



Understanding Myeloma

A guide for people with cancer,
their families and friends

Cancer
information

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13 11 20



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Note to reader

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

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

Cancer Council NSW

Cancer Council is the leading cancer charity in NSW. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and people with cancer, and raising funds for cancer programs. This booklet is funded through the generosity of the people of NSW. To make a donation to help beat cancer, visit cancercouncil.com.au or phone 1300 780 113.



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About this booklet

This booklet has been prepared to help you understand more about the blood cancer known as myeloma. 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

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

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What is blood cancer?

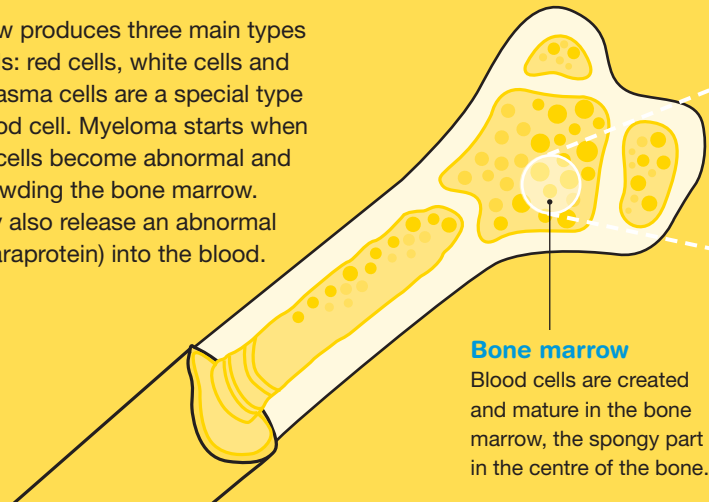
Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as breast cancer, the abnormal cells form a lump called a tumour.

Myeloma, however, is a blood cancer. It begins in the bone marrow, the spongy part in the centre of the bone where blood cells are produced. In myeloma, a particular type of blood cell called a plasma cell is affected. When plasma cells become abnormal they are known

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 the plasma cells become abnormal and multiply, crowding the bone marrow. They usually also release an abnormal antibody (paraprotein) into the blood.



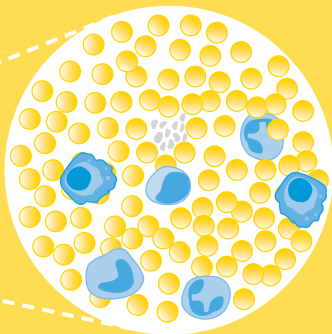
Bone marrow

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

as myeloma cells. They can reduce the bone marrow's ability to produce normal levels of other blood cells, which affects the way that the rest of the body works.

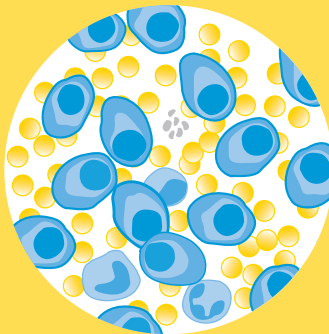
Usually, the myeloma cells produce an abnormal antibody called paraprotein. This spills into the bloodstream, weakening the immune system and damaging the kidneys.

