



Supporting you through your multiple myeloma journey

Information for patients with multiple myeloma

Johnson&Johnson

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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 of this binder 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 the symptoms of multiple myeloma

As multiple myeloma develops, the symptoms can get worse. These symptoms may vary from one person to another. The following pages provide some guidance about how you can best manage these symptoms and get some relief. Always talk to your doctor or nurse to get advice, especially if there has been a sudden change. You can also take proactive steps to improve your general quality of life:



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.

Managing bone pain

You may experience bone pain, which can feel like a dull, constant pain, usually in your back, ribs and hips. Apart from taking painkillers, **here are some things you can do to relieve bone pain:**



Use hot water bottles or ice packs.¹



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.¹ Take time to talk about your worries with your family and friends, or discuss them with your doctor or nurse.



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.

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?

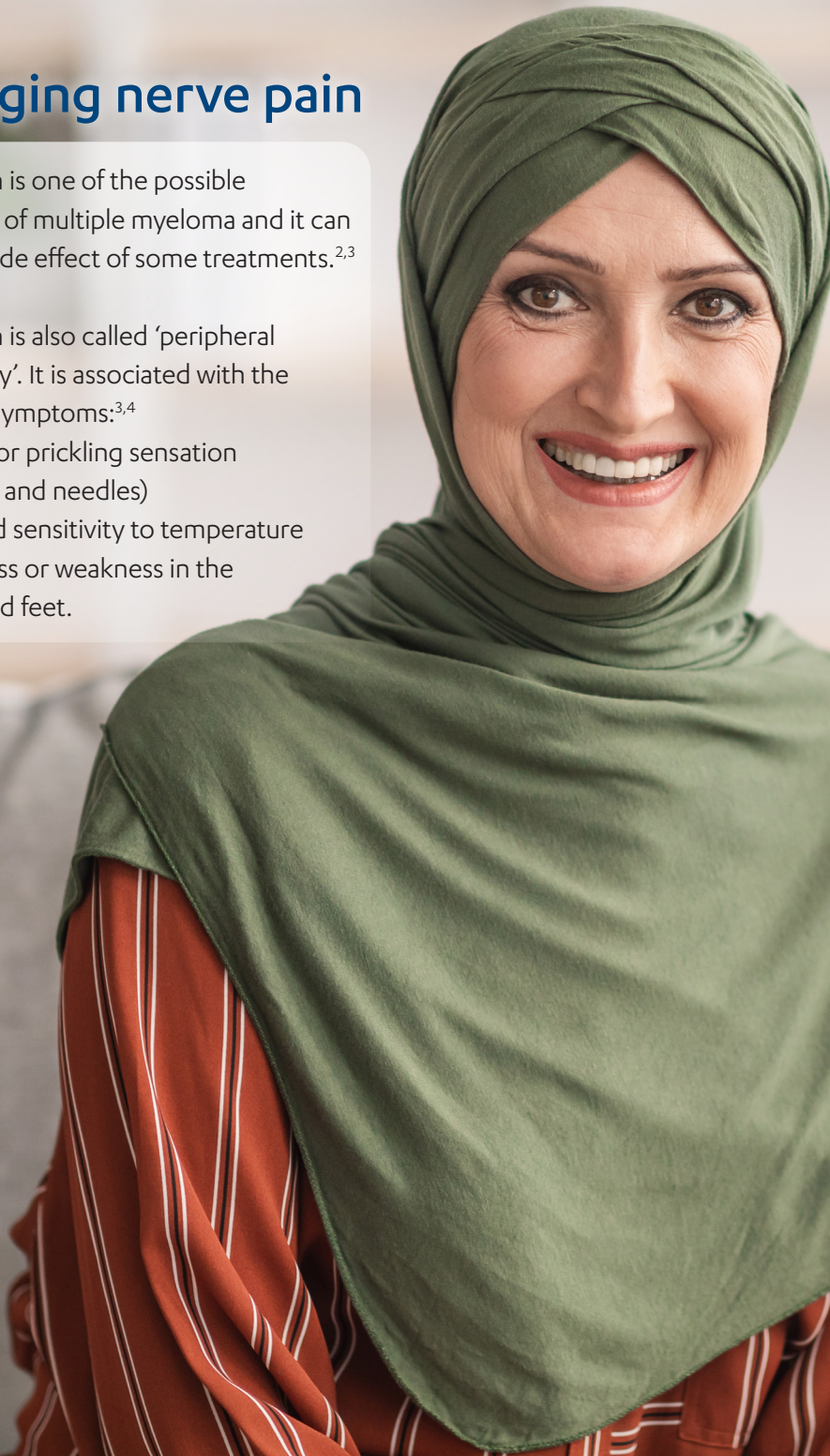


Managing nerve pain

Nerve pain is one of the possible symptoms of multiple myeloma and it can also be a side effect of some treatments.^{2,3}

Nerve pain is also called 'peripheral neuropathy'. It is associated with the following symptoms:^{3,4}

- 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 exercise, such as walking, to improve your blood circulation.



Stop smoking.



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

Managing fatigue

Fatigue is a common symptom of multiple myeloma and can also be a side effect of some treatments.⁵ 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).⁵

Extreme fatigue is a symptom of anaemia.^{3,5} Fatigue can manifest as:⁵

- 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 dietician.



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



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



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

Reducing the 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.^{3,4}

An infection generally shows up as a fever (over 38°C), but symptoms can also include:^{4,5}

- feeling unwell
- 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 reduce 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 gel-based hand sanitizer 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.

Managing kidney problems

Multiple myeloma itself is the main cause of impaired kidney function. Some medicines can also affect the kidneys. The type of symptoms you may get associated with kidney problems include a persistent feeling of thirst, nausea and needing to urinate frequently.⁶

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.

Coping with 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 exercise could I do to help me rest more easily?

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.

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.

Ask for help

Living with multiple myeloma and managing its various symptoms can be an exhausting experience.

Support groups

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

Talk to family and friends

They are 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.

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.

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.

