

Myeloma

A comprehensive guide



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Myeloma Australia acknowledges the Traditional Custodians and Owners of the lands on which we live and work. We pay our respect to Elders past, present and emerging, and extend that respect to all First Nations people.

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About Myeloma Australia

Myeloma Australia is a national not-for-profit organisation dedicated to providing information and support to people affected by myeloma. Founded in Victoria in 1998 by three families personally touched by myeloma, the organisation has grown to become a significant provider of services and support for the myeloma community.

Myeloma Australia:

- supports, informs and empowers people living with myeloma, their families, friends and health professionals, through its specialist programs and resources
- raises awareness of myeloma
- provides funding for research projects facilitated by our Medical and Scientific Advisory Group
- advocates to state and federal government for support in access to new therapies.

Myeloma Australia Telephone Support Line

1800 MYELOMA (1800 693 566)
Mon-Fri 9 am-5pm AEST/AEDT
www.myeloma.org.au
Email: nurses@myeloma.org.au

If you would like to talk to someone about any aspect of myeloma, its treatment and management, you can call our free Telephone Support Line during business hours Monday to Friday (AEST).

A Myeloma Australia Nurse will answer your call in confidence and address your questions. They can also connect you with support services in your area.

You can also access more information and support by visiting **www.myeloma.org.au** or by emailing our Myeloma Australia Nurses: **nurses@myeloma.org.au**.

Thank you

Thank you to those who gave freely of their time and expertise in reviewing this booklet:

- **Dr Nicholas Weber**, Medical and Scientific Advisory Group member
- **Lori Hobbs**, Royal Melbourne Hospital social worker
- **Cindy** and **Stephen Goodwin**, **Daniel Carter**, and **Helen Chapman**, consumer representatives

Thank you to everyone who provided photos and quotes about their experience of living with myeloma.

Important note

This guide provides general information about myeloma and is not intended to replace medical care or the advice of your treating team.

Please talk to your doctor if you have any questions about your diagnosis or treatment. Your doctor can answer your questions, talk with you about your treatment goals, and provide you with extra support.

While the advice and information in this guide is believed to be true and accurate in the Australian setting at the time of publication, neither the authors, editors, reviewers, nor the publishers accept any legal responsibility for the content.

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The contents of this guide are of value only to the owner. If found, please return to:

Name	Email
Phone	Address
Email	Name
Phone	Email
Phone	Phone
Phone	Address

My treating team

General practitioner (GP)

Name
Phone
Address
Haematologist or oncologist
Name
Email
Phone
Address

Other important contacts

You can use this space to jot down the details of other contacts, such as who to call if you are experiencing new side effects from treatment, or for extra support.

Name	Name
Email	Email
Phone	Phone
Name	Name
Email	Email
Phone	Phone

About this guide

Receiving a new diagnosis of myeloma is understandably a very challenging and emotional time for you, your family, and friends. For many people, this will be the first time they have heard of myeloma. As well as your initial shock, you and the people who care for you are likely to have many, many questions.

We hope that this guide will help to answer a lot of those most pressing questions: helping to make sense of your diagnosis, learn about treatment options, and provide you with networks, information and practical tools to support yourself physically, practically, and emotionally. Empowered with this knowledge, our wish is that you will feel confident about the positive steps you and your treating team can take together to manage your myeloma.

There's a lot of information in this guide, so please don't feel like you need to read it from beginning to end! You might like to start by browsing the contents list on the next page and choosing the information you'll dip into first, and then come back to other sections when you're ready to learn more.

At the beginning of each section, you'll find a summary of main points, which you might find helpful to read first. The quotes from other people living with myeloma will provide insight into how others are navigating their treatment and their lives.

While reading this guide, you're sure to think of more questions of your own, so we've included space in the guide for you to jot these down as they come to mind, and then chat them through with your treating team.

There is much more to learn about myeloma. Throughout this guide, we've linked to other resources, including more detailed information about treatment options and living well with myeloma.

Our aim is to help support you at each step of your treatment pathway, helping you to work with your treating team and live as well as you can. Please remember to ask for the support you need, and know that you can talk to our Myeloma Australia Nurses on our Telephone Support Line on 1800 693 566 or by email at nurses@myeloma.org.au at any time.

*Your Myeloma
Australia Team*



Throughout this guide, you'll find 'Learn more' circles that include a magnifying glass icon. Simply click on the magnifying glass and it will take you to the website listed where you can enter the suggested search terms to find some more helpful information.

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Finding out you have myeloma



Things to remember

- Receiving a new diagnosis of myeloma is understandably a very challenging and emotional time for you, your family, and friends. For many people, this will be the first time they have heard of myeloma.
- You're likely to experience a whole range of thoughts and feelings, including shock, confusion, anger, sadness, fear – or you may feel ready to take on the challenge. It's helpful to know that all of these responses are very normal, and might change or ease over time.
- Sharing how you feel and building a support network can help you to feel less isolated and manage better – now and into the future
- Navigating the first few months of living with myeloma can be busy and complex. While you work out your 'new normal', be kind to yourself and prioritise sleep, rest, nutritious foods, gentle exercise and spending time with family and friends.
- There are many health professionals who will be involved in your care, who are called your treating team. Learning more about what each team member does can help you to be more actively involved in your healthcare.
- Remember, there is always someone available to answer your questions and provide extra support when you need it.

Ray, 70

- Professional percussionist
- Teacher
- Amateur writer
- Sports enthusiast
- Living with myeloma

“ Keeping busy and doing what I like helps me mentally.”

If you've just found out that you have myeloma, you're likely to be experiencing a mixture of strong emotions and wondering how and where to start making sense of your feelings as well as a lot of new medical information.

This section of the guide will help guide you through those early weeks following a myeloma diagnosis: understanding some basic facts about your condition, processing your emotions, building support, telling others, and getting to know the many health professionals in your treating team.

“I was blindsided when my doctor said I had myeloma. It was such a shock, I'd never heard of myeloma before.”

Bruno, Western Australia

Myeloma at a glance

- Myeloma is a type of blood cancer that changes the behaviour of plasma cells, which are normally found in the bone marrow and form part of our immune system.
- These abnormal plasma cells are known as myeloma cells, and they divide and expand within your bone marrow, eventually leading to bone damage and failure of the marrow to make healthy numbers of blood cells.
- Each year, around 2700 people are diagnosed with myeloma in Australia.
- Although most people with myeloma are aged over 60 when diagnosed, it does affect much younger adults as well. Men are affected slightly more often than women.
- Myeloma is the second most common blood cancer worldwide. It accounts for 15% of blood cancers and 1.6% of cancers overall.
- Myeloma is often considered as a chronic or ongoing condition that people live with over the longer term. After initial treatment, it will return, when it will need different types of treatment to help get it under control until it returns again. This is sometimes called a relapsing-remitting cancer, and makes it different from many other cancers.
- While myeloma currently cannot be cured, there are many treatments that are able to slow its progress, put it into remission or plateau phase, control symptoms, and give you the best quality of life for as long as possible.
- With many new developments in its treatment and management, the outlook for myeloma is improving all the time. Research is continuing to develop new treatments and find ways to use existing treatments more effectively. These advances are having a very positive impact on survival rates, and people with myeloma are now living longer than ever before.

The emotional impact of a myeloma diagnosis

Each person will deal with the news that they have myeloma in their own way.

You and your family are likely to be experiencing a whole range of thoughts and feelings, such as shock, confusion, anger and sadness – as well as questions and fear about what the future holds. You may feel numb, overwhelmed, or have a sense of disbelief or denial that this can't be happening to you, especially if your diagnosis was unexpected. You may also be feeling positive and motivated to take on the challenge – and that's okay too. For some people, reaching a diagnosis of myeloma can finally provide the answer and a sense of relief about why they have been feeling unwell for some time.

It's helpful to know that **all** of these thoughts, feelings and questions are very normal. Over time, your emotions might change, and they may ease as you begin to adapt to a new way of life. It's also very important to know that you don't need to manage this intense experience by yourself.

Building your support network

Sharing how you feel and building a support network can help you to feel less isolated and manage better – now and into the future.

You might like to start by talking through your feelings with a partner, close friend, or family member. These are the people who can cry and laugh with you, and who don't need apologies or explanations when you get angry and frustrated. When you're able to be open with the people who care most for you, it helps everyone to understand that your myeloma is not an 'off limits' subject, and that it's positive for all of you to acknowledge how you feel. That can be a big relief for others as well as you.

It can also be helpful to talk to someone outside your immediate support circle. This can give you a new perspective, help you to explore all your feelings and emotions without filtering them to protect someone you know, and find other practical ways of coping. You might like to talk to your GP, another health professional, your community leader, or other trusted spiritual adviser.

Myeloma Australia Nurses understand many of the issues you are dealing with, can answer your questions, and put you in touch with other support services. You can reach them on our Telephone Support Line on **1800 693 566** during business hours or via email at nurses@myeloma.org.au.

Sometimes, you just want to talk with someone who's been in your shoes and knows what it's like to live with myeloma. That's where support groups can help. Myeloma Australia has many Information and Support Groups throughout Australia. A Myeloma Australia Nurse can tell you more, or visit www.myeloma.org.au for details of each group's meeting times.

Online support groups available through social media platforms like Facebook can also provide a convenient way to connect with other people who are going through a similar experience. Keep in mind that not all the information you get from these groups may be accurate or suitable for you. Be sure to talk to your doctor before trying any suggestions you come across in an online group.

“When my husband was first diagnosed with myeloma, it felt like a black cloud was hanging over our heads. With the support of the nurses at Myeloma Australia, I feel more optimistic, and it's more like a grey cloud following us now.”

Carolyn, Victoria

Always ask for more help when you need it

For some people, the intense emotions experienced at the time of diagnosis don't go away. Or, you may find that living with myeloma causes ongoing challenges that make you anxious or depressed, where your mood is low and doesn't improve. This is when it's important to find some extra support.

Your GP or a Myeloma Australia Nurse can refer you to specialised counselling services.

'What support is available?' at the end of this guide includes more information about emotional support and your mental health.

Telling other people

It's a big step to share your myeloma diagnosis with other people – and you can do this when you feel ready and in a way that feels right for you. You might like to ask a family member, close friend or your doctor to help you.

You can't predict how other people will react to your news. Some may ask a lot of questions; others may not want to know details. You may also find that some friends and family become closer, while others become more distant. Try not to get upset about other people's reactions – news about cancer can stir different feelings for different people, and this isn't your responsibility.

You may find it helpful to share some written information about myeloma with others, helping them to understand how it's different from other cancers, and that you will have times when you are on and off treatment. The 'Myeloma at a glance' information on page 2 of this guide can provide a helpful introduction.

You'll also find information about talking to children about myeloma on page 81 of this guide.

“I found sharing my diagnosis with my family brought us closer together, although there are some friends who have been wonderful and others who found it too difficult to deal with and have become disconnected.”

Robert, New South Wales

Navigating the first few months

Navigating the first few months of living with myeloma can be busy and complex.

You will be learning about your condition and treatments and getting used to new routines – a new way of life. You will need to have many tests and may have several trips to hospital.

During these first few months in particular, it's important to look after yourself as well as you can. Do your best to prioritise sleep and rest, eat a wide range of nutritious foods, enjoy some gentle exercise like walking, and spend time in nature, and with family and friends who make you feel good.

Over time, this early, unsettling stage of living with myeloma will begin to settle and you will find your 'new normal'. For many people, treatment will gradually reduce the level of myeloma in their body, which may help to reduce symptoms and provide a sense of relief.

In some cases, the first treatment combination may not be as effective as you and your doctor had hoped. Your treating team will work with you to change your treatment until the myeloma starts to respond.

Ann, David and baby Claire, New South Wales



Getting to know your treating team

There are many health professionals who will be involved in your care. Throughout this guide, we will refer to them as your treating team. Here are some of the people who will have a role to play in managing your care.

What is a multidisciplinary team?

Australian cancer services are organised so that each hospital usually has a range of healthcare professionals working together as a team. This is called a multidisciplinary team.

Your treatment is likely to be discussed by the team, although only one doctor (usually the consultant haematologist) will manage your treatment.

Medical team

Haematologists and oncologists are specialist doctors who have extensive training and experience in diagnosing and treating people with blood conditions and cancers like myeloma. Within your team, there will be other doctors such as trainee doctors (registrars) and other medical officers, who will also provide care.

Specialist nurses have further training in cancer and myeloma. They coordinate your care, help you manage any side effects, and provide education and support to you and your carer. Not all hospitals will have a specialist nurse as part of the team.

Registered nurses work in the inpatient or outpatient wards, administering medicines and supporting your overall health and wellbeing. They also provide education about side effects and how to manage them.

Hospital pharmacists dispense your prescribed medicines and help you understand the safest way to take medicines and manage any side effects.

The palliative care team supports you and the treating team with managing side effects such as pain and nausea. The palliative care team is a support service during your whole experience of myeloma, not just at the end of life.

Radiation oncologists are doctors who prescribe and plan radiotherapy. Not everyone with myeloma will need radiotherapy – only those who have a specific area that is particularly painful or unstable.

Allied health professionals

Dietitians can help with issues such as taste changes, loss of appetite, weight loss, weight gain, and managing diabetes. They can develop a personalised eating plan for you, helping you to get all the different nutrients you need.

Exercise physiologists and physiotherapists (physios) can guide you on safe ways to exercise and build strength within any limitations caused by myeloma and any other health conditions you may have.

Occupational therapists (OTs) can help you to develop, recover, or maintain activities that are important to you. These may be activities at home, work or in the community. An OT can assess your situation and then help you come up with practical ways to make all types of everyday activities more manageable. OTs can also provide advice on pacing yourself and managing fatigue.

Psychologists and counsellors provide important emotional support to help you manage the challenges of living with a chronic illness. They can help you work through your feelings, especially if you're feeling anxious or depressed.

Social workers provide emotional and practical support, helping you to access other helpful services such as financial support and advance care planning.

Podiatrists help to keep the skin and nails on your feet comfortable and free from infection. This is especially important if you have peripheral neuropathy, which is explained on page 18 of this guide.

Community healthcare team

Your **general practitioner (GP)**, also called a family doctor, plays a very important role in overseeing all your health conditions, including myeloma. It's important to have a regular GP to help you stay on top of your regular health screening, vaccinations and prescriptions. The hospital team will provide regular updates to your GP.

Community pharmacists can help you to understand more about your prescription and over-the-counter medicines – and how to use them correctly and safely. For consistency of care, it can be a good idea to use the same local pharmacist. There may be some medicines that are only dispensed by the hospital pharmacy.

Myeloma Australia Nurses provide education, dedicated support, empowerment and advocacy for you and your loved ones. They also offer the opportunity for you to connect with other people living with myeloma through support groups, seminars and community events.



What is myeloma?



Things to remember

- Myeloma, which is also called multiple myeloma, is a type of blood cancer.
- Myeloma originates from a type of white blood cell called a plasma cell, which is found in your bone marrow.
- All people who eventually develop myeloma initially had a precursor condition called *monoclonal gammopathy of undetermined significance* (MGUS). Most people live with MGUS without ever realising they have it. Each year, only about 1% of people with MGUS slowly progress to develop myeloma.
- *Smouldering myeloma* or *asymptomatic myeloma* is an early phase of myeloma that does not need treatment. But because it is more likely to progress to myeloma than MGUS, it is monitored closely with regular blood tests.
- It's thought that the risk of developing myeloma increases as we age and with the reduction in immune function that's associated with ageing.
- Myeloma is an individual disease, with people experiencing many differences in their symptoms and response to treatment.
- Many of these differences are because of the different biological subtypes of myeloma – or Ig types. These are labelled with English and Greek letters, based on the type of paraprotein the myeloma cells produce.
- As well as the different Ig types of myeloma, there are some rarer myeloma-related conditions, including plasmacytoma, plasma cell leukaemia and AL amyloidosis.

Christine, 79, with husband, Peter

- Community nurse
- Positive thinker
- Keen gardener, reader and crafter
- Family is her greatest joy
- Living with myeloma

“I always try to stay positive and read as much as I can to learn about myeloma.”

Understanding plasma cells, bone marrow and immunoglobulins

When describing different types of cancer, we usually refer to the part of the body that the cancer cells originate from – like the breast, prostate, bowel or lung. These are all 'solid tumour' cancers.

Blood cancers are different because they develop in the bone marrow. Bone marrow is the spongy material found in the centre of larger bones in our bodies and serves as the production centre of blood cells, which include red blood cells, white blood cells and platelets.

Myeloma, also referred to as multiple myeloma, originates from a specific white blood cell called a plasma cell.

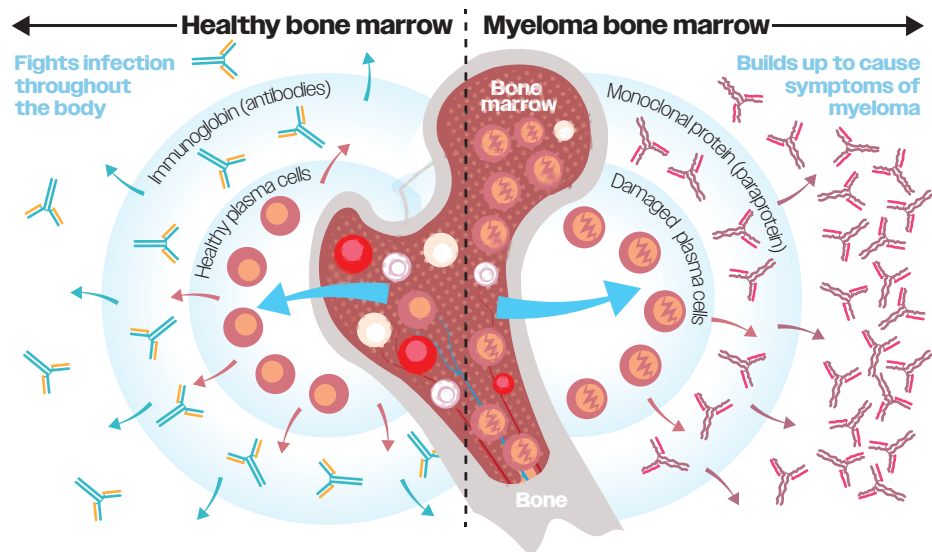
Plasma cells are found in bone marrow, where they form part of our immune system. Normal plasma cells produce *antibodies*, also called *immunoglobulins*, to help fight infection. We will use the term immunoglobulins from now on in this guide.