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



Normal bone marrow

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



Bone marrow with myeloma

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



Plasma cells



Other white blood cells



Red blood cells



Platelets

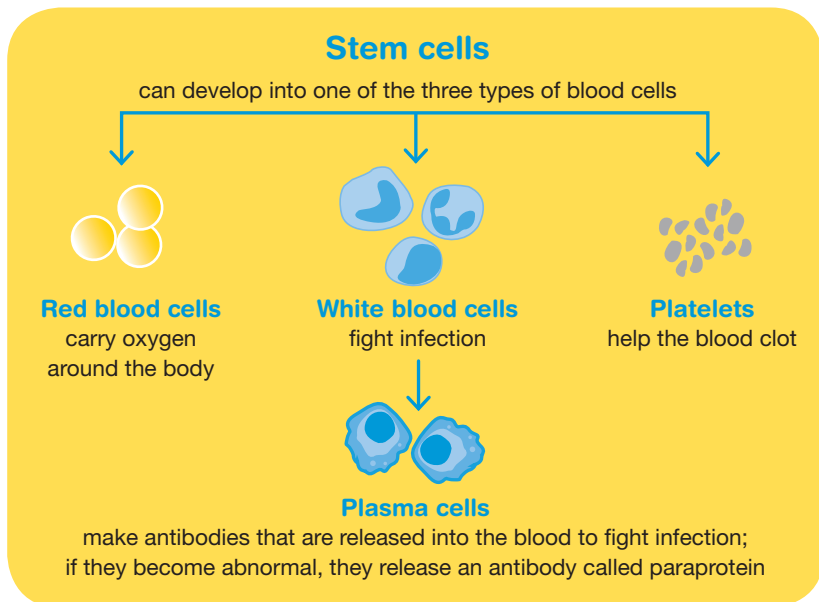


The blood

Blood is pumped around your body to provide oxygen and nutrients to your tissues, and to remove waste products. It is made up of red blood cells, white blood cells and platelets, and each has a set 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, which is the spongy part in the centre of the bones.

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





Key questions

Q: What is myeloma?

A: Myeloma is a type of blood cancer. It develops from cells in the bone marrow called plasma cells. As 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 a wide variety of antibodies that help the body fight infections, but myeloma cells make an abnormal antibody known as paraprotein, M-protein or monoclonal protein. Paraprotein is found in the blood of most people who have myeloma (see page 13 for more information).

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

- normal plasma cells and other white blood cells can make a person more likely to get infections
- red blood cells (anaemia) can cause fatigue
- platelets (thrombocytopenia) can cause bleeding and bruising.

Q: How is it different from leukaemia?

A: Myeloma and leukaemia are both types of blood cancer, but they affect the body differently. Leukaemia is a cancer of the white blood cells and is easily detected on a blood test. Myeloma is a cancer of the plasma cells, which are not usually found in the blood. Plasma cells normally stay in the bone marrow.



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

Q: What are the symptoms?

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

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

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

Q: What are the risk factors?

A: The causes of myeloma are unknown. We know that plasma cells become cancerous when there are certain changes in their DNA. DNA is found in all cells. It carries instructions that control how cells work. However, we do not yet know what causes DNA to change.

Exposure to certain chemicals (e.g. dioxins used in industry), high levels of radiation (e.g. from working in a nuclear power plant) and viruses (such as HIV) have been linked to an increased risk of myeloma, but they have not been proven to cause it.

People with monoclonal gammopathy of undetermined significance (MGUS) are more likely to develop myeloma (see page 20).

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

Q: How common is myeloma?

A: Myeloma is not a common disease. About 1750 people in Australia are diagnosed with the disease each year.² It accounts for 15% of blood cancers and 1% of all cancers generally.³ The disease is more often found in people over 60, which is partly explained by the ageing population. It is rare in people under 40. Myeloma is slightly more common in men than in women.

Q: Which health professionals will I see?

A: Your general practitioner (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. Occasionally in regional areas, people may see a medical oncologist instead.

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
radiation oncologist*	treats cancer by prescribing and coordinating 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 during and after treatment

The haematologist will arrange further tests. If myeloma is diagnosed, the haematologist will consider treatment options. 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	consists of pain specialists and nurses who work together to treat pain, particularly if it is difficult to control
dietitian	recommends an eating plan to follow while you are in treatment and recovery
social worker	links you to support services and helps you with emotional, practical or 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 manage your emotional response to diagnosis and treatment

** Specialist doctor*



Diagnosis

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

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

Blood tests

Several blood tests are used to diagnose myeloma.

Serum analysis – The main blood test is called serum protein electrophoresis. This measures the level of paraprotein in your blood. Another blood test called the serum free light chain assay may be used to check for a form of paraprotein known as free light chains (see the *Understanding paraprotein* box on the opposite page).

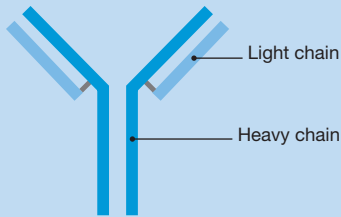
Blood tests – These check for too few red blood cells (anaemia), too much calcium in the blood (hypercalcaemia), and how well your kidneys are working.

