

Patient information from BMJ

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Multiple myeloma

It can be devastating to be diagnosed with 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 straight 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.

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, but 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 60. 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:

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- Pain in their bones, often felt as backache. About 80 in 100 people with myeloma have bone pain. It's caused by the build-up of myeloma cells. This may also make your bones weak and more likely to break.
- Anaemia. This means you don't have enough red blood cells carrying oxygen around your body. You may feel very tired or look pale.

About 70 in 100 people with myeloma have anaemia. It happens because your bone marrow can't produce enough normal blood cells.

Because you don't have enough healthy white blood cells you may get lots of infections, like urinary tract infections or pneumonia.

Some people with myeloma get too much calcium in their blood (called hypercalcaemia). 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 to find out.

The first test for myeloma is done on your urine and blood. The laboratory is looking for signs of paraprotein. If the test shows paraprotein in your urine or blood, you probably have myeloma.

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

You'll have a series of x-rays of your body to look for damage to your bones. This is called a skeletal survey. You may also have MRI or CT scans if the doctors want to get a clearer look at your bones.

You will also have a sample of your bone marrow taken to check for myeloma cells in your bone marrow. A bone marrow sample is taken using a needle put into your bone (usually your hip bone). You'll have a local anaesthetic 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 and 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 afterwards 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. Doctors 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 newer treatments), which may be followed by **transplants of stem cells**.

Not everyone with myeloma needs treatment straight away. Some people have signs of paraprotein 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 reproduce and cause symptoms.

Anti-cancer drugs

Chemotherapy drugs are designed to kill off your myeloma cells. They do this by targeting cells that are dividing rapidly.

This means they kill cancer cells but also some healthy cells, 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 newer treatments along with one chemotherapy drug, although the drugs will differ depending on

- the state of your 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 given by an IV drip. Others are taken as tablets.

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.

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Transplants of stem cells

Some people have very high doses of chemotherapy followed by transplants of stem cells. High doses of chemotherapy kill the myeloma cells, but they also kill your bone marrow stem cells. These are early stage cells that grow into red blood cells, white blood cells, and platelets.

Having a stem cell transplant replenishes these early stage cells, so you 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 have.
- An **allogeneic** stem cell transplant means the transplant comes from donated stem cells, 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 high-dose chemotherapy. They'll be stored until after your chemotherapy.

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 weakness. If you have bad bone pain in a particular area you may have **radiotherapy** 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 anaemia.

You'll probably need pain relief, which could be simple **paracetamol**. Or your doctor may prescribe stronger pain relief medicines if your pain is very bad or if you have nerve pain.

All these stronger painkillers are likely to have side effects. Your doctor will tell you what to expect and how to manage any side effects or keep them to a minimum.

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.

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- Drink plenty of water. Having myeloma can increase the amount of calcium in your blood, which can damage your kidneys. Kidneys filter fluid in the body. 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, chemotherapy 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 to 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 mask 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 priorities, 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.

- Many of the treatments for myeloma should help with bone pain. But if you're still in pain tell your doctor or nurses. They can give you strong painkillers to reduce your pain.

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 half of people are still alive five years after being diagnosed. As with other types of cancer, earlier diagnosis is linked to better outcomes.

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. 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. Working part time at first may help. You may need some help to get back to your normal life: for example, a physiotherapist 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.

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