In myeloma, damage occurs to the DNA (chromosomes) of developing plasma cells, causing them to transform into cancerous myeloma cells. These damaged cells start to multiply and spread, **crowding out the bone marrow so it can't make enough red and white blood cells and platelets.**

Instead of making helpful immunoglobulins to fight infection, the myeloma cells make and release an abnormal type of immunoglobulin, called monoclonal (M) protein or paraprotein.

Paraprotein has no useful function in the body, and can build up in your blood and urine, where it can cause some of the symptoms of myeloma.

Myeloma is often diagnosed and monitored by measuring this paraprotein. Myeloma is also classified into different types and subtypes depending on the type of paraprotein the myeloma cells make. You can read more about the different immunoglobulins in 'What are the different types of myeloma?' on pages 12-13.



How does myeloma develop?

Understanding MGUS and its role in myeloma

All people who eventually develop myeloma initially had a precursor condition called *monoclonal gammopathy of undetermined significance* (MGUS). People with MGUS produce a low level of paraprotein in their blood or urine that does not cause any symptoms or damage to the body, and does not need any treatment. Most people live with MGUS without ever realising they have it.

MGUS is often diagnosed when routine blood tests discover a higher-than-normal total protein level in the blood. It is then monitored with yearly blood tests to check for any increase in the paraprotein level.

Even though all myeloma begins as MGUS, it's very important to know that not everyone with MGUS will develop myeloma.

Each year, only about 1% of people with MGUS will slowly progress to develop myeloma.

Please see our **MGUS** information sheet @myeloma.org.au

What is smouldering myeloma?

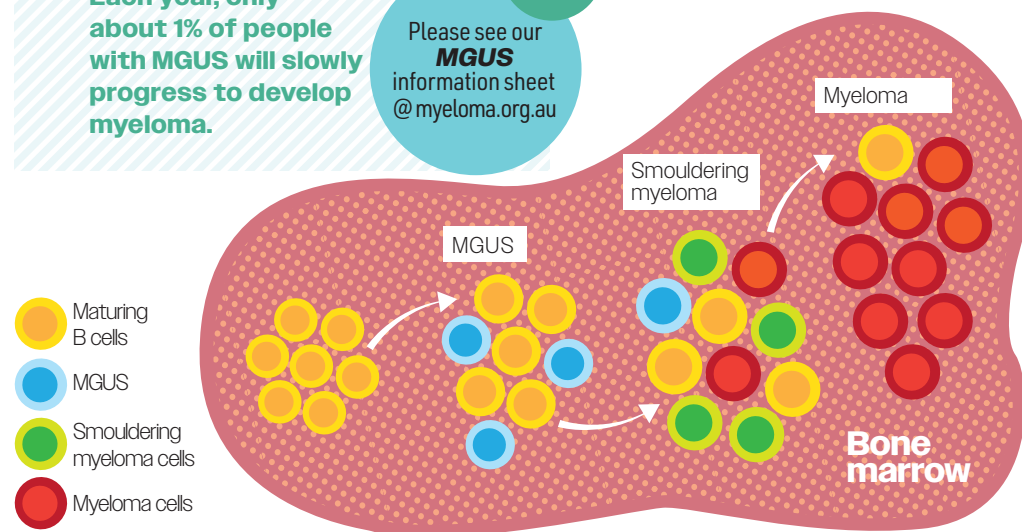
Some people discover that they have abnormal plasma cells in their bone marrow and a measurable paraprotein in their blood or urine, but otherwise feel well and have no symptoms. This is called *smouldering myeloma* or *asymptomatic myeloma*.

Similar to MGUS, this early phase of myeloma does not require treatment. However, the risk of progression to myeloma that requires treatment is higher, and closer monitoring is therefore needed. Your doctor will monitor your paraprotein level with regular blood tests every 3-6 months.

Treatment only needs to begin when your paraprotein starts to rise consistently, or you develop a symptom of myeloma.

Learn more

Please see our **Smouldering myeloma** information sheet @myeloma.org.au



What causes myeloma?

Although there has been a large amount of research into myeloma's potential triggers, no definite causes have been confirmed.

Because it's more common to develop myeloma later in life, it's thought that a person's susceptibility may increase with the ageing process and reduction in immune function that's associated with ageing. As we age, our cells make more mistakes when making new cells, and our immune system is less able to detect these abnormal cells.

A lifetime of accumulated exposure to certain chemicals, radiation, viruses, and a weakened immune system may also be potential triggers.

Is myeloma hereditary?

Myeloma is not thought to be a hereditary condition. However, you are more likely to develop myeloma if you have a family member who has been diagnosed, although this is very rare.

There are no screening tests for myeloma and no way of predicting who will develop a paraprotein.

If you have a family member with myeloma and you have symptoms, or are concerned, have a chat to your GP, who will be able to do a health check.

What are the different types of myeloma?

Myeloma is often described as being a very individual disease, with the symptoms experienced and response to treatment varying greatly. Some of these differences are because of the different biological subtypes of myeloma.

One of the ways of classifying myeloma is based on the type of abnormal immunoglobulin, or paraprotein, that the myeloma cells produce.

Each immunoglobulin (called Ig for short) is a Y-shaped structure that is made up of two heavy chains and two light chains.

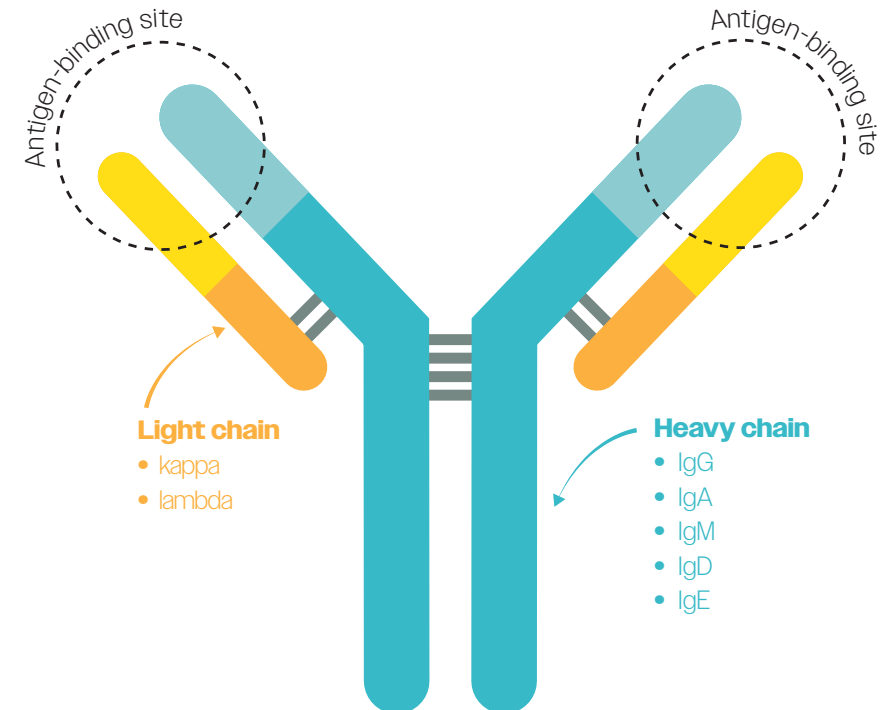
There are five possible types of heavy chains, and these are labelled using the letters G, A, D, E and M.

There are two possible types of light chains, and these are labelled using the Greek letters kappa (κ) and lambda (λ).

Each individual immunoglobulin can have only one of the five possible heavy chains and only one of the two possible light chains. These combinations are what define the different Ig types of myeloma:

- **IgG** type affects about 65% of people with myeloma. This means their myeloma cells produce the heavy chain immunoglobulin type G + either the light chain kappa or lambda.
- **IgA** type with either the light chain kappa or lambda is the next most common type of myeloma.
- **IgM, IgD and IgE** type myelomas are all quite rare. In fact, IgM abnormality can often be diagnosed as another condition called Waldenström macroglobulinaemia.

- **About 20% of people with myeloma produce light chains only.** This is called light chain or Bence Jones myeloma. This is the type of myeloma that's most likely to cause kidney damage, as excess light chains are removed from the body through the kidneys.
- In about 1–2% of cases, myeloma cells produce very little or no immunoglobulin of *any* type. This is called non-secretory myeloma, making diagnosis and monitoring more difficult.
- As well as the different Ig types of myeloma, there are a number of myeloma-related conditions, which include plasmacytoma, plasma cell leukaemia, and AL amyloidosis. These conditions are all rarer than myeloma itself.



What is plasmacytoma?

In some people, abnormal plasma cells collect in the bone or tissue, forming a tumour called a plasmacytoma.

A plasmacytoma can develop on its own, or alongside other features of myeloma.

If one plasmacytoma develops on its own, it is called a solitary plasmacytoma, and can be treated with localised radiotherapy.

If a plasmacytoma develops along with other features of myeloma, it needs treatment that travels through the bloodstream, reaching and affecting cells all over the body (systemic therapy).

What is plasma cell leukaemia?

Plasma cell leukaemia (PCL) is an aggressive form of myeloma where the myeloma cells that are usually contained to the bone marrow can be found circulating in the bloodstream. PCL may be present at the time of your initial diagnosis (where it is called *primary PCL*), or may develop later in the course of your myeloma (where it is called *secondary PCL*).

PCL usually needs intensive treatment and close monitoring. Your doctor will talk with you about different treatment options and what they recommend for you, which will depend on the stage of your PCL, your age, and overall health. You will usually start treatment as soon as possible.

What is AL amyloidosis?

AL (amyloid light chain) amyloidosis is a condition where light chains are deposited in tissues and organs throughout the body.

The light chains can bind to tissues in the heart, liver, spleen, nerves and kidneys rather than being removed from the body through the kidneys.

Some people are diagnosed with just AL amyloidosis or both myeloma and AL amyloidosis together.

Like myeloma, AL amyloidosis is a relapsing-remitting condition. While it cannot be cured, treatment can be effective in controlling AL, reducing symptoms and improving your quality of life.

Your doctor will talk with you about different treatment options and what they recommend for you, which will depend on your age and overall health.

“I had no symptoms of myeloma at all until I injured my shoulder while playing basketball. Scans revealed a plasmacytoma, which had caused weakness in my bones. From there, I was diagnosed with non-secretory myeloma.”

Geoff, Victoria

What are the signs and symptoms of myeloma?

Things to remember

- Signs and symptoms of myeloma may be vague and similar to those of other conditions, which is why it can take quite some time for myeloma to be diagnosed for many people.
- The most significant myeloma symptoms are often described using the acronym CRAB, where each letter stands for different symptoms:
 - **Calcium** elevation (increased calcium in your blood, also called *hypercalcaemia*)
 - **Renal** insufficiency (reduced kidney function)
 - **Anaemia** (low red blood cell count)
 - **Bone** involvement
- Developing CRAB symptoms is often the reason for starting myeloma treatment.
- Other symptoms of myeloma include fatigue and having repeated infections.
- Myeloma can damage nerves causing a problem called peripheral neuropathy, which results in changed sensations like numbness, tingling, burning and pain, often in your hands and feet.
- Some people develop thickened blood, called hyperviscosity. This can cause headaches, blurred vision and high blood pressure.

Fiona, 49 with Marlo, 10

- Enthusiastic traveller and paddle-boarder
- Quokka-lover
- One-eyed Essendon supporter
- Loves a good book and a glass of wine
- Living with myeloma

“I’ve learned to just get on with whatever comes my way and not let myeloma define who I am.”

Learn more

Please visit myeloma.org.au to download our information sheets on many of these symptoms and how to manage them.

This section provides brief information about some of the main signs and symptoms of myeloma and why they happen.

We've also produced a range of information sheets that provide more detailed, practical information about living with and managing many of these symptoms.

CRAB symptoms

Signs and symptoms of myeloma are sometimes referred to as myeloma-defining events. They may be vague and similar to those of other conditions, which is why it can take quite some time for myeloma to be diagnosed for many people.

The most common myeloma-defining events are often described using the acronym CRAB, which stands for:

- **Calcium** elevation (increased calcium in your blood, also called *hypercalcaemia*)
- **Renal** insufficiency (reduced kidney function)
- **Anaemia** (low red blood cell count)
- **Bone** involvement

The onset of CRAB symptoms is often the reason for starting myeloma treatment.

There are many other possible symptoms of myeloma, and we have explained some of these additional symptoms on page 18.

The signs and symptoms you have at diagnosis may change with each relapse. It's important to report any new symptoms to your treating team.

CRAB

Calcium elevation

(increased calcium or hypercalcaemia)

Calcium is a mineral normally found in bones. It helps keep our bones strong and is involved with many other bodily functions, such as muscle movement, nerve conduction and blood flow.

When bones are damaged by myeloma cells, they can release calcium into the bloodstream. This can lead to higher levels of calcium in your blood, known as *hypercalcaemia*. Symptoms of hypercalcaemia include confusion, constipation and thirst.

Renal insufficiency

(reduced kidney function)

Your kidneys' main function is to cleanse blood of toxins and turn the waste into urine. Sometimes, when myeloma cells produce high levels of light chains, these can block the filtration mechanism of the kidneys. This can affect your kidneys' ability to function at full capacity.

Myeloma treatments such as chemotherapy can also cause stress on your kidneys.

Anaemia

(low red blood cell count)

Red blood cells are produced in the bone marrow and are responsible for carrying oxygen around the body. When there are high levels of myeloma cells in your bone marrow, they can take up too much space and not leave enough room for healthy levels of red blood cells to be produced. This results in anaemia, which can cause symptoms including fatigue, shortness of breath and dizziness.

Bone involvement

The bones of our skeleton are maintained by a process called remodelling. This means our bones are constantly being broken down and rebuilt at an even pace. Myeloma cells release a chemical that can upset this process, resulting in bone being broken down faster than it can be rebuilt. Signs that myeloma has affected your bones include pain, fractures, osteoporosis (bone weakening), and destructive tumours, which are called *lytic lesions*.

Other signs and symptoms

Recurrent infections

Myeloma cells can affect your immune system's normal function, increasing your risk of developing infections. Often, people have experienced repeated infections just before being diagnosed with myeloma.

Fatigue

Myeloma cells put pressure on many functions of the body, which in turn causes fatigue. Fatigue is one of the most common symptoms of myeloma. It can be persistent and difficult to relieve with sleep or rest.

“The fatigue can be overwhelming at times. It's hard for my family and friends to comprehend just how tired I can feel. I try to pace myself and plan my activities on the days that I have the most energy.”

Jan, Western Australia

Peripheral neuropathy

Myeloma cells can cause direct damage to your nerves, causing a problem called peripheral neuropathy. This can cause changes in sensation, such as tingling, numbness, pain or a burning feeling, most commonly felt in your hands and feet. Some treatments for myeloma can also cause peripheral neuropathy.

Hyperviscosity

In some people, high levels of myeloma cells (paraprotein) can cause their blood to thicken, which is called *hyperviscosity*. This results in sluggish blood flow which can cause symptoms including headaches, blurred vision and high blood pressure.

Learn more

Please visit myeloma.org.au to download our information sheets on many of these symptoms and how to manage them.

Ann, and baby Claire, New South Wales



A portrait of a man with short, dark hair, looking slightly to the right. The image is overlaid with a teal gradient.

Geoff, 49

- Devoted father, husband and friend
- Enjoys the great outdoors
- Passionate myeloma patient advocate and fundraiser
- Living with myeloma

“I find that there is so much that happens in life that is out of my control. Therefore, I try to only ‘worry’ about what I CAN control.”

How is myeloma diagnosed and monitored?



Things to remember

- Diagnosing and monitoring myeloma is like putting together pieces of a jigsaw puzzle, involving many different tests that may vary from person to person.
- You will have regular blood tests where your paraprotein and light chain levels are measured. Your paraprotein results show how your myeloma is responding to treatment, or if you need to start treatment.
- Other blood tests check your blood cells, kidney function, calcium in your blood, and albumin, as well as molecules and enzymes that can be a sign that your myeloma is active.
- Some people will have a urine test to check for myeloma cells called Bence Jones protein.
- Because myeloma can affect your bones, your treating team will keep an eye on your bone health using the best type of imaging or scans for your needs.
- A bone marrow aspirate and trephine (BMAT) biopsy looks for the percentage of plasma cells in your bone marrow and is done under local anaesthetic with pain relief.
- Cytogenetic testing involves testing samples of your bone marrow to look for changes in chromosomes, which can help to work out if your myeloma is high-risk and guide treatment choices.
- Your doctor will use all your test results to work out if your myeloma is stage one, two or three. The stage helps your doctor to work out the best management plan for you.
- Your doctor is the best person to talk to about their expectations of treatment for you. Survival rates that you may read about are based on statistics and averages, but you are an individual, and those statistics may not apply to your individual situation.

Blood tests

Diagnosing and monitoring myeloma is like putting together pieces of a jigsaw puzzle. Many different tests and other investigations are used to build the picture for each person. As myeloma is a very individual condition, the types of tests used may vary from person to person.

In the next pages, we've included details about some of the common tests that your doctor may order.

Your paraprotein will be measured through a test called *serum protein electrophoresis*.

You'll have your paraprotein measured regularly to see how you are responding to treatment.

If you're not on any treatment, your paraprotein will be checked for any increases that may need to be addressed.

A full blood count measures the makeup of important cells in your blood including red blood cells, which transport oxygen; white blood cells, which help fight infection; and platelets, which help your blood to clot.

