



Myeloma
Australia

TREATMENT INFOSHEET

Steroids

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Steroids


This treatment infosheet tells you more about a group of medicines called corticosteroids, usually simply called 'steroids'.

Steroids are commonly used as part of myeloma treatment, usually in combination with other medicines.

This infosheet tells you about how steroids work, their more common side effects, and other issues to be aware of. Please keep in mind that you'll also need to know about the side effects and warnings associated with any other medicines you are taking in combination with steroids, so please check Myeloma Australia's treatment infosheets for any other treatments you are prescribed.

Things to remember

- **Steroids are a common part of myeloma treatment, usually used in combination with other medicines.** Steroid medicines such as dexamethasone and prednisolone can help kill myeloma cells, support other treatments to work better, and reduce inflammation, pain, nausea, and allergic reactions.
- **Your steroid treatment plan will be tailored to you.** Steroids are usually taken as tablets, often in quite high doses, and sometimes on a 'pulse' or intermittent schedule. Your treating team may adjust the type, dose, or timing to balance benefits with side effects.
- **Side effects are common, but many can be prevented or managed.** Stomach irritation, changes in mood, sleep, blood sugar, and appetite, as well as fluid retention and increased risk of infection are common side effects. Keeping a side effect diary can help you and your treating team spot patterns and respond early.
- **Speak up early and get urgent help for red flags.** Let your treating team know about any side effects that worry you, but never stop steroids suddenly without a plan. Take extra care to prevent infections, and always seek urgent medical help for signs of infection — including a temperature of 38°C or higher.

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 are steroids?

Naturally-occurring steroids are hormones that are made in small amounts by our body's adrenal glands. These steroids influence many different systems in the body, including regulating the immune system and blood pressure, and reducing inflammation.

Synthetic steroids are steroids that are made as medicines to mimic the action of the body's naturally-occurring steroids.

Dexamethasone and **prednisolone** are two different steroid medicines that are commonly used to treat myeloma. They belong to a class of steroids called *glucocorticoids*. One of these is often used in combination with other anti-myeloma medicines as part of your treatment program.

These steroid medicines are different from anabolic steroids, which are used to build muscle.

How do steroids work?

Both dexamethasone and prednisolone are used to help treat many different health conditions.

When they are used in myeloma, they:

- actively kill myeloma cells
- help other anti-myeloma medicines to work better
- prevent inflammation, which can help to reduce pain that's part of myeloma bone disease
- help reduce nausea that's a side effect of chemotherapy and other treatments
- help manage allergic (hypersensitivity) reactions to some other myeloma treatments.

During your treatment for myeloma, you are likely to have several courses of steroid treatments.

How do I take steroids?

Dexamethasone or prednisolone can be taken as tablets or given by an infusion into a vein (intravenously).

In myeloma, steroids are most often taken as tablets. The dose of steroids given in myeloma is usually quite high, so you may need to take several tablets at once.

Some people may be on a 'pulse' or intermittent dosing schedule, where you have alternating periods on and off steroids. This allows larger doses of steroids to be used for

a short period to increase their therapeutic effects and reduce their side effects.

Each person with myeloma will have a different treatment plan, and so the dose and length of treatment will be tailored to your individual goals and needs. These will depend on different factors, including your stage of myeloma, treatment combination, age, and any other health conditions you have. Your treating team will discuss this with you.

What is the difference between dexamethasone and prednisolone?

Dexamethasone is very effective at killing myeloma cells when used in high doses. However, the side effects associated with high-dose dexamethasone can be difficult to tolerate for some people. Sometimes it is necessary for your treating team to adjust the dose of dexamethasone to a level that you can better tolerate.

Prednisolone is also effective at killing myeloma cells. It can usually be better tolerated with less severe side effects than dexamethasone, especially if you are older or have other health conditions.

What are the possible side effects of steroids?

All medicines, including steroids, have possible side effects. These can vary a lot from person to person and may be mild or more serious. The number of side effects often increases with higher doses, longer treatments periods, and increased age.

People living with myeloma tell us that the side effects of steroids are amongst the most difficult for them to manage. Knowing about these possible side effects and talking openly about them with your treating team can help you to plan together and quickly get on top of any that you experience.

It can be helpful to remember that many side effects with steroids are temporary and can be prevented or managed. Side effects

will generally go away when you stop taking steroids.

The goal of treatment is to find a balance between the benefits of steroids in treating your myeloma and your ability to live with any side effects. That's why it's important to let your treating team know about any side effects you are experiencing and how they are affecting your quality of life. There's always something your doctor can do to help, which may include using other supportive medicines or changing your steroid dose.

The side effects listed here are the most common. For a complete list, please ask your pharmacist for the consumer medicine information (CMI).

Keeping a side effect diary

Side effects with steroids often follow a predictable pattern.

