Patient information from BMJ

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Multiple myeloma

It can be devastating to be told you have a cancer like multiple myeloma. But there are treatments that can help you live longer and feel better.

What is multiple myeloma?

Multiple myeloma is a type of cancer that affects the blood. It's often just called myeloma. The "multiple" bit means that it can affect lots of parts of your body.

It's a very individual disease that affects everyone differently. Many people who have it don't have symptoms for years. Others get symptoms right away.

New blood cells are made in the middle of your bones, in a substance called bone marrow.

There are three types of blood cells:

- Red blood cells, which carry oxygen
- White blood cells, which are important for fighting infection
- Platelets, which help your blood to clot in order to stop bleeding.

If you have myeloma, your body starts making an abnormal type of white blood cell. These abnormal white cells are called myeloma cells. They can't do their usual job of fighting infection. Instead they build up in your bone marrow.

This build-up of myeloma cells can damage the bone and cause bone pain. It also means that the bone marrow can't make enough healthy blood cells.

The average age for being diagnosed with myeloma is about 69.[1] It's more common in men than in women. Myeloma is not common in young people.

Doctors don't know what causes myeloma.

What are the symptoms?

Not everyone with myeloma gets symptoms. But these are the most common problems people get:

- Pain in their bones, often felt as backache. About 70 in 100 people with myeloma have bone pain.[2] It's caused by the build-up of myeloma cells. This may also make your bones weak and more likely to break.
- Anemia. This means you don't have enough red blood cells carrying oxygen around your body. It happens because your bone marrow can't produce enough normal red blood cells. You may feel very tired or look pale.
- About 70 in 100 people with myeloma have anemia.[3]
- Because you don't have enough healthy white blood cells you may get lots of infections, like flu or pneumonia.

Some people with myeloma get too much calcium in their blood (called hypercalcemia). Too much calcium can cause problems with your kidneys and your heart.

Other symptoms are caused by a substance called paraprotein, which is made by the myeloma cells. This can damage your kidneys and nerves, among other things.

The symptoms you get depend on the type of paraprotein your myeloma cells make. You can ask your doctor about this.

What tests will I need?

If your doctor suspects that you may have myeloma, you'll need a range of tests.

The first test for myeloma is done on your urine and blood. The laboratory is looking for signs of certain antibodies and paraproteins.

The rest of the tests are done to confirm whether you have myeloma, or to find out what stage the illness is at, and how it's affecting your body.

You are likely to have some scans of your body to look for damage to your bones. You may hear them called CT (computed tomography) scans or MRI (magnetic resonance imaging) scans. If these types of scans are not available you may have a series of X rays.

You will also have a sample of your bone marrow taken to check for myeloma cells. A bone marrow sample is taken using a needle put into your bone (usually your hip bone). You'll have a local anesthetic to numb the area so it doesn't hurt.

You'll need regular blood tests. These help your doctors see what your myeloma cells are doing. Test also show how you are responding to treatment. Things doctors check include:

- How much calcium you have in your blood
- How many healthy blood cells you have
- How well your kidneys are working
- How much paraprotein you have in your blood.

What treatments are available?

There's no cure for myeloma. But treating myeloma may help get rid of your bone pain, and afterward you should feel less tired.

You may then have months or years when you don't have any symptoms or signs of myeloma. This is called remission. Experts are working on new treatments all the time, which may work even better than current treatments.

The type of treatment you need will depend on your general health, your age, and how the cancer has affected your body. The main treatments for myeloma are **anti-cancer drugs** (chemotherapy and nonchemotherapy treatments), which may be followed by **transplants of stem cells**.

Not everyone with myeloma needs treatment right away. Some people have signs of myeloma in their blood but no symptoms.

These people usually have blood tests every three to six months to keep an eye on their condition. But they won't need treatment unless the myeloma cells start to build up and cause symptoms.

Anti-cancer drugs

Chemotherapy drugs are designed to kill off your myeloma cells. They do this by working on cells that are growing rapidly.

This means they kill cancer cells but they also kill some healthy cells that grow quickly, such as those that grow your hair, and cells inside your mouth and gut. So you're likely to get side effects while you're taking chemotherapy drugs.

These side effects may include losing your hair, getting mouth ulcers, and having an upset stomach. After you finish treatment, these problems should go away and your hair should grow back.

Most people with myeloma will have nonchemotherapy treatments along with one chemotherapy drug, although the drugs you are offered will depend on:

- Your general health
- Your age
- What other treatments you are having, and
- How myeloma is affecting your body.

Combinations of different drugs are also used. Some of these drugs are injected directly into your blood. Others are taken as pills.

