



Myeloma  
Australia

HEALTH CONDITION INFOSHEET

# Smouldering myeloma


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*This infosheet tells you more about an early form of myeloma called smouldering myeloma: what it is, how it is diagnosed and monitored, practical things you can do to potentially reduce the risk of progression, when you might need to begin treatment, and how to find the support you need.*

## Things to remember

- **Smouldering myeloma is a non-cancerous early form of active myeloma.** It's often called SMM and sits on a spectrum that begins with monoclonal gammopathy of undetermined significance (MGUS). It usually progresses slowly to active myeloma.
- **Most people have no symptoms.** Smouldering myeloma is usually found by chance during routine blood tests or while monitoring MGUS.
- **Monitoring is key.** Regular blood and urine tests, plus scans and a bone marrow biopsy when needed, help check for any signs of progression. You'll also be asked to look out for symptoms.
- **No treatment is needed until smouldering myeloma progresses to active myeloma.** Ongoing monitoring means treatment can begin as soon as it's needed.
- **Risk of progression is about 10% per year.** The risk is highest in the first 5 years after diagnosis and then decreases.
- **Your haematologist will use your test results to work if you are at low, intermediate or high risk** of progressing to active myeloma within 2 years.
- **Healthy habits can help.** Keeping to a healthy weight, eating a plant-focused diet, staying active, and reducing harmful habits support your overall health and may help reduce the risk of progression.
- **Take it one step at a time and reach out for support.** Stay up to date with monitoring, focus on healthy habits, and lean on trusted people or our Specialist Myeloma Nurses.


If you're reading a printed version of this infosheet, we've used a magnifying glass symbol  throughout to let you know where you can search for more information in the '**Learn more**' section at the end of this infosheet.

# What is smouldering myeloma?

*Smouldering myeloma is an early form ('precursor') of multiple myeloma. It is considered as the second stage of a disease spectrum which starts as monoclonal gammopathy of undetermined significance (MGUS), and may progress to become active myeloma, but usually at a slow rate. Myeloma is a blood cancer that affects plasma cells. Smouldering myeloma is often called SMM for short (which stands for smouldering multiple myeloma).* 

Plasma cells are found in bone marrow (the spongy centre of our bones) where they form part of our immune systems. Healthy plasma cells make antibodies (which are also called immunoglobulins), to help fight infection.

In smouldering myeloma, some of these plasma cells become abnormal because of DNA changes. Instead of making helpful immunoglobulins to fight infection, the abnormal plasma cells make and release an abnormal type of immunoglobulin, called *paraprotein*.

This paraprotein doesn't have any useful function in your body, and can become harmful at higher levels. Because there is only a small amount of paraprotein in your body, it usually doesn't cause any problems. You can read more in our infosheet, [Understanding paraprotein in myeloma](#). 


In smouldering myeloma, abnormal plasma cells begin to build up in the bone marrow but do not cause any damage to the bones.

Most of the time, smouldering myeloma doesn't cause symptoms, which is why it's sometimes

called 'asymptomatic' and why many people don't realise they have it. You may only find out you have smouldering myeloma by chance when you're having blood tests done for another reason.

If you've been told you have smouldering myeloma, you usually won't need any treatment, but your doctor will ask you to have regular blood and/or urine (wee) tests, and check for any symptoms to see if there are any changes in your condition. We cannot predict exactly when smouldering myeloma will progress to active myeloma, which is why it's important to monitor for signs of progression.

Some people with smouldering myeloma will progress to active myeloma. In the first 5 years after being diagnosed, about 10% (1 in 10 people) with smouldering myeloma will progress to active myeloma. The risk of progression lessens over time – meaning the longer you have smouldering myeloma without it progressing, the less likely it is to become active myeloma. A small number of people may develop a different, related condition called AL amyloidosis.