Keeping a side effect diary can help you to identify these patterns over the day and night or across a treatment cycle. This can help you to quickly see what's happening and then work with your treating team to find ways to better manage side effects.

This may include changes to the time of day or night when you take your steroids, and possibly the dose.

Just remember that it's important not to change your schedule or dose before talking to your treating team. Never stop taking your steroids suddenly. Your treating team will give you a plan for when it's time to stop treatment, which may involve gradually cutting down your dose (called *tapering*).

Stomach irritation

Steroids can cause stomach irritation in many people, and may damage the lining of your stomach and sometimes cause stomach ulcers. This irritation can result in stomach pain, indigestion, or heartburn.

What can help?

- Tell your treating team straight away if you have any symptoms of stomach irritation, or if you vomit blood.
- Always swallow steroid tablets whole, and take them with milk or food to help protect your stomach lining.
- While you are taking steroids, your doctor will usually prescribe a type of antacid called a proton pump inhibitor (PPI) to help protect your stomach lining.

Mood and energy changes

Steroids can cause mood and energy changes in many people. These can be more obvious when you are taking high doses and if you are on a 'pulse' dosing schedule where you have alternating periods on and off steroids.


Mood changes may include:

- mood swings – where your mood changes from high to low very quickly
- anxiety
- depression
- irritability and agitation
- difficulty concentrating
- effects on your judgement and decision-making
- tearfulness.

Changes in your energy levels are often intertwined with mood changes and may include:

- hyperactivity with increased energy and difficulty sleeping (insomnia) on the days you take steroids
- let-down or withdrawal effect with low energy and mood on the days after taking steroids.

What can help?

- Let your family and friends know that you are taking steroids and that these may affect your mood and energy. This will help family and friends to be more understanding and supportive – and also to look out for times when you might need extra help from a healthcare professional.
- If your mood and energy changes are very difficult to live with, let your treating team know, and they may change your dose or treatment schedule.
- It may be helpful to talk through your mood changes with a counsellor or psychologist, who can provide you with practical tools to help you manage them. Ask your GP about a Mental Health Treatment Plan to help with the cost of seeing a psychologist.
- If you experience a severe let-down effect, your treating team may taper your steroid dose when you come off it.
- Do your best to plan activities around your steroid schedule. You may be able to plan work, more vigorous exercise and other physical activities when your energy levels are high, and this may help to 'work off' your extra energy. When your energy and mood is low, you may feel better with gentle exercise, meditation, and enjoying favourite activities.
- Manage fatigue by keeping up regular exercise, eating a wide range of nutritious foods, keeping up your fluids, and resting when needed.
- [Beyond Blue](#) has a wide range of information resources to help manage mood changes and sleeping problems. 



Steroids can have a wide range of effects on your mood, potentially causing problems with your mental health. Your treating team has a lot of experience in helping people to manage the side effects of steroids. Always talk to your team and let them know how you are feeling, especially if you are depressed, anxious, or having thoughts about suicide.



Steroids make me so hungry, but I've learnt to be prepared with snacks that I know are doing my body some good! I cut up fresh veggies and fruit and have hardboiled eggs on hand. I store them in containers in the fridge and have high-protein options to dip them in – hummus, cottage cheese, Greek yoghurt and almond butter are favourites."

Dawn, South Australia



I've found that I get better sleep by taking my steroids in the evening, before the wakefulness side effects have had a chance to kick in."


Marco, Northern Territory

Sleeping problems

Problems falling asleep and staying asleep (insomnia) are common when taking steroids.

What can help?

- You may be able to reduce the impact of steroids on your sleep by taking your medicine in the morning. However, if the hyped-up effect of steroids has a delayed onset for you, you may be able to take your steroids at night and get a better night's sleep before the side effects kick-in. Because this can vary so much from person to person, you may need to try taking steroids at different times to see what works best for you, and has the least impact on your sleep.
- Meditating or practicing relaxation, both during the day and before sleep, can help you to manage anxiety and racing thoughts, and wind down for better sleep. There are many free resources and apps that can guide you – we've listed a couple of favourites in the 'Learn more' section at the end of this infosheet.
- If sleep continues to be a challenge, chat to your doctor to see if a short-term sleep aid may be an option.

Myeloma Australia's Living well infosheet, [Fatigue and myeloma](#), includes more practical tips to help you manage fatigue and get better sleep. 

Increased blood sugar

Steroids can affect your body's ability to handle glucose and may increase your blood sugars. This is especially important to be aware of if you have diabetes. Sometimes, diabetes can develop for the first time while taking steroids.

What can help?

If you have diabetes, you may need to monitor your blood sugar more frequently.


