

Cipla

Lenalidomide

Taking Care

**A caregiver's guide to
supporting someone with
multiple myeloma
Australia**

This brochure contains information needed for caregivers of someone with multiple myeloma.

If you provide support to someone with an illness, you may be referred to as a “caregiver.” Within your role, you might provide emotional and/or physical support. Your role may change as multiple myeloma can change over time. Inside this brochure, you’ll learn how multiple myeloma can affect the one you care for and how you can best care for them and yourself.

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1. What is multiple myeloma?

Multiple myeloma (MM) is a type of blood cancer; specifically, it's a cancer of the plasma cells in your bone marrow. When your plasma cells are healthy, they work as part of your immune system to fight infections and diseases. With MM, these plasma cells become abnormal and start to push out your healthy cells. This can cause:

- **Bone damage:** Pain, weakness, and broken bones
- **Low red blood cell count (anemia):** Weakness, shortness of breath, and dizziness
- **Low white blood cell count (leukopenia):** Lowered ability to fight infection
- **Excess calcium in the blood:** A frequent result of MM cell activity; this can put extra strain on the kidneys
- **Kidney problems:** Damage and failure

Treatment is important. There is no cure for MM, but a long-term treatment strategy can help manage it.

2. How does multiple myeloma develop?

- Scientists still don't know the exact cause of MM. But they do know how MM works. The graphic below explains the difference between what typically happens in the body and what happens with MM.

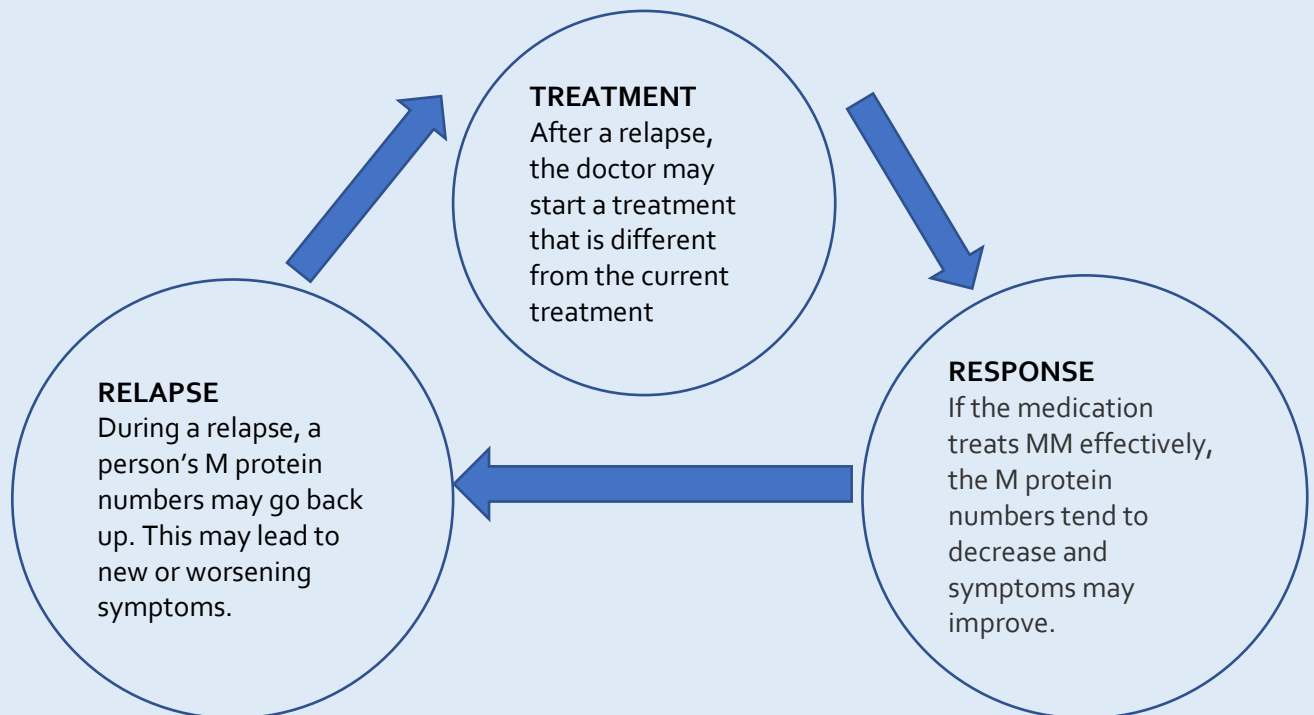
WHAT TYPICALLY HAPPENS	WHAT HAPPENS WITH MM
Stem cells Live in the bone marrow and divide to become different types of cells, such as white blood cells.	Stem cells Begin to form into white blood cells but undergo a genetic change causing damage to the cell's DNA.
White blood cells Can become plasma cells.	Damaged white blood cells DNA damage causes white blood cells to make abnormal plasma cells.
Plasma cells Make antibodies that help the body fight infection.	Abnormal plasma cells Turn into cancerous myeloma cells.
No myeloma cells Your immune system functions normally as your plasma cells retain their regular function	Myeloma cells Multiply quickly and crowd the bone marrow, reducing the space for healthy blood cells to develop and increasing the risk of infection.
Normal antibodies Guard against infection and disease	M proteins Instead of making normal antibodies, myeloma cells make M proteins that can't fight infection.

