Multiple Myeloma Patient Guide

What this leaflet is about: what multiple myeloma is, how it causes its symptoms, how it is investigated and staged, and how it is monitored.

> Quick emergency advice
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> Tell your doctor about any new or worsening symptom - bone pain, thirstiness and passing a lot of urine, numbness or tingling, tiredness, repeated infections, or any bleeding. Myeloma causes changes that build up gradually, and reporting them early makes a real difference.
> A fall, or sudden severe back or rib pain, in someone with myeloma needs to be reported the same day, because a fracture may be present. Telephone the clinic on Tel: +60 3 4289 5000 or Tel: +60 3 4270 2500.

What is multiple myeloma?

Multiple myeloma is a cancer of the plasma cells. Plasma cells are a specialised type of white blood cell, and they live in the bone marrow. Their normal job is to make antibodies - the proteins that protect us from infection.

In myeloma, a single group of abnormal plasma cells grows uncontrolled in the marrow. Because these cells all come from one original cell, they all make the same abnormal protein, called a paraprotein or an M protein. This abnormal protein is what shows up in the blood and urine tests.

Myeloma is a gradually accumulating disease. As the abnormal cells increase, they crowd out the normal cells in the marrow, the paraprotein and light chains damage the kidneys, and the myeloma cells and their protein switch on bone breakdown. The result is the characteristic combination of anaemia, bone disease, kidney failure and recurrent infection that you see in the table below.

Signs and symptoms

What is affected	What it causes
Bone marrow and red cells	Anaemia, with tiredness, weakness, lack of energy, breathlessness, palpitations, poor appetite and weight loss, and pallor.
Bones	Weak bones that break easily after only a minor knock; bone pain, especially in the back, ribs and pelvis; a high calcium level, which causes thirst, thirstiness, passing a lot of urine, constipation, confusion, nausea and abdominal discomfort; and a vague abdominal discomfort and constipation from the high calcium.
Kidneys	Kidney failure, which may need dialysis. Also nausea, poor appetite, vague abdominal discomfort, tiredness, and swelling of the ankles.
Nerves	Peripheral neuropathy, meaning numbness, tingling, burning or shooting pain in the hands and feet, and weakness of the muscles, which can cause difficulty walking or holding things. Occasionally pressure on the spinal cord from a collapsed vertebra, which needs urgent attention.
Immune system	A low level of normal antibodies, and suppression of normal immune cells, leading to frequent and sometimes unusual infections - chest infections, urinary infections, shingles and sinus infections.

How myeloma is investigated

A blood and urine work-up, imaging, and a marrow sample together usually give the diagnosis, the stage and the information needed to plan treatment.

- Full blood count, to look for anaemia, a low normal white cell count and a low platelet count.
- Blood chemistry, to check kidney function, calcium, protein and albumin, liver function and uric acid.
- Antibody level, the immunoglobulin levels, which are often disturbed in myeloma.
- Protein studies, to look for the paraprotein or M protein and to measure the free light chains.
- A urine test, using a 24-hour collection where possible, to look for abnormal protein in the urine. This is called Bence Jones protein.
- X-rays, which show lytic lesions - holes in the bone - in the skull, spine, ribs, pelvis and long bones.
- CT scan or MRI, used when nerve compression or a fracture of the spine is suspected, and to see the myeloma cells themselves.
- Occasionally a whole-body PET/CT scan, which can find small areas of disease that other scans miss, particularly in the soft tissues and the bones.
- A bone marrow examination, to confirm the diagnosis, to measure how many abnormal plasma cells there are, and to look at the chromosome and gene changes, which guide both prognosis and treatment choice.

Staging systems

There are two main staging systems, and you will see both mentioned in your reports.

Durie-Salmon staging

The older system. It is based on the level of the paraprotein, the haemoglobin, and whether there is damage to bones or to calcium, and it divides myeloma into stages I, II and III, sometimes with A or B depending on kidney function and calcium. It is still commonly used in clinical trial reporting and is a useful description.

International Staging System (ISS)

The system used more widely now. It is simpler and it uses the two measurements that are known to predict outcome best: the level of beta-2 microglobulin in the blood, which reflects tumour burden and how well the kidneys are working, and the level of albumin in the blood, which reflects how well the person is generally. ISS stage I, II and III correspond to broadly better, intermediate and worse outlook. Newer refinements add the chromosome and gene information from the marrow sample.