 ***I don't think anybody wants to hear they have a serious health condition, especially out of the blue, and one they have never heard of before. But, with the support and information from my health professionals about what the future could look like, I have accepted it as part of what life throws at us. Worrying about it does not change anything. I try not to worry and I work on improving my overall wellbeing.***

**Nigel, Victoria**



*I was having regular blood tests for MGUS, and when my paraprotein numbers started climbing more rapidly, the blood tests got closer together. I then had a bone marrow biopsy and more tests, and was told I now had smouldering myeloma, but still did not need treatment.*

Simon, Tasmania

## About the smouldering myeloma disease spectrum

- **All cases of smouldering myeloma start as monoclonal gammopathy of undetermined significance (MGUS)**, a non-cancerous condition where small numbers of damaged plasma cells in the bone marrow produce a paraprotein that can be detected in your blood. Everyone with smouldering myeloma first had MGUS (even if you weren't aware of it). The reason people develop MGUS remains unknown. You can read more about MGUS in our [infosheet](#).
- When the damaged plasma cells start to produce a higher level of paraprotein and/or build up at higher levels in the bone marrow, but cause **no symptoms or harm** to the body, **MGUS has progressed to smouldering myeloma**.
- Some people with smouldering myeloma will eventually progress to active myeloma. When paraprotein levels and plasma cell numbers start to cause symptoms or damage to the body, smouldering myeloma has progressed to **active myeloma** and needs treatment.

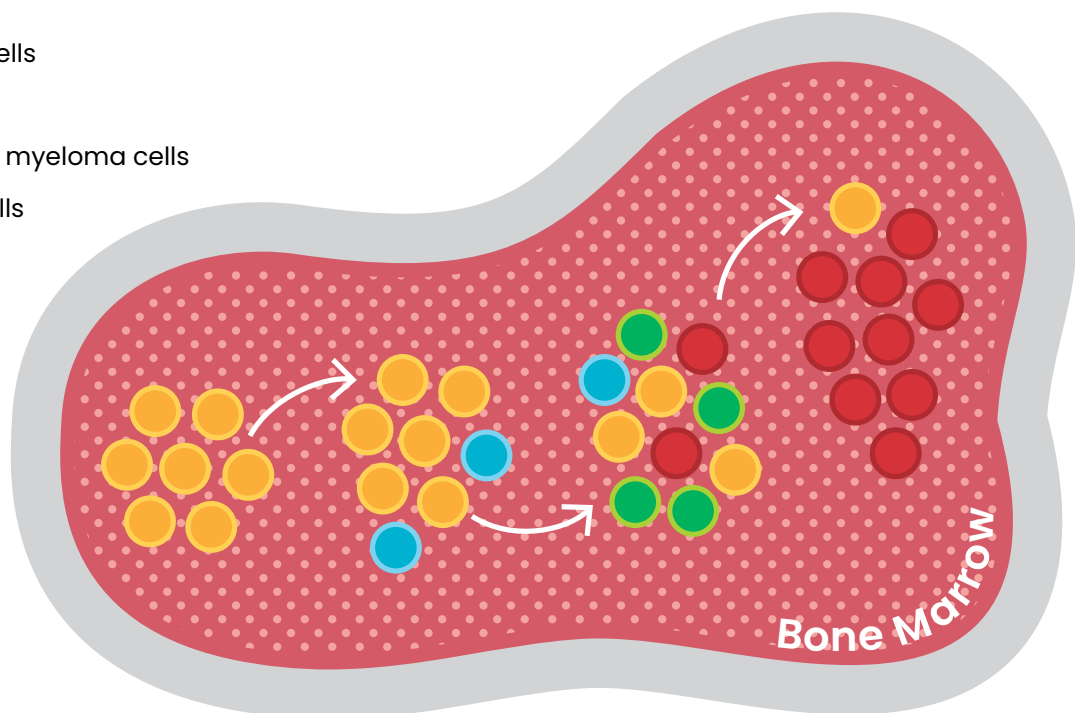
The image below gives a visual guide to the differences between MGUS, smouldering myeloma, and active myeloma.

Maturing B cells

MGUS

Smouldering myeloma cells

Myeloma cells



The table below shows the features of MGUS, smouldering myeloma, and active myeloma.