3. Why does multiple myeloma keep coming back?

Currently, there is no cure for MM. Treatment can help reduce the number of myeloma cells in your body. However, these cells often stop responding to medication and can begin to grow uncontrollably again—and the cycle of MM restarts.

4. Relapsing MM is progressive and cyclic

It's common for someone with MM to go through periods of successfully responding to treatment and then periods of relapse



It's important for patients to stay on their MM treatment, so make sure that the one you care for discusses any side effects with their doctor

5. Dealing with a multiple myeloma diagnosis and providing care

A diagnosis of MM can be difficult for you and the one you care for emotionally, physically, and logistically. They face new challenges, and you must take on greater responsibilities. On top of that, they may have to make major life changes, such as:

- Taking multiple medicines
- Visiting a healthcare professional regularly
- Getting routine blood work and other testing
- Managing MM symptoms or treatment side effects

6. Common responsibilities of a caregiver

A caregiver may provide a range of important support mechanisms, such as:

- Helping with daily activities
- Giving emotional support
- Working with your loved one's healthcare team
- Managing medication, insurance, and medical expenses
- Driving to the doctor and managing appointments
- Assisting with cooking, cleaning, personal care, or childcare

Whether you've been a caregiver in the past or are just starting out, the tips on the following pages can help you provide the best care for the affected person.

7. Speaking up for someone with multiple myeloma

At times, patients with MM may be too overwhelmed to pay attention or to grasp what the doctor is telling them. That's where you can step in - by going to doctor visits, asking questions, and being their advocate - you can assist them in understanding the complexities of their diagnosis.

If you are unsure about something the doctor or nurse is saying, don't be afraid to ask for more information or to have them explain it again. Make sure that you understand everything before you leave the office. It can be helpful to take notes or record the healthcare professional with their permission.

If you have any specific questions for the healthcare team, you should write them down before each visit. It may be helpful to prioritize them ahead of time. Some topics you might want to discuss openly with a doctor or nurse are:

- The diagnosis of the one you care for
- A change in their health
- Concerns about new symptoms
- A new medication or changing medication
- Possible side effects
- The results of lab tests

8. Practical tips for caregivers

There is no "one way" to be a caregiver, but these tips can assist you as you navigate the challenges and opportunities

9. Practice patience with your loved one

MM may be stressful for patients, and they may not know how to talk about it. When they are ready to talk, let them set the tone and topic of the conversation. One of the best ways to support them during this time is to stay positive and actively listen to them. Whilst it can be hard to remain optimistic in the face of adversity, being with them on their journey can help to keep them afloat.

10. Accepting the help of other people

It's important to know that you are not alone on this journey. There are things others can do to help. When asking others for help, first ask if they would like to share in some of the caregiving tasks. Then clearly explain the task needed and what would be most helpful to you and the one you are caring for.

Your family and friends may even volunteer to do certain tasks you haven't yet considered. Let them know how much this is appreciated. As the day of the task draws nearer, remind them they are needed and ensure they are available to help.

11. Know when to step back

Completing tasks and taking care of oneself can provide a sense of dignity and independence, something your loved one may want to hold onto for as long as possible. Don't assume that you need to take over right away. Pay attention to how they are feeling; you may only need to step in when they are feeling poorly.

12. Take care of yourself

It's just as important to care for yourself as the one you care for. It's easy to become focused on their needs and forget about your own. It can be helpful to:

- Make time to focus on yourself and the activities you enjoy
- Share your feelings either with a friend, an MM support group, or a professional counsellor
- Be kind to yourself. Know that it's natural to have a wide range of feelings during this process
- Understand your employer's policies regarding paid and unpaid leave
- Monitor your own health, particularly if you have known medical issues
- Be sure to visit your doctor for routine checkups
- Keep an eye on stress and take time to exercise, even if it's just going for walks
- Don't put too much on your plate—be honest with yourself about how much you can do.

13. Helpful resources for caregivers

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National Alliance for Caregiving	https://www.caregiving.org/
Well Spouse Association	https://wellspouse.org/
Multiple Myeloma Research Foundation (MMRF)	https://mmrf.org/
Cancer Hope Network	https://www.cancerhopenetwork.org/
Caring Bridge	https://www.caringbridge.org/
National Comprehensive Cancer Network	https://www.nccn.org/
Cancer Support Community	https://www.cancersupportcommunity.org/
International Myeloma Foundation	https://www.myeloma.org/
The Myeloma Beacon	https://myelomabeacon.org/
Myeloma Crowd	https://www.myelomacrowd.org/
Lotsa Helping Hands	https://lotsahelpinghands.com/

14. Contact Details

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