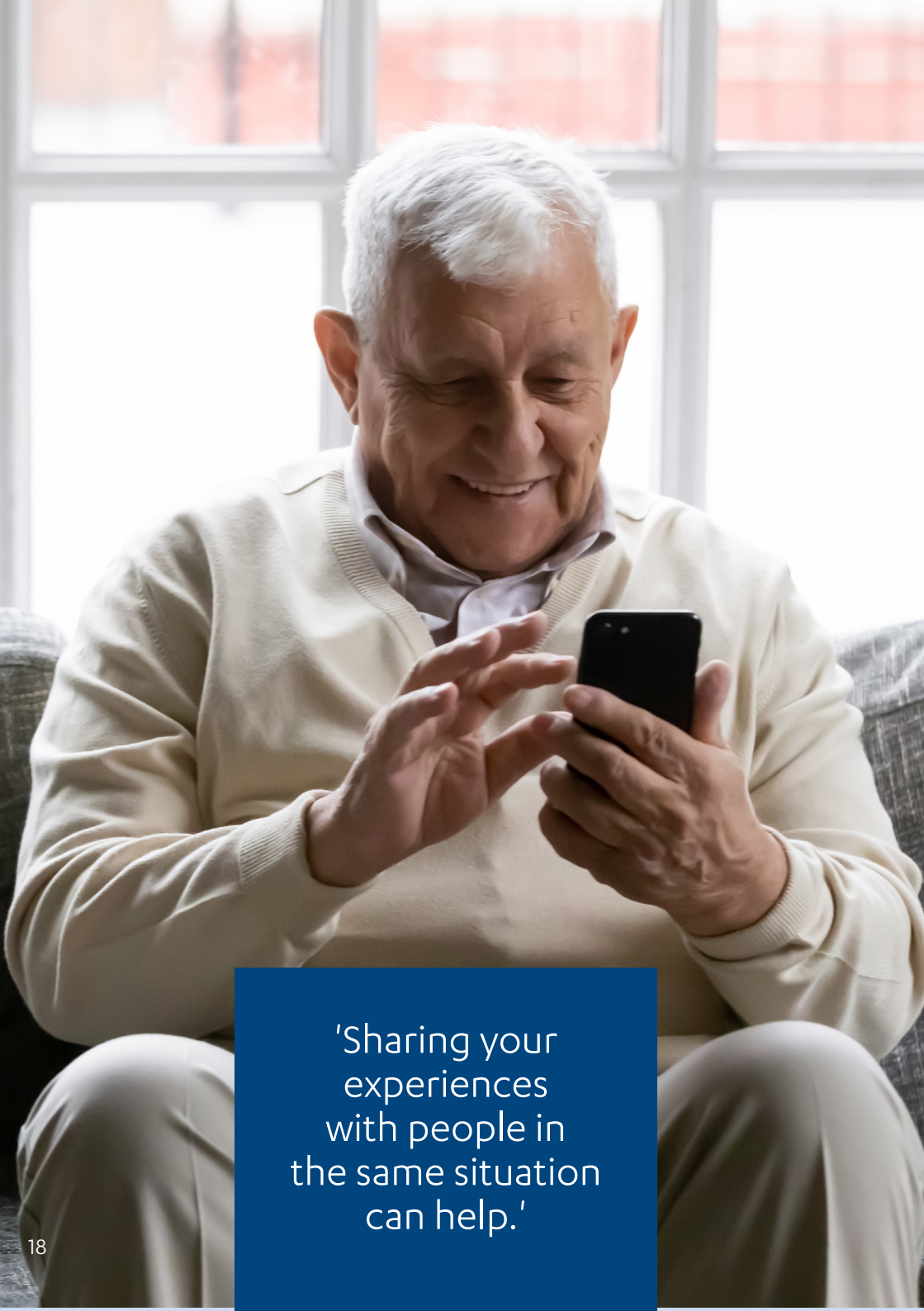
Some signs of depression are:⁷

- you find it hard to sleep.
- you are unable to concentrate.
- 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.





'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).



Keep active when possible.



Use relaxation techniques.



Get help at home.

Eating well

When you feel unwell or stressed, you may find it hard to eat properly. This can be even more difficult during and after a treatment.⁸

Some medicines and treatments can change your sense of taste and so your appetite may be reduced.⁸

Has your treatment changed your eating habits and sense of taste? If it has, one way of addressing this problem is to eat small portions every 2 to 3 hours until you are feeling better.

