

# Treating Myeloma - A Quick Guide



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This is a brief summary of the information on Treating myeloma from our website. You will find more detailed information on the website.

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## The stages of myeloma

The stage of a cancer tells your doctor how far it has grown or spread. This information helps your specialist plan the treatment that is most appropriate for you. Doctors use the International Staging System (ISS) to help them predict how your myeloma might respond to treatment. The Durie Salmon staging system used to be widely used but is now less common.

Doctors look at whether your myeloma is affecting your body tissue and organs and causing symptoms. They then group you as having either no symptoms (asymptomatic myeloma) or myeloma with symptoms (symptomatic myeloma). Myeloma can respond very well to treatment and go into remission. This means that there is no sign of active myeloma in your body. Or the abnormal proteins produced by the myeloma can remain at the same level. This is called stable disease.

## Relapsed multiple myeloma

If the myeloma comes back or the protein levels rise again, it is called relapsed myeloma or recurrent myeloma.

## Statistics and outlook for myeloma

Outlook means your chances of getting better. Your doctor may call this your prognosis. The outcome of treatment for myeloma depends on a number of different factors.

On our website, we present further information about the likely outcome of myeloma. There are no national statistics available for different stages of cancer or treatments that people may have received.



The statistics we present are pulled together from a variety of different sources, including the opinions and experience of the experts that check each section of our patient information. For the more complete picture in your case, you'd have to speak to your own specialist.

**How reliable are cancer statistics?**

No statistics can tell you what will happen to you. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

### Types of treatment for myeloma

The main treatments for myeloma are chemotherapy, steroids and biological therapies. Radiotherapy may also be used for pain control. Bisphosphonates are sometimes used to reduce bone damage.

If you are fit enough, your specialist may suggest intensive treatment with high dose chemotherapy. The aim of treatment is to try to get the myeloma under control (into remission). Remission means that there is no sign of the myeloma in examinations or tests.

**Myeloma without symptoms**

If you don't have symptoms, you may not have treatment straight away. Treatment can cause side effects, so if you are feeling well your doctor may keep treatment in reserve.

**Myeloma with symptoms**

If your myeloma is causing symptoms you are most likely to have chemotherapy treatment. You often have this alongside a

steroid and a biological therapy drug. The drugs you have will depend on how the myeloma is affecting you, your general health, and your level of fitness.

High levels of abnormal protein (immunoglobulin) in your blood can make it too thick. If you have this you may have a treatment called plasmapheresis, which uses a machine to remove the excess protein.

**Treatment of myeloma that has come back**

If your myeloma was in remission for longer than 6 months after initial treatment, you may have treatment with the same combination of drugs again. But if it comes back sooner than that, your doctor may suggest a different type of treatment.

Even if it is not possible to get your myeloma into remission, you can have treatment to help control any symptoms it causes.

### About chemotherapy for myeloma

Chemotherapy uses anti cancer (cytotoxic) drugs to destroy cancer cells. These drugs work by disrupting the growth of cancer cells. The drugs circulate in the bloodstream around the body.

The type of chemotherapy that you have will depend on whether or not your doctor is planning for you to have a stem cell transplant. You can have chemotherapy drugs for myeloma by mouth as tablets (orally), or into your vein (intravenously).

You may also have steroid treatment or biological therapy alongside the chemotherapy.



## Chemotherapy drugs for myeloma

For myeloma, your doctor may treat you with chemotherapy drugs alongside a steroid drug. They may also use a biological therapy as well. The drugs commonly used to treat myeloma include cyclophosphamide, melphalan (Alkeran), doxorubicin (Adriamycin) and idarubicin (Zavedos).