A free light chain test will be taken at the same time as your serum protein electrophoresis, and is used to measure your kappa and lambda light chain levels.

An increase in light chains may be an indicator of myeloma, but can also increase for other reasons, such as an immune response to a vaccine.

The level of urea and creatinine in your blood will be measured to check your kidney function.

These waste products are normally filtered out by your kidneys, and high levels can indicate poor kidney function.

Blood tests

Calcium is a mineral normally found in bone.

If you have active bone disease due to myeloma, calcium is released from your bone into your bloodstream.

Blood tests check for these higher levels of calcium in your blood, which is called *hypercalcaemia*.

Albumin is a type of protein that normally makes up most of the protein found in our blood.

In myeloma, hormones (or cytokines) produced by the myeloma can suppress albumin production. This means that your albumin level can be another sign that your myeloma needs treatment.

Beta 2 microglobulin (β2M) is a molecule that sits on the cell surface of a type of white cell (lymphocyte), which includes myeloma cells.

An increased level of β2M can be a sign that myeloma is active.

Lactate dehydrogenase (LDH) is an enzyme found in nearly all living cells.

If cells are damaged by injury or disease, LDH is released into the bloodstream.

Increased LDH can be a sign that myeloma is active.

Urine tests

A urine test may be used to check for myeloma cells, which are called Bence Jones protein when found in urine.

Your urine might be collected as a small sample or a 24-hour urine collection, which involves collecting your urine at home over a 24-hour period.

“My doctor checks my bloods once a month. It's nerve-racking waiting for the results, but it's good to keep an eye on everything.”

**Bob,
Australian Capital
Territory**

Imaging

Myeloma can affect your bones, and so it's important to keep an eye on your bone health, which can be done using a range of different types of imaging or scans. Your treating team will recommend the type of scans they think will be best for you, depending on the location and type of symptoms you have.

Not all scans are available in every centre, and some are not covered by Medicare. Your treating team will consider all of this when recommending the scan or scans you need.

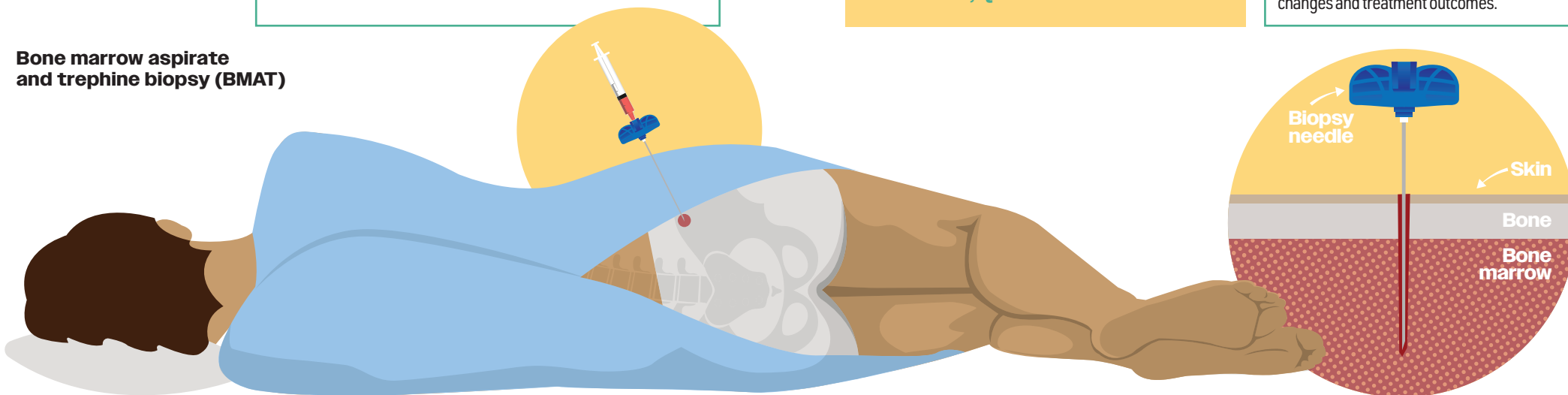
Whole-body low-dose CT (WBLDCT) is a modified type of computerised tomography (CT) scan that uses a lower dose of radiation than conventional CT scans and can identify myeloma-related bone changes and bone damage called *lytic lesions*.

Magnetic resonance imaging (MRI) provides detailed images of your bones and soft tissue without using radiation and can show the amount and pattern of myeloma in your bone and bone marrow, and sometimes outside the bone.

An MRI can also allow your spinal cord to be assessed in special situations.

Positron emission tomography-computed tomography (PET/CT) scans involve having a radioactive medicine called fluoro-deoxy-glucose injected into a vein to highlight areas of rapid cell growth such as tumours.

Bone marrow aspirate and trephine biopsy (BMAT)



Bone marrow aspirate and trephine biopsy

A **bone marrow biopsy or BMAT** is a procedure that looks for the percentage of plasma cells in your bone marrow. The procedure is done under a local anaesthetic with pain relief.

A thin needle is used to take a small sample of fluid (aspirate) and a small core of bone (trephine) from your bone marrow – usually from your pelvic bone.

These samples are then examined under a microscope. Normal bone marrow has fewer than 5% plasma cells; bone marrow in people with myeloma may have between 10% and 90% plasma cells.

“The bone marrow biopsy was a bit daunting, but I was given some pain relief, and it was over really quickly.”

Sunita, Queensland

Cytogenetic testing

Cytogenetic testing involves testing samples of bone marrow to look for changes (mutations) in chromosomes, which are the structures that carry genetic information in our cells. This is usually done using a test called *fluorescence in situ hybridisation* (FISH).

During mutation, bone marrow can gain chromosomes (addition), lose chromosomes (deletion), or chromosomes can break off and reattach somewhere else (translocation).

Cytogenetic results may be useful to work out if your myeloma is considered high-risk. This information is used to guide treatment choices. Chromosomal abnormalities that seem to be related to a higher-risk myeloma include translocations t(4;14), t(14;16), t(14;20), deletion of chromosome 17p, and certain abnormalities of chromosome 1.

Researchers are currently exploring the relationship between different cytogenetic changes and treatment outcomes.

How is myeloma staged?

Once you have had all your tests, your doctor can use your results to work out the stage of your myeloma.

To do this, they use the International Myeloma Working Group's Revised International Staging System (R-ISS) to decide if you fit into stage one, two or three. This helps your doctor make a plan to most effectively manage your myeloma.

The criteria in this staging system are written in medical terms that your doctor can explain to you more clearly.

Revised International Staging System (R-ISS) for myeloma

Stage	Criteria
R-ISS I	<ul style="list-style-type: none">ISS I (Serum β2 microglobulin <3.5mg/L and serum albumin >35g/L) andNormal LDH andNo high-risk FISH profile (defined as del17p and/or t(4;14) and/or t(14;16))
R-ISS II	Patients failing to meet criteria for R-ISS I or III
R-ISS III	ISS III (Serum β 2 microglobulin >5.5mg/L) and High-risk FISH or High LDH

Understanding survival rates

The full version of the staging system attempts to provide an average survival rate for each stage. We haven't included these rates here, because how well your myeloma responds to treatment and what this means for you in the longer term depends on so many different factors. Your doctor has all the information about your myeloma and general health, and is the best person to talk to about their expectations for you.

It's also important to remember that published survival rates are based on people who had treatment many years ago with different therapies than the ones we have available today.

Always remember that there are a lot of statistics, which show averages, but you are an individual, and those statistics may not apply to your individual situation.

“When I was first diagnosed, the average life expectancy according to internet sources was 3–5 years.

Twelve years later, I'm still here!

Only your treating team can provide accurate information specific to your situation.”

Helen, Victoria



How is myeloma treated?



Things to remember

- The treatment and management of myeloma is very individual, just like the condition itself. It's important to make an informed choice about what treatment you will have.
- If your myeloma isn't causing any specific problems, your doctor may recommend active monitoring and you may not need to start treatment yet.
- When you do start treatment, it's usually a combination of medicines, called a treatment regimen. The different medicines target myeloma cells at different points in their life cycle.
- Your doctor will explain the treatment options available to you at diagnosis and at each relapse. You and your doctor will consider many different factors about your health and personal preferences when making treatment choices.
- Your treatment will usually include medicines to help control the myeloma itself, as well as supportive care treatments for other symptoms and complications caused by myeloma.
- There are two main treatment pathways for myeloma:
 - Autologous stem cell transplant (AuSCT) is recommended as part of treatment for people where the benefits will outweigh the side effects. This is made up of 3 – 6 cycles of initial therapy followed by the transplant.
 - If AuSCT is not suitable for you, then you will usually be offered 6 – 12 cycles of initial therapy.
- Within both of these pathways, there are many different families or classes of treatment and new ones are being constantly developed.
- Participating in a clinical trial can have benefits for you and others in the future. Ask your treating team if there is a clinical trial available that's suitable for you.
- Your doctor will monitor your response to treatment through ongoing tests.
- Preparing for your medical appointments and being clear about the questions you want to ask will help you to get the most out of each appointment and be more actively involved in your healthcare.

Joe, 38

- Avid landscape and wildlife photographer
- Nature-lover
- Ocean-swimmer
- Living with Myeloma

“I try to keep as active as I can, get enough rest, and don't let myeloma stop me from enjoying life. I'm not the same as I used to be, but that doesn't mean I can't still enjoy myself.”

Your treatment pathway

The treatment and management of myeloma is very individual, just like the condition itself.

“When I was first diagnosed, I had smouldering myeloma, so didn’t need any treatment.

It was only when my paraprotein reached a certain level that my treatment started.”

Ravi,
New South Wales

Not everyone diagnosed with myeloma will need to start treatment straight away. Your doctor may talk with you about *actively monitoring* your myeloma and waiting until it is causing specific problems before beginning treatment.

When you do begin treatment, it will usually be made up of a combination of two or three different medicines, called a *treatment regimen*. This helps to ensure that the myeloma cells are being targeted at different points of their life cycle to achieve the maximum response. The aim of treatment is to achieve maximum response without unacceptable side effects.

There are many different types of treatments available on the Australian Pharmaceutical Benefits Scheme (PBS). There are also new treatments available through clinical trials and special access programs.

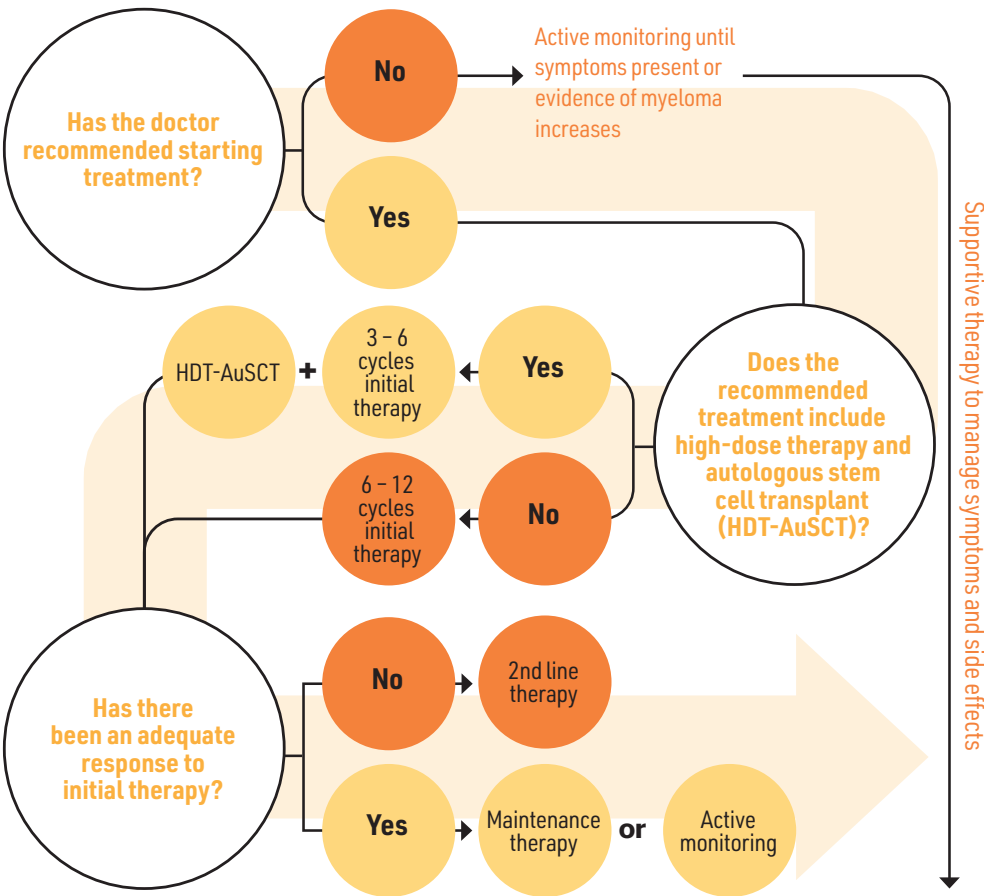
Your doctor will explain the treatment options available to you at diagnosis and at each relapse. There are many factors that you and your doctor will consider when making treatment decisions, these include:

- availability of the treatment through the PBS, a clinical trial, or special access program
- your current level of myeloma
- your general health and age
- any pre-existing health conditions you have
- your response to any previous treatments
- side effects you experienced with previous treatments
- your personal preference due to circumstances and lifestyle.

Your treatment will usually include medicines to help control the myeloma itself, as well as supportive care treatments for other symptoms and complications caused by myeloma. You can read more about supportive care treatments in pages 51-57 of this guide.

When you and your doctor decide that it is time to start treatment, they will choose one of two different treatment pathways depending on whether or not you are eligible for autologous stem cell transplant (AuSCT).

Generally, AuSCT is recommended as part of initial treatment for people who are aged under 70. Above this age, the toxicity of the procedure may outweigh the benefits. However, the decision to use AuSCT is more about your overall health than your age. You can read more about stem cell transplant on pages 36-37 of this guide.



What are the different treatments for myeloma?

There are new treatments constantly being developed for myeloma. Over the next few pages, we've covered the main families or classes of treatments that are currently used. These may change in the future, so always ask your doctor about the most suitable treatment options for you.

Immunomodulators (IMiDs)

Immunomodulators, or IMiDs, are medicines that work by modifying your immune system. They act in many different ways to treat myeloma, which include:

- directly killing or stopping the growth of myeloma cells
- boosting the immune response against myeloma cells
- altering the production of chemical messages involved in the growth and survival of myeloma cells
- blocking the growth of new blood vessels that supply myeloma cells with oxygen and nutrition (this is called *anti-angiogenesis*)
- preventing myeloma cells from sticking to the bone marrow.

IMiDs are taken orally as tablets.

Commonly used IMiDs are thalidomide (Thalomid®), lenalidomide (Revlimid®), and pomalidomide (Pomalyst®). Ixazomib and ixazomib are two newer IMiDs in development.

Please visit www.myeloma.org.au to download our fact sheets about individual IMiDs, their current availability, what to expect during treatment, and how to prevent and manage side effects.

Learn more

Proteasome inhibitors (PIs)

Proteasomes are large molecules that are present in all cells in the body. They are involved in cell regulation and help to remove, breakdown and recycle damaged proteins.

Proteasome inhibitors, or PIs, work by temporarily blocking the action of proteasomes in cells, causing proteins to build up, and the myeloma cells to stop growing and die.

These medicines are taken orally as tablets or may be given by injection into the skin (subcutaneously) or into a vein through a drip (intravenously).

The most commonly used PIs in myeloma include bortezomib (Velcade®), carfilzomib (Kyprolis®), and ixazomib (Ninlaro®).

Please visit www.myeloma.org.au to download our fact sheets about individual PIs, their current availability, what to expect during treatment, and how to prevent and manage side effects.

Learn more

Monoclonal antibodies (mAbs)

Monoclonal antibodies, or mAbs, are engineered in the laboratory to copy the process that our immune system usually uses to recognise and fight foreign substances.

In myeloma, mAbs recognise and bind to proteins, called antigens, that are found in large amounts on the surface of myeloma cells and 'flag' these cells for your immune system to destroy them. Different types of mAbs target different antigens on myeloma cells.

mAbs are given as an injection into the skin (subcutaneously) or into a vein through a drip (intravenously). They are usually used in combination with other anti-myeloma treatments plus a steroid.

The two mAbs currently used in myeloma treatment are daratumumab (Darzalex®) and elotuzumab (Empliciti®). Isatuximab and siltuximab are mAbs in development.

Please visit www.myeloma.org.au to download our fact sheets about individual mAbs, their current availability, what to expect during treatment, and how to prevent and manage side effects.

Learn more

Selective inhibitors of nuclear exports (SINEs)

Selective inhibitors of nuclear exports, or SINEs, are a newer class of medicines used to treat myeloma.

The SINE, selinexor (Xpovio®), works by blocking the action of a protein called exportin 1 (XP01) in the centre of myeloma cells. Myeloma cells have a high level of XP01. Blocking this protein's actions allows genes that control tumour growth to be retained in the nucleus of the myeloma cells, leading to their controlled death.

Selinexor is taken orally as a tablet.

Please visit www.myeloma.org.au to download our fact sheet about selinexor, its current availability, what to expect during treatment, and how to prevent and manage side effects.

Learn more

“All the different treatments and side effects can be really hard to understand. I found asking lots of questions and keeping notes helped me get my head around it all.”

Elizabeth, South Australia

Chimeric antigen receptor T-cell therapy (CAR T-cell therapy)

CAR T-cell therapy is a once-only procedure that involves extracting, reprogramming, and reinfusing a person's own immune cells to fight myeloma.

In CAR T-cell therapy, a small amount of your T cells are collected and sent to a laboratory to be 'retrained' by adding genetic information to them so they are able to recognise, bind to and destroy cancer cells. You will be given bridging chemotherapy to control the myeloma while this process takes place. The CAR T-cells are then infused into a vein through a drip (intravenously).