FEATURE	MGUS	SMOULDERING MYELOMA (SMM) (also called <i>asymptomatic myeloma</i> )	ACTIVE MYELOMA (also called <i>multiple myeloma</i> or simply <i>myeloma</i> )
<b>Paraprotein</b>	Less than 30g/L OR an abnormal free light chain ratio	More than 30g/L OR an abnormal free light chain ratio	More than 30g/L OR an abnormal free light chain ratio
<b>Plasma cells in bone marrow</b>	Less than 10%	10–60%	10% or more
<b>Symptoms</b>	None	None	Yes
<b>CRAB Symptoms</b>	None	None	Yes
<b>Treatment needed?</b>	No – monitoring only	No – monitoring only Unless high-risk* (see the next row)	Yes – treatment recommended
<b>*No symptoms but considered high-risk SMM</b>		Some people with SMM who have high-risk disease features are now considered to have active myeloma even though they don't have any CRAB symptoms. It is recommended that these people start treatment.	
<b>Diagnosis changes to active myeloma when you have CRAB symptoms</b>		CRAB stands for: <b>C</b> - Calcium (high levels in the blood) <b>R</b> - Renal (kidney) problems <b>A</b> - Anaemia (low red blood cell count) <b>B</b> - Bone disease (fractures or lesions)	

## A bit more about immunoglobulins (antibodies)

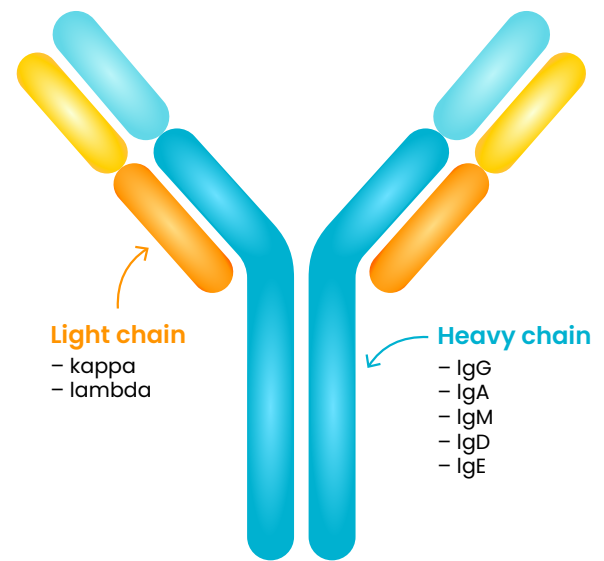
Immunoglobulins, which are written as 'Ig' for short, are substances made by our plasma cells to help fight infection. They are shaped like a Y and have two parts:

- 1. Heavy chains:** There are five types: IgG, IgA, IgM, IgD, and IgE.
- 2. Light chains:** These can be either kappa or lambda.

Each immunoglobulin has one type of heavy chain and one type of light chain.

In smouldering myeloma, abnormal plasma cells produce an incomplete or abnormal version of these immunoglobulins, called paraprotein, which serves no useful function in fighting infections.

The image below shows the Y shape of immunoglobulins and their heavy and light chains.



## What are the different types of smouldering myeloma?

There are different types of smouldering myeloma, which are named after the type of abnormal protein (paraprotein) being made:

TYPE OF SMOULDERING MYELOMA	FEATURE	EXAMPLE
<b>Heavy chain</b>	Heavy chain smouldering myeloma can be IgG, IgA, IgM, IgD or IgE, depending on which heavy chain is overproduced + either the light chain kappa or lambda.	A common heavy chain type is called <b>IgG kappa smouldering myeloma</b> .
<b>Light chain</b>	Light chain smouldering myeloma is when kappa or lambda light chains break away from the heavy chain and start producing a paraprotein on their own.	A common light chain type is called <b>lambda light chain smouldering myeloma</b> .

 Read more in our [Understanding Paraprotein in Myeloma](#) infosheet. 

## What causes smouldering myeloma?

The cause of smouldering myeloma is not yet known, although researchers believe that there are genetic and environmental factors involved.