Once myeloma has been confirmed, further blood tests will help your doctor work out the stage of the disease (see pages 18–19). Changes in the level of paraprotein may indicate changes in the activity of the myeloma. If you are diagnosed with myeloma, your paraprotein 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 during periods when you are not having treatment.

Understanding paraprotein

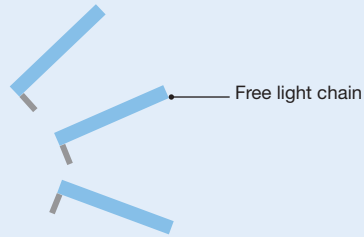
Myeloma cells produce an antibody known as paraprotein. To make a diagnosis of myeloma, doctors will look for this paraprotein in the blood or urine. Once you have been diagnosed with myeloma, doctors will regularly check your paraprotein levels to monitor the disease.

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 detected in a urine test. Some people produce both intact paraprotein and free light chains.

Non-secretory myeloma

Fewer than 1 in 50 people with myeloma produce little or no paraprotein. This is known as non-secretory myeloma. It makes diagnosis more difficult.

Urine test

A urine test may be used to check for the Bence Jones protein, which is the light chain part of paraprotein (see page 13). About one-third of people with myeloma make enough Bence Jones protein for it to be measurable in the urine.

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

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

Bone marrow aspiration and trephine biopsy

This test is used to examine cells from the bone marrow. 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.

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

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

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

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



Cytogenetic tests

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

There may be changes in the structure of the chromosomes within myeloma cells, such as a part missing or deleted. The most common chromosomal abnormalities found in myeloma include $t(4;14)$, $t(14;16)$, $del(17p)$ and $del(13q)$. They help classify myeloma as either high risk or standard risk.

Cytogenetic or fluorescence in situ hybridisation (FISH) tests can look for changes in the chromosomes of plasma cells found in the bone marrow sample. By identifying any changed or damaged

chromosomes, genetic tests help the medical team plan the most effective treatment and predict how the myeloma might respond.

Imaging scans

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

X-rays

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

CT scan

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

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

MRI scan

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

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

Other scans

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

Dye injection for CT or MRI

CT and MRI scans of organs sometimes involve the injection of a dye (contrast) into a vein, probably in your arm. This dye makes the pictures clearer. Before having scans, let the person doing the scan know 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 or have had a reaction to contrast during previous scans, are diabetic or are pregnant. Scans of bones usually do not need any contrast to be injected.

🗨️🗨️ Calling 13 11 20 after I was diagnosed helped me take in the new information. I eventually joined a support group, which was also a great help. 🗨️🗨️ *Jenni*

Staging myeloma

The test results allow the haematologist to work out how far the disease has progressed. This process is called staging, and the information will help your doctor assign a stage to the myeloma. This is an indication of how much the myeloma has affected your body and how it is likely to respond to treatment.

If you have 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 stages I, II and III based on the results of various blood tests that check:

- **levels of beta-2 microglobulin (β2M)** – a protein produced by myeloma cells that indicates the extent of disease
- **levels of albumin** – a protein produced by the liver that indicates overall health
- **levels of lactate dehydrogenase (LDH)** – an enzyme released into the blood when cells are damaged or destroyed
- **genetic information** – the presence of one or more specific chromosomal abnormalities may identify people at highest risk of the disease progressing.

Significant signs of myeloma

Doctors usually use the CRAB criteria of myeloma-defining events to help identify people with myeloma who need to start treatment (see next page). The SLiM criteria was added as part of the R-ISS and consists of a set of three specific signs known as biomarkers. When used together, the criteria are known as the SLiM-CRAB criteria.

CRAB criteria: myeloma-defining events

C	increase in calcium level in blood
R	renal (kidney) damage
A	anaemia (low levels of red blood cells)
B	bone 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	significant plasmacytosis (more than 60% of abnormal plasma cells in the bone marrow)
Li	light chain ratio (a high level of free light chains in the blood)
M	MRI lesions (more than one area of bone abnormality found by MRI – this is called a focal lesion and must be 5 mm or more in size)

When to start treatment

The test results will help your doctor work out whether you have myeloma or a pre-myeloma condition, and when to start treatment.