The genetic information added to the T-cell targets a specific antigen that is on the surface of cancer cells. In myeloma, the most common target is B-cell maturation antigen (BCMA).

Other target antigens are also being researched. Two examples of CAR T-cell therapy are cilta-cel (Carvykti®) and ide-cel (Abecma®).

Please visit www.myeloma.org.au to download our fact sheet about CAR T-cell therapy, its current availability, how it is given, what to expect during treatment, and how to prevent and manage side effects.

Learn more

“When I first started treatment I noticed that I had a really short fuse and would cry at the drop of a hat. I then found out it was the steroids causing the change in my mood. My doctor was great at helping me manage these symptoms.”

Peter, Tasmania

Antibody-drug conjugates (ADCs)

Antibody-drug conjugates, or ADCs, are made up of two different types of medicines that are linked together to treat myeloma.

Belantamab mafodotin (Blenrep®), is a combination of a monoclonal antibody, belantamab, linked with the chemotherapy, mafodotin. It is given into a vein (intravenously).

Belantamab, the monoclonal antibody part of the treatment, is engineered in the laboratory to find a receptor on the surface of myeloma cells called B-cell maturation antigen or BCMA. Belantamab attaches to BCMA, sending a signal to your immune system to recognise and kill the cells.

Mafodotin, the chemotherapy part of this treatment, is very effective at killing myeloma cells and works better if it is guided to enter the myeloma cells by an antibody directed at myeloma. When it is given as part of the antibody molecule, the chemotherapy becomes active once it is guided to and enters the myeloma cells that have BCMA on the surface. When mafodotin enters the myeloma cells, it disrupts the skeleton of the cells and causes their death.

This means that the myeloma cells are killed by both the immune system and chemotherapy.

Please visit www.myeloma.org.au to download our fact sheet about belantamab mafodotin, its current availability, what to expect during treatment, and how to prevent and manage side effects.

Learn more

Bi-specific T-cell engagers (BiTE®s)

Bi-specific T-cell engagers, or BiTE®s, help the immune system recognise and kill cancer cells. They are designed to form a bridge between cancer cells and a type of immune cells (T cells), so the cancer cells are more likely to be killed by the immune system.

These medicines are made up of two targeting proteins, called receptors. One receptor finds and locks onto antigens on the surface of cancer cells and the other receptor locks onto proteins on the surface of the T cells.

BiTE®s are in their early stages of development. Products in development include teclistamab, elranatamab and cevostamab.

BCL-2 inhibitor

BCL-2 is a protein that prevents programmed cell death and can be found in higher amounts in myeloma cells.

BCL-2 inhibitor medicine inhibits the action of BCL-2, causing myeloma cells to die. This medicine works best in people who have a certain genetic abnormality called translocation of chromosomes 11 and 14 (t(11;14)).

Venetoclax (Venclexta®) is the most well-studied BCL-2 inhibitor used in myeloma, and is currently being evaluated in clinical trials.

Please visit www.myeloma.org.au to download our fact sheet about venetoclax, its current availability, what to expect during treatment, and how to prevent and manage side effects.

Learn more

Steroids (corticosteroids)

Steroids are medicines that are made to copy hormones that are naturally produced in the body. They are commonly used as part of myeloma treatment.

The steroids that are used in myeloma are known as *glucocorticoids*, and are different from the steroids used to build muscle. Glucocorticoids can change the body's immune system responses, reduce inflammation, and cause myeloma cells to die.

Steroids are also used to enhance the effects of other anti-myeloma treatment combinations.

Sometimes, steroids can help to reduce symptoms such as nausea caused by chemotherapy, or hypersensitivity (allergic) reactions to certain medicines or blood products.

Steroids can be given alone or in combination with chemotherapy or other anti-myeloma treatments. They can be taken as tablets or given into a vein through a drip (intravenously).

The two most commonly used steroids in myeloma are dexamethasone and prednisolone.

Please visit www.myeloma.org.au to download our fact sheet about steroids, how they are given, what to expect, and how to prevent and manage side effects.

Learn more

Chemotherapy (chemo)

Chemotherapy, which is often called 'chemo' for short, is used alone or in combination with other medicines to kill cancer cells.

The treatment works by disrupting the way that rapidly dividing cells, like myeloma cells, divide and reproduce.

Chemotherapy can be used at different times along your myeloma treatment pathway, and can be taken orally as tablets or may be given by injection into the skin (subcutaneously) or into a vein through a drip (intravenously). It is usually given in 'cycles', which include a period of active treatment with a rest period in-between to allow healthy blood cells to recover.

Chemotherapy medicines used for myeloma include melphalan and cyclophosphamide.

Radiotherapy (radiation therapy)

Radiotherapy is used in myeloma to treat some specific problems such as lesions and plasmacytomas, and to relieve pain. Not everyone with myeloma will need radiotherapy.

Radiotherapy works by breaking the chain of myeloma cell replication. It damages the cell's DNA, causing the cell to die.

If you need radiotherapy, a radiation oncologist will prescribe the type, dose and frequency of radiotherapy that is suitable for you.

Before treatment, you will have an initial planning appointment with the radiotherapy team, which usually takes around 2 hours. The team will then follow-up with you to make your treatment appointment times. Your actual radiotherapy treatments will each take only a couple of minutes.

Stem cell transplant (SCT)

There are two different types of stem cell transplant, autologous (where your own stem cells are used), and allogeneic (where donor stem cells are used). Both can be used as treatment options in myeloma, although autologous stem cell transplants are much more widely used.

High-dose therapy and autologous stem cell transplant (HDT-AuSCT) is a treatment option that usually follows initial therapy in people who are eligible for the treatment. HDT-AuSCT involves retrieving a person's own stem cells using a process called apheresis. The stem cells are later reinfused to 'rescue' the bone marrow after high-dose chemotherapy.

HDT-AuSCT is most often used in people aged under 70. However, the decision to use this treatment is more about your overall health than your age. You will have kidney, lung and heart function tests done to make sure you can tolerate the large dose of chemotherapy.

The purpose of HDT-AuSCT is to achieve a longer and deeper response to treatment by giving a larger dose of chemotherapy. Without the stem cell infusion, the bone marrow would take a long time to regenerate healthy red cells, white cells and platelets, causing too much risk of complications.

An allogeneic SCT involves using stem cells from a matched donor, who may or may not be a relative. The main advantage of allogeneic transplants is that they aim to use the immune system of the donor to help fight the myeloma cells and potentially prevent relapse.

However, the risk of this procedure is that the donor's immune cells can also attack the recipient's healthy cells, leading to graft-versus-host disease, which can be serious and potentially life-threatening. That's why allogeneic transplants are only considered in a small number of people where it's thought to be the most appropriate treatment option at that time.

Our booklet, **Autologous Stem Cell Transplant**, includes detailed information about this treatment, the different steps involved, managing side effects, and recovery. Visit www.myeloma.org.au to download the booklet.

Learn more

Maintenance treatment

Maintenance treatment is treatment that aims to maintain or further deepen your response to a line of therapy.

This might involve:

- continuing with a current treatment regimen at a lower dose or with less frequent doses
- starting a lower-dose treatment following HDT-AuSCT.

It's important to know that not all people will benefit from maintenance therapy. You and your doctor will talk about balancing any benefits against possible side effects before making the best decision for your situation.



Peter, Queensland, having his stem cells collected

Clinical trials

Treatments and outcomes for people living with myeloma are constantly improving, and the main way this happens is through clinical trials, where new treatments can be developed, evaluated and compared with current treatments.

Clinical trials provide a robust and ethical way to find out if new treatments are safe and effective, and the results of these trials help to decide which treatments will be reimbursed through the Australian Pharmaceutical Benefits Scheme (PBS).

Participating in a clinical trial can provide the individual person with myeloma with a better outcome, and can also benefit other people with myeloma who may eventually receive the treatment being trialled.

Is there a clinical trial suitable for me?

At any time, there are a number of clinical trials available for myeloma treatment in Australia.

Each trial is designed to focus on treating different stages of myeloma, and each will have its own inclusion and exclusion criteria that need to be met for someone to be included in the study.

To learn more about clinical trials currently available in Australia, talk to your treating team and ask if there is a clinical trial that might be suitable for you.

You can also search for clinical trials on www.australiancancertrials.gov.au or www.clintrialrefer.org.au. Clin Trial Refer also has an app that you can download on your smartphone. Once you have found any trials of interest, you can print out the details and discuss them with your family and treating team.

“ Taking part in a clinical trial not only helps me, but gives me an opportunity to help researchers find better treatments for others in the future. ”

Helen, Victoria

The phases of a clinical trial

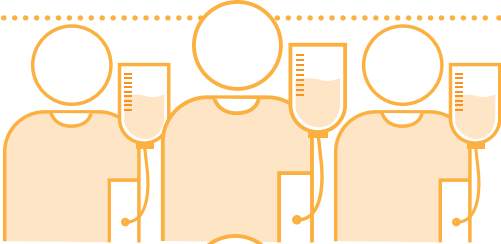
Pre-trial phase

Initial laboratory-based research



Phase 1

First study in people to test the treatment's safety, work out the safest dose, and identify side effects.



Phase 2

Builds on phase 1 and begins to work out how well the new treatment works.



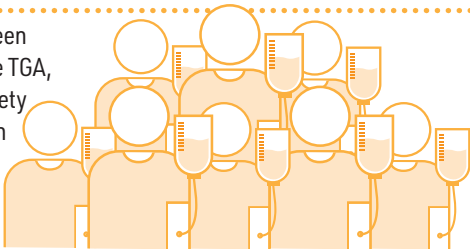
Phase 3

Tests if the new treatment is better than the current standard treatment, and compares side effects, survival and quality of life.



Phase 4

Once the new treatment has been approved and registered by the TGA, phase 4 looks at long-term safety and benefits of the treatment in a wider population. Not all clinical trials have this phase.



How do I decide which treatment to have?

Making an informed choice about what treatment you will have is important, and you will usually be able to take as much time as you need to reach your decision.

In addition to talking with your doctor, it's a good idea to read reliable Australian resources to get a better understanding of myeloma and the treatment options available. Your hospital, Myeloma Australia, and other support organisations such as the Cancer Council and Leukaemia Foundation, are all good places to look. We've also included a list of reliable information and support services at the end of this guide.

Talking things over with family, friends, or other people who have myeloma can help you to make better sense of information, how it may apply to you, and give you a clearer perspective. Myeloma Australia holds information and support groups around Australia, which provide an ideal way for you to connect with the myeloma community.

When considering different treatment options, think about your personal priorities and lifestyle. Each treatment choice will have both benefits and difficulties, and it's vital to discuss these openly with your doctor.

As part of your treatment decisions, it's important for you to tell your doctor what you want to achieve from treatment – and this won't be the same for everyone. Do you want an intense treatment pathway with the goal to live as long as possible? Or would you prefer a less intense treatment option that might offer you a better quality of life, but not the best long-term survival? Once your doctor knows the answers to these questions, they will be better able to recommend a treatment option that suits your goals.

You might find it helpful to make a list of pros and cons of the different treatment options provided to you and take this with you to discuss with your doctor.

ChoiceApp is a useful tool to help you work out what's most important to you when deciding between treatment options.

Go to
**choiceapp.
com.au**
to learn more

Learn
more

“I live an hour and a half from the hospital, so I needed to really think about how I would be able to get myself there each week for treatment.”

John, New South Wales



While there is usually plenty of time to make treatment decisions, in some situations, where myeloma is causing damage to your body, it may be necessary to begin treatment straight away. In this case, your doctor will recommend the most effective and safest option for you at the time.

Then, once you have some improvement and it is safe to do so, you and your doctor can talk further about your ongoing treatment program.

What if I don't want to have any treatment?

You may decide that you don't want to have any treatment. In this case, it's important to have an open conversation with your treating team about your wishes. They will then recommend supportive measures that can help to relieve any symptoms.

The priority for your care will simply change from treating the myeloma to keeping you functioning as well and as comfortably as possible.

Should I get a second opinion?

“My specialist came highly recommended, but I found they weren't good at listening to me or explaining things at my level. I changed specialist and am much happier, as I now feel my concerns are being considered.”

Peter, Queensland

There may be times when you or your doctor feel that you would benefit from the opinion of another haematologist (myeloma specialist).

This may be because there is a clinical trial available, you are eligible for a treatment that's only offered in certain hospitals, or you might want to be sure that the treatment plan you've been recommended is the best option for you.

Because myeloma accounts for less than 2% of cancers overall, and choosing the right treatment is sometimes complex, you may need a second opinion to ensure that your diagnosis is correct, the treatment plan is appropriate, and that all other options have been considered.

Doctors are generally happy for people to ask for a second opinion, and doing this will not offend them. Your current specialist or GP may be able to recommend another myeloma specialist.

It's important to keep in mind that you will have a lot of contact with your treating team, so it's vital you feel comfortable with them so that you can maintain a good therapeutic relationship.

If you're unsure about your current treatment plan, you may find it helpful to talk to a Myeloma Australia Nurse on 1800 693 566.

What are the common side effects of treatment?

All medicines, including treatments for myeloma, have side effects that you need to be aware of. The type and severity of side effects is different for each person, so it's important to let your treating team know about any changes you are experiencing, even if you're not sure that they have been caused by a treatment. In most cases, there are simple tools and tips that your team can recommend to help you feel and function better.

The most common side effects of myeloma treatments include fatigue, increased risk of infections, anaemia, nausea, appetite changes, diarrhoea, constipation, changes to sensations in your hands and feet (peripheral neuropathy), blood clots, mood changes, sleep disturbances, and problems with short-term memory and concentration ('chemo brain').

Infusion-related or allergic reactions

There are some medicines that use your own immune system to reduce myeloma cells in your body (called immunotherapies).

These medicines can cause an infusion-related or allergic reaction in some people.

If this happens, you might experience a scratchy throat, shortness of breath, chest tightness, or a rash. This usually only happens with the first dose.

Your treating team will tell you more about infusion-related reactions, monitor you closely during your infusion, and may slow down or stop your infusion until these symptoms have gone away. Your doctor may give you some medicine to help with the symptoms too.

“I've realised that you don't have to put up with side effects. There can often be adjustments made to treatments to help me tolerate them better.”

Richie, Victoria

Download information about specific treatments, their side effects and how to manage them

Learn more

Go to
myeloma.org.au

'What can I do to help myself?' in this guide, includes information on managing fatigue, sleep issues and 'chemo brain' – as well as tips for eating well, exercise, and looking after your emotional wellbeing, which can help to manage side effects.

Learn more

Go to
page 58
in this guide

How will I know if my treatment is working?

Once you have started treatment, you might notice some of the symptoms caused by myeloma start to reduce. This can be a sign that treatment is working.

Your doctor will monitor your response to treatment regularly, usually through blood and/or urine tests. They might also order scans or a bone marrow biopsy to check for a reduction in your bone lesions or plasma cells in your bone marrow.

You can read about how myeloma is monitored on pages 22-25 of this guide.

Response criteria

When measuring your response to treatment, your doctor will use the International Myeloma Working Group's Response Criteria to define the depth of your response according to the number of plasma cells in your bone marrow, the level of paraprotein in your blood or urine, and the presence of bone disease. These different responses are summarised in the diagram on the right.

While it is very desirable and encouraging to see that no myeloma can be detected, it's important to know that not everyone achieves a complete response from their treatment. Many people can live with a certain level of myeloma in their blood and bone marrow, often for a long time, without it causing any problems. This is called a plateau period.

Your doctor will also be interested in the *duration* of response you have to a treatment, and will take this into account when recommending future treatment options.

Minimal residual disease (MRD)

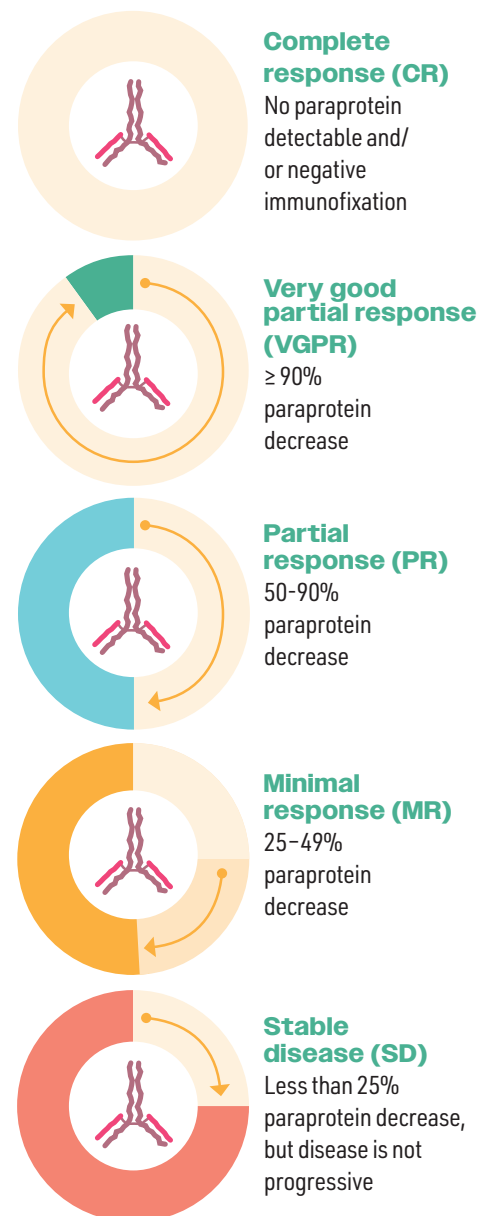
There can be some low-level disease in your bone marrow, even when you have had a complete response to treatment. This low-level disease is not usually visible through conventional tests and is known as minimal residual disease (MRD).

It is increasingly thought that being able to assess MRD is key to predicting relapse in any person. Specific genetic tests and improved scanning techniques are methods that are being used to look for MRD. In time, assessing MRD may help to develop more personalised treatment plans.

Go to
myeloma.org
'Black Swan
Research
Initiative'

Learn
more

Different responses to treatment



Why does myeloma come back?

