



Stay healthy, stay informed

Information for people with multiple myeloma

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Cover artwork by a person living with chronic illness.

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Janssen Oncology has produced this text with the greatest care in February 2022.

All the photographs of people in this booklet are models and are included just to illustrate the publication.

Introduction

Multiple myeloma can have a significant impact on your life – from a physical as well as an emotional perspective.

- What symptoms do you get?
- How can you relieve them?
- How do you handle these new emotions?
- How can your friends and family help?

In this booklet, you will find practical tips and advice to help you cope with the disease and its symptoms.

Making the most of your appointments

Before your appointment



Use the 'Notes' section at the end of this booklet to write down any questions you have as you think of them and take it with you to your appointment.



Make sure you share your questions with your doctor at the start of your appointment. Don't wait until the end, when the doctor has run out of time.



You could ask a family member or friend to come with you to your next appointment. Perhaps they can take notes while you talk to the doctor.

During your appointment



Sometimes it's too much to remember everything that is said during an appointment. You might want to write down what your doctor says so you can refer to your notes afterwards. Also, many smartphones these days have a voice recorder app. It might be easier to simply record the consultation so you can listen to it later. However, you need to tell the doctor before you start recording.



Sometimes you may not understand medical terms mentioned during your consultation or treatment. If there is a word you have not heard of before, ask the doctor or nurse to explain it.

Managing symptoms

Because multiple myeloma grows slowly, about one-third of those with it do not show symptoms, and those who do will likely not show any for some time. However, as multiple myeloma develops, symptoms can get worse and you are more likely to experience them.¹

This booklet describes some of the most common symptoms and how they can be managed.

Remember though, always talk to your doctor or nurse to get advice if you are experiencing symptoms, especially if there has been a sudden change.



Eat healthily and eat enough.



Drink enough water.



Be sensible about moving around, taking your abilities into account.



Record any symptoms or side effects you are experiencing in the 'Notes' section. Be sure to tell your doctor about these.



Keep your own record of your:

- medical history
- treatments
- test results

It will help give you a better understanding of your condition. It may also be helpful when dealing with other healthcare professionals who may not be as familiar with your condition, like your dentist.

Bone pain

You may experience bone pain, which can feel like a dull, constant pain, usually in your back, ribs and hips.

How to manage bone pain



Use hot water bottles or ice packs.²



Find a comfortable position when you are sitting or lying down so you feel as little pain as possible. Use pillows to prop you up in bed.



Try to keep your anxiety and stress levels as low as possible, because these can make pain worse.² Take time to talk about your worries with your family and friends. **Also speak with your doctor or nurse about how you are feeling, as they may be able to suggest resources or refer you to someone who can help.**



If you are in pain, a gentle massage can help you relax. See an experienced massage therapist and explain your situation to them. **Always check with your haematologist before seeking complementary therapy such as this.**



Try to rest and sleep as much as you need to.



Make sure you always discuss bone pain symptoms with your doctor or nurse.



You may be recommended or prescribed pain killers, take these only as per the advice of your healthcare professional. **If a healthcare professional other than your haematologist is prescribing you pain killers, make sure they are aware of any other treatment you're taking first.**

If your current pain relief does not seem to be working



Talk to your healthcare team

Tell your doctor or nurse so that they can adjust the dose or offer you a different pain relief treatment.

Some tips to help you describe the pain you are experiencing to your doctor



How intense is the pain?

Use a scale of 0 to 10, when 0 means no pain and 10 means unbearable pain.



Where and when do you get bone pain?

How long does the pain last and how often does it occur?
Is it brief or constant?



What type of pain is it?

Dull and continuous or sharp and stabbing?



Nerve damage

Nerve damage (or 'peripheral neuropathy') can be caused by multiple myeloma and it can also be a side effect of some treatments.³⁻⁵

It is associated with the following symptoms:^{3,5}

- pain
- tingling or prickling sensation (like pins and needles)
- increased sensitivity to temperature
- numbness or weakness in the hands and feet



How to relieve nerve pain



Keep your hands and feet warm.



Use light bed covers. This reduces the pressure on your legs and makes it easier to move in bed.



Be careful when using sharp objects such as knives or scissors. Numbness can affect your grip.



Wear appropriate shoes to avoid pain and check your feet every day for redness or blisters.



Check the temperature of your bath or shower water before you get in to avoid scalding yourself. Use a bath thermometer or ask someone else to check the temperature for you.



Do light physical activity, such as walking, to improve your blood circulation.



Stop smoking. Nicotine and other chemicals in cigarettes (including e-cigarettes) can damage blood vessels, making it harder to manage your symptoms. Smoking can also delay healing after treatment. Talk to your healthcare team for information about support available to help you quit.⁶



Think about using mobility aids, such as a walking stick or frame, to help with your everyday tasks.