Category	Test results	Need for treatment
monoclonal gammopathy of undetermined significance (MGUS)	<ul style="list-style-type: none">• low level of paraprotein in blood or urine• low level of myeloma cells in the bone marrow• no other significant signs of myeloma	<ul style="list-style-type: none">• MGUS is not cancer – it needs active monitoring (see page 25)• one out of every 100 people diagnosed with MGUS develops myeloma each year
smouldering myeloma (asymptomatic myeloma)	<ul style="list-style-type: none">• medium level of paraprotein in blood or urine and/or myeloma cells in the bone marrow• no other significant signs of myeloma	<ul style="list-style-type: none">• smouldering myeloma usually doesn't need treatment straightaway• may progress to active myeloma, so it needs active monitoring (see page 25)
active myeloma (symptomatic myeloma)	<ul style="list-style-type: none">• medium or high level of myeloma cells in the bone marrow, or myeloma cells in the bone or another part of the body• significant signs of myeloma (see previous page)	<ul style="list-style-type: none">• active myeloma requires treatment (see pages 25–34)

Prognosis


Prognosis means the expected outcome of a disease. It is not possible for any doctor to predict the exact course of the disease, but your medical team can predict how the myeloma will respond to treatment based on 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 also have tests throughout your treatment that show how well the treatment is working.

The outlook for people with myeloma is improving constantly. While treatment cannot 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 much longer periods. When the disease becomes active again (disease progression, also called relapse or recurrence), further treatment will be needed.



Living with myeloma may make you feel anxious. It may 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 55).



Key points about diagnosing myeloma

What it is Myeloma is a type of blood cancer that develops from plasma cells in the bone marrow.

Tests The main tests to diagnose myeloma are:

- blood and urine tests to measure the level of paraprotein
- bone marrow tests to measure the amount of myeloma cells in the bone marrow. 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 x-ray (skeletal survey) to look for areas of bone damage (lytic lesions).
- If a clearer picture of the bones is needed, you may have a CT or MRI scan.
- The tests allow your doctor to classify the myeloma. MGUS is not cancer, but may progress to myeloma. Smouldering myeloma does not have symptoms. Both MGUS and smouldering myeloma need active monitoring. Active myeloma or symptomatic myeloma requires treatment.
- The SLiM-CRAB criteria are two sets of signs that help doctors decide when myeloma has become active and therefore requires treatment.

Staging You may be told the stage of the myeloma. This indicates how much the myeloma has affected your body and how likely it is to respond to the proposed treatment.



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 – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as 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 pages 10–11) 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 tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. 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

Treatment for myeloma is highly individual and depends on several factors, such as the type and stage of myeloma, your symptoms and your general health. The aim is to try to get the myeloma under control rather than to cure the cancer.

Treatment options

Active monitoring – People who have been diagnosed with monoclonal gammopathy of undetermined significance (MGUS) or smouldering myeloma (see page 20) usually do not need treatment straightaway. Most people with MGUS never develop active myeloma. In most cases of smouldering myeloma, having treatment early does not offer any clear benefit.

If tests show you have MGUS or smouldering myeloma, you will need check-ups every 3–12 months (see page 51). This is called active monitoring. Your doctor will start treatment if you develop symptoms or other significant signs of myeloma.

Treatment to control the myeloma (pages 27–34) – This is often called induction or first-line treatment. It includes a combination of different drugs (see next page). A stem cell transplant may be suggested for some people. Active treatment may be followed by periods of stable disease (plateau phase or remission) when no treatment is needed.

Treatment for the symptoms and side effects caused by myeloma (pages 34–37 and 34–46) – This helps manage issues associated with myeloma, such as bone disease, pain, tiredness, kidney damage, hypercalcaemia, frequent infections and fatigue.

Treatment to prevent the disease returning (pages 28–30) –

This is called maintenance or consolidation therapy and involves a longer, lower-dose course of an immunomodulator such as thalidomide, steroids and/or other drugs. It is often used after a stem cell transplant and sometimes after other first-line treatment.

Treatment when the disease comes back (disease progression, also called relapse or recurrence) – You may be offered a different type of chemotherapy, a stem cell transplant, steroids or other drugs to regain control of the disease. In some cases, you may receive a treatment that has previously worked well for 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 traditional chemotherapy drugs and steroids, as well as newer therapies that are known as immunomodulators (see page 28) and proteasome inhibitors (see page 29).