In myeloma, plasma cells have become damaged or cancerous. These cells multiply faster than the healthy plasma cells. The damaged cells can vary in their genetic makeup, producing slightly different versions of themselves, called *subclones*. During each active phase of myeloma, there will usually be one or more dominant subclones that are detectable in the bone marrow that cause symptoms.

Treatments for myeloma can be very effective at reducing the dominant subclone. However, some of the other subclones may be resistant to treatment. They can lay dormant for a long time, but eventually become active, leading to relapse and the need for your next treatment.

When myeloma returns, it may be the same subclone that was detected at diagnosis – or it may be a different subclone that has become dominant or detectable. This is why it's possible for myeloma to change the way it behaves. For example, in the beginning, the myeloma cells may only produce an abnormal paraprotein. Then at relapse, you may develop higher levels of light chains that were not present when you were diagnosed. Your doctor is always monitoring you to look for these possible changes.

There is currently no way of predicting when myeloma will come back, but it helps to know that periods of response or stable disease can last from months to many years.

See our
**Relapsed
& Refractory
Myeloma**
booklet @
myeloma.org.au

Learn
more

Getting the most out of your medical appointments

You will be having regular appointments with your haematologist (myeloma specialist). There's usually a lot of information to cover in each of these appointments, so it's really helpful to be organised and get the most out of them. Often, people leave an appointment and then realise that they didn't ask a pressing question, or left without one of their scripts! Here are some tips that can help.



“Since starting treatment, my memory is terrible! It's really helpful to have a second pair of ears come with me when I see my doctor.”

Ruth, Western Australia

Tips to prepare for your haematologist appointments

- Write down your questions – and leave space to write down your answers (we've included some suggested questions over the page). You might like to keep a piece of paper or notebook with you, or use the Notes or Google Keep app on your phone to add to your list of questions as you think of them.
- Ask the most important questions first.
- If you have a lot of questions or several issues to cover in one appointment, ask to make a double or long appointment.
- Before you leave the house for your appointment, check your medicine supplies and repeat prescriptions so you can ask your haematologist for more scripts if needed (or ask which scripts you should get from your GP).
- You might like to take another family member or a friend to your appointment – they may be able to help you ask questions and to chat with you afterwards about what the haematologist has said. If your family member or friend can't go to the appointment with you in person, ask if they will be available to take a phone call if needed to be part of a three-way conversation while you're in the appointment.
- Ask your doctor for an interpreter if you have difficulty communicating in English. You can contact Translating and Interpreting Service (TIS) on 13 14 50 – or ask your doctor's office to do this for you.
- Ask if it's okay for you to record your consultation so that you can play it back and go through the information again later. Your haematologist should be happy for you to do this, and some hospitals may offer this service.
- If you don't understand something your haematologist has said, ask them to explain it again.
- You generally don't need to make treatment decisions on the spot. If your haematologist has suggested a new treatment, it's fine to tell them you need some time to think and talk about it with your family.
- Ask as many questions as you need to about any new treatment your haematologist suggests – including the benefits, side effects and costs.
- Before you leave your appointment, remember to ask:
 - for your prescriptions
 - if you need blood tests or scans before your next appointment – and make sure you have the request forms
 - how and when you should follow-up on any test results
 - when you need your next appointment and where it will be.

Tips for keeping track of test results

- At each doctor's appointment where you receive blood test or scan results, ask if you can have a copy of these. Don't be shy about asking – it's your body and your right to have a copy.
- Keep your blood tests in date order where they are easy to find: a clear plastic folder works well.
- Medical imaging providers have online portals where they store scans and their accompanying reports. You can contact the imaging provider to get access to your scans and reports.
- Remember to take test results and images along to any appointment where you are seeing a new healthcare professional for the first time.

Questions to ask your treating team

Here are some questions that might help to get you started.

We've left some space at the end for you to add extra questions of your own. Remember, there's no such thing as a silly question!

Diagnosis

- What type of myeloma do I have?
- What is the stage of my myeloma?
- Do I have any abnormal cytogenetics?
- What tests and scans do I need?
- Are my bones affected?
- Are my kidneys affected?
- Do I need to start treatment?
- Who will be my main point of contact at the hospital from now on?
- Who should I contact if I have specific questions such as:
 - making or changing an appointment
 - requesting a lost or forgotten test form
 - resolving a billing issue
 - getting quick advice on managing side effects?

Remember to jot these contact details in the front of this guide, your diary, or phone.

Treatment

- What are all my treatment options?
- Is there a clinical trial available that is suitable for me?
- Do I have any cytogenetic abnormalities you would take into consideration when recommending a treatment type?
- Which of these treatment options do you recommend for me and why?
- What would happen if I don't start this treatment straight away, or decide I don't want to have treatment?
- What are the possible side effects of these treatments?
- How can I prevent and manage side effects?
- What should I do if I have a side effect or symptom that is new or getting worse?
- What should I do if I have a fever?
- Will this treatment affect my ability to have children?
- Will I need to go to hospital or can I have the treatment at home?
- Are there any out-of-pocket costs to me for this treatment?
- How often will I need to have blood tests?
- Do I need a pathology request form today?
- Do I need to have bone-strengthening medicine while on this treatment?
- Are there any other supportive care medicines I need to take?
- When is my next appointment?
- What is the contact number for the hospital where I will have treatment?

My questions

You can use this space to jot down your own questions:

A woman with blonde hair is lying on her back on a yoga mat, performing a relaxation pose. She is wearing a white t-shirt and dark pants. Her eyes are closed, and her hands are resting on her knees. The background shows a yoga studio with ropes hanging from the ceiling and a wooden floor.

What are supportive care treatments for myeloma?



Things to remember

- Supportive care treatments are medicines and special measures that you take *in addition* to the medicines that reduce myeloma cells in your body.
- These supportive care treatments help to keep you well for as long as possible and manage many of your symptoms.
- These treatments are aimed at:
 - supporting your immune system and helping to prevent infections
 - correcting hypercalcaemia (calcium in your blood), controlling bone disease, and reducing the risk of fracture and bone pain
 - preventing blood clots
 - supporting your bone marrow to make red and white blood cells and platelets
 - relieving pain.
- Many people with myeloma look to complementary medicines and therapies to support them. Some complementary medicines can interact with myeloma treatments. Always talk to your doctor before trying any complementary medicine or therapy.
- Alternative medicines and therapies are treatments that are promoted instead of conventional treatments. These treatments have not been rigorously tested or endorsed by the Australian Therapeutic Goods Administration (TGA). If you are interested in these, it's important to discuss the potential risks with your doctor.

Karen, 72

.....➔
“I prioritise time to relax and let go. My yoga and meditation practices teach me to listen to my breath and silence the chatter of my mind. They help me deal with the challenges of myeloma on all levels: physically, mentally and emotionally.”

Supporting your immune system

You'll hear your treating team talk about supportive care treatments for your myeloma. These are medicines and special measures that you'll need to take *in addition to* medicines that directly reduce myeloma cells in your body. These supportive care treatments will help to keep you well for as long as possible, and help to manage many of your symptoms.

“At first I didn't want to make a fuss, but now I know how important it is to avoid infections. I let all my visitors know to stay away if they're sick, and I keep some hand sanitiser at the door so people can use it on their way in.”

Shari, Western Australia

Because myeloma cells and treatments reduce your immune system's ability to fight infections, you and your doctor will need to take extra steps to help prevent infections and support your immune system.

General steps to help prevent infections

There are many simple, common-sense steps you can take to help prevent infections:

- Keep up good hand hygiene at all times with regular hand washing, or by using alcohol-based hand sanitiser, especially after using the toilet, and before preparing or eating food.
- Avoid crowded areas and contact with friends, family members or work colleagues who are unwell with symptoms such as a cough, runny nose, sore throat, diarrhoea or rashes. If you're in a situation where you can't avoid crowds or you feel uncomfortable, you can wear a mask.
- When gardening, wear gloves to reduce exposure to toxins in soil and a mask to reduce exposure to dust.
- Wear a mask when you're in a dusty environment. Dust can carry bacteria and fungi that can cause infection.
- Use disposable gloves to handle pet waste. If you are scratched by an animal, watch the area closely for signs of infection, such as redness or swelling.

Specific steps to help prevent infections

Preventative medicines

Some treatments for myeloma can increase the risk of serious infections. Your treating team will usually prescribe medicines to reduce this risk during treatment or after a stem cell transplant. Medicines prescribed may include an antibiotic (such as Bactrim®), an antiviral (such as valaciclovir), or an antifungal (such as fluconazole).

If you are prescribed any of these medicines, it's vital that you take them regularly, following your treating team's instructions. If you experience any side effects, it's important to talk to your doctor about these rather than stopping your medicine. Often, there are different medicines you can take to reduce side effects and keep protecting you from infections.

You may need to take anti-infective medicines long-term, so it's important to make sure you always have a current prescription.

Vaccinations

Vaccination can be an effective way to protect you from certain types of serious infections.

If you are offered a vaccine, it's important to check if it is an 'inactive' or 'live' vaccine. During treatment for myeloma, all inactive vaccines are safe for you to have. However, live vaccines, such as the measles, mumps and rubella (MMR) vaccine are not safe, unless your doctor has specifically advised that you can have it.

People with myeloma should have the inactive influenza vaccination every year before winter begins. You should also be vaccinated to protect against pneumococcal infection, the bacteria that causes serious pneumonia and meningitis. Please ask your doctor to recommend the most suitable influenza, pneumococcal and other vaccines for you.

The large dose of chemotherapy that's given as part of stem cell transplantation can reduce some of the protection of childhood vaccinations. Your transplant team will usually recommend being revaccinated against a range of infections about 6 months after your transplant.

COVID-19 vaccination and treatment recommendations for people with myeloma are constantly evolving. Please ask your doctor to recommend the most appropriate protection against COVID-19 for you at the moment.

Overseas travel

If you are planning to travel overseas, it's important to be aware of extra steps you'll need to take to protect your health. Make an appointment well ahead of your travel to chat with your doctor or a travel health clinic about:

- additional vaccinations that you may need to have, which may take up to 2 weeks to have their full effect, and will usually depend on your destination/s. Certain travel vaccines, such as yellow fever, are live vaccines, which you will need to avoid. A travel health clinic can recommend different preventative medicines or vaccines that can be used by people with myeloma
- any additional preventative medicines that you need to take
- how to prevent blood clots, especially on long flights
- any extra prescriptions you may need so you can pack enough medicines for your trip
- providing you with a summary of your recent myeloma treatment, which can be helpful if you have an emergency
- giving you a signed and dated letter that lists all medicines you are currently taking. Carry this letter in your hand luggage with your medicines and keep a copy on your smart phone, electronic tablet or lap top computer.

Supporting your bones

Specific steps to help prevent infections

Immunoglobulin therapy

Immunoglobulin is part of the blood's plasma which contains antibodies that help to fight infections. If you're experiencing recurrent infections and your doctor discovers you have low levels of immunoglobulin IgG, you may be able to access immunoglobulin therapy.

When people make a blood donation, the immunoglobulin part of the blood is removed, tested and then bottled ready for transfusion to people who need immunoglobulin therapy. It can be given as an injection into the skin (subcutaneously) or into a vein through a drip (intravenously) to help your immune system respond to infections.

Recognising early signs of an infection

If you do develop an infection, it's important to seek medical attention at your nearest emergency department as quickly as possible to avoid becoming very unwell.

Common signs of an infection include:

- a temperature of 38°C or above
- chills and/or sweats
- cough, sore throat, or runny nose
- shortness of breath
- burning or pain on urination
- a red, swollen, or inflamed area
- neck stiffness
- rash.

Bisphosphonate therapy

In Australia, two bisphosphonates are currently approved to treat hypercalcaemia and/or bone disease in myeloma:

- zoledronic acid (Zometa®), which is given as an intravenous infusion
- pamidronate (Aredia®), which is given as an intravenous infusion.

There is also a monoclonal antibody treatment that can improve bone strength, called denosumab (Xgeva®). Denosumab works by blocking the chemicals produced by myeloma cells that upset the healthy balance of bone formation. This medicine is given as an injection into the skin (subcutaneously) once a month. Ask your doctor if this medicine is suitable for you.

Our **Managing myeloma bone disease** information sheet includes more detailed information about the causes of bone disease in myeloma, how it is diagnosed and monitored, treatments, and steps you can take for your bone health.

Learn more

Please visit myeloma.org.au to download the information sheet.

“Make sure you have a reliable thermometer at home. You want to be sure to catch a fever as early as possible.”

Trish, Queensland

Preventing blood clots

Anticoagulants

People with myeloma have an increased risk of developing blood clots, called *venous thromboembolism*, both because of myeloma itself and some of its treatments.

Your treating team may prescribe anticoagulant medicine to help prevent a clot from forming. This is usually given either as a daily tablet or subcutaneous injection. Your treating team will let you know if you need this preventative medicine and will give you more information.

“I found out I had myeloma after I donated blood and they found some extra protein in my blood. I now have a new appreciation for blood donors!”

Kevin,
Northern Territory

Supporting your bone marrow

Transfusions

People with myeloma may need blood transfusions from time to time. This is because both myeloma and its treatments can affect your bone marrow's ability to make enough red blood cells and platelets.

Signs you may be low in red blood cells (anaemia) are shortness of breath and fatigue. A blood test to check your haemoglobin will determine if you need a blood transfusion.

Signs you may be low in platelets (thrombocytopenia) include bruising and bleeding easily. A blood test to check your platelet level will determine if you need a platelet transfusion.

Always let your treating team know if you have any signs of low red blood cells or platelets.

Growth factor injections

Myeloma and its treatments can also affect your bone marrow's ability to make enough white blood cells, which your immune system needs to help fight infections.

If your white blood cells have fallen below a level that is safe for you, your doctor may prescribe an injection to help. Granulocyte-colony stimulating factor (G-CSF) is a protein used to promote white cell production in your bone marrow. It is given as an injection into the skin (subcutaneously).

G-CSF is also given before stem cell collection to ensure you have a strong enough blood count for the stem cells to be collected.

Pain management

Pain is a very common symptom experienced by people with myeloma. It can be acute (comes on quickly and lasts for a relatively short period of time) or chronic (does not go away or comes back often).

In myeloma, pain can be caused by bone disease, peripheral neuropathy, infections, and side effects of treatment.

Pain can have a big impact on your quality of life, which is why having an individual pain management plan is such an important part of your myeloma treatment. This begins with communicating openly with your treating team and then working with them to find the right combination of medicines, treatments, tools and lifestyle adjustments to help manage your pain so you can experience an improved quality of life.

In some cases, the palliative care and pain teams might be included to help develop your pain management plan.

Our **Managing myeloma pain** information sheet includes more detail about the causes of pain in myeloma, medical pain management options, as well as physical, psychological and complementary therapies that can help.

Please see our **Managing myeloma pain** information sheet @myeloma.org.au

Learn more

How the palliative care team can help – at any stage of myeloma

The palliative care team is a vital member of the treating team. They are able to support you at any stage of living with myeloma, not only at the end of life.

The palliative care team members have expertise in managing symptoms, and can work with you and your treating team to make recommendations for managing nausea, vomiting, severe hiccups, constipation, delirium, breathlessness, fatigue and pain.

If your treating team suggests including the palliative care team to help manage your pain or other symptoms, don't be alarmed and think that this means your myeloma can no longer be treated. Instead, lean on the team's special knowledge and skills, which can help to make living with myeloma much more comfortable.

“When my doctor said she was going to introduce me to palliative care, I thought they were giving up on me! Now, I understand that palliative care can provide help at any stage, and they were fantastic in sorting out my pain medicine.”

Stan, Tasmania

Complementary and alternative medicines and therapies

Complementary medicines and therapies

are ones that are used *in addition to* prescribed treatments for myeloma. Examples of complementary *medicines* include vitamin, mineral and herbal supplements, and complementary *therapies* include acupuncture, massage and reiki.

Many people look to complementary medicines to support them through their time on and off treatment for myeloma. They may be looking to control a side effect, gain better overall health, or they may be hopeful that there will be some anti-myeloma effects.

It's important to know that although complementary medicines can be derived from natural substances, they may still have harmful effects. In some cases, complementary medicines may interact with other medicines, causing more side effects or preventing the treatment from having its full effect. For example, high doses of vitamin C and green tea are known to reduce the effect of the myeloma therapy, bortezomib (Velcade®).

Some complementary medicines may be safe to take when you have myeloma, but you need to be open with your treating team so they can make sure there are no risks involved. Your pharmacist can do a cross-check of any complementary medicine you are considering against each conventional prescribed medicine to check for interactions.

You'll also need to talk with your treating team about any complementary *therapies* that you may be considering, as not all therapies may be suitable for people with myeloma, or may need adjustments or extra considerations. For example, due to myeloma bone disease, any massage treatments will need to be tailored to protect your bones.

Alternative medicines and therapies are treatments that are promoted *instead of* conventional treatments.

Conventional treatments for myeloma have been well-tested in clinical studies, we have a clear understanding of how they work, and they have been approved as safe and effective for use by the Australian Therapeutic Goods Administration (TGA). By comparison, alternative medicines and therapies have not been rigorously tested, and are not endorsed by the TGA.

If you would prefer to explore alternative medicines and therapies to control your myeloma, it's important to discuss the potential risks with your doctor. Your treating team will need to be aware of any alternative methods you are considering or using. This is especially important if you might choose conventional treatments later on.

Read more about **complementary and alternative medicines and therapies**.

Please see our information sheet @myeloma.org.au

Learn more

What can I do to help myself?



