Myeloma Australia

LIVING WELL INFOSHEET

Fatigue and myeloma

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Things to remember

- Fatigue is a common, difficult and complex symptom of myeloma and is often called 'cancer-related fatigue' or CRF. Cancer-related fatigue has many possible causes — and there are also many different ways to address those underlying causes to help you feel better. It's best to start by talking with your treating team.
- Cancer-related fatigue feels different from everyday tiredness. It may not relate directly to anything you have or haven't done, and may not always improve with rest and sleep. Thankfully, there are plenty of tools that people living with cancer have used successfully to help their fatigue, which can help you too.
- Fatigue may be caused by symptoms and complications of myeloma itself, the side effects of treatments — or by other factors, like difficulty eating and drinking, the emotional impact of having myeloma, sleeping problems, and being less active.
- Your treating team will work with you to treat any underlying causes of fatigue — such as anaemia, reduced kidney function, infection, and pain. Your doctor may be able to adjust treatments that are causing fatigue if your myeloma is under control.
- Getting emotional support, eating well, keeping up your fluids, and balancing exercise and rest can all help your overall wellbeing as well as fatigue — and there are health professionals who can help you with each of these.
- Sleep is also an important tool in managing fatigue and wellbeing. We've included plenty of tips to help with this very challenging part of living with myeloma.

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.

Fatigue and myeloma

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 that the type of fatigue associated with myeloma can be persistent and distressing, doesn't necessarily improve with rest or sleep, and isn't necessarily related directly to anything you've done (or haven't done). This makes cancer-related fatigue all the more frustrating and difficult to live with — but there are many things that you and your treating team can do to help. The first step is understanding a little more about cancer-related fatigue and its causes, and the next step is to come up with a management plan.

What does cancer-related fatigue feel like?

Cancer-related fatigue often causes symptoms beyond tiredness. You may notice:

- lower energy levels
- feeling weak or lethargic
- limbs feeling heavy
- needing to sleep more than usual
- difficulty sleeping
- difficulty completing everyday tasks
- reduced concentration and/or memory
- brain fog
- irritability
- mood swings and tearfulness
- being short of breath
- less sex drive
- less appetite
- it's harder to socialise
- feeling isolated.

When I'm really tired, I become irritable and snappy. I've explained this to family and friends and asked them to forgive me in advance for what might come out of my mouth sometimes!

Mai, South Australia

It can be difficult to work out what's a sign of cancer-related fatigue and what might be caused by other health problems. Living with myeloma can also impact your mental health, causing some of these symptoms. Always talk to your treating team about any symptoms that are new or becoming worse for you.

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, or the hydration you need to function well.
- **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 management strategies, chat to your treating team about checking for any other health conditions that may be contributing to your tiredness.

> ***Once I acknowledged the emotional toll of my myeloma diagnosis and started talking to a psychologist to help my mood, I found that my fatigue improved as well. Don't delay in asking for help if you need it. Learning to live with myeloma is a big adjustment and it's very 'normal' to need help doing that.***
>
> Veda, Western 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

What can help with fatigue?

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 help you to work out the underlying causes and what's most 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.
- **Treating anaemia.** Both myeloma and its treatment can cause a drop in haemoglobin, a protein in red blood cells that carries oxygen around your body. Low haemoglobin can result in anaemia, causing fatigue, dizziness and shortness of breath. If needed, your treating team will recommend a blood transfusion, which can restore haemoglobin levels and reduce your symptoms.
- **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.
  - **Learn more:** Read our *Managing myeloma pain* infosheet, 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.
- **Emotional support.** If you are experiencing an ongoing low mood, depression, stress or anxiety, it's important to get the support you need, which can help to improve your fatigue as well.
  - **Learn more:** Read more about emotional wellbeing and support on **pages 72–73** and **80–81** of *Myeloma: A comprehensive guide*.

> ***Joining a myeloma support group has done wonders for my overall mood, and I find I leave each meeting with a renewed sense of energy and optimism.***
>
> **Maria, Victoria**

- **Eat well and keep up your fluids.**
  - **Learn more:** Read our *Nutrition and myeloma* infosheet for lots of practical tips to help you eat and drink well (even when you don't feel like it), to help keep up your energy.

- **Rest.** 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.
- **Exercise.** Although it might be 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 about all the benefits of exercise and guidelines for safer exercise in our *Exercise and myeloma* infosheet.