We do know that some factors increase the risk of developing smouldering myeloma:

- **Age:** As we get older, our cells make more mistakes when making new cells and our immune system is less able to detect these abnormal cells.
- **Ethnicity:** Smouldering myeloma is more common in people of Black ethnicity.
- **Family history:** If a close relative has MGUS, smouldering myeloma, or active myeloma, you have a slightly higher chance of developing smouldering myeloma.
- **Having a health condition that affects the immune system or certain viruses,** such as HIV, hepatitis or herpes.
- **Exposure to certain chemicals or radiation,** including agricultural chemicals, benzene, and solvents.

## Does smouldering myeloma have symptoms?

People with smouldering myeloma don't have any symptoms, which is why it's sometimes called 'asymptomatic myeloma'. If you do notice symptoms, they are probably due to other health issues, not smouldering myeloma itself.



Let your GP or haematologist know if you have any new symptoms or symptoms that you're worried about.

## How is smouldering myeloma diagnosed?

As smouldering myeloma doesn't cause any symptoms, it is usually diagnosed when paraprotein is found by chance when you're having a routine check-up or tests for other health conditions.

If you have been diagnosed with MGUS, your treating team may find it has progressed

to smouldering myeloma when doing your regular MGUS monitoring tests, or because you develop symptoms and your team then does further tests.

Once the paraprotein has been found, your doctor will need to do some more tests to confirm that you have smouldering myeloma.


These further tests are usually ordered by a haematologist and include:

**1. Blood tests:**

- **Serum protein electrophoresis (SPEP):** This test identifies the type and level of paraprotein in your blood.
- **Other blood tests** check your full blood count, kidney and liver function, and calcium level. These tests check your general health and also look for any damage caused by the paraprotein that may suggest your smouldering myeloma is progressing to active myeloma.

**2. Urine tests:** Paraprotein, especially light chains, may also show up in your urine (wee), so it's likely that a sample of your urine will be sent for testing. Sometimes, a 24-hour urine collection may be performed, where you collect all your urine in a large container for a 24-hour period and it is sent off for testing.

**3. Imaging tests:** You might have X-rays, an MRI (magnetic resonance imaging), or CT (computed tomography) scan to check for bone damage. You may also have a bone density test. Active myeloma can cause bone damage, so it's important to check your bone health to make sure your smouldering myeloma isn't progressing to active myeloma.

**4. Bone marrow aspiration and trephine (BMAT) biopsy:** A small sample of bone marrow will be taken from the back of your hip to see how many plasma cells are in your bone marrow, and to look for abnormal plasma cells. 

## When will my myeloma become active?

### Low-, intermediate- and high-risk smouldering myeloma

Once your haematologist has confirmed that you have smouldering myeloma, they will then work out your risk of progressing to active myeloma.

While we can't pinpoint exactly when your smouldering myeloma will start progressing, there are some factors that help us understand your risk of progressing sooner rather than later. These include:

- paraprotein level higher than 20g/L
- free light-chain ratio higher than 20
- more than 20% abnormal plasma cells in your bone marrow.

The number of risk factors you have will be used to work out if you are at low, intermediate or high risk of progressing to active myeloma within 2 years.

#### Risk score for progression to active myeloma

Number of risk factors	Risk group	Risk of progression to active myeloma over 2 years
0	Low-risk	6.2%
1	Intermediate-risk	17.9%
2-3	High-risk	44.2%




**When I was diagnosed with SMM, my doctor told me that I had some high-risk features. She explained that this meant I had a high chance of progressing to active myeloma sooner rather than later. At first, I felt very anxious about this, but now I have more understanding and am confident about the plan my doctor and I have in place for monitoring – and for when I need to start treatment. I also found speaking to a psychologist and others living with SMM helped me cope with my anxiety.**

Fatima, Northern Territory

## FISH testing

Your haematologist may also order a type of genetic test called *fluorescent in situ hybridisation* (FISH) to look for DNA abnormalities. This test is done using the sample taken when you had a bone marrow biopsy.

The results of your FISH test may be combined with your risk score from the table to give more information about your possible rate of progression to active myeloma. You can read more about the FISH test in our [Understanding bone marrow tests in myeloma](#) infosheet. 

Your haematologist will use all these test results to decide how often you will need monitoring so that progression to active myeloma can be picked up as soon as possible.