Things to remember

- There are many lifestyle strategies you can use alongside your treatments to help support your body and mind when you are living with myeloma.
- Eating a balanced diet with a wide range of fresh, unprocessed foods will help you to keep up your energy levels, improve your mood, sleep better, and improve overall wellbeing.
- Enjoying regular, safe exercise can help to improve your quality of life, stamina, sleep, memory and concentration. A physiotherapist or accredited exercise physiologist can help you with a tailored exercise plan.
- Fatigue is a common, difficult and complex symptom of myeloma – it has many different causes. There are many ways to treat underlying causes and help manage fatigue. It's best to start by talking with your treating team.
- It's really important to look after your emotional wellbeing. Look for ways to keep your life rich and fulfilling: enjoying time with family and friends, participating in sport and artistic activities, volunteering, and trying relaxation or mindfulness exercises.
- Pain, stress and medicines used to treat myeloma can cause problems with sleeping. Going to bed and getting up at the same time every day, exercising during the day, avoiding caffeine for 6 hours before bed, and not using technology in the hour before bed can help you to get more restful sleep.
- Ask your general practitioner (GP) about a GP Management Plan (GPMP) or Mental Health Treatment Plan to help you access allied healthcare professionals – like a dietitian, physio or psychologist – who can help provide support, and help you to manage the different symptoms of myeloma.



Karen, 72

- Yoga and meditation devotee
- Enjoys Nordic walking on her horse farm
- eBike-riding gives her independence
- Surrounded by the love and compassion of her family
- Living with myeloma

“Exercise is the antidote to fatigue.”

Alongside your myeloma and supportive care treatments, there are many lifestyle strategies and simple tools that can help to support your body and mind when you are living with myeloma. These ideas can help to manage some of the symptoms of myeloma itself, as well as manage side effects of treatment, helping you to live and feel as well as possible.

Our **MyeConversations** podcast series includes many episodes on living well with myeloma, covering nutrition, exercise and more.

Listen to our
MyeConversations
podcast
[@myeloma.org.au](https://myeloma.org.au)

Learn more

Our Wellness, **Exercise and Nutrition** seminar video provides an evidence-based update on many of these topics presented by local healthcare professionals with a special interest in myeloma.

Watch our
Wellness, Exercise & Nutrition
seminars
[@myeloma.org.au](https://myeloma.org.au)

Learn more

Nutrition: food and fluid

Keeping up your food and fluid intake and enjoying a well-balanced diet is a vital part of living well with myeloma.

Your body works best when you eat a balanced diet with a wide range of fresh, unprocessed foods, while limiting processed, fatty, salty and sugary foods.

“ Sometimes I don't have the energy to prepare healthy meals. This is when my friends and family step in. I really appreciate their help, and they feel good about being able to help me too. ”

Svetlana, New South Wales

Eating in this way and including plenty of water can help you to:

- keep up your energy levels
- promote recovery after periods of treatment
- maintain your muscle mass and strength
- experience a greater sense of general wellbeing
- better manage the side effects of some treatments
- improve your mood
- sleep better
- maintain a healthy weight
- improve your body's ability to fight infection
- prevent or manage other health problems, like diabetes and heart disease.

Both myeloma itself and its treatments can affect your appetite and your dietary needs. This section includes more information about what makes up a balanced diet, as well as some simple tips for times when eating and drinking may be more difficult.

What are the building blocks for healthy eating?

A well-balanced diet is one that will supply your body with all the nutrients it needs to help you live as well as possible.

We've included some general nutritional guidelines below, which you can adapt based on your dietary preferences (such as following a vegetarian or traditional diet), and based on any food intolerances or allergies you may have. You'll find more details about how to put these guidelines into practice in our **Nutrition and myeloma** information sheet available from www.myeloma.org.au

Plant foods should make up the biggest part of your diet with wholegrain-based foods, vegetables, fruits and legumes making up more than half the foods you eat each day.

These will provide your body with carbohydrates for energy, and essential vitamins, minerals and antioxidants, which help strengthen bones, maintain healthy nerves, repair cells, heal wounds, and support your immune system.

Plant foods are also a rich source of fibre, which you need for healthy digestion.

Choose plant foods with a wide variety of colours, and include the skin and seeds whenever possible.

Your body needs protein to help build new cells and replace old ones.

Protein is an important building block for bones and muscles, and we need more protein as we get older, where it's especially important to prevent muscle loss.

Dairy products include milk, yoghurt and cheese, which are a valuable source of calcium and other minerals needed as building blocks for bone.

Fats provide your body with a valuable source of energy and are needed to transport some vitamins around the body. Choose healthier fats from oily fish, unsalted raw nuts and seeds, avocados and olive oil. Go easy on saturated and trans fats found in meat, and processed foods like cakes, biscuits, ice-cream and chocolate.

Fluids are essential to keep you well-hydrated and to keep your kidneys functioning well so they can eliminate waste products. It's ideal to drink at least 2 litres of fluid (around 8 large glasses) each day, unless your doctor has told you to restrict fluids. Water is the best fluid to choose most of the time.

Green tea interferes with the action of bortezomib (Velcade®), and so you will need to avoid green tea during your course of treatment.



Learn more

What can make a well-balanced diet difficult?

Myeloma itself and many of its treatments can cause side effects that make eating and drinking more difficult at certain times. Some of the problems you may experience include:

- reduced appetite and enjoyment of food
- changes in taste and smell, including a metallic taste after treatment and a decreased sense of smell
- a sore, dry mouth, especially after high-dose chemotherapy
- nausea and vomiting
- tiredness or fatigue
- diarrhoea or constipation
- anxiety and depression
- increased appetite that can lead to weight gain and cause heartburn (caused by steroids).

Tips when you don't feel like eating

When you don't feel like eating, these tips can help to give your appetite a bit of nudge and get the nutrients and energy you need:

- Eat small amounts regularly throughout the day - aim for more snacks and mini meals rather than large meals.
- Light, gentle exercise like walking can help to stimulate your appetite, improve fatigue, and keep your bowel moving.
- If the smell of hot food is off-putting, try cold meals instead.
- You may find that softer, cooler or frozen foods are more appealing. Try yoghurt, milkshakes, smoothies or frozen yoghurt.
- Try squeezing lemon juice on food to help bring out the flavour.
- Help keep your mouth fresh and clean by using a non-alcohol-based mouthwash.

- When you're feeling well and less fatigued, try cooking a bigger batch of a favourite recipe and freezing some for another day.
- Ask friends and family to help with food shopping and cooking.
- Stock up on simple, nutritious snacks, so that when you feel like eating, there's something within easy reach.
- When you don't feel like eating much, it's important to still drink enough fluids. Keep a water bottle nearby and take regular sips. Add a squeeze of lemon juice or ice to your water to make it more enjoyable to drink.
- If you're experiencing a sore mouth or taste changes, ask your treating team about topical treatments that can help.
- Some myeloma treatments can give you a metallic taste in your mouth. Try using plastic or bamboo cutlery at mealtimes to help minimise this.
- If you're struggling to eat well, ask to see a dietitian who can give you extra information and tools to help make sure you're getting all the nutrients you need.

Please visit www.myeloma.org.au to read more in our **Nutrition and myeloma** information sheet.

Our podcast episodes, 'All things nutrition and myeloma parts 1 and 2', available at www.myeloma.org.au cover many topics including the role of prebiotics and probiotics, neutropenic diets, sugar and cancer, steroids and weight gain, weight loss while on treatment, tips for dealing with nausea, and much more.

To learn more about current research-based recommendations for eating well when you have cancer and during treatment, visit the World Cancer Research Fund's website at www.wcrf-uk.org and search for 'Eat well during cancer' to download their helpful booklet.

Exercise

Exercise is an important part of a healthy lifestyle for everyone. It can help improve general wellbeing, increase energy and reduce fatigue, and help with managing your weight. It can also help to prevent and manage chronic health problems like diabetes and heart disease.

Living with myeloma – both the condition itself and the side effects of treatment – can impact many parts of your physical and mental wellbeing, which are often long-lasting and complex. Some of these effects can make exercise more challenging, but they also make exercise especially important in helping to manage symptoms and side effects, and to feel as well as possible.

Research shows that people with myeloma who participate in prescribed exercise programs experience an improved overall quality of life, including improved mood and self-esteem, regained independence, increased stamina, better sleep, improved memory and concentration, and possibly, a shorter hospital stay.

It's often said that if we could manufacture a medicine with all these benefits, it would fly off the shelves!

Exercising safely with myeloma does have some additional challenges. The suggestions in these pages will help you to exercise as safely as possible. Remember to always talk with your treating team before starting a new exercise program. Your physiotherapist or an accredited exercise physiologist can provide you with more information that's specific to your needs.

What types of exercise are best?

After a long period of illness or immobility, a physiotherapist or accredited exercise physiologist is the best person to help get your body moving safely again. These health professionals can tailor an exercise program to help cater for and improve myeloma bone damage, muscle weakness, pain, balance, motivation and fatigue.

Learn more

Please visit www.myeloma.org.au to read our **Exercise with myeloma** information sheet, which includes more on the benefits of exercise, special considerations for exercising with myeloma, and how to gradually increase the amount of exercise you can do.

“I was surprised by how weak I was after my stem cell transplant. I found that moving my body every day, no matter how little, helped me regain my strength.”

Roger, Queensland

Some types of exercise that may be especially helpful for people with myeloma include:

Walking is an easy and convenient way to exercise. It's free, you can enjoy it in most weather, and you can choose to walk by yourself, with a four-legged friend, or with a group.

Tai chi, yoga and Pilates can help to improve balance, posture, strength and flexibility. They can also help to reduce stress and fatigue.

Stationary cycling helps to build strength and aerobic fitness, and you can exercise in any weather whilst watching TV or reading. It's also a safer option than cycling outside.

Swimming helps to build strength and aerobic fitness without putting stress on your joints. Sidestroke, backstroke or walking in water are the best options, as swimming facedown for longer periods can put stress on your lower back

Swimming isn't recommended if you have a central venous access device in place, such as a PICC (peripherally inserted central catheter) or Hickman line. If your white blood cell counts are low, your doctor may recommend avoiding swimming in heated, public pools, due to the increased risk of infection.

Are there any exercises or sports I should avoid?

There are some exercises that may place unnecessary stress on your bones and joints, or increase the risk of fracture or injury, especially if you have myeloma bone disease. It is usually best to avoid:

- lifting heavy loads and extreme ranges of motion such as overhead exercises, deep squats, leg or bench presses – however, light resistance training guided by a professional can be beneficial
- high impact exercises and sports such as jogging, tennis and squash
- contact sports, such as football, basketball and boxing.

Playing golf may also need some special consideration because of the extreme rotating motion of the golf swing.

Your physiotherapist or exercise physiologist can provide more detailed and specific advice about exercise or sports that might pose risks for you, and ways to modify them to make them safer.

How often and how much should I exercise?

It's ideal to exercise on as many days of the week as possible without increasing symptoms such as pain, cramps or fatigue.

Start with a small amount of exercise, increasing a little each time. Aim to build up to at least 30 minutes of moderate intensity exercise on most days.

Your doctor, physiotherapist or exercise physiologist can provide you with more specific advice about the ideal amount and intensity of exercise for you.

Fatigue is one of the most common, difficult and complex symptoms of myeloma, and is often called 'cancer-related fatigue' or CRF. This type of fatigue is different from the everyday tiredness experienced by people who don't have cancer or other ongoing health conditions, and can have a big impact on your quality of life.

You've probably already discovered for yourself that the type of fatigue associated with myeloma can be persistent and distressing, doesn't necessarily get better with rest or sleep, and it doesn't seem to relate directly to anything you've done (or haven't done). This makes myeloma fatigue all the more frustrating and difficult to live with – but there are many things you can do to help. The first step is understanding a little more about what causes myeloma fatigue, and the next step is to come up with your own plan to help you manage it.

Myeloma UK has a detailed infoguide on fatigue.

Learn more

Go to
myeloma.org.uk
Q 'Fatigue infoguide'

What causes fatigue in myeloma?

Fatigue in myeloma may have many different causes, and it's often a combination of these that sap your energy.

Common causes of fatigue may include:

- **Symptoms and complications of myeloma itself** - including anaemia (low haemoglobin), reduced kidney function, metabolism changes, pain and infection.
- **Side effects of myeloma treatments** - including chemotherapy, radiotherapy, some targeted treatments, and stem cell transplants.
- **Difficulty eating and drinking** - some myeloma treatments cause side effects that make it more difficult for you to eat and drink well, meaning you may not be getting the energy you need from food.
- **The emotional impact of myeloma** - learning that you have myeloma and living with the condition can have a huge emotional impact on you, which can be exhausting. Sometimes, myeloma can have a longer-lasting effect on mood, leading to problems like depression and anxiety, which can increase fatigue.
- **Problems sleeping** - the emotional impact of myeloma, as well as some treatments, especially steroids, can cause difficulties sleeping, making you more tired, emotional, and irritable.
- **Being less active** - bone disease and other symptoms of myeloma can make it harder to stay as active as you were in the past. Being less active can make you feel more tired, add to sleeping problems, cause muscle wastage, and contribute to a low mood.

If the cause of your fatigue isn't clear or doesn't improve after trying treatment strategies, chat to your treating team about checking for any other health conditions that may be contributing to your tiredness.

What can help?

Treating and managing your fatigue depends on its causes, and will usually involve a combination of medical treatment and self-help strategies. It's best to start by talking openly with your treating team about your fatigue. They can then work with you to help work out the underlying causes and what's likely to help you most.

Treating underlying problems like anaemia, reduced kidney function or infection. Your doctor will do tests to keep a close eye on any of these underlying problems and will recommend a treatment plan if needed.

Adjusting your myeloma treatments. If your myeloma treatment is causing fatigue, and you are at a point where your myeloma is under control, your doctor may suggest a change to your treatment dose or schedule. Sometimes simply changing the time of day you take a medicine can make a big difference to your fatigue.

Remember that you always need to talk to your doctor before making any changes to your treatment dose or schedule.

Controlling your myeloma. Even though many myeloma treatments can initially cause fatigue, they can help it in the longer term.

Myeloma treatments aim to destroy myeloma cells and reduce the amount of substances called cytokines in your body, which should lead to reduced fatigue.

Managing your pain. Talking with your treating team about your pain and coming up with a treatment plan can help to manage your pain, sleep and fatigue, which are all very closely linked. Sometimes it can take some trial and error to work out the best pain management plan for you, and to minimise pain medicines that may make fatigue worse.

Please visit www.myeloma.org.au to read our **Managing myeloma pain** information sheet, which includes more detail about the causes of pain in myeloma, medical pain management options, as well as physical, psychological and complementary therapies that can help.

Learn more

Emotional support. If you are experiencing an ongoing low mood, stress or anxiety, it's important to get the support you need, which can help to improve your fatigue as well.

Read more in '**Emotional support**' on page 80 of this guide.

Learn more

Eat well and keep up your fluids. See our tips on pages 60–63 of this guide to help you eat and drink well (even when you don't feel like it), to help keep up your energy.

What can help?



Planning regular rest or nap times during the day is an important part of managing fatigue for most people with myeloma. Try to work out the times of day and the activities that make you most fatigued and plan rests around these times. You may prefer to have one longer rest or several smaller rests during the day – try both to see what works best for you. Try not to sleep for more than 60 minutes or too late in the afternoon, so you don't affect your night-time sleep

Our **Fatigue and myeloma** information sheet includes more detailed information on the causes of fatigue in myeloma and how to manage it, and also includes an Energy diary to help you track the times when you have more or less energy and manage your days around those.

Learn more

Please see our **Fatigue and myeloma** information sheet @myeloma.org.au

Sleep helps you to recharge both mentally and physically. Getting enough good quality sleep when you're able to (and we understand how difficult that can be), can help you manage many parts of living with myeloma, so we've included more information and our top tips for better sleep on page 74.

Exercise. As much as it might be really hard to find the motivation when you are already fatigued, planned exercise and general physical activity can help to give you *more* energy. Just a small increase in your activity level can help to improve your overall health and sense of wellbeing, reduce stress, boost energy and help you to sleep better. It can be very helpful to have a physiotherapist or accredited exercise physiologist to plan an exercise program that's safe, supportive and effective for you.

Learn more

Read more about all the benefits of exercise and guidelines for safer exercise on pages 64-65 of this guide.

Pace yourself so that you don't end up exhausted (and often from doing the things that are least important to you):

- Plan your days, prioritising the things you *really* want and need to do most.
- Decide if there's anything that can wait until tomorrow.
- When you have a short list for the day, think about how you can break tasks down into smaller ones, resting in-between if you need to.
- Try switching between tasks that take a lot of physical and mental energy and tasks that take less energy.
- Remember to schedule time for hobbies, relaxation, meaningful work and volunteering, and positive friends and families that fill up your energy cup.
- When on treatment, you'll start to notice that there are days of the week when you have more energy than others. Making note of this will help you plan activities on days when you know you'll have more energy, and allow you to give yourself permission to rest on the days when your energy is low.

Short-term memory and concentration ('chemo brain')

Many people with myeloma notice changes in their ability to remember things, find words in conversation, and a reduced level of concentration that makes it difficult to focus on work or study, or simply reading a novel.

“Chemo brain has affected me in numerous ways.

Most frustrating and debilitating are my short attention span, not finding the right words, and being unable to learn new skills.

To manage, I tackle the most important and difficult jobs when my energy levels are the highest and my mind is clearest.”

Susan, Queensland

These changes in memory and concentration are often referred to as 'chemo brain', but it can be quite a distressing experience, especially if it's an unexpected side effect. The formal term for this problem is cancer-related cognitive impairment.

The exact cause of chemo brain is unknown. Some possible causes include treatments for myeloma (including treatments other than chemotherapy), medicines used to manage side effects, sleep disturbances, fatigue, stress, and inflammation in the body.

It's helpful to know that many people living with myeloma experience these cognitive changes, and that there are many practical things you can do to help.

Some people will notice that their memory and concentration gradually begin to improve once their treatment has finished. This can be a slow process, so be patient with yourself.

If you are on continuous therapy, you will need to learn to manage its side effects, including cognitive changes, over the longer term.

Cancer Council Australia's *Understanding Changes in Thinking and Memory* fact sheet provides more practical tips and resources and information about cognitive rehabilitation and brain training.

Go to
cancer.org.au
Q 'Thinking and memory'

Learn more

What can help?