Fatigue

Fatigue is a common symptom of multiple myeloma and can also be a side effect of some treatments.⁷ Myeloma can also cause a reduction in the number of red blood cells in your body, which can lead to anaemia (a lack of iron caused by having fewer red blood cells).⁷ Fatigue is a symptom of anaemia.⁷ Fatigue can manifest as:⁷

- overwhelming exhaustion
- shortness of breath
- poor memory
- feeling despondent (in low spirits)
- problems concentrating
- difficulty sleeping

If you have symptoms like these, do not hesitate to tell your doctor.

How to manage fatigue



Eat a balanced diet and choose foods that are rich in iron.



Drink plenty of water.



If you have problems eating, ask your doctor to refer you to a dietitian.



Get enough sleep and establish a routine by going to bed and getting up at the same time every day.



Do some light physical activity every day; this can really help boost your energy levels.



Plan some daily activities and also give yourself time to rest during the day.

Increased risk of infection

Multiple myeloma affects the immune system (our body's natural defence against infections and illnesses). Some medicines used to treat multiple myeloma can also weaken the immune system. This means you can become particularly sensitive to infections.^{3,5,7}

An infection generally shows up as a fever (over 38°C), but symptoms can also include:^{5,7}

- chills
- a cough
- sore throat
- diarrhoea
- redness or swelling around a wound

If you have any signs of infection, contact your nurse or doctor immediately.

How to manage the risk of infection



Wash your hands regularly, and try not to touch your mouth, nose and eyes.



When you go out, make sure you always take some alcohol-based hand sanitiser gel to keep your hands clean.



Try to stay away from people who have recently had (or still have) a contagious illness, like chickenpox or the flu.

Kidney problems

Multiple myeloma itself is the main cause of impaired kidney function.⁸ Some medicines can also affect the kidneys.⁸ Symptoms you may experience associated with kidney problems include a persistent feeling of thirst, nausea and needing to urinate frequently.⁸

How to protect your kidneys



Make sure you stay hydrated and try to drink 2–3 litres of water a day (unless your doctor has advised otherwise).



If you are having dialysis, tell your doctor and nurse.

New feelings

It's only natural to feel uncertainty and have negative emotions after you are diagnosed with multiple myeloma. You may feel confused, anxious, depressed or even angry, and may want to withdraw from people. This does not always happen, but feelings like these are only human. Your situation is complicated, and everyone reacts in their own way.

If you are anxious about your illness or treatment, do not hesitate to talk to any of the healthcare professionals taking care of you. As the saying goes: knowledge is power. The more information you have, the more in control you will feel. And you will then be in a better position to make informed decisions.

Focus on your priorities

- What is really important to me?
- What practical steps can I take to improve my quality of life today?
- How can I spend more time with my family and friends?
- Can I spend more time on my hobbies and interests?
- What can I hope for?
- What could help me to relax?
- What type of physical activity could I do to help me rest more easily?

Tips to help you in the adjustment period

Keep a diary

Keeping a diary helps you get a handle on your feelings. It's also another place where you can make a note of any symptoms or side effects you may be experiencing.

Reach out to support groups

You can join a support group to share your experiences with people in the same situation.

Talk to family and friends

They can be a fantastic source of support, both practical and emotional.

Talk openly

Be frank with your loved ones about your illness, treatment and worries. The better they understand, the more they can support you.

Ask for help

Living with multiple myeloma and managing its various symptoms can be an exhausting experience. Don't be afraid to ask family, friends, or support groups for help.

Talk to your doctor and nurse

They are used to the questions and doubts that you have. They can also be a real source of support.

Set your own pace and goals

Take each day as it comes. Focus on what you can control here and now, and on your current quality of life rather than on unknowns.

On good days you can set small goals or realistic tasks: going for a walk, calling a friend for a chat. Make a list of simple tasks to keep you occupied. Each day, you can tick off what you have managed to do. You can save what you were not able to do for tomorrow. Above all, try not to make too many changes to your life at the same time.

Watch out for symptoms of depression

It is important to recognise when your stress or negative feelings are turning into depression. If this happens to you, you must talk about it with your doctor or nurse. They may refer you to a psychologist or psychiatrist who can help you.