## Side effects of chemotherapy for myeloma

Drugs affect people in different ways. Some people will have very few side effects, others will have more. The common side effects that you are likely to have with chemotherapy for myeloma are

- Tiredness (fatigue)
- Low levels of blood cells
- Feeling and being sick
- Hair loss or hair thinning
- A sore mouth and mouth ulcers
- Diarrhoea or constipation
- Tingling of your hands and feet
- An increased risk of blood clots

## What to ask your doctor about chemotherapy for myeloma

- Why do I need chemotherapy?
- How much treatment will I need?
- What will the side effects be?
- What can I do to help with side effects?
- Who can help me manage side effects?
- Can you prevent any of the side effects?
- Will any of the side effects be permanent?

- How long will the treatment take?
- When will you know if the chemotherapy has worked?
- What will happen if it doesn't work?
- Which chemotherapy drugs are you going to give me?
- Is there written information I can have about these drugs?
- What should I do if I am at home and worried about a side effect?
- What should I do if I get a temperature?
- Will I have to stay in hospital and if so, for how long?
- Can I have any of this treatment as an outpatient?
- Should I have a special diet?
- Can I carry on working?
- Can I travel?
- Should I have the flu jab if I am having chemotherapy?
- Who can I call if I have any questions about my treatment?
- Who can I call if I have any questions about my treatment?

## Steroid treatment for myeloma

Steroids are substances made naturally in the body. They can also be made artificially and used as drugs. Steroids are commonly used with chemotherapy to treat myeloma. Doctors have found that treatment is more successful when steroids and chemotherapy drugs are given in combination.

### Side effects of steroids

You will not be taking the steroids for very long without a break, so you are not likely to have bad side effects from them. But there are quite a few side effects you may notice. These can include increased appetite, increased energy and wakefulness, indigestion and mood swings.



When you have been taking steroids for some time you may notice some swelling in your hands, feet or eyelids. You may also put on weight. Steroids are irritating to the lining of your stomach. You must tell your doctor or specialist nurse if you get stomach pains after taking steroids.

Your doctor or nurse will be looking out for other side effects of your steroids including a raised blood pressure and sugar in your urine.

It is important for any doctor treating you, for any reason, to know that you are taking steroids. Your doctor will give you a card to carry, saying you are taking steroids. They will ask you to carry the card with you at all times.

### Radiotherapy for myeloma

Radiotherapy uses high energy rays to kill cancer cells. The radiation used is similar to that used for X-rays. Myeloma can damage areas of bone and make them weaker or painful. Radiotherapy can strengthen the bone and reduce pain in those areas.

Sometimes radiotherapy is used as part of a stem cell transplant or bone marrow transplant. Doctors call this total body irradiation and it involves giving a high dose of radiotherapy to the whole body as well as high dose chemotherapy. This treatment kills off the bone marrow, including myeloma cells, before you have a drip of stem cells or bone marrow, so that your bone marrow starts to make blood cells again.

You can find more information in the radiotherapy section of our website.

### Biological therapy for myeloma

Biological therapies are treatments that use natural substances from the body, or that change the way that cells signal to each other. Biological therapies stimulate the body to attack cancer cells or control their growth. Some biological therapy drugs can control the growth of myeloma cells. Biological therapies used in myeloma treatment include

- Thalidomide
- Bortezomib (Velcade)
- Lenalidomide (Revlimid)

You may have them alongside other treatments for myeloma, such as chemotherapy or steroids.

### Intensive treatment for myeloma

Some patients with multiple myeloma have high dose chemotherapy. This intensive treatment is used to improve the chance of complete remission. Remission means that there is no sign of active disease in your body. Some trials using high dose chemotherapy have shown good results, with long periods of remission. Your specialist will only offer you intensive treatment if you are fit enough to get through it.

The main reason for having this treatment is that it is likely to give you the longest period of good health, with your myeloma in complete remission. Your specialist may also suggest intensive treatment if your myeloma is causing troublesome symptoms. If you have already had chemotherapy and your myeloma has not responded, high dose treatment is unlikely to help you.