It's important to acknowledge any memory and concentration problems you are experiencing, accepting that they are a real part of living with myeloma, and that you need to be easy on yourself. This simple act of acknowledgment might help to reduce pressure on yourself, and in turn, help to ease your symptoms or at least make them easier to live with.

Let your family, friends and colleagues know that you're having some memory and concentration problems caused by myeloma and its treatment, and ask for their support.

Use a calendar, diary or smartphone to keep track of appointments, important dates and tasks. Many people find it's really helpful to set reminders on their phone.

Write separate lists of things you need to remember: phone calls to make, emails to return, items to buy, books to read, TV shows to watch, questions to ask your treating team, topics you want to cover in your next phone call with a friend or family member, and more.

You might like to write a list with pen and paper, or try using the 'Notes' or 'Google Keep' app on your smartphone. If there's something really important you need to remember before leaving the house, try putting a sticky note on the inside of your front door.

Schedule tasks that require the greatest concentration for the times of day when you feel most alert and least fatigued.

Keep your brain active with crosswords, puzzles, Sudoku, reading, interesting conversations and hobbies. Don't push yourself though. If you find activities that you used to enjoy are requiring more concentration than you have, switch to something lighter and easier for the time being – for example, choosing a magazine or short story over a complex novel.

Mindfulness, meditation and daytime rests can help your mind to rest and recuperate.

Enjoy plenty of regular exercise at a level that's suited to you – see pages 64–65 of this guide for more ideas. Exercise is great for your brain and helps with sleep too, which is important for memory.

Talk to your treating team if you have ongoing concerns about your memory and concentration. They may suggest seeing another healthcare professional to help using tools such as cognitive rehabilitation, a more intense and targeted form of brain training. This can be part of a Mental Health Treatment Plan, where Medicare pays part or all of your appointment costs. See 'Accessing support from different healthcare professionals' on page 75 for more details.



Nat, Victoria, makes caring for her emotional wellbeing a priority

An important part of living well with myeloma is staying connected and involved with the people and activities that provide you with enjoyment and satisfaction. This is what helps to make all our lives rich and colourful.

When you're living with an ongoing health condition like myeloma and experiencing pain and uncertainty, you can sometimes fall into the trap of doing less of the very things you enjoy most.

You may worry that some of the activities you've enjoyed in the past will make your pain worse, or that you're just too tired to keep up with your hobbies and social outings. These concerns can stop you from doing the things you love and that can actually help you to feel better. In turn, this can leave you even more focused on your pain, fatigue and other symptoms, and worrying more about your future.

That's why it's really important to stay connected with friends and family, and stay focused on activities that make you happy. Think of this as 'filling up your tank' so that you have more to draw from when you need it most.

Filling up your tank might include:

catching up with friends for a walk, coffee, or going to the movies or dinner

participating in sporting and social clubs

discovering an artistic outlet like painting, jewellery-making, writing, calligraphy or music – this could be an ideal time to explore something you've always wanted to do, but never quite got around to

volunteering for a cause that's important to you

trying relaxation exercises, meditation or mindfulness

travelling to new locations – simply being a tourist in your own town can be lots of fun

getting out and about with your family.

“Staying positive doesn't make depression better. Depression needs medical treatment. Being told to be positive made me feel guilty for my feelings of despair. This is where a trained professional such as a Myeloma Australia Nurse can help enormously.”

Wendy, Victoria

These activities and the connections they create are good for your emotional wellbeing, and can help to distract you from your symptoms and worries. It doesn't mean that your symptoms aren't real or that you can make them go away, but that you can train your mind to focus on more enjoyable things instead. There may be some activities that you can no longer do, or that you need to modify, so try to focus on what you can do and enjoy.

Many people with myeloma will have times when they need some extra support for their emotional and mental health.

Page 80 of this guide includes where to go for more help, especially if you have signs of anxiety or depression.

Learn more

Go to **page 80** in this guide

Myeloma UK has produced a really helpful interactive series of modules where you can learn more about emotional wellbeing when you have myeloma. It includes lots of tips on simple things you can do to help yourself feel better.

Learn more

Go to **myeloma.org.uk** **Q**'emotional wellbeing tool'

Sleep

Sleep is vital for recharging and repairing our bodies and minds. We simply don't function well when we don't get enough sleep, and this can cause symptoms that affect your general and mental health, as well as your quality and enjoyment of life.

What causes sleep problems in myeloma?

Difficulty falling asleep or staying asleep, or insomnia, is a very common problem for people with myeloma.

These sleeping problems may be caused by:

- steroid medicines, which are included in most myeloma treatment combinations
- stress and anxiety
- myeloma pain.

What can help?

These tips may help you to get more restful sleep:

Do your best to get into a regular sleep pattern where you go to bed and get up at the same time each day. This helps your body clock to regulate how it produces the hormones you need to go to sleep (melatonin) and to stay awake (serotonin). It's helpful to stick to your routine, even on weekends, and when you haven't slept well the night before.

Exercise during the day, including gentle exercise, can help you to fall asleep and stay asleep longer.

Avoid caffeine for at least 6 hours before bed. Caffeine hangs around in your body for longer than you may think, so try having your last caffeinated tea or coffee for the day by around 2pm (or even earlier) and see if that makes a difference.

Stop using technology at least 1 hour before going to bed – and definitely don't use devices in bed. Computer, electronic tablet and smartphone screens emit blue light that delays melatonin production and decreases sleepiness. Blue light can also reduce the amount of time you spend in deep restorative sleep that you need for healthy brain function and memory.

Your bedroom should be like a cave: cool, quiet and dark! To fall asleep, your body's core temperature needs to drop, so keep your bedroom cool (but not cold) rather than warmer. If you need to, use ear plugs to block out sound, and black-out curtains or an eye mask to block out light.

If you can't sleep, get up and do something quiet, like reading, listening to light music, doing some breathing exercises, or gentle stretching until you feel sleepy again. Try not to get anxious if you can't fall asleep; simply resting is good for you too.

Talk with your doctor if you are still having trouble sleeping, or if pain is making it difficult to sleep. They can see if there are ways of better managing your pain, or if a short-term sleep aid might be helpful.

Accessing support from different healthcare professionals

When living with a chronic condition like myeloma, most people will need a range of different healthcare professionals to provide support and help manage their symptoms at different times.

These healthcare professionals might include a:

- physiotherapist (physio) or accredited exercise physiologist (EP) to plan an exercise program
- dietitian to help you eat well and get enough nutrition during treatment
- psychologist or counsellor to support your mental and emotional wellbeing
- podiatrist to help care for your feet, especially if you have peripheral neuropathy
- social worker to assist with practical matters like returning to work, caring for children, accessing payments and more.

“When I'm struggling to get to sleep, I listen to audio books read by people with calming voices – like Stephen Fry and Sir David Attenborough. This helps me either drift off or relax enough to feel rested.”

Stuart, Tasmania

There are a few different ways to access different healthcare professionals. You can:

- **Chat to your treating team** to find out which of these services are available through your hospital. If you are being treated at a public hospital, these will generally be available at no cost to you.
- **Make an appointment with your general practitioner (GP) and ask them to write a GP Management Plan (GPMP) with you.** This plan allows more streamlined communication and care between your GP and community-based allied healthcare professionals. The plan includes five sessions in a calendar year with the allied healthcare professionals that you and your GP name, and Medicare will pay for part or all of the cost. Your visits can be with one or more different types of health services.

Remember to check with each healthcare professional about any out-of-pocket costs you will need to pay.

- **You can also ask your GP to create a Mental Health Treatment Plan** where Medicare will pay for part or all of the cost for appointments with a specialised healthcare professional who can help you to manage anxiety, depression and other mental health conditions. Remember to check with each healthcare professional about any out-of-pocket costs you will need to pay.

- **Book an appointment directly with your chosen allied healthcare professional at their private clinic.** Private healthcare professionals' fees vary, so remember to ask about the cost when you book your appointment. If you have 'extras' as part of private health insurance, it may pay for part of the cost.

What support is available?



Things to remember

- There are many people and organisations that can provide you with information and support to help make daily life with myeloma a little easier.
- Myeloma Australia Nurses, a social worker, your family GP, family and friends, and your local council can help you find practical support such as preparing meals, childcare, garden maintenance, household repairs and more.
- Everyone living with myeloma will need some type of emotional support, which can come in many forms. Joining a support group is an ideal place to start for many people.
- If living with myeloma becomes overwhelming or you think you have signs of anxiety or depression, it's really important to talk to a healthcare professional as soon as you can and get the help you need. There are many effective treatments for anxiety and depression.
- Having myeloma will affect your relationships with others, and your sexuality and intimacy. Communicating honestly and openly with the people you care about is an important first step, and there are counsellors and psychologists who specialise in relationships, sexuality and cancer.
- Talk with your treating team about any out-of-pocket expenses for your treatment. A social worker at your treatment hospital can help you find out about financial entitlements that may be available to you and your carers.
- It's ideal to make plans for your future healthcare and organise documents such as an advance care directive and a will. Planning like this can be positive, reassuring you that your plans are clear and that you can focus on your treatment and living as well as possible.
- Caring for a partner, family member or close friend with myeloma is demanding work. It's important for carers to form their own support network, make time to do things for themselves, take care of their own wellbeing and to reach out to carers support services that can provide all types of help.

Nimo, 81

- Current affairs aficionado
- Gym-goer
- Table tennis pro - played for Sri Lanka and umpired for Australia
- Carer for wife, Gita, who is living with myeloma

“ We learnt to gracefully accept support from family and friends. It was important that we had friends we could lean on.”

Practical support

Living with myeloma can have an impact on many parts of your life, creating all kinds of new challenges. Fortunately, there are also many people and organisations that can provide you with information and support to help make daily life a little easier.

This section will tell you more about some of the different types of support available, both for people with myeloma, and for their family, friends and carers. Make the most of everything these support systems can offer.

Life will be very different after a diagnosis of myeloma, and you're likely to find many areas of day-to-day life where you and your family can do with some additional help. The need to buy groceries, prepare meals, care for children, look after the garden, and keep on top of household repairs doesn't go away when you are unwell.

You may find that you particularly need some extra support when you are first diagnosed and when you are having intensive treatment. Often, it's a matter of finding the right person or organisation to steer you in the direction of the services that will help you most. You might like to start by chatting to:

- Myeloma Australia Nurses on 1800 693 566 or email nurses@myeloma.org.au
- a social worker at the hospital where you are having treatment – coordinating all different types of support is their specialty
- your family GP
- your local council.

Asking for and accepting help from family and friends

Family and friends usually want to help, but often don't know how.

They will appreciate you letting them know the specific type of help you need and being given a task. You might like to ask one person to help with meals, another to help with transport, and another to help around the house – keeping in mind your different friend's skills and how you usually like to support each other.

You may feel more comfortable asking your partner, or another family member or close friend to organise this help for you. They may like to organise a roster of helpers, so that everyone is clear about what they are doing on certain days.

Ron and Freddie, South Australia, at Aoraki Mount Cook National Park



Emotional support

Being diagnosed and living with the ongoing challenges of myeloma stirs up all kinds of thoughts and emotions, which will be different for each person.

Everyone living with myeloma will need some type of emotional support, which can come in many forms. 'The emotional impact of a myeloma diagnosis' on pages 3-4 of this guide provides helpful ideas for building your support network – from talking through your feelings with the people closest to you, chatting to our Myeloma Australia Nurses, and joining a support group. You might like to look back at this section and think about the different types of support that can be most helpful for you.

Even with these support networks, there will be times when living with myeloma feels overwhelming, or feelings of distress, anxiousness or a low mood don't improve and make it difficult for you to relax, sleep, concentrate, or feel any joy. It can help to know that it's quite common for people with myeloma to experience anxiety or depression – and that there is a lot that can be done to help:

Cancer Council Australia's *Emotions and Cancer* booklet covers common reactions to a cancer diagnosis, tools for coping, talking to others, getting support and more.



- If you think you may have signs of anxiety or depression (or you are caring for someone who is showing these signs), it's really important to talk to a healthcare professional as soon as you can.
- Start by chatting to your GP, who can recommend and link you to a counsellor, psychologist or psychiatrist who they think can best help you. Your GP might suggest creating a Mental Health Treatment Plan, which means that Medicare will pay for part of the cost for you to see certain mental health professionals.
- A mental health professional may suggest talking therapies, medicines, or a combination of these to help you feel better.
- After you have started feeling mentally well again, it's really important to keep up your support networks and draw on the sense of community and strength they can offer at any stage of living with myeloma. Many people find that the people they meet through a support group – whether online or in-person – become some of their most meaningful friendships for life.

Myeloma UK has produced a really helpful interactive tool where you can learn more about emotional wellbeing through a series of modules. It includes lots of tips on simple things you can do to help yourself feel better.



Talking to children about myeloma



We understand you may have questions about talking to your children or grandchildren about myeloma.

You may be wondering when it will be the right time to tell them, how to tell them, and how much information to share. You know your children and grandchildren best, and there is no right or wrong way to talk to them.

Usually, it's helpful to talk to children sooner than later, as they may guess that something is wrong, and being honest can help to allay many of their fears and help them cope better. How much you tell them will depend on their age.

You may like to ask your partner or another relative or friend to help you talk to children.

Myeloma Australia has a comic book about myeloma that's aimed at children aged 7–12 years.

www.parentingthroughcancer.org.au is a free support community provided by Canteen and Camp Quality that provides free expert advice, counselling, and the chance to connect with other parents in a similar situation. They also provide resources for parents impacted by cancer, including the booklet *How to talk to your children about cancer*.

Go to **myeloma.org.au** to read online or order a print copy

Learn more

Relationships



“It’s funny how, when we travel through life, we gain in some areas, and lose in others. My gains far outweigh my losses. And that’s what life is all about.”

Jo, New South Wales

Being diagnosed and living with myeloma will affect everyone in your family and your network of close friends, bringing different challenges to each of you and the way you relate to each other.

Your family and friends may experience a range of emotions, in a similar way as you. And they will have good days and bad days, just like you. The people who are closest to you have the challenge of wanting to be strong for you while also coming to terms with their own feelings.

You may find that myeloma strengthens some of your relationships, while straining others.

If you have a partner, myeloma can cause new challenges in your relationship and will often change the dynamics and roles you each have.

Communicating as openly and honestly as you can with the people closest to you can help to lead the way and let others know that they also have permission to share their feelings and needs.

Remember that relationships are often the greatest source of joy and comfort in our lives. Making time to talk with and do the things you have always enjoyed with the people you care about will continue to be an important part of your life and wellbeing.

Myeloma UK's Infopack for living well with myeloma includes a detailed section on relationships.



Sexuality and intimacy

Our sexuality is an important part of who we are, how we see and express ourselves, and relate to others intimately. Sexuality is about much more than having sex or your sexual orientation.

Intimacy is about feeling close to someone – physically or emotionally, and this can be expressed in many different ways.

And just like all other parts of yourself, myeloma can have a profound impact on your sexuality and intimacy, whether or not you have a partner.

Myeloma and its treatments can change the way you see and feel about yourself and your body, reduce your sexual desire (libido), and may affect some areas of sexual function. Pain and fatigue, as well as changing emotions and relationships all contribute to these feelings.

Understanding these changes and communicating openly about them is an important first step in getting back in touch with your body and strengthening your relationships.

It can often be really hard to talk about our sexual needs, but it's also really important. These ideas might help:

- Try setting aside time in a comfortable and quiet place where you can talk as freely as possible.
- Tell your partner how you are feeling and ask them to do the same. By taking the first step, you can show your partner that it's okay to talk about your sexual feelings, which helps to build trust and closeness.
- You might find it helpful to talk with a counsellor or psychologist who specialises in sexuality and cancer.
 - Ask your GP or a trusted member of your treating team to connect you with someone who can help.
 - You can also call our Myeloma Support Nurses 1800 693 566, or the Cancer Council Helpline 13 11 20 for a referral.
- Once you have begun talking, it can open up the way to explore many different ways of being intimate so that you can start helping each other feel good in your bodies and with each other again.
- Touching, massaging, cuddling, kissing or simply holding each other can be satisfying alternatives to or additions to sex.
- There are many things you can do to increase your desire for, and enjoyment of sex again. You may like to try:
 - planning ahead to make the most of times when you have less pain and more energy
 - trying new or less demanding positions
 - using a vaginal lubricant or moisturiser
 - using erectile dysfunction aids
 - finding ways to add some romance back into your lives – you might like to plan a dinner out, or a quiet night in with music and dancing, leave little love notes for each other, surprise your partner with flowers, chocolates, or an unexpected kiss.

Myeloma UK's Infopack for living well with myeloma includes a section on sex and intimacy.



Cancer Council Australia's Sexuality, Intimacy and Cancer booklet provides more information and helpful tips.



Financial support

Living with myeloma can impact your financial situation in a number of ways, causing added stress for you and your family.

If you are still working and a main provider for your family, you will need to consider how treatment will impact your ability to work, which can result in lost income. Your partner or another family member may also need to take time off work to help care for you. At the same time, your daily living expenses will continue, and you will have out-of-pocket medical expenses.

There are many different forms of financial assistance that can help to ease these pressures. Here are some pointers to help you navigate your way through the maze of financial information and services so that you can find the support and benefits to which you are entitled.

Medical expenses

- Ask your treating team about the out-of-pocket expenses for tests and scans, any hospital stays, treatment and medicines. Knowing what these costs will be can help you to plan for them, and may allow you to negotiate a payment plan if you cannot pay the full amount upfront. Your out-of-pocket costs will vary depending on the provider, whether you are having treatment through the public or private health system, and if you have private health insurance.
- If you do have private health insurance, contact your insurer to find out how much they will pay towards any hospital costs and allied healthcare professional costs (if you have 'extras' cover).
- Medicare Safety Nets are designed to help people who have a lot of medical expenses. Once you have spent a certain amount for out-of-hospital medical costs in a calendar year, you may be able to receive a higher amount back (rebate) from Medicare for future medical costs. This means that you then pay less for costs like seeing a doctor or specialist or certain scans for the rest of the year. If you're enrolled in Medicare, you're automatically enrolled for their Safety Nets. If you're part of a family or couple you can combine your costs by registering as a family so you can get the higher rebates sooner.