Combinations of drugs are used because each type of drug works differently to kill myeloma cells,

and the combined effect helps treat as much disease as possible.

The choice of combination will depend on the type of myeloma, 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 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). A hospital stay may be needed for some treatments, but this stay is usually short. Your doctor will tell you about the drugs you are having and how long treatment will last. You may have chemotherapy in combination with other treatments, such as one of the immunomodulator drugs used for myeloma (see pages 28–29).

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

These side effects are temporary and there are ways to prevent or reduce them. Tell your doctor or nurse about any side effects you experience. Your doctor may prescribe medicine, consider a break in your treatment, or change the treatment you are having. For more information, see the *Managing symptoms and side effects* chapter on pages 39–47.

➤ See our *Understanding Chemotherapy* booklet.

Immunomodulators

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

Thalidomide is an old drug that has new uses. It was given to pregnant women in the 1950s as an anti-nausea drug, but was banned because it caused severe birth defects. We now know 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. Because these drugs increase the risk of blood clots, most people also take a blood thinner.

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

Women taking immunomodulators should not become pregnant as the fetus would develop abnormalities. Sperm is also affected – men should not conceive and should not donate sperm.

Proteasome inhibitors

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

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, low blood counts, shingles and peripheral neuropathy. Carfilzomib may cause heart problems or worsen pre-existing conditions. Most side effects can be managed.

New drug therapies

A range of new drug therapies for myeloma are being developed.

These include new proteasome inhibitors such as ixazomib and oprozomib, as well as monoclonal antibodies such as daratumumab and elotuzumab.

Monoclonal antibodies are made in a laboratory, but behave like the natural antibodies that our bodies produce to fight infection and disease. They target cancer

cells and affect their growth or survival.

The cost of these new drugs is not subsidised for myeloma on the Pharmaceutical Benefits Scheme (PBS), so they are expensive. If your doctor thinks they are the most promising treatment for you, ask whether there are any clinical trials or compassionate access schemes that may be able to help with the costs.

Steroids

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

How they are given – The typical steroids used for myeloma are dexamethasone and prednisolone or prednisone. 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 periods only.

Side effects – Common side effects include difficulty sleeping, mood changes, increased appetite, fluid retention, heartburn and weight gain. To reduce the risk of sleeplessness at night and irritation to your stomach, take steroids in the morning with food or milk.

Some steroids can affect blood sugar levels. If used for a long period, steroids may cause diabetes. If you have diabetes, you will need to monitor your blood sugars more often. Ask your GP for a review, or call Diabetes Australia on 1300 136 588 to talk to a diabetes educator.



Let your doctor know if you are finding it hard to cope with the side effects of steroids as they may be able to adjust your dose. Always consult your doctor if you want to reduce the dose or stop using steroids. Changing the dose or stopping steroids suddenly can cause serious withdrawal effects.

Stem cell transplant

You may be offered a stem cell transplant, also known as high-dose therapy and stem cell rescue, to destroy any remaining myeloma cells and increase the length of the plateau phase (remission).

This treatment is done in several stages. Before the process begins, you have induction treatment to put the myeloma into a plateau phase. Once this is achieved, the stem cells are removed and frozen. You then have high-dose chemotherapy followed by the return of your stem cells. See pages 32–33 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 aggressive it is and how it responds to treatment. Stem cell transplants are available only at some hospitals, so you may need to be referred to another hospital. The haematologist will discuss the risks and benefits of a stem cell transplant with you.

Most people receive their own previously collected stem cells (autologous transplant). Rarely, stem cells from another person are used (allogeneic transplant).

The entire procedure, including recovery, can take months and may take up to a year.

Stem cell transplant steps

A general autologous transplant process is described here, but the process varies from person to person. Detailed information is available from leukaemia.org.au.

1 Collecting stem cells

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

2 Separating and storing stem cells

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

3 Receiving high-dose chemotherapy

- High-dose chemotherapy, often referred to as conditioning therapy, is given through a vein. A long, flexible plastic tube is usually used. This may be a peripherally inserted central catheter (PICC line), a Hickman catheter or a central line.
- About 24 hours before the transplant, you'll have high-dose chemotherapy to kill the myeloma cells. This will also destroy the stem cells in the bone marrow. Before and after the chemotherapy is given, you will have fluids through a drip to prevent dehydration and kidney damage.
- Common side effects from the high-dose chemotherapy include infection, nausea, diarrhoea and mouth sores. Because your stem cells have been destroyed, your blood count will be low and you will be more at risk of infections (see pages 43–44).