Your risk of progressing to active myeloma is lower if you have had smouldering myeloma for a long time without signs of progression.

## How is smouldering myeloma managed?

Most people with smouldering myeloma don't benefit from treatment because the condition isn't causing any harm to their body. Instead, regular monitoring is essential to make sure progression to active myeloma is picked up early.

Monitoring usually involves blood and urine tests to track your level of paraprotein or free light chains. Your haematologist will let you know how often you need these tests. Usually, you will be monitored more often at first (about every 3 months), and this may change if your smouldering myeloma is stable.

It's important to know that your paraprotein or light chain levels may go up and down – and

this is normal. However, if you have a steady or large increase over time, or you develop new symptoms, you will need more tests.

If you're at high risk of progression, you may be offered a clinical trial for early treatment. Ask your doctor about trials that might be available to you.

Normally, treatment will begin when your smouldering myeloma is developing into active myeloma. The timing of starting treatment will depend on your individual test results, symptoms, general health and other individual factors, which you and your haematologist will discuss together.

# What are the signs that my smouldering myeloma might be progressing?

As well as keeping up-to-date with your monitoring tests, it's important to watch for any new symptoms and let your haematologist know as soon as you notice these — don't wait for your next blood test or appointment.

## Contact your haematologist if you notice:



- an unexpected broken bone (from only a small or unknown injury)
- unexplained pain, especially in your back or ribs
- unexplained bruising or bleeding
- feeling tired, light-headed or breathless
- tingling or numbness in your hands or feet
- losing weight without trying
- frequent infections or infections that don't get better easily
- feeling less healthy overall.

## In your blood or urine tests, your doctor will be looking for:

- increased calcium levels
- reduced kidney function
- anaemia (low red blood cells)
- increasing paraprotein or light chain levels.



*I started having nose bleeds every couple of days, and tests showed that I was progressing to active myeloma. My haematologist suggested a clinical trial in Melbourne where I was able to access treatments that were not yet available in Australia. I achieved the best possible outcome: complete remission!*

*Simon, Tasmania*

# Is there anything I can do to help stop my smouldering myeloma from progressing?

Smouldering myeloma most often progresses to active myeloma, but we don't fully understand the causes of progression, and it's not possible to be certain when this will happen. We do know that having [certain risk factors increase the likelihood and timing of progression](#), and that the risk is lower after you have had smouldering myeloma for a long time without any signs of progression.

There are also some clear guidelines that can help everyone to reduce their overall cancer risk, and some of these may be specifically helpful for people with smouldering myeloma.

The World Cancer Research Fund and the results of recent clinical trials on MGUS and smouldering myeloma progression and diet suggest that these healthy lifestyle tips are worth trying:



**1. Keep to a healthy weight:** Recent research suggests a potential link between having a high body mass index (BMI), obesity, and the progression of MGUS and smouldering myeloma. Staying within a normal BMI may reduce the risk of progression to myeloma. BMI is a way of measuring whether you are a healthy weight for your height, but it's worth keeping in mind that BMI has some limitations. A dietitian can talk with you about different ways to measure your body composition and help you develop an eating plan that's tailored to your health needs and food preferences.

- Visit [World Cancer Research Fund](#) to learn more about a healthy weight and how to work out your BMI. [i](#)



**2. Eat a balanced, whole food diet:**

- Build your diet around wholegrains, vegetables, legumes (beans, lentils and peas), fruits, nuts, seeds, and plant-based proteins.
- Limit sugary drinks, processed foods, red meat and processed meats.



**3. Boost your gut health:** Aim to eat 30+ different plant foods a week and 30g of fibre every day. Remember to aim for quantity *and* variety. A diet focused on fibre-rich whole plant foods supports your gut microbiome – the trillions of microorganisms that live in your gastrointestinal tract. A healthy gut microbiome is associated with many health benefits, including an improved BMI, better immune function, and early research suggests it may play a role in reducing the risk of MGUS and smouldering myeloma progressing to active myeloma.