> ***I was so physically tired; it was like dragging my arms and legs through molasses. I saw an exercise physiologist who tailored a plan for me – it's really helped me to rebuild my muscle strength and has also helped to reduce that physical sense of tiredness. To my surprise, my sleep has improved too.***
>
> **Aris, New South Wales**

> ***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**

- **Pace yourself** so that you don't end up exhausted (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.
  - Once you have a short to-do 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 those days and give yourself permission to rest on the days when your energy is low.

All about 'chemo brain'

Many people with myeloma notice changes in their ability to remember things, find words in conversation, and experience a reduced level of concentration. This is often called 'chemo brain' — its formal name is 'cancer-related cognitive impairment'.

There's a lot of overlap between cancer-related fatigue and the experience of chemo brain. Hopefully, you'll find that many of the steps you take to help fatigue will help with your concentration and short-term memory too. Learn more on **pages 70–71** in *Myeloma: A comprehensive guide*.

Sleep

Sleep helps you to recharge physically, mentally and emotionally. Getting enough good quality sleep when you're able to (and we understand how difficult that can be), is an important tool in helping you to manage fatigue and many other parts of living with myeloma.

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, which may include muscle cramps and spasms.

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, stay asleep longer, and improve the quality of your sleep.
- **Avoid caffeine for at least 6 hours before bed.** About 6 hours after you consume caffeine, half of it is still in your body, 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,** stay in bed and listen to light music or a sleep story, read, or do breathing exercises. Alternatively, get up and do a relaxing activity, such as 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.

> ***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**

> ***I use the 'Calm' app on my phone and choose a meditation or sleep story that feels right for me at the time to help ease my racing mind and drift off to sleep.***
>
> **Patricia, Victoria**

Keeping an energy diary

It's true that both rest and exercise (and other meaningful activities) can help you manage fatigue – so how do you know when you need more or less of each? An energy diary is a useful tool to help work out the most beneficial balance of rest and activity for you. This balancing act between rest and activity is called pacing.

You don't need to make your energy diary complicated (that would be too tiring!), just jot down these things a few times a day:

- time of day
- your fatigue score — where 1 is energised and 10 is very fatigued
- symptoms or side effects you're experiencing
- medicines recently taken
- when and what you had last eaten
- any exercise or activities you'd just done
- how you're feeling emotionally
- how you slept the night before
- anything else that might be affecting your energy levels
- any strategies you've tried that have helped your energy levels.

After a week or so, look for patterns. Is there a time of day when you have more energy? Is there a time when you are more fatigued? Do either of these seem to relate to what you have been eating or doing? Is there anything that seems to particularly make your fatigue better or worse?

Once you start to see some patterns, you can use this information to adjust your activities.

For example:

- If long walks leave you fatigued, what happens if you break these up into shorter walks?
- If there is a time of day when you have the most energy, perhaps block this out in your diary to focus on meaningful activities – like spending time with friends, enjoying a favourite hobby, or working.
- Are you trying to pack too much into your days? How can you prioritise only what you really want and need to do and leave the rest?
- If there is a consistent time of day when your energy is lowest, this could be pointing to the ideal nap time for you?

> ***Keeping an energy diary has helped me to see just how much short daytime naps and high protein snacks help my energy levels. Now I know I can use these tools to quickly restore my energy when it's flagging, or to give myself an extra boost before tackling a task that takes more effort.***
>
> **Jun, Australian Capital Territory**

Learn more

You'll find more information about living as well as possible with myeloma in these resources available from myeloma.org.au:

RESOURCE	NAME	LINK
INFOSHEETS	→ 'Exercise and myeloma living well infosheet' → 'Nutrition and myeloma living well infosheet' → 'Complementary therapies and myeloma living well infosheet' → 'Managing myeloma pain living well infosheet'	Go to: myeloma.org.au Search for the document using the name following the icons
BOOK	→ You'll also find more information about emotional wellbeing, 'chemo brain' in our book, Myeloma: A comprehensive guide.	Go to: myeloma.org.au Search for 'Myeloma – A comprehensive guide'.

More information and support

- **Myeloma UK's** has a detailed infoguide on fatigue.
  - Go to myeloma.org.uk and search for 'Fatigue Infoguide'.
- **Our Specialist Myeloma Nurses** are available on our Telephone Support Line to talk with you about any aspect of myeloma, its treatment and management.

  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.

We hope you've found some helpful ideas to support your energy levels and sleep so you can experience a greater sense of wellbeing while living with myeloma.

The information in this sheet is not intended to replace medical care or the advice of your treating team. Please talk to your treating team about the fatigue you are experiencing. Your team can then work with you to find the causes — as well as the management and support that can best help you.