



# Guidance for carers

**Information for those caring for people with cancer**

iMR Code: EM-137048  
Date of preparation: August 2023

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*Untitled*

Cover artwork by a person living with chronic illness.

# Contents

Introduction	3
How you can help	4–6
Looking after yourself	7–8
Finding help and support	9
Summary	10–11

Janssen Oncology has produced this text with the greatest care in July 2023.

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

# Introduction

Caring for someone with cancer 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. Most often it is a partner or spouse.

Moving from being part of an equal partnership to a relationship in which one depends on the other for care and support can sometimes be challenging. 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.

It's also important to recognise that you might need help for yourself in this new role. 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.

# How you can help

Caring for someone can range from being a sympathetic ear, to providing more hands-on assistance, like driving to and from hospital appointments or helping them with daily activities like getting dressed, shopping or doing tasks around the home.<sup>1</sup> Here are some of the ways you can help.

## Giving 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 living with cancer.

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.



## Helping with medicines, hospital appointments and questions



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

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

- questions they have about their treatment or symptoms
- how they have been coping with the treatment

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



The person you are caring for may experience symptoms and side effects related to either their condition or treatment.

People undergoing treatment for myeloma should try to eat little and often when they feel like eating. It is a good idea to freeze food in small, individual portions for the person you care for to have when they feel like it. Patients and carers should always tell the doctor about any other medicines or supplements, including vitamins, that the person with myeloma is taking, as some can interfere with myeloma treatment.

The person you are caring for can ask their doctor or nurse about medicines to help with pain. You may be able to help them find a more comfortable position when sitting or lying down.

If they have difficulty sleeping, check that 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 team know if symptoms or side effects don't improve.

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



From time to time, the person you are caring for may feel too tired or weak to manage everyday things.

Helping with household tasks, such as cooking, cleaning and shopping can make a huge difference. It may 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.



# 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 as supporting the person you care for.<sup>1</sup>

## Eating well<sup>1,2</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.

## Staying healthy<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 and have the seasonal flu vaccine every year. As a carer, you may be entitled to the flu vaccine free of charge.

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 you could go to a local gym. Physical activity is also proven to help lift your mood and alleviate stress and anxiety.

## Getting enough 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.

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, making uninterrupted sleep difficult, look at taking naps during the day.

## Taking 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.



# Finding help and support

## Getting help for yourself

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.

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.

## Some useful organisations and support groups include:

### **Eurocarers**

[www.eurocarers.org](http://www.eurocarers.org)

Eurocarers is the European network representing informal carers and their organisations. It is for all carers, no matter what the age or health needs of the person they are caring for.

# Summary

This booklet describes how being a carer for someone can involve providing a range of support.<sup>1</sup> Here is a summary of some of the ways you can help:

## Your wellbeing matters

- Taking care of your own health and wellbeing
- Taking breaks every once in a while
- Accepting help and support from others
- Seeking professional help if you are feeling overwhelmed

## Emotional support

- Being a good listener when they need to talk
- Encouraging them to talk about how they are feeling
- Being a calming and positive presence
- Arranging more formal support with the help of the healthcare team, such as a counsellor or psychologist, if required





## Medical support

- Taking notes and asking questions during appointments
- Reminding them to take any medicines they have been prescribed
- Monitoring them for any side effects when they are not in hospital
- Immediately alerting the healthcare team if you notice any side effects
- Support when symptoms occur

## Care/nursing support

- Driving them to and from appointments
- Shopping and preparing meals
- Collecting prescriptions
- Helping to organise visits from family and friends
- Making sure they are comfortable
- Keeping the house clean

## References

1. Myeloma UK. Infopack for carers of myeloma patients. Available at: <https://www.myeloma.org.uk/wp-content/uploads/2021/09/Myeloma-UK-Infopack-for-carers-of-myeloma-patients.pdf>. Last accessed: June 2023.
2. Myeloma UK. Infopack for living well with myeloma. Available at: <https://www.myeloma.org.uk/wp-content/uploads/2023/04/Myeloma-UK-Infopack-for-living-well-with-myeloma.pdf>. Last accessed: June 2023.

This information is intended to provide guidance on self-care for people caring for someone with cancer.