4 Transplanting stem cells and engraftment

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

Some people continue to have drug therapies after a stem cell transplant. This is known as maintenance treatment. It is used to keep myeloma responding to treatment for longer.

Side effects of stem cell transplant

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

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

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

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

Supportive treatment

You may 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 and radiation therapy for bone pain and damage, and plasma exchange for dangerous levels of paraprotein in the blood.

Bisphosphonates

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

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

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

An uncommon but severe side effect associated with prolonged bisphosphonate use is osteonecrosis of the jaw (ONJ). This condition causes bone tissue of the jaw to break down, leading to pain and infection. See your doctor if you experience mouth ulcers or jaw problems while taking bisphosphonates.

It is important to visit your dentist for a check-up and try to have any invasive dental work done before you start taking bisphosphonates. Keep up good dental hygiene by brushing and flossing daily, and have annual dental reviews. If you need dental work during treatment, let your dentist know you have been taking bisphosphonates and discuss whether it's possible to have a break from the regime with your haematologist. 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

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

Radiation therapy, also known as 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 your normal tissue.

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 can take 1–3 hours, which includes time setting up the machine, seeing the radiation oncologist and having tests. Radiation therapy may be given as a single dose, or as multiple smaller 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 side effects go away in time, usually within days to weeks of treatment finishing. Tell your radiation oncology team about any side effects, as there are ways to reduce any discomfort.

➤ See our *Understanding Radiation Therapy*, *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

Plasma exchange

Plasma exchange may be used if the level of paraprotein in the blood is very high, making the blood thicker and slowing down circulation (hyperviscosity syndrome, see page 42). This causes symptoms such as blurred vision and decreased alertness.

How it is given – The process begins with a needle being placed into a vein in each arm. Blood is slowly removed from one arm and then passed through a machine that separates it into each of the blood components. The plasma – the clear fluid part of the blood that contains much of the extra paraprotein – is removed and replaced with either plasma from a donor or a plasma substitute such as albumin (a blood protein). The blood is then mixed together and returned to the body via the other arm. This process usually takes a few hours and is not painful.

Palliative treatment

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

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



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 traditional chemotherapy drugs, steroids and another type of drug, such as thalidomide, lenalidomide or bortezomib
- supportive treatment for myeloma symptoms and side effects
- maintenance treatment to prevent myeloma coming back.

Other treatments

- While not suitable for everyone, some people will have a stem cell transplant to help destroy 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 the presence of paraprotein in the blood or urine. This chapter discusses how to manage these symptoms. Your cancer specialists may refer to these as supportive treatments.

Bone disease

Bone disease is one of the most common complications experienced by people with myeloma. The myeloma cells release chemicals that damage the cells that normally repair damaged bone. When this happens, the bone breaks down faster than it can be repaired, causing bone pain, bone 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 pages 41–42.

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. For more information on bisphosphonates, see page 35.

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

Pain

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

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

Some people may need further treatment to manage pain. This may include localised radiation therapy or, in some specific cases, vertebroplasty. This involves injecting medical-grade cement into the spine because it has collapsed.



Tips for managing pain

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

Kidney damage

Kidney problems can develop in people with myeloma for various reasons. The paraprotein produced by myeloma cells can damage the kidneys. This is particularly common with the Bence Jones protein (see page 13). 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 drink three litres of fluids a day. This can include water, tea, coffee, fruit juice and milk. Ask your doctor if it's necessary to avoid using painkillers that contain a non-steroidal anti-inflammatory drug (NSAID), because these can also damage the kidneys. It is important to treat any infections promptly (see pages 43–44) to limit further stress on the kidneys.

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

High calcium levels in the blood

The 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 symptoms such as tiredness, nausea, constipation, bone pain, thirst, irritability and confusion. In some people, hypercalcaemia is discovered during a blood test before any symptoms develop.