Whichever system is used, it is important to remember that staging describes the current extent of the disease, and it is not a prediction of what will happen to one individual. It helps us choose treatment and estimate outlook, and it is reviewed as treatment goes on.

Supportive care

Myeloma itself is treated by the haematology team, but much of everyday myeloma care is about protecting you from the damage the disease does while it is being treated. This is called supportive care, and it is as important as the cancer drug.

- Bone protection: bisphosphonates, and sometimes denosumab, to slow down the breakdown of bone and reduce fractures and high calcium.
- Fracture prevention: a fall is a serious event in myeloma. Good lighting at home, no loose rugs, sensible footwear, and an assessment of your balance and your bones are worthwhile.
- Kidney protection: very good control of blood pressure and diabetes, avoiding dehydration, and avoiding nephrotoxic medicines such as ibuprofen and diclofenac unless we say otherwise.
- Anaemia: iron and other supplements if there is a deficiency, and sometimes a blood transfusion or an erythropoiesis-stimulating medicine.

- Infection prevention: vaccinations against influenza, pneumococcus, varicella-zoster and hepatitis B, prompt treatment of infections, and the neutropenia advice in the leaflets in this series if your white cells are low.
- Pain control, and the treatment of any bone pain, which should never be simply accepted as unavoidable.
- Thrombosis prevention: myeloma raises the risk of blood clots, so thinning medicines are often needed during treatment. This is one reason the treatment plan changes so often.
- Diet, exercise, and a social worker or support group, because myeloma is a long illness and the practical, financial and emotional load is real.

Monitoring your myeloma

Myeloma is one of the few cancers that is often followed with regular blood tests rather than repeated scans, so your treatment decisions are usually made from the paraprotein level, the blood count, the kidney and calcium levels, and how you feel.

- Tell your doctor about any problem, however small it seems. New bone pain, increasing thirst, more urine, numbness, tingling, or an unexplained fever are all worth reporting. Do not wait for your next appointment if something changes in between.
- Remember that a response takes weeks to months to assess. Feeling completely normal again on day 3 is not possible, and feeling a bit flat on day 3 does not mean the treatment has failed. A meaningful judgement takes several cycles.
- Keep to your treatment and your follow-up appointments. The benefits of staying on a working treatment, and the value of an early review when something changes, are both well established, and appointments are often available sooner if you are unwell.
- Bring your results to each appointment, and keep a note of your paraprotein level and your blood counts if you find that reassuring.
- Tell us about every medicine, supplement and herbal product you take. Many interact with myeloma drugs, and some make kidney damage worse.

> Report the same day, without waiting for an appointment: any new or sudden severe back pain, a fall or a suspected fracture, new weakness or numbness in the legs, or difficulty passing urine. These can mean a collapsed vertebra or pressure on the spinal cord, and they need to be seen the same day. Telephone the clinic on Tel: +60 3 4289 5000 or Tel: +60 3 4270 2500, or go to the emergency department.

When to contact us

If you are worried about yourself, or about the person you are caring for, please get in touch. We would always much rather hear from you early than late. If you have read something in this leaflet that worries you, that is a good reason to telephone us, even if you feel well.

Visit us
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If you cannot reach us, or you are very unwell

Please go to the emergency department of KPJ Ampang Puteri Specialist Hospital, or call the emergency ambulance service. Do not wait for a routine appointment, and do not wait for a reply to an email.

Important medical disclaimer

This leaflet is written for patients and their families and carers. It is general patient education only. It is not a substitute for medical advice, and it is not a substitute for the diagnosis and treatment that your own haematologist, nurse, pharmacist or doctor will give you.

Nothing in this leaflet should be used to change, stop or start a medicine, a test or a treatment. If anything you read here is different from what your healthcare team has told you, follow your healthcare team and ask us about the difference.

Information about medicines names, strengths, test turnaround times and supportive care is current at the time this leaflet was prepared. It may be updated from time to time, and the version printed here may therefore not be the newest one. Please ask reception for the current copy.

If you think that you or someone you care for is seriously unwell, do not wait for an appointment and do not wait for this leaflet to be read. Contact the clinic, or go to the emergency department of KPJ Ampang Puteri Specialist Hospital, straight away.

We Listen. We Care. Evidence-based Medicine.

Dr K Y Goh Haematology & Internal Medicine Clinic | KPJ Ampang Puteri Specialist Hospital | Tel: +60 3 4289 5000

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