- Let your doctor know straight away if you notice any changes in your blood sugar readings.
- If high blood sugar levels are a problem, your doctor may need to adjust the dose of your insulin or other medicines.
- A dietitian can help you make changes to your diet to help manage high blood sugar.


Increased appetite

Steroids can increase your appetite, and cause changes in weight and body composition.

What can help?

- Your body needs more food and nutrients when you're having treatment for myeloma – so think of this as an opportunity to eat more of the foods that your body really needs, especially lean protein and whole plant foods.

- Do your best to plan ahead and have healthy snacks on hand so they're ready when hunger strikes!
- Keep in mind that much of the weight gain when taking steroids is caused by fluid retention, so when you are weaned off steroids, that weight often comes off as quickly as it appeared.
- A dietitian can help with managing blood sugar and appetite changes while on steroid treatment, as well as many other areas of optimising your diet while living with myeloma. To search for a dietitian in your area who specialises in cancer nutrition visit dietitiansaustralia.org.au/find-dietitian and choose 'Cancer' under the 'Help me with' option. 


Myeloma Australia's [Nutrition and myeloma](#) infosheet includes many practical tips to help with the challenges of healthy eating when you are living with myeloma. 

Muscle weakness and muscle cramps

Steroids can cause muscle weakness, especially towards the end of your treatment course.

Some people experience muscle cramps for a short time after finishing their steroid treatment, and muscle cramps can be a side effect of other anti-myeloma medicines often used with steroids.

What can help?

- You can help to offset muscle weakness by staying as active as possible and including strength training as part of your exercise program. An accredited exercise physiologist (EP) or physiotherapist can develop an exercise program suited to your needs. Our [Exercise and myeloma](#) infosheet has lots of helpful tips on staying active too. 
- To help with muscle cramps, our Specialist Myeloma Nurses often suggest staying well hydrated, eating bananas and drinking tonic water or an electrolyte replacement drink (like Powerade®) to provide temporary relief from cramps. Massage and stretching out your muscles can also help.
- If cramps are an ongoing problem for you, talk to your treating team, who may recommend having your electrolyte levels checked and may prescribe magnesium to help.

Fluid retention

Steroids can cause your body to retain fluid, which can make your hands, ankles and feet swell. Fluid can also collect in your tummy, making you feel bloated. Occasionally, fluid can collect in your chest and make you feel short of breath.

What can help?

- Keeping up your exercise plan and elevating your legs when you are sitting or lying down can help to reduce fluid retention.
- Chat to your treating team if your fluid retention is severe or bothering you. They may prescribe diuretics (medicines that make you wee) to help remove the excess fluid.
- Get urgent medical attention if you become very short of breath, where you cannot speak in full sentences.

Increased risk of infection

Steroid treatment can suppress your immune system, especially when used at high doses or for a long time. This can increase your risk of infection or make infections worse. In people with myeloma, even a minor infection can develop into something more serious if not treated quickly.

What can help?

- Take extra care to prevent infections, such as washing or sanitising your hands regularly and staying away from people with coughs, colds or other infections.
- Be aware of the signs of an infection, and let your treating team know straight away if you notice:



- a temperature $>38^{\circ}\text{C}$



- pain when passing urine (wee)



- a productive cough



- any areas of swelling or inflammation.

- If you do develop an infection, your doctor may prescribe antibiotics.

Sepsis

Sepsis, which is also called blood poisoning, is a rare but serious complication of infection. In sepsis, bacteria enter the blood and the body overreacts to the infection. Sepsis is life-threatening and needs to be treated urgently in hospital with antibiotics given into a vein.

Because sepsis can happen so quickly and needs to be treated urgently, it's important to be aware of the signs, which can include:

- a temperature of 38°C or higher
- extreme shivering, muscle pain or sweating
- confusion or slurred speech
- breathing very fast or being short of breath
- not having a wee all day
- feeling extremely unwell
- pale or mottled-looking skin.



Having a temperature of 38°C or higher is a common sign of infection. Always get urgent medical attention for a temperature of 38°C or more.

Skin thinning

Your skin can become thin and tear more easily with continued steroid use.

What can help?

- Take extra care to avoid cuts and scratches, especially from pets or in the garden, as these may be more prone to infection.
 - Wear long gloves and long pants when gardening to help protect skin.
 - Quickly clean and cover any cuts or scratches.
 - Use a gentle soap-free cleanser and a low-irritant moisturiser to help soothe dry skin.
- Petroleum-free sorbolene cream works well for many people and can be used as both a cleanser and moisturiser.
- Protect your skin from the sun. Cover up with a wide-brimmed hat and loose-fitting clothing that covers as much skin as possible when you are outdoors, and use an SPF50+ sunscreen that's formulated for sensitive skin on any areas that are exposed to the sun.

