Living with MULTIPLE MYELOMA
Multiple Myeloma Ireland is the only charity organisation focused on Multiple Myeloma in Ireland. MMI received charity status in July 2013. Our charity no is CHY20751.

Multiple Myeloma Ireland aims and objectives include:

**Providing information and support for multiple myeloma patients, families and carers**

**To provide a network of communication for multiple myeloma patients, families and carers**

**To promote and facilitate ongoing education and research in multiple myeloma in Ireland**

**To raise public awareness of multiple myeloma**

The MMI board consists of healthcare professionals, patients and carers. The general responsibilities of the board are to ensure that the charity organisation is meeting its objectives and working within our constitution. All board members are voluntary.
Multiple myeloma is a blood cancer of plasma cells. These are white blood cells that produce antibodies, which fight infection. Unlike other cancers it does not exist as a lump or a tumour.

When a plasma cell becomes malignant, it often continues to produce an antibody in excessive amounts. This antibody can be measured as a ‘paraprotein’ in the blood /urine and is a useful indicator of the amount of disease within the body.

Multiple myeloma can occur in multiple sites in the body, hence the name. Most of the medical problems related to myeloma are caused by the build-up of the abnormal plasma cells in the bone marrow or the presence of monoclonal paraprotein in the blood and/or urine.

Myeloma is a relapsing-remitting cancer. This means there are periods when the myeloma is causing symptoms and/or complications and needs to be treated, followed by periods of remission or plateau where the myeloma does not cause symptoms and does not require treatment. For patients not in remission, maintenance treatment may be required.

On average 270 people are diagnosed with multiple myeloma each year in Ireland (National Cancer Registry, 2017). It is more common in men than women and the incidence increases with age, with the majority of patients aged over 65.

While not considered a curable disease, myeloma is very treatable. Many people live with the condition for many years and have a good overall quality of life.
Diagnosis

Diagnosis of multiple myeloma can often be delayed, due to the vague and non-specific nature of the associated symptoms.

If multiple myeloma is suspected a number of investigations need to be carried out including:

• Patient history and physical examination
• Blood tests including full blood count, kidney function tests, immunoglobulins, beta2 microglobulin (protein on the surface of plasma cell), serum free light chain assay
• Bone marrow aspirate, biopsy and cytogenetics (samples from bone marrow examined in the laboratory for cell activity and cell chromosomes)
• X-rays and scans of bone
• Urine sample testing for the presence of abnormal proteins

The most common symptoms and complications usually involve the bone, blood and kidneys (Figure 1).

Not everyone will experience all or any of these. Some may be related to the disease itself, or the course of treatment. Supportive treatments are commonly used alongside and after anti-myeloma treatment to relieve, stabilise and in some cases, help prevent these symptoms and complications.
Care

Who is involved in patient care?

The multidisciplinary team includes:

• GP
• Specialist haematology doctors
• Specialist nurses

Depending on patients’ symptoms and complications, other specialists are involved including:

• Specialist renal doctors (if kidney complications occur)
• Specialist orthopaedic doctors (if bone damage occurs)
• Dietician
• Social worker
• Psychologist
• Counsellor
• Physiotherapist
• Palliative care (to help control symptoms e.g. pain)
• Dentist (good oral care is required when receiving bone strengthening drugs)
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Treatment

Treatment aims in multiple myeloma are to:

• Control the disease, aiming for remission
• Improve survival
• Manage symptoms
• Improve quality of life

Treatment choices are based on each individual patient’s disease, performance status, suitability, international guidelines, and drug licensing.

Newer drugs introduced in the past 25 years have resulted in increased 5-year relative survival rates, which is the percentage of people with cancer who will be alive 5 years after diagnosis. These include:

• Immunomodulatory drugs e.g., thalidomide, lenalidomide, pomalidomide
• Proteasome inhibitors e.g., bortezomib and carfilzomib

Myeloma treatment is almost always with a combination of drugs over periods of time known as cycles. Cycles may last from weeks to months. The number of cycles a patient receives varies, as does the length of each cycle. Your doctor/nurse will explain how your treatment cycle is given.

Treatment combinations are usually made up of two or three different types of drugs which work well together and can include chemotherapy drugs (e.g. cyclophosphamide and melphalan), steroids (e.g. dexamethasone and prednisolone) and/or an immunomodulatory drug/proteasome inhibitor.

Depending on the treatment combination you may require prophylactic medications to prevent complications of multiple myeloma or side effects of treatment. Your haematology doctor and your specialist nurses will explain these in detail.

Haematopoietic stem cell transplantation is another treatment option for some multiple myeloma patients. This is known as an autologous stem cell transplant (ASCT) as the patient’s own stem cells are collected, chemotherapy administered, and the stem cells then returned. Suitability will depend on how physically well and active a patient is, their age, and other medical conditions.

A number of novel treatments are being investigated in clinical trials, which Irish patients may have the opportunity to participate in. Patients should speak to their haematology team about their suitability.

Other treatments offered may include:

• Bisphosphonates to help minimise myeloma bone disease, as well as hypercalcaemia (above average calcium levels in blood) and bone pain, and improve survival
• Painkillers
• Radiotherapy for areas of localised bone disease and pain
• Blood transfusions and/or erythropoietin (EPO) for anaemia

Some of these drugs may result in side effects, which your doctor/nurse will outline for you before you commence treatment. It is important to be vigilant for any of these specified adverse effects.