Visit www.servicesaustralia.gov.au and enter 'Medicare Safety Nets' into the search bar to learn more.

- **The PBS Safety Net** helps with the cost of prescription medicines if you or other family members need a lot of medicines in a year. Once you have spent a certain amount in a calendar year (the Safety Net threshold), you can get your PBS medicines cheaper or free for the rest of the year.

“Many benefits can't be backdated - or if they can - it's only for a short period. It was important for me to apply for benefits as soon I could. I kept a folder with all my documents and financial expenses to support my claim and asked for help when I needed it.”

Wendy, Victoria

- Chat to your pharmacist so they can keep track of your spending on PBS medicines. If you go to different pharmacies, you'll need to ask for a printout of your spending from each pharmacy or keep track of these yourself.

Visit www.servicesaustralia.gov.au and enter 'PBS Safety Net' into the search bar to learn more.

- **The Low Income Health Care Card** is a concession card that gives you cheaper healthcare and some discounts if you're on a low income.

Visit www.servicesaustralia.gov.au and enter 'Low Income Health Care Card' into the search bar to learn more and apply.

- **If you need to travel for your myeloma treatment**, the Patient-Assisted Travel Schemes (PATS) in your state or territory can help towards the costs. Some private health insurance policies now offer travel and accommodation benefits under hospital cover - contact your health insurer to see if they offer this benefit.

Visit www.healthdirect.gov.au/travelling-to-your-healthcare-appointment to learn more.

Centrelink and other financial benefits

- **A social worker at the hospital** where you are having treatment can help with information about the full range of financial entitlements available to you and your carers, help work out which you are eligible for, and assist you in making claims.
- **The Cancer Council Helpline 13 11 20** can offer advice about financial assistance available to you, including some of Cancer Council's own services, and can help you to access their booklet, *Cancer and Your Finances*.
- You may be able to get **Centrelink's JobSeeker Payment** while you are sick and can't do your usual work or study. This will depend on your assets, family situation, and any other income you and your partner are earning.

Visit www.servicesaustralia.gov.au and enter 'JobSeeker Payment' into the search bar to learn more.

You can contact Centrelink and find out more about any benefits you're entitled to through your MyGov account. Go to <https://my.gov.au> to login or create an account.

See the information for carers on **page 90** of this guide to learn more about payments available to carers.

- Ask your employer about sick leave or any other leave you may be entitled to.
- You may be able to make a claim on your income protection, trauma, disability or life insurance, and may be able to gain early access to your superannuation. Contact your insurer, super fund provider or financial planner to see what claims or withdrawals you are able to make.

Myeloma Australia has a partnership with AFRM Claims Advocacy.

Visit www.afrmclaimsadvocacy.com.au/myeloma or call Myeloma Australia to learn more.

Working with myeloma

If you were still doing paid work when you were diagnosed with myeloma, you'll need to consider how myeloma and its treatment will affect your ability to work. A lot of this will depend on the type of job you have (whether it's very physical, for example), how myeloma and its treatment is affecting you, and your family and financial situation.

Working – whether it is paid or voluntary – is good for your mental, social and physical wellbeing. You're likely to want to explore how you can continue working, which will mean both you and your employer will need to have some flexibility. Here are some helpful tips:

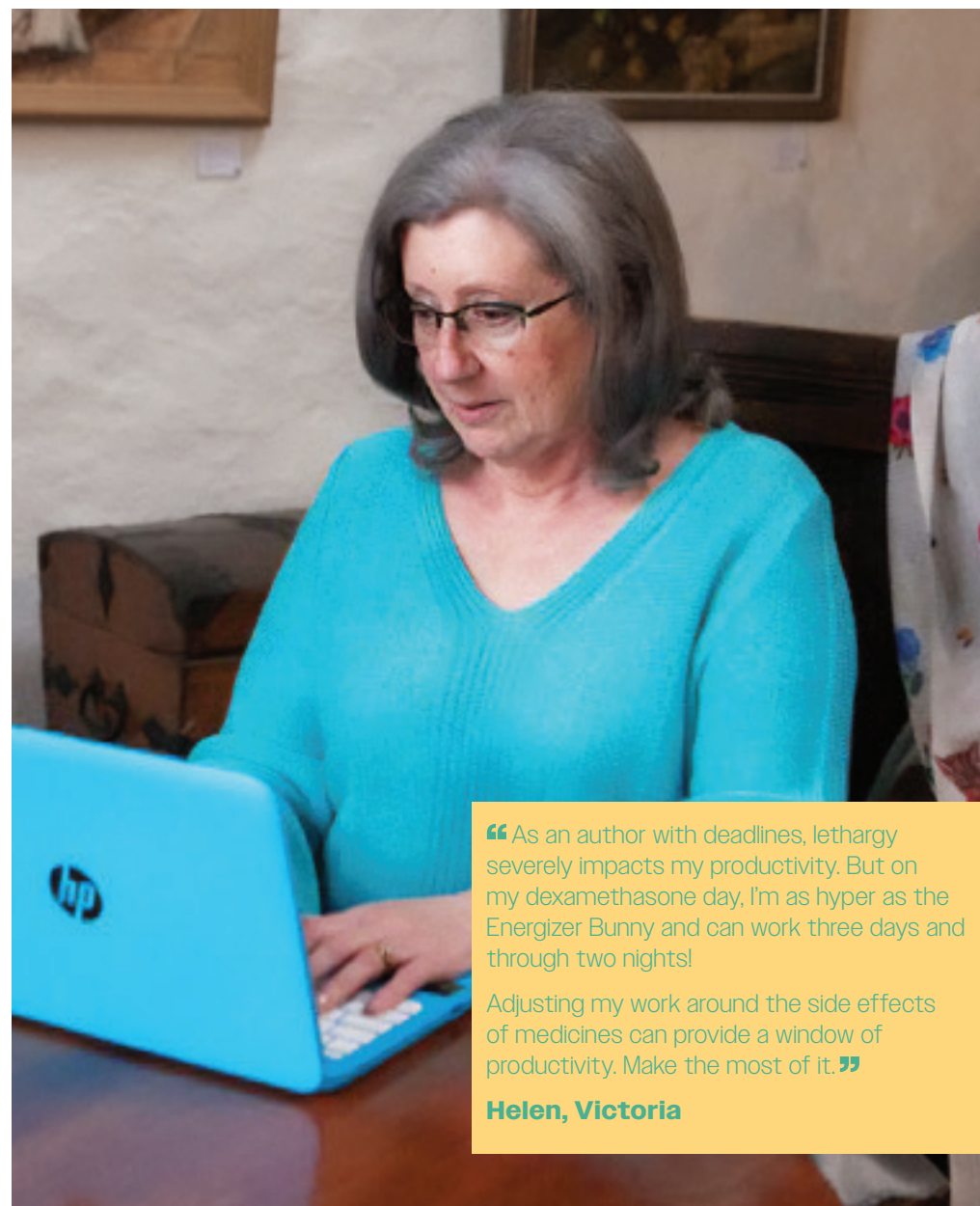
- **Talk to your employer as soon as you can** and work out a realistic plan about what work you are and are not able to do, your working hours, and when you may need time off. If you work for a larger organisation, you may have a human resources (HR) team member who you can talk to, who will know about the organisation's policies and support systems.
- **Ask your treating team to write a letter to your employer** explaining your diagnosis and treatment. You can ask for the team to share as much or as little information as you are comfortable with.
- **Cancer Council Helpline 13 11 20** can tell you more about your work rights and help you to access their booklet, *Cancer, Work & You*.
- **Cancer Council Pro Bono service** can help small business owners with accounting support. You can access this service by calling the Helpline on 13 11 20.

For some people, being diagnosed with myeloma may mean they need to change their job, and others may decide that early retirement is a good option. These are big decisions that you will need to talk through with family and friends – and you may also like to chat with someone outside your usual network, like a social worker at your treatment hospital, or with a counsellor or psychologist.

“I kept my cancer private, as I didn't want it to affect my workplace relationships.”

Ken, Victoria

Helen, Victoria, enjoys staying productive at work



“As an author with deadlines, lethargy severely impacts my productivity. But on my dexamethasone day, I'm as hyper as the Energizer Bunny and can work three days and through two nights!

Adjusting my work around the side effects of medicines can provide a window of productivity. Make the most of it.”

Helen, Victoria

Planning ahead

It's ideal for everyone, whatever their age and health, to plan ahead about the healthcare they want and organise documents such as an advance care directive and their will, and appoint someone to make decisions for them if they become unable to.

You may not need to use the documents for quite some time. Planning ahead doesn't mean that you've given up or that you will die soon. In fact, planning ahead like this can provide you with a sense of relief, reassure you that your wishes are clear, and help you to focus on your treatment and living as well as possible.

Advance care planning

'Advance care planning' is a broad term that covers the process of planning for your future healthcare – both through talking about it and then creating written documents.

Advance care planning helps you to make some decisions now about the healthcare you would or would not like to receive in the future if you were to become seriously ill and unable to communicate your preferences or make treatment decisions. Planning like this helps to ensure your loved ones and your treating team know what matters most to you, and that they respect your treatment preferences.

This planning usually results in you creating a written document, which is called an 'Advance Care Directive'. As part of this directive, you also appoint a 'substitute decision-maker'. This is a person you trust and choose to make medical treatment decisions for you if you are not able to.

The terminology used for advance care planning can sometimes be confusing, and different states and territories may use slightly different terms for an 'Advance Care Directive' and for a 'substitute decision-maker' (which may be called a 'Medical Enduring Power of Attorney').

Your will and other legal documents

Your will is a legal document that says what you want to happen to your house, money and possessions after you die. If you have children aged under 18, your will can also include your wishes about your children's guardianship and provide money for this guardian.

You may wish to include other information in your will, such as who will care for your pets, as well as name any special items you would like given to certain people. Some people also include funeral plans as part of their will.

If you do not write a will, your estate will be divided based on the law, and this may not reflect what you want. It's not difficult to write a will, but it does need to be done in the correct way, so that it is legally valid.

You can also authorise a substitute decision-maker to deal with your legal and financial matters if you need support, or are unable to do this yourself. This person is generally called an Enduring Power of Attorney.

A lawyer can provide you with advice and support on preparing both wills and powers of attorney.

The social worker at your treating hospital or Cancer Council on 13 11 20 may be able to connect you with a lawyer who can help.

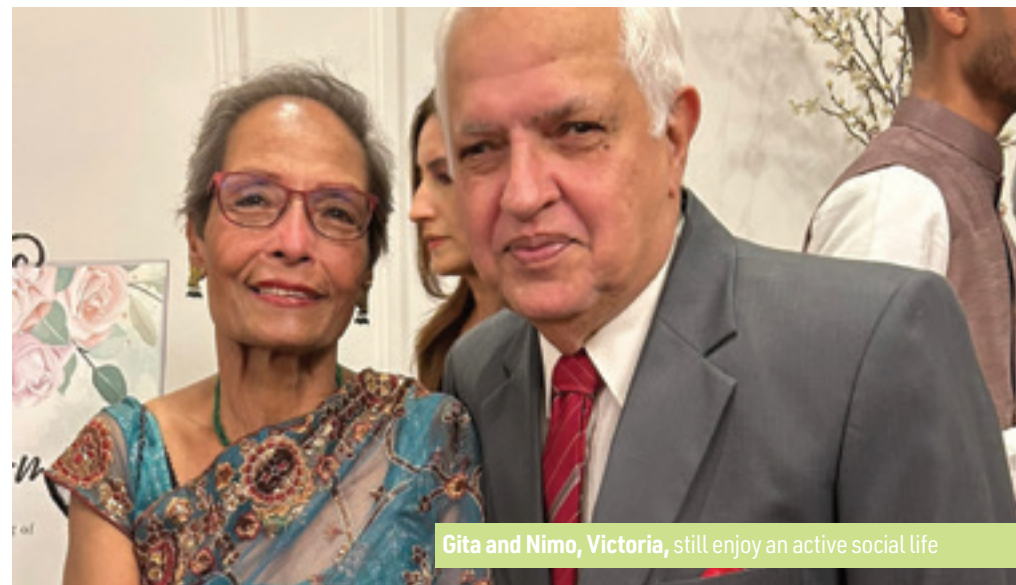
You can learn more about general and enduring powers of attorney by searching online, generally outlined on government websites in the state or territory where you are based.

Advance Care Planning Australia explains the planning process and provides links to create your plan based on the state or territory you live in.

Learn more

Go to advancecareplanning.org.au
Q 'Create your plan'

Palliative care



Gita and Nimo, Victoria, still enjoy an active social life

Palliative care is often misunderstood, with people thinking it means that treatment has failed or you have given up.

It's helpful to know that palliative care can help you manage pain and other symptoms at *any time* while you are living with myeloma, helping to give you the best quality of life possible.

Some people may access palliative care while they are still having active treatment for myeloma, while other people may access these services when they have finished active treatment.

Palliative care also provides support for loved ones in their caring roles, and in grief and bereavement.

Palliative care services can be provided in your home, in hospital, an outpatient clinic, or in a hospice or specialty palliative care unit.

Many people say that they wish they had made contact with a palliative care service earlier in their illness to help improve their quality of life and support their physical, social and emotional needs.

Palliative Care Australia is the national organisation that represents member palliative care organisations throughout Australia.

Go to palliativecare.org.au

Learn more

Support for carers

When a partner, family member or close friend is diagnosed with myeloma, it is the beginning of a long journey into unfamiliar territory.

While you are adjusting to the news that someone you are very close to has myeloma, you are also adjusting to what this may mean for you as a potential carer. You are likely to be worried about how your relationship with the person who has myeloma will change, as well as how it will impact your relationships with others, and many other areas of your life.

As a carer, you're likely to take on the responsibility of taxi driver, medicine manager, cook, appointment coordinator, researcher, home nurse, family spokesperson, and the main emotional support person.

These caring roles are physically, socially and emotionally demanding. This means that one of the most important parts of caring for someone else is looking after yourself.

These tips and links to other resources have helped many people in their caring roles:

- **Form a support network of close family and friends** to share the responsibility of driving to appointments, cooking meals, and generally supporting each other. There are lots of free websites and apps that can help you draw up a roster and share it with each other so that everyone in your network knows what they are looking after each week – this helps to take the responsibility away from one carer needing to coordinate all these activities.
- **Use social media or messaging apps** to communicate information to concerned family and friends at the same time. It can be exhausting repeating the same information to many different people. You might like to nominate another trusted family member or friend to be the main spokesperson for this communication.
- **Maintain a good relationship with your own GP**, keeping up with your own health checks and vaccinations.
- **Learn about carers payments** that you may be eligible for by visiting www.servicesaustralia.gov.au and entering 'Caring for someone' into the search area. There are three different payments: Carer Payment, Carer Allowance, and Carer Supplement – and different conditions for each. You can ask a social worker at your treatment hospital or call **Carer Gateway on 1800 422 737** to help you work out your eligibility for these payments.

- **Make time to do something that you find relaxing** and is just for you, *every day*. This could be as simple as going for a walk in the fresh air, catching up with a friend, listening to some music, or reading a book.
- **Take care of your own physical and mental wellbeing** with healthy eating, regular exercise, a good sleep routine, connecting with friends, and continuing to enjoy activities that give you joy and a sense of purpose.
- **Talk about how you are feeling**. Having someone objective to offload your thoughts and feelings onto can be a huge help. You might like to join a Myeloma Australia support group that caters for people with myeloma and their carers, or join a specific support group for carers – there's nothing quite like the support of other people who are in the same situation as you. Or you might like to see a counsellor or psychologist.
- **Most importantly, if your caring role is getting on top of you, ask for help**. The health professionals looking after the person with myeloma are also there to support you, and can help you find the support and services you need.

“Myeloma Australia was a great help. We learnt to gracefully accept support from family and friends. It was important that we had friends who we could lean on.

We are thankful every day to the superior power for the specialists, doctors, nursing staff, family and friends who have supported us.”

Nimo, Victoria

The Australian Government's Carer Gateway connects you with a network of providers that provide emotional and practical services and support for carers.

Go to carergateway.gov.au to see the range of services

Learn more

Leukaemia Foundation Australia has a free online course to help carers learn how to recognise their own emotional and practical needs, as well as help in accessing the services, support and guidance that's available to carers.

Go to leukaemia.org.au Q 'Caring for the carer'

Learn more

Cancer Council Australia's booklet ***Caring for Someone with Cancer*** includes information on practical, financial and emotional support, caring for yourself, how relationships change, as well as information on caring for someone with advanced cancer.

Go to cancer.org.au Q 'Caring for Someone with Cancer'

Learn more

Where can I find more information and support?

Myeloma Australia www.myeloma.org.au Telephone Support Line 1800 MYELOMA (1800 693 566)	Advance Care Planning Australia www.advancecareplanning.org.au
Cancer Council Australia www.cancer.org.au Information and support line: 13 11 20	Services Australia (for information on Medicare and government payments) www.servicesaustralia.gov.au
Leukaemia Foundation www.leukaemia.org.au	Carers Couch www.carerscouch.com
International Myeloma Foundation www.myeloma.org	Carer Gateway www.carergateway.gov.au
Myeloma UK www.myeloma.org.uk	Carers Australia www.carersaustralia.com.au
Australian Cancer Trials www.australiancancertrials.gov.au	National Center for Complementary and Integrative Health www.nccam.nih.gov
Australian New Zealand Clinical Trials Registry www.anzctr.org.au	EviQ Cancer Treatments online www.eviq.org.au
ClinTrial Refer www.clintrialrefer.org.au	NPS MedicineWise www.nps.org.au
Myeloma and Related Disease Registry www.mrdr.net.au	My Aged Care www.myagedcare.gov.au