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

Thicker blood

Occasionally, the myeloma cells release so much paraprotein into the blood that the blood becomes thick and starts to circulate more slowly. This is known as hyperviscosity 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 37) 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 this happens, your doctor may suggest a blood transfusion to increase your red blood cell count. The blood will be given to you through a catheter inserted into a vein in your arm.



Brigita's story

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

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

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

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

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

Infections

Myeloma, high-dose steroids and treatments such as bortezomib, lenalidomide, thalidomide and chemotherapy can weaken your immune system. This makes you more likely to get infections and less able to fight any infections that do occur. See the next page for ways to reduce your risk and when you need to contact your doctor urgently.

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

Taking care with infections

Reduce your risk

To prevent the spread of infection:

- check with your doctor about having the flu vaccine
- ask people close to you to consider having a flu shot
- ask family and friends with a 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 with soap and water before preparing food and 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, seafood, meat, eggs and soft cheeses; wash fruits and vegetables well before eating.

When to seek medical help

Contact your doctor or go to the nearest hospital emergency department immediately if you experience one or more of the following symptoms:

- a temperature of 38°C or higher
- chills or shivering
- sweating, especially at night
- burning or stinging feeling when urinating
- 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
- prolonged faintness or dizziness and a rapid heartbeat
- any sudden deterioration in your health.

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 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 a common side effect of 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 at cancercouncil.com.au/podcasts.

Nerve and muscle effects

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

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



Tips for managing peripheral neuropathy

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



Key points about symptoms and side effects

Common symptoms and side effects

- Bone disease – usually treated with drugs called bisphosphonates.
- Pain – often linked to bone disease or nerve damage.
- Kidney problems – the kidneys usually recover, but if the problem is permanent, you may need dialysis.
- Excess calcium in the blood (hypercalcaemia) – breakdown of bone cells can cause symptoms such as tiredness and nausea.
- Thicker blood and damaged nerve cells – 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 signs of infection.
- Extreme tiredness and lack of energy (fatigue) – a common side effect that may last for weeks or months.
- Peripheral neuropathy – with tingling 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 you have. They may be able to suggest strategies or adjust your treatment.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to 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 and 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 and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer 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 with a social worker or Cancer Council whether any financial assistance is available to you.

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

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It 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 – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

➤ 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 cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer 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 had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See Cancer Council's *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 had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call beyondblue 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

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

Blood tests, urine tests, and bone marrow biopsies may be used to check your health. Occasionally x-rays and scans may also be used. Your doctor may note the levels of antibodies and proteins in the blood and urine.

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

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

When myeloma returns

When myeloma returns, it is called disease progression, or relapse or recurrence. You and your doctor will need to consider what treatment is needed to try to regain control of the disease.

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, and your views and the disease characteristics may have changed.

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

Treatment options for resistant disease may include:

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



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



Seeking support

A cancer 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. Cancer 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 cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer 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 Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit **cancercouncil.com.au**.

Practical help

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



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

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**.



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 care professionals through its specialist myeloma support nurses.

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

Support groups – Find details of myeloma-specific support groups for people affected by the disease by searching Myeloma Australia's website or calling the support nurses on 1800 693 566. In NSW, a telephone support group is available through Cancer Council 13 11 20 for those unable to access a group in person.

Information resources – Download a comprehensive range of information resources, including booklets and fact sheets on many aspects of myeloma, its treatments and supportive care issues, from myeloma.org.au/resources or call 1800 693 566 for copies.

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 Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Institute NSW	cancer.nsw.gov.au
Carer Gateway	carergateway.gov.au
Carers NSW	carersnsw.org.au
Department of Health	health.gov.au
Department of Human Services	humanservices.gov.au
Healthdirect Australia	healthdirect.gov.au
Australian Bone Marrow Donor Registry	abmdr.org.au
Leukaemia Foundation	leukaemia.org.au
Myeloma Australia	myeloma.org.au
The <i>Thing About Cancer</i> podcast	cancercouncil.com.au/podcasts

International

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



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. 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 both 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 NSW – Carers NSW is a statewide organisation specifically for carers. Phone 1800 242 636 or visit carersnsw.org.au for more information about services for carers.