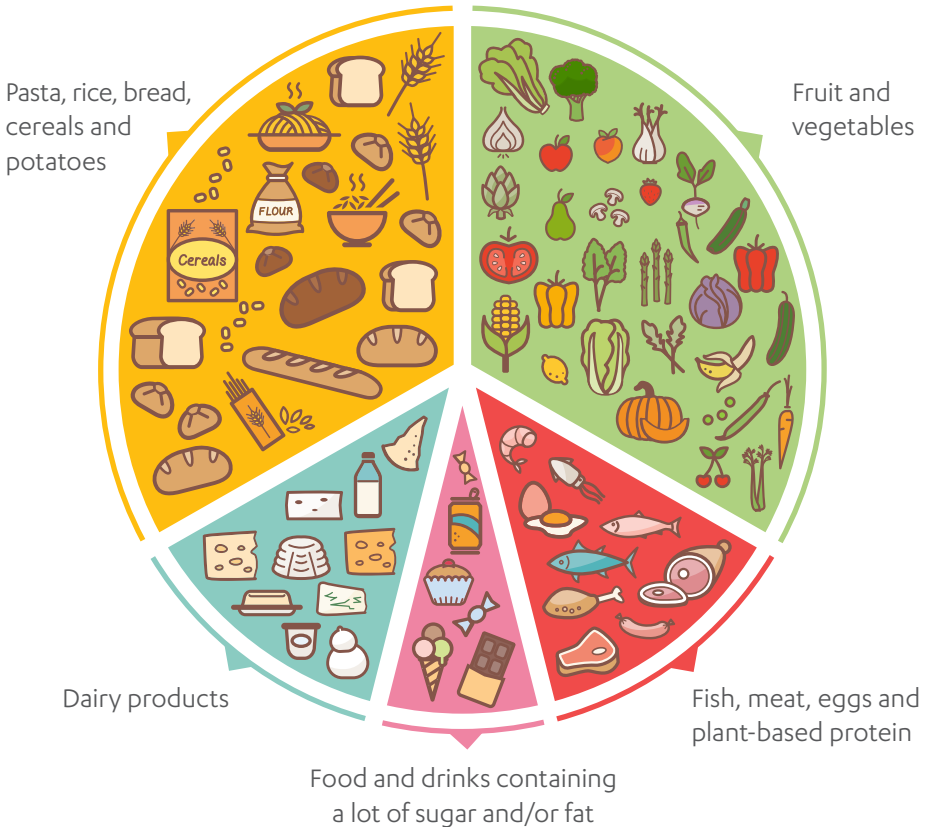
What is a healthy diet?

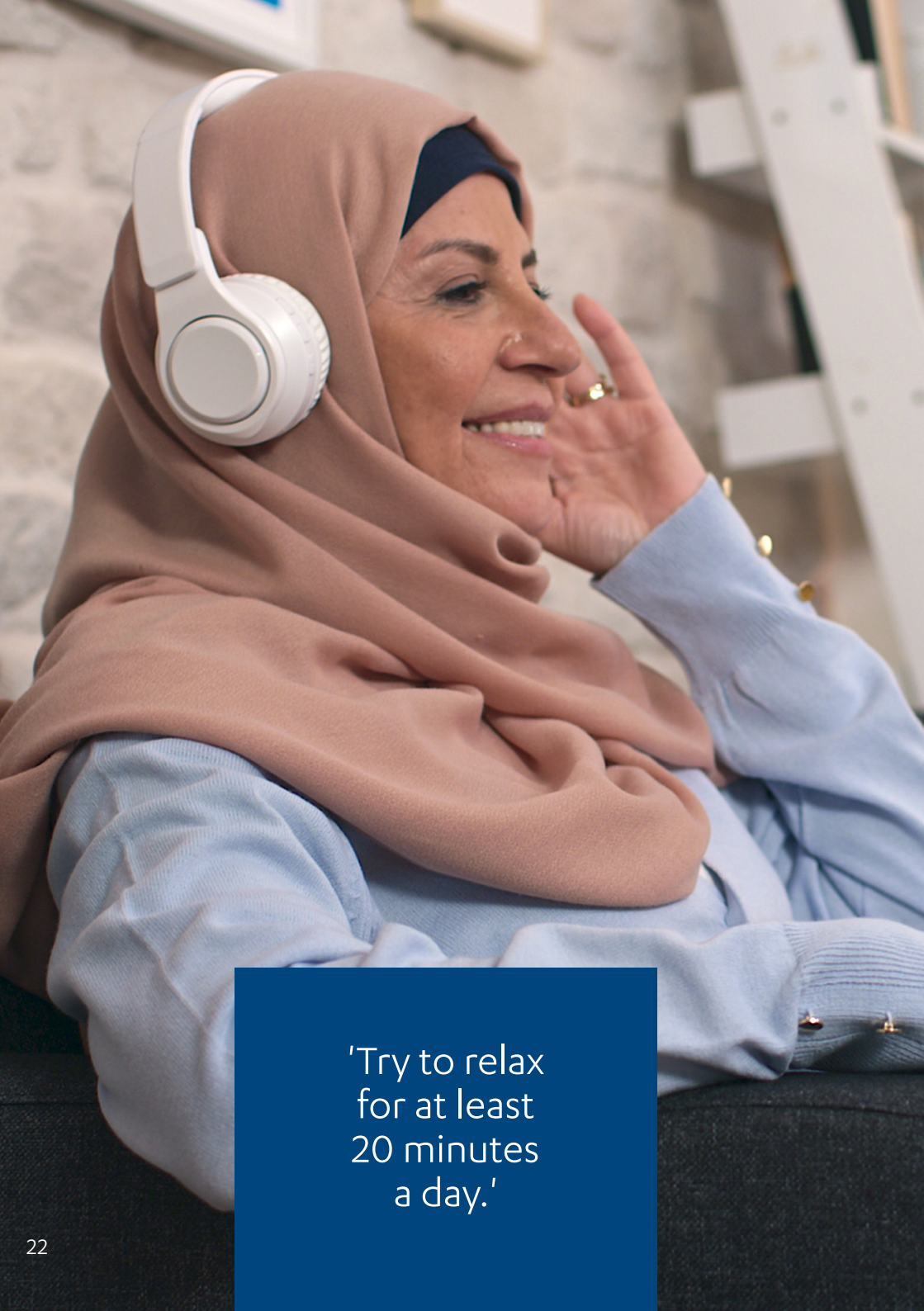
Your doctor or dietician may advise you to change some of your eating habits. For example, some foods – such as shellfish or unpasteurised cheese – carry a risk of infection for those with weaker immune systems, and so it might be best to avoid them.⁸ Other foods are especially good for you, because they can strengthen your immunity (vitamin and mineral-rich foods) or increase your energy levels (bread, pasta and rice).⁸

