myeloma so needs active monitoring. Also known as asymptomatic myeloma.

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

staging
The use of various tests to work out how far the disease has progressed.

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

stem cell transplant
A treatment in which diseased blood cells are destroyed by high-dose chemotherapy and then replaced by healthy stem cells. An autologous transplant uses the person's own stem cells for treatment. An allogeneic transplant uses stem cells from another person (donor).

steroids (or corticosteroids)
A group of drugs that are mostly used to reduce inflammation.

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.

Can’t find a word here?

For more cancer-related words, visit: cancercouncil.com.au/words

References

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2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia 2023*, AIHW, Canberra, viewed 9 September 2024, available from aihw.gov.au/reports/cancer/cancer-data-in-Australia.
3. MA Dimopoulos et al. on behalf of the EHA Guidelines Committee and ESMO Guidelines Committee, “Multiple Myeloma: EHA-ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up”, *Annals of Oncology,* vol. 32, issue 3, 2021, pp. 309-322.

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 other Pink events, 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 experienced health professionals 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.

If you need information in a language other than English, an interpreting service is available. Call 131 450.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. accesshub.gov.au

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

For information & support
on cancer-related issues,
call Cancer Council 13 11 20

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Myeloma Australia

Visit our website: cancercouncil.com.au

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To support Cancer Council, call 1300 780 113.

Cancer Council