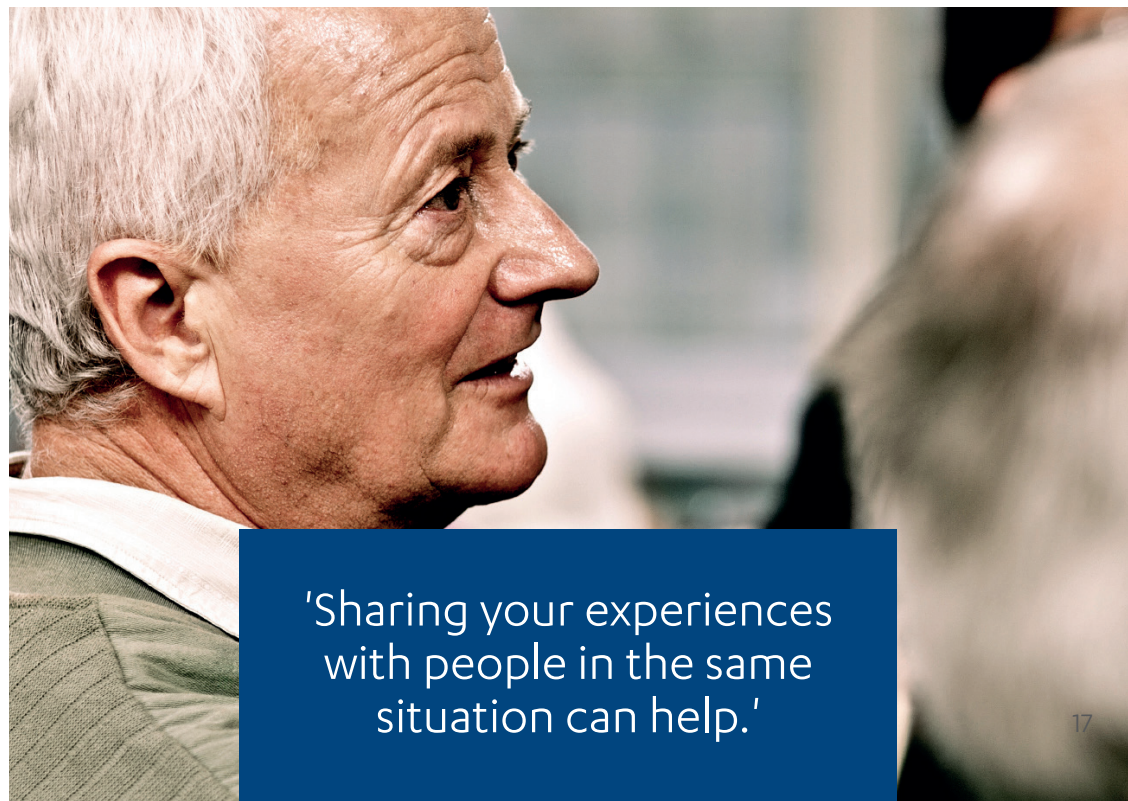
Some signs of depression are:⁹

- you find it hard to sleep
- you find it difficult to make decisions
- you lose interest in most activities
- you regularly feel low

If you're depressed, let people know why. Some friends or family members may not understand why you feel depressed. Keep being open and honest with them and encourage them to take the same approach with you.

Patient advocacy groups

Reach out to patient advocacy groups for support and to share your experiences with people in the same situation. Links to pan-European myeloma patient advocacy groups can be found on the JanssenWithMe site. There may also be local groups you can turn to for support.



'Sharing your experiences with people in the same situation can help.'



Adapting your lifestyle to your illness

Your diagnosis and treatment should not change who you are, but it makes sense to introduce small, realistic changes that might make a big difference. You should also discuss these changes with your doctor or nurse.

You can improve your quality of life with practical and positive changes



Eat well.



Drink enough water (although check with your haematologist if you have problems with your kidneys).



Limit your alcohol consumption.



Keep active when possible.



Use relaxation techniques.



Get help at home.

Eating well

Sometimes, particularly if you are receiving treatment and are feeling poorly, it may be difficult to keep a healthy balanced diet.¹⁰

Some medicines and treatments can change your sense of taste and your appetite may be reduced.¹⁰

Has your treatment reduced your eating appetite? If it has, one way of addressing this problem is to eat small portions regularly throughout the day instead of trying to eat 'three square meals.'¹⁰