If your appetite is weak, a nurse or dietician can advise you on how best to include some healthy calories in your diet. You may be advised to take food supplements between meals.³

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.





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

Keeping active

There is nothing like light physical exercise (such as walking) to help you:^{5,9}

- 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 exercise is painful, stop straight away. Talk to your doctor or nurse about the type of physical exercise 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. 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 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. You can ask your doctor or nurse for patient groups existing in your country.

Professional counselling options

Many people living with multiple myeloma experience anxiety, depression and other serious psychological stresses that require help from a healthcare professional.⁵

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

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SE Reporting

If you experience any treatment-related side effects, talk to your doctor or nurse. Do not try to treat your symptoms on your own. You can also report side effects directly via the national reporting system listed below. In case of side effects related to a Janssen medicine, you can also report these via the below Janssen mailbox.

KSA:

SFDA (National Pharmacovigilance and Drug Safety Department)

Email: npc.drug@sfda.gov.sa

Tel: 19999

Fax: +966 11 2057662

Online: <http://ade.sfda.gov.sa>

UAE:

Ministry of Health and Prevention/Drug Department/ Pharmacovigilance and Medical Device section

Email: pv@mohap.gov.ae

Tel: 80011111

Website: <https://www.mohap.gov.ae/en/services/adverse-drug-reaction-reporting>

P.O. Box:1853 Dubai, United Arab Emirates

Kuwait:

Pharmaceutical and Herbal Medicine, Registration and Control Administration, Ministry of Health, Sulaibkhat - Jamal Abdel Nasser Street, PO Box 5 Zip Code 13001, Kuwait,

Tel: +96524815382,

Website: <https://eservices.moh.gov.kw/HSDrugComplaints.aspx>.

Oman:

Department of Pharmacovigilance & Drug Information MOH

Tel: +96822357686 & 0096822357687,

Fax: +96822358489,

Website: www.moh.gov.om,

All GCC Countries:

Janssen mailbox: GCC-PV2@ITS.JNJ.com

United Arab Emirates & Other Gulf Countries

P.O. Box 505080 - Dubai, UAE Tel: +97144297200 Fax: +97144297150

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