- Find out more about the ongoing research in this area in the 'Learn more' section at the end of this infosheet.
- Download OnCore Nutrition's free [Plant Variety Checklist](#) to help you explore, track and expand the different plant foods you eat. [i](#)
- Read our [Nutrition and myeloma](#) infosheet, which includes lots of tips for healthy eating that apply to people with smouldering myeloma too. [i](#)



- 4. Stay active:** Regular exercise has many health benefits, including helping you keep to a healthy weight, improve bone and muscle strength and immune function, reduce inflammation, and boost your mood, sleep and gut health.

It can be helpful to see an accredited exercise physiologist (EP) or physiotherapist (physio) so they can prescribe an individualised exercise program to meet your needs and goals.

- Read more about the World Cancer Research Fund’s [recommendations for exercise](#).



- 5. Limit harmful habits:** Don’t smoke, limit alcohol, get good quality sleep, and manage stress.

All of these strategies work together to help keep you healthy, so do your best to include as many of these as you can.

- Read more about the World Cancer Research Fund’s [recommendations for cancer prevention](#).



*My diagnosis with smouldering myeloma has motivated me to make major improvements to my lifestyle. I now follow a pescatarian diet, don't drink any alcohol, and have significantly increased my physical exercise. My general health is the best it has been for a long time. I am conscious of symptoms that suggest I may be progressing, and discuss changes in my body with my GP and haematologist.*

**Nigel, Victoria**

# Living well with smouldering myeloma

*Being diagnosed with smouldering myeloma is understandably a challenging and unsettling time that can create anxiety about the future for you and your family.*

It can be especially challenging to be told you have a health condition that is likely to progress, but for which treatment is not yet recommended. People with smouldering myeloma tell us that they are often most anxious when they are first diagnosed and then each time as they are waiting for the results of their monitoring tests.

Additionally, you and your family and friends may not have heard of smouldering myeloma before your diagnosis, and this can make living with the condition feel quite isolating at times.

While it's natural to be concerned, there are ways to help you manage these feelings, while staying positive and proactive.

Here are some ideas for finding support, dealing with uncertainty, and staying positive:

- **Talk to someone:** Share your feelings with a trusted friend, family member, or your treating team. See the last page of this infosheet for Myeloma Australia support services.
- **Living with uncertainty:** Even though your anxiety may be worse when your monitoring tests and results are due, you can feel reassured that that these tests mean that any changes will be found early, helping your treating team to take any action as soon as needed. Keep up-to-date with your monitoring tests and appointments, and let your haematologist know about any new symptoms so they can be checked. Keep in mind that new symptoms may not be related to myeloma.
- **Take it one step at a time:** While it's normal to have bad days, try not to let the 'what ifs' and worry take over. Do your best to stay present and focus on the people and activities that bring you joy.
  - Many people find that relaxation, mediation and mindfulness practices can help them to live better with uncertainty.
- **Focus on what you can control:** Living a healthy lifestyle – like eating well, staying active, and prioritising your sleep – can boost both your physical and mental wellbeing.

If you ever feel anxious or overwhelmed, don't hesitate to reach out to your treating team or our Specialist Myeloma Nurses for support. They're here to help you every step of the way.

## The Nutrivention trial

The Nutrivention trial was a pilot intervention trial in 20 people with MGUS or smouldering myeloma who had a BMI over 25 (classified as overweight). People in the trial ate a whole-food plant-based diet for 12 weeks and had health coaching for 24 weeks.

The trial showed improvements in quality of life, BMI, insulin resistance, microbiome diversity, and immune markers. After 1 year, two people who had a significant reduction in their BMI showed a potential reduced risk of progression to myeloma.

There is now a larger Nutrivention trial to better understand how eating a whole-food plant-based diet may delay progression of MGUS and smouldering myeloma.

You can read more about the trial [here](#). 

## Questions to ask your treating team

- What Ig type of smouldering myeloma do I have?
- Is my smouldering myeloma considered low-, intermediate- or high-risk?
- Have I had a FISH test, and do I have any DNA abnormalities?
- How often will I need to have blood or urine tests?
- How often will I have appointments with you?
- What symptoms should I be monitoring for?
- Who do I contact if I have new or worsening symptoms?
- At what point would you consider starting treatment?
- Is there a clinical trial available that might be suitable for me?
- What support is available to me?