Intensive treatment will kill off all your healthy bone marrow cells as well as the myeloma cells. To replace the bone marrow cells, you can have a drip of one of these

- Stem cells from your own blood (peripheral blood stem cell rescue or autologous stem cell transplant)
- Your own bone marrow (autologous bone marrow transplant)
- Someone else's bone marrow or stem cells (allogeneic transplant)

There is detailed information about bone marrow and stem cell transplants in the cancer treatment section of our website.

### Controlling symptoms of myeloma

If you are having troublesome symptoms from your myeloma, you may have treatment to try to reduce and control them. If you have a low red blood cell level (anaemia) you may have blood transfusions. You will have antibiotics if you get an infection. If you have pain caused by bone damage, you may have painkillers and also drugs called bisphosphonates that strengthen the bones. Radiotherapy can also sometimes help to reduce pain.

If you have numbness in your fingers or toes caused by myeloma treatment, your doctor may prescribe medicines such as low dose anti depressant drugs or low dose anti epileptic drugs.

If you have fractures in the bones of the spine your doctor may refer you for specialist surgical techniques that inject special cement into the spine to strengthen it and reduce pain. The surgical

techniques are called vertebroplasty and balloon kyphoplasty.

Sometimes proteins produced by the myeloma cells can thicken the blood, which can clog up small blood vessels and cause confusion, dizziness or stroke like symptoms. If you have this, you may have a procedure called plasmapheresis which removes the excess protein from the blood. The abnormal protein can cause kidney damage and to prevent this it is important to drink 2 to 3 litres of fluid a day.

#### Palliative care teams

These teams include doctors, nurses and other health professionals who specialise in controlling symptoms of diseases, especially cancer. You may be referred to the palliative care team if you have pain that is proving difficult to control. The team will advise on treatments or drugs that will control your symptoms.

#### Follow up for myeloma

What happens at follow up appointments  
It is likely that the myeloma will become active again at some stage after you have finished treatment. Because of this, you will have regular check ups with your specialist following your treatment. These check ups will usually be every 1 to 3 months and will continue for life. During these visits you will have blood tests and urine tests. If you have any pain in your back or bones you may need X-rays.

At these check ups your doctor will check for any signs that the myeloma is active so that it can be treated. The doctor will also be checking or monitoring any longer term side effects from your treatment,



such as tingling or numbness in your hands and feet (peripheral neuropathy).

Your doctor will ask you how you feel and whether you have had any symptoms or are worried about anything.

If you are worried between appointments  
If you are worried or notice any new symptoms between appointments, you must let your doctor or nurse know as soon as possible. You don't have to wait until your next appointment.

Many people find counselling helpful after cancer treatment. This can be a time when people feel very anxious and low, even though the treatment has finished.

### Myeloma research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know they are safe.

Firstly, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe to test are they tested in people, in clinical trials.

There is research looking into biological therapies (including bortezomib (Velcade), thalidomide, lenalidomide (Revlimid) and vaccines), transplants, treating bone pain and fractures, and targeted radiotherapy.

### What to ask your doctor about treating myeloma

- What treatment would you recommend and why?

- What are the risks and benefits of this treatment?
- Are there any other treatment options?
- How long will I be in hospital for?
- How often will I have to come back to hospital?
- What are the side effects of this treatment?
- How long will they last?
- What are the long term side effects?
- What do you expect the treatment to achieve?
- What is the chance of the myeloma coming back after I have been treated?
- Will I be able to go back to work after this treatment?
- Will I still be able to have children after this treatment?
- Will the treatment cause an early menopause?
- How can you treat an early menopause?
- Can you arrange sperm banking for me before I start my treatment?
- Will I have any hair loss?
- When will my hair grow back?
- Can you arrange a wig for me on the NHS?
- Will I have difficulties with eating and drinking?
- What can help me to eat and drink as well as possible?
- Is there a clinical trial I may be suitable for and will it help me?



## More information

For more information about myeloma, visit our website  
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on 0808 800 4040 9am till 5pm Monday to Friday

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Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in May 2012. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2012. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666).