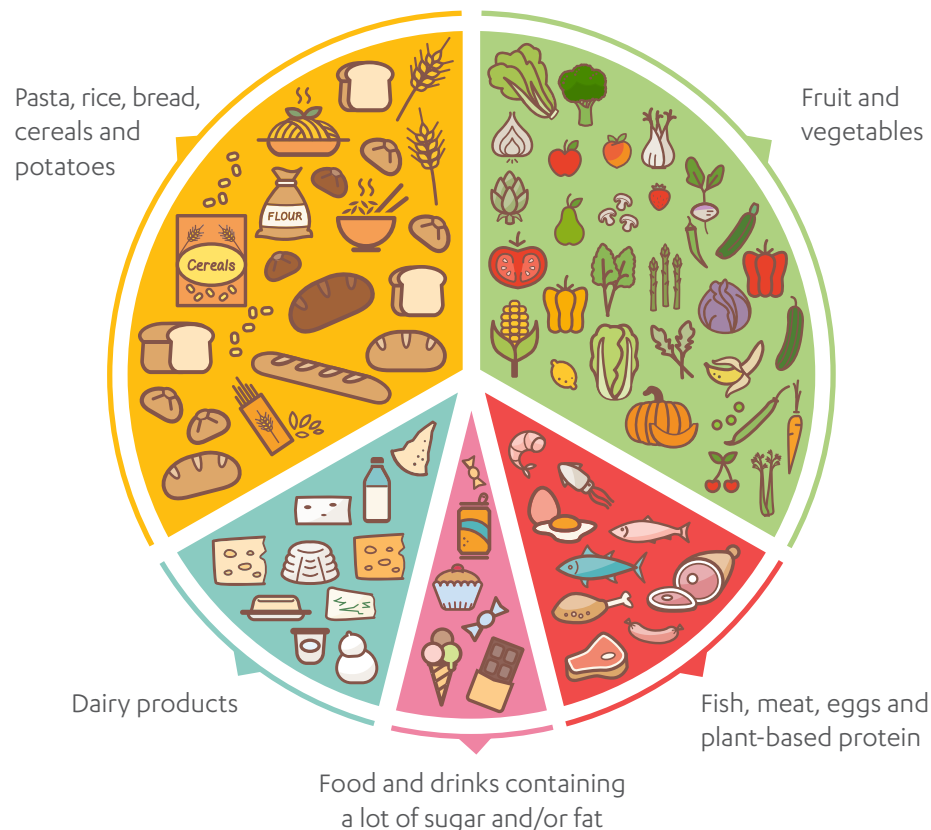
What is a healthy diet?

Your doctor or nurse may advise you to change some of your eating habits. For example, some foods – such as shellfish or unpasteurised cheese – carry a risk of infection for those with weaker immune systems, and so it might be best to avoid them.¹⁰ Other foods are especially good for you, because they can strengthen your immunity (vitamin and mineral-rich foods) or increase your energy levels (bread, pasta and rice).¹⁰

If your appetite is weak, a nurse or dietitian can advise you on how best to include some healthy calories in your diet. You may be advised to take food supplements between meals.¹⁰

A healthy diet is essential, but it is also important that you enjoy what you eat

It's all about balance. The chart below gives a sense of how your diet should be divided. Note that foods containing lots of sugar or fat, or both, should make up the smallest part of your diet. Remember to drink an appropriate amount of water and limit your alcohol consumption.





'Try to relax
for at least
20 minutes
a day.'

Keeping active

There is nothing like light physical activity (such as walking and yoga) to help you:⁷¹¹

- feel better
- manage your emotions more easily
- get better sleep

Listen to your body and do not expect too much of yourself when you are not fit. If physical activity is painful, stop straight away. Talk to your doctor or nurse about the type of physical activity that suits you.

Using relaxation techniques

Look for easy ways to reduce your stress. You could consider talking to a friend, listening to your favourite music or trying to relax to help you feel better. A feeling of relaxation does not necessarily have to come from physical effort – many people get it from music or other activities. It is essential that the relaxation techniques are not too difficult. If you are working with a facilitator, tell them that you have multiple myeloma. When you have found a technique that seems to work for you, try to practise it for at least 20 minutes a day. The more you do it, the easier and more effective it becomes.

Preparing for relaxation



Plan when to do it in advance so you do not forget or feel rushed.



Find a quiet and warm place where you will not be interrupted. Turn off or silence your phone. Make yourself comfortable and close your eyes.



As well as your prescribed treatments, you may use other therapies that will help you to relax. However, it is important to discuss this with your doctor first to make sure there will not be any interactions with your medication.

Finding help and support

Support groups

You are not alone in your diagnosis of multiple myeloma. Patient groups can be a good way to get support and advice from other people living with multiple myeloma who understand what you're going through. These groups are also a way to share your own experiences. If you are unable to find a myeloma-specific group in your area, you may be able to find a general haematology support group that welcomes those affected by blood cancers, including multiple myeloma.

If you find it difficult to get out or if you need someone to talk to when no-one else is around, then online groups can also be a great source of information and support.

Professional counselling options

People living with multiple myeloma can experience anxiety, depression and other serious psychological stresses that may require help from a healthcare professional.⁷

If you feel as if you need help, then do not hesitate to ask your specialist or doctor to recommend someone. Your doctor may even suggest professional counselling if you've kept them up to date with how you're feeling.

Your notes

Lined area for taking notes.

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This information is intended to inform patients with multiple myeloma about the clinical characteristics and treatment of their condition. You are receiving this information through the doctor treating you.