Many people also find it helpful to ask for a printout of their test results so they can keep track of any changes. Store these in a folder that you keep within easy reach and take these along to each haematologist's appointment to help guide your discussion.



***Having the support of Myeloma Australia and the information available on their website, along with knowledge of the work that Myeloma Australia is doing in the background, is a great comfort. Myeloma Australia is my go-to place for the current state of play for treatments, information, and a way of connecting with others affected by myeloma.***






***I'm a regular attendee to the VIC Statewide Cuppa and Catch Up and Smouldering Myeloma Support Group (via Teams meetings). There are lots of positive people and good advice in these groups.***

**Nigel, Victoria**



## Learn more

You'll find more information in these resources available from [myeloma.org.au](https://myeloma.org.au).

RESOURCE	NAME	LINK
INFOSHEETS	<ul style="list-style-type: none"><li>→  <a href="#">'Monoclonal gammopathy of undetermined significance (MGUS) infosheet'</a></li><li>→  <a href="#">'Understanding paraprotein in myeloma infosheet'</a></li><li>→  <a href="#">'Understanding bone marrow tests in myeloma infosheet'</a></li><li>→  <a href="#">'Understanding the bone marrow biopsy procedure in myeloma infosheet'</a></li></ul>	<p>Go to:</p> <p><a href="https://myeloma.org.au">myeloma.org.au</a></p> <p>Search for the document using the name following the  icons</p>
RECORDED SEMINARS	<ul style="list-style-type: none"><li>→ <a href="#">Understanding Smouldering Myeloma</a></li><li>→ <a href="#">Investigating the impact of dietary interventions in progression of MGUS &amp; smouldering myeloma to active myeloma</a></li></ul> <p>Learn about the research into diet, gut health, MGUS and smouldering myeloma by listening to haematologist Dr Urvi Shah's online seminar recorded for Myeloma Australia.</p>	<p>Go to:</p> <p><a href="https://myeloma.org.au/resources/recorded-seminars/">myeloma.org.au/resources/recorded-seminars/</a></p> <p>Scroll down the page to find the seminar.</p>



## More information and support

- **World Cancer Research Fund** has lots of helpful information about [cancer prevention](#), [healthy weight](#) (including how to calculate your BMI), and [staying active](#).
  - 🔍 Go to [wcrf.org](http://wcrf.org) and search for 'Our recommendations'.
  - 🔍 Go to [wcrf.org](http://wcrf.org) and choose 'Preventing cancer' and then choose 'Weight and obesity' from the topics list.
  - 🔍 Go to [wcrf.org](http://wcrf.org) and choose 'Preventing cancer' and then choose 'Physical activity' from the topics list.
- **Download OnCore Nutrition's free [Plant Variety Checklist](#)** to help you explore, track and expand the different plant foods you eat.
  - 🔍 Go to [store.oncorenutrition.com](http://store.oncorenutrition.com) and search for 'Plant Variety Score'.
- **Read more about the [Nutrivention trial](#)** where people with MGUS or smouldering myeloma ate a whole-food plant-based diet and experienced improved quality of life and other benefits.
  - 🔍 Enter 'Nutrivention trial' into your search engine.
- **Our Specialist Myeloma Nurses** are available on our Telephone Support Line to talk with you about living with smouldering myeloma, your monitoring results, and any concerns you may have.

To book a 30- or 60-minute call with a Specialist Myeloma Nurse:

📞 call **1800 MYELOMA** (1800 693 566)  
Monday–Friday, 9am–5pm AEST/AEDT, or

🖱️ go to **[myeloma.org.au](http://myeloma.org.au)** and click on the  
'Book a call with a Specialist Myeloma Nurse' button.

✉️ email [nurses@myeloma.org.au](mailto:nurses@myeloma.org.au) to contact a Specialist Myeloma Nurse at any time.

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We hope this infosheet has helped you to understand more about smouldering myeloma and feel confident about your monitoring and living well with this condition.



The information in this sheet is not intended to replace medical care or the advice of your treating team. Please talk to your team about the monitoring and management plan they recommend for you.