You're likely to have several "cycles" of treatment, lasting around four to six weeks each. In between, you have time for your body to recover.

Transplants of stem cells

Some people have very high doses of chemotherapy followed by transplants of stem cells. Stem cells are the young cells your body makes, that grow into red blood cells, white blood cells, and platelets. High doses of chemotherapy kill the myeloma cells, but they also kill the stem cells in your blood marrow.

Having a stem cell transplant helps replace these young cells, so your body can make healthy blood cells again.

There are two types of transplant:

- An **autologous** stem cell transplant means the transplant comes from your own stem cells. This is the type of transplant most people with multiple myeloma have.
- An **allogeneic** stem cell transplant means the transplant comes from stem cells donated by someone else, usually from your brother or sister, if they have the same tissue type as you. This is less common.

Transplants are given as infusions into your bloodstream. It's a bit like having a blood transfusion.

If you have a transplant using your own stem cells, you'll have your stem cells collected from your blood before you have anticancer drug treatments. They'll be stored until after your drug treatment and until they are needed .

High-dose chemotherapy and stem cell transplants are only suitable for people in generally good health. Doctors don't usually recommend these treatments for people aged over 70.

Other treatments

You may also need treatments to relieve your symptoms of myeloma. Drugs called **bisphosphonates** are used to treat bone pain and help prevent bone damage. Many of the treatments for myeloma should also help with bone pain. But if you're still in pain, tell your doctor or nurse. They can recommend pain relief, which could be simple acetaminophen. Or they may prescribe stronger pain relief medications if your pain is very bad or if you have nerve pain.All these stronger pain relievers are likely to have side effects. Your doctor or nurse can tell you what to expect and how to manage any side effects or reduce them.

If you have bad bone pain in a particular area you may have **radiation therapy** to target the myeloma cells in that part of your bone marrow.

You may need **blood transfusions**, or you may need to take medication to treat severe anemia..

Things you can do for yourself

There are several things you can do to help yourself keep healthy and get the most out of treatment.

- Drink plenty of water. Having myeloma can increase the amount of calcium in your blood, which can damage your kidneys. If you drink plenty of fluid, your kidneys have a better chance at coping with the extra calcium.
- Tell your doctor quickly if you get any infections. Myeloma means your body finds it harder to fight off infections, so it's important to get them treated quickly. Also, anticancer treatments can make it hard for you to fight infections.

- Make sure you are up to date on your flu and pneumonia vaccinations. This will help protect you against these common infections.
- Talk with your doctor about side effects from treatment. Your doctor may be able to switch you to a different type of treatment or give you other treatments that help reduce the side effects.
- Think about what you most want to get out of your treatment and make sure your doctor knows. Different people have different ideas about how they want to be treated, so it's important that you and your doctor are both aiming for the same results.

  For some people, pain relief and a good quality of life are the most important things. For others, it's about having the treatment that can help them live as long as possible.

What to expect in the future?

It's very hard to say what will happen to any individual with myeloma because it affects people in very different ways.

Some people don't live very long after being diagnosed, while others live for many years. About 60 to 80 in 100 people are still alive five years after their myeloma is found.[4] As with other types of cancer, if your myeloma is found earlier, there is a better chance of your treatment being successful.

Your individual outlook will depend on many things, including how old you are, how generally healthy you are, and how quickly your myeloma cells are growing. It will also depend on which type of treatment is suitable for you.

If your treatment is successful, you may live many years without any signs of myeloma. This is called remission. If you work, you'll be able to return to your job once your blood tests are back to normal.

But you may feel very tired for the first few months. You may need some help to get back to your normal life: for example, a physical therapist can help you strengthen your muscles.

Some people take long-term medicines (called maintenance treatment) to keep their myeloma in remission for as long as possible.

But even after successful treatment, myeloma comes back eventually for most people. When this happens there are a number of further treatments you can try. You can talk to your doctors about what's right for you.

1. National Cancer Institute; Surveillance, Epidemiology, and End Results program (SEER). Cancer stat facts: myeloma. November 2023 [internet publication].

2. Kyle RA. Multiple myeloma: review of 869 cases. Mayo Clin Proc. 1975 Jan;50(1):29-40.

3. Kyle RA, Gertz MA, Witzig TE, et al. Review of 1027 patients with newly diagnosed multiple myeloma. Mayo Clin Proc. 2003 Jan;78(1):21-33.

4. National Cancer Institute; Surveillance, Epidemiology, and End Results program (SEER). SEER*Explorer: an interactive website for SEER cancer statistics. Oct 2023 [internet publication].

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