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 tests do I need?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

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 the 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? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- 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?
- When 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 needs treatment because it is causing symptoms or because test results indicate a high risk of the disease progressing. Also known as symptomatic or high-risk myeloma.

albumin

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

allogeneic stem cell transplant

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

anaemia

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

anaesthetic

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

antibody

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

antigen

Any substance (such as bacteria) that causes the body's immune system to respond. This response often involves making antibodies.

apheresis

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

asymptomatic myeloma

See smouldering myeloma.

autologous stem cell transplant

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

Bence Jones protein

The name of a light chain protein found in the urine of some people with myeloma.

benign

Not cancerous or malignant.

beta-2 microglobulin (β2M)

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

biopsy

The removal of a 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

The red fluid that flows through the circulatory system. Blood contains 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 a sample of blood.

bone marrow

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

bone marrow aspiration

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

calcium

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

cannula

A plastic tube inserted into a narrow opening (usually a vein) so that fluids can be introduced or removed.

central line

A type of thin plastic tube used to give direct access to a large vein in the chest or neck.

chemotherapy

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

clinical trial

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

corticosteroids

See steroids.

CRAB criteria

A set of criteria used to identify people who need treatment. The letters stand for the events: C = calcium elevation; R = renal damage; A = anaemia; B = bone abnormalities. Often combined with the SLiM criteria to form the SLiM-CRAB criteria.

CT scan

Computerised tomography scan. This scan uses x-rays to create a detailed picture of the inside of the body.

cytogenetic test

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

disease progression

When tests show myeloma is increasing and needs treatment. Also known as relapse or recurrence.

engraftment

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

fluorescence in situ hybridisation (FISH)

A test that uses special dyes to look for abnormal chromosomes.

free light chains

See light chains.

granulocyte-colony stimulating factor (G-CSF)

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

growth factor

A protein that stimulates the development and growth of cells.

haematologist

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

heavy chains

Long chains of proteins in an antibody such as paraprotein.

Hickman line

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

high-risk myeloma

See active myeloma.

hypercalcaemia

Higher than normal levels of calcium in the blood.

hyperviscosity syndrome

A group of symptoms triggered when blood thickens and starts to circulate more slowly. Symptoms include blurred vision, headache, dizziness and confusion.

immunoglobulin

See antibody.

immunomodulators

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

induction treatment

The first treatments used to make further treatments more effective.

light chains

Short chains of proteins in an antibody such as paraprotein. Often referred to as

Bence Jones protein when found in the urine of people with myeloma, or as free light chains when found in their blood.

lymphocyte

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

lytic lesions

Areas where bone has been damaged.

malignant

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

monoclonal antibodies

A group of drugs that lock onto a protein on the surface of cancer cells to interfere with the growth or survival of cancer cells.

monoclonal gammopathy of undetermined significance (MGUS)

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

M-protein

See paraprotein.

myeloma

Cancer of the plasma cells. Also called multiple myeloma.

oncologist

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

osteonecrosis of the jaw (ONJ)

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

osteoporosis

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

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other symptoms of cancer.

paraprotein

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

pathologist

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

peripheral neuropathy

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

plasma

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

plasma cells

A type of white blood cell (lymphocyte) 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. May be used if high levels of paraprotein are causing hyperviscosity.

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. These help the blood to clot and stop bleeding.

prognosis

The predicted outcome of a person's disease.

proteasome inhibitors

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

radiation oncologist

A doctor who specialises in treating cancer with 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 to find free light chains in the blood, which can be a sign of myeloma.

side effect

Unintended effect of a drug or treatment.

SLiM criteria

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

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

smouldering myeloma

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

solitary plasmacytoma

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

spleen

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

stage

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

stem cells

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

stem cell transplant

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

chemotherapy, then replaced by healthy stem cells.

steroids

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

symptomatic myeloma

See active myeloma.

trephine biopsy

The removal of a bone tissue sample using a needle.

white blood cells

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

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancerivc.org.au/glossary
- cancersa.org.au/glossary

References

1. H Quach and H Miles Prince on behalf of Medical Scientific Advisory Group (MSAG) to the Myeloma Foundation of Australia (MFA), *Clinical Practice Guideline: Multiple Myeloma*, Myeloma Australia, V.4, updated March 2017.
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Multiple myeloma*, AIHW, Canberra, December 2017.
3. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2017*, AIHW, Canberra, 2017.



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 cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

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

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



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

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



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

For further information and details, visit our website, cancercouncil.com.au.

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