



# Guidance for multiple myeloma caregivers

Information for those caring for  
multiple myeloma patients

**Johnson & Johnson**



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# Introduction

Caring for someone with cancer such as multiple myeloma can be complex and demanding both physically and emotionally. A carer is anyone who provides help for someone else who is unable to manage without this support. This may be a friend, close relative, or even a neighbour.

Carers are not trained to help patients, which makes them different from professionals like nurses or care workers. Recognising your role and responsibilities as a carer is important. It is the first step you need to take to make sure you get the help you might need now or later on.

# How you can help

Caring for someone can involve a range of support, from being a sympathetic ear, to providing more hands-on assistance, like driving to and from hospital appointments or helping them in and out of bed.<sup>1</sup> Here are some of the ways you can help.

## Give emotional support<sup>1</sup>



A person's emotional and psychological wellbeing can be affected at any time following their diagnosis and can change over time. You can give emotional support by simply being a good listener when the person you are caring for needs to talk.

Or you might help to arrange more formal support, like a counsellor or psychologist.

Stress, anxiety and fear are natural emotions that can affect a person after such a devastating diagnosis. Having someone to talk to allows them to express their feelings and make a start at coming to terms with their situation.

There may be times when it feels more difficult than others, but also times when you can focus on the positives, particularly during periods of remission.



## Help with medicines, hospital appointments and questions



As part of their check ups treatment, the person you care for will have regular hospital appointments and check ups. They will probably need to go to hospital every week or every few weeks to receive these treatments, but they will be able to have some at home.

You may be able to help them to prepare for appointments by discussing:

- questions they need to ask
- how they have been coping with the treatment.

## Helping to manage side effects<sup>1,2</sup>



The person you are caring for will experience symptoms and side effects. These may occur as the cancer progresses or as the treatment gets to work.

There are things you can do to help, like:

- cooking foods they find easier to eat if they are feeling sick
- making small meals they can more easily manage.

There are medicines that can help with pain, and you can encourage them to talk to their doctor or nurse about these.

There are things you can do too, like helping them find a more comfortable position when sitting or lying down.

If they have difficulty sleeping, help by making sure their room is at a comfortable temperature, and ask the nurse about a pressure-relieving mattress.

It is important to let the person's healthcare professional know if symptoms or side effects don't improve.


## Helping with daily activities<sup>1</sup>



Some people with cancer may feel too tired or weak to manage everyday things. This may be because they are coping with the symptoms and complications of the disease or due to side effects of treatment.

Helping with household tasks, such as cooking, cleaning and shopping can make a huge difference. It may eventually be necessary to give physical support, such as helping someone in and out of bed, or helping with personal care like bathing and going to the toilet.

Many patients will find it difficult to accept this loss of independence, and it can be difficult for the carer to adapt to this new relationship, especially with a loved one.

A woman wearing a black hijab and a man wearing a white thobe and ghutra are looking at a tablet together. The woman is holding the tablet and has a pair of glasses in her hand. They are both smiling and appear to be in a professional or educational setting.

# The importance of looking after yourself

When you're caring for someone else, it's easy to overlook your own needs. But looking after your own health and wellbeing is just as important and means you'll be able to offer better care.<sup>1</sup>



## Get help for yourself too

If you think you might need help for yourself, or that you might be experiencing an emotional problem, the first step is usually to talk to your doctor.<sup>1</sup> They should also be able to help you identify ways of getting support, whether practical or financial, including local carers' services and social care support.

## Eat well<sup>1</sup>



Here are a few pointers to help you get the energy you need in order to take care of yourself:

- Eat at least five portions of a variety of fruit and vegetables every day.
- Base most of your meals on starchy foods like potatoes, bread, rice or pasta.
- Have some dairy or dairy alternatives (like soya drinks).
- Eat some beans, pulses, fish, eggs, meat and other protein.
- Choose unsaturated oils and spreads, but eat them in small amounts.
- Drink plenty of fluids.
- Try to limit your intake of foods and drinks that are high in fat, salt and sugar.

## Look after yourself<sup>1</sup>



Staying healthy means being careful that you don't neglect your own health and wellbeing. Make sure that you keep up to date with regular health and dental check-ups.

Caring can be physically demanding. If your role involves lifting or carrying, you could suffer from aches and pains, particularly in your back. Exercising regularly is beneficial in lots of ways and can help give you the stamina and strength to be the best carer you can be. It can be as simple as a nice walk, or involve regular classes at the local gym. Exercise is also proven to help lift your mood and alleviate stress and anxiety.

## Get some rest<sup>1</sup>



There are many reasons why looking after someone can make it difficult to get enough sleep. Worrying about things may keep you awake, or the person you are caring for may need help at night-time.

To help you relax and to clear your head, you could try to incorporate some time for yourself into your day, whether it's reading a book or having a warm bath – whatever helps you relax.

If the person you care for needs a lot of assistance at night-time and makes uninterrupted sleep difficult, look at taking naps during the day.

## Take a break<sup>1</sup>



Taking a break every once in a while is important. Ask those around you if they can take over from you for a regular time each week, and plan things to look forward to.

Making time to see friends and relatives and carrying on with some of your usual hobbies can help avoid the build-up of stress.

The person you're looking after might find it easier if they do not feel like they are relying on you too much and they might also appreciate some time to themselves.

## Don't be afraid to ask for help<sup>1</sup>



Caring for someone is a huge responsibility. Strong and confusing emotions are common, and they are not a sign of weakness. It is not selfish to think carefully about taking care of yourself, in fact it's crucial, both for your own wellbeing and for that of the person you care for.

If you have worries or concerns, or feelings of guilt, don't keep them to yourself.

# Finding help and support

Carers' groups can be a good way to get support and advice from other carers who understand what you're going through as well as a way to share your own experiences.<sup>1</sup> 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 always ask the doctor or nurse for carers' and patient groups existing in your country.

## References

1. Myeloma UK. Infopack for carers of myeloma patients. Available at: [www.myeloma.org.uk/wp-content/uploads/2018/03/Myeloma-UK-An-Infopack-for-carers-of-myeloma-patients.pdf](http://www.myeloma.org.uk/wp-content/uploads/2018/03/Myeloma-UK-An-Infopack-for-carers-of-myeloma-patients.pdf). Last accessed Aug 2018.
2. Myeloma UK. Living well with myeloma - your essential guide. Available at: [www.myeloma.org.uk/wp-content/uploads/2018/03/Myeloma-UK-Living-well-with-Myeloma-Essential-Guide.pdf](http://www.myeloma.org.uk/wp-content/uploads/2018/03/Myeloma-UK-Living-well-with-Myeloma-Essential-Guide.pdf). Last accessed: Oct 2018.

## **SE Reporting**

If you experience any treatment-related side effects, talk to the 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](mailto: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](mailto: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](http://www.moh.gov.om),

### **All GCC Countries:**

Janssen mailbox: [GCC-PV2@ITS.JNJ.com](mailto: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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