Other side effects

Other side effects with steroids may include:

- bloating or rounding of your face (moon face)
- flushing and increased sweating – if these do happen, it's usually on the days you take steroids
- blurred vision – if this does happen, it's usually on the days you take steroids
- extra hair growth
- skin rashes or acne
- increased risk of cataracts
- headache
- dizziness
- easy bruising
- slow wound healing
- osteoporosis (brittle or weak bones) or osteopenia (loss of bone density).

Let your treating team know if you develop any side effects that are concerning you.



It may take a few doses before you know how you react to steroid treatment. If you experience changes in concentration and judgement, or have dizziness or blurred vision, do not drive, use tools, operate heavy machinery, or do anything else that may be dangerous.

Effects on intimacy, fertility, pregnancy and breastfeeding

We understand that myeloma and its treatment can impact your intimate relationships, sexual function, and libido (desire for sex). This can be due to fatigue, pain, feeling unwell, physical changes that can affect your body image, emotional stress, and hormonal changes. Longer-term steroid treatment can affect the production of sex hormones, which can result in lowered libido. You may also have questions about which intimate activities are safe with your treatment.

Recognising these changes and communicating about them openly can help to ease any anxiety and help you get back in touch with your body and maintain intimacy. You can continue to connect and enjoy intimacy through touch, cuddling and gentle massage, without having intercourse.

If you feel ready to, it is usually safe to resume penetrative sexual activity once your neutrophil count is above 1.0 and your platelet count is above 50.

Do I need to use barrier protection during sexual activity?

Steroids are not cytotoxic, which means they are not toxic to normal cells. There is very little risk to a partner who comes in contact with the semen, vaginal fluids or saliva of someone being treated with steroids. However, because steroids

are nearly always given with other treatments for myeloma, please check Myeloma Australia's treatment infosheets for any other treatments you are taking to see if these are cytotoxic and if you may need to take extra precautions.

What about fertility, pregnancy and breastfeeding?

It is generally not recommended to use steroids during pregnancy. Other myeloma treatments that are often used with steroids – including lenalidomide, thalidomide and pomalidomide – are known to cause birth defects. In fertile couples, it is important to use effective contraception and barrier protection to avoid pregnancy whilst on treatment with these medicines, and you should not breastfeed.

If you are taking lenalidomide, thalidomide or pomalidomide (and some other myeloma treatments) together with steroids, you will need to wait 6–12 months after completing treatment before trying to conceive. Ask your doctor about fertility preservation options if you are planning to have children in the future.

Questions to ask my treating team

Here are some suggested questions you might like to ask your treating team to help you understand more about what to expect with your steroid treatment.

We have included some space for you to write down answers, as well as space to write down any extra questions of your own. Remember, there's no such thing as a silly question!





- How long will I continue treatment with steroids?
- How will I know if the treatment is working?
- Will my dose be changed throughout treatment?
- What should I do if I have a new or worsening side effect or symptom while on treatment?
- What can you do to help me manage the side effects?
- Are you happy for me to change the time of day I take my steroids to help manage insomnia?
- What should I do if I am already taking or need to start taking any other medicines?

My questions and notes

Learn more



You'll find more information in these Myeloma Australia resources available from myeloma.org.au.

RESOURCE	NAME	LINK
INFOSHEETS	→  'Fatigue and myeloma' living well infosheet	Go to: myeloma.org.au Search for the document using the name following the  icons
	→  'Nutrition and myeloma' living well infosheet	
	→  'Exercise and myeloma' living well infosheet	



More information and support

- **Beyond Blue** has a wide range of information resources to help manage mood changes and sleeping problems.
 - 🔍 Go to beyondblue.org.au and search for the issue you'd like help with, such as 'anxiety' or 'sleep'.
- **Smiling Mind** is a 100% free Australian app with lots of helpful resources and meditations for sleep (as well as other mental fitness practices). Download the app on the Apple AppStore or Google Play.
 - 🔍 Once you've downloaded the app, enter 'sleep' into the search bar to find their sleep meditations.
- **Cancer Council's *Finding Calm During Cancer*** podcast includes a series of meditation and relaxation practices that you can listen to on your computer or phone, and can download to listen to at any time.
 - 🔍 Go to cancerCouncil.com.au and search for 'Finding calm during cancer'.
- **Search for a dietitian** in your area who specialises in cancer nutrition.
 - 🔍 Visit dietitiansaustralia.org.au/find-dietitian and choose 'Cancer' under the 'Help me with' option.
- **Our Specialist Myeloma Nurses** are available on our Telephone Support Line to talk with you about any concerns you have about your steroid treatment.
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** and click on the 'Book a call with a Specialist Myeloma Nurse' button.
 - ✉️ email nurses@myeloma.org.au to contact a Specialist Myeloma Nurse at any time.



The information in this sheet 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.