How long myeloma patients should remain on treatment is uncertain, and decisions are reached based on evidence-based guidelines and each patient’s needs, such as their response and tolerance to treatments.
Health and wellbeing

- Patients should drink 2-3 litres of fluids daily to prevent kidney damage.
- Gentle physical activity is important but patients should avoid lifting heavy items or doing demanding physical exercise, especially if bone disease is present in the spine. Discuss the appropriate level of exercise for you with the multidisciplinary team.
- Patients should have vaccinations (e.g. seasonal influenza) as indicated by their GP or haematology specialist.
- Patients should be aware of susceptibility to infection and minimise contact with others with infection, avoid raw/uncooked meats, etc.
- Patients should be vigilant as to any symptoms of excessive tiredness, dehydration, infection (such as fever), or feeling unwell. If any of these are experienced patients should contact their GP/haematology team/emergency department.

Where can patients and families find support?

A diagnosis of multiple myeloma can have a huge impact on patients and their loved ones. The time around diagnosis is particularly difficult and psychological and emotional support is vital during this period. Your nurse will arrange referral to appropriate services as appropriate e.g. counselling, psychologist etc.

Patients can feel particularly isolated due to the “unknown” nature of the illness – many people will have never heard of myeloma or will confuse it with melanoma (skin cancer). Support groups can be helpful for both patients and families – there are ongoing support groups in Tullamore, Dublin, Limerick, Sligo (see the Multiple Myeloma Ireland website for further details).

Resources:
- Multiple Myeloma Ireland website – multiplemyelomaireland.org
- Irish Cancer Society – cancer.ie
- MyelomaUK – myeloma.org.uk
- International Myeloma Foundation – myeloma.org

For information on clinical trials see:
- Cancer Trials Ireland – cancertrials.ie
- Blood Cancer Network Ireland – bloodcancers.ie
How did I get multiple myeloma?
There is no known cause for multiple myeloma. There are a number of factors associated with an increased risk of developing the disease such as increasing age, African origin, family history and male gender. Other factors associated with increased risk for cancer include obesity, exposure to chemicals, exposure to viral infections, autoimmune disorders and previous radiotherapy treatment.

How is multiple myeloma staged?
It is important for your haematology team to stage your disease i.e. determine the extent and severity of your myeloma so they can plan your individual treatment. Staging is based on the extent of disease and evaluated using your results on bloods, bone marrow and radiology imaging.

Has my multiple myeloma spread to other parts of my body?
Multiple Myeloma is unlike other cancers and does not spread like other cancers. Multiple myeloma typically involves multiple sites within the bone marrow and can affect the bones, kidney and immune system.

Is multiple myeloma curable?
While not considered a curable disease, multiple myeloma is highly treatable. Many people live with the condition for many years and have a good overall quality of life.

Is multiple myeloma genetic?
Multiple myeloma isn’t hereditary, but there is a genetic component; if your parent, sibling or child is diagnosed with multiple myeloma, you are between two and six times more likely to develop it. Even with risk factors, the overall risk is very low.

How do I enroll in a clinical trial for a new treatment?
Speak to your haematology specialist who will know if you are suitable for a particular trial.

How will I know if my disease is relapsing?
When multiple myeloma disease becomes active again (relapse) patients may experience symptoms similar to diagnosis or new or worsening symptoms. Your haematology team will check during each visit for any signs or symptoms of relapse by monitoring your symptoms and your bloods.
Who should I contact if I feel unwell/have concerns?

The multidisciplinary team should be contacted for multiple myeloma or treatment-specific concerns. For general health queries, consult your GP as normal.

Should I get a second opinion?

It is important you are happy with your diagnosis, treatment plan and your haematology team. If you wish to seek a second opinion you are free to do so. Don’t be afraid to ask your haematology team about this and request details of other haematology specialists with an interest in multiple myeloma. Your team can also help provide a summary of your myeloma and treatment so far. This will not affect your care.

Can I travel?

Yes you can travel but you will need to discuss with your haematology team if there is any specific advice for you. It is important to ensure you have adequate travel insurance. It’s also important to ensure you have adequate supply of your medications for longer than the duration of your holidays. Your haematology team will advise you of any special precautions you need to take. Liaise with them regarding the timing of your holidays and your treatment plan.

How often do I need to be seen by the haematology team?

This will vary depending on your treatment. Usually patients on treatment are seen at the start of each treatment by the team. If you have symptoms or side effects from treatment or the disease itself you may require more regular review. For patients off treatment the majority are seen every month, but this may be extended to three months if you are in long-term remission.

‘While not considered a curable disease, multiple myeloma is highly treatable. Many people live with the condition for many years and have a good overall quality of life.’
JOE O’BRIEN

I always ran as I used to be an athlete, and as I reached 50 I was still running nine or 10 miles, two to three times a week. Yet suddenly I couldn’t shake off the stiffness. It kept creeping in the whole time. Soon I was crippled with pain. The night doctor had to come visit me a few times, and on one occasion I was given morphine I was in so much pain – my muscles went into spasm and would keep me awake all night with the pain. A bone marrow biopsy helped diagnose multiple myeloma in 2011. I was on chemotherapy for 16 weeks and then had a stem cell transplant. I had a relapse in 2016 but I am responding well to a different drug regimen.

I now do gentler forms of exercise, such as walking and cycling, and I took up Pilates to help with my posture. I regularly attend the support group in Tullamore, which is absolutely brilliant. I now discuss everything in my support group in terms of side effects, etc. And it is fabulous, as you can really talk about things like that with people who know what you are going through. Previously, the only person you might open up to was your medical practitioner.

ANGELA FORDE

I was diagnosed with multiple myeloma in February 2011, began treatment shortly afterwards and had a stem cell transplant in September of that year. I was in remission and symptom-free for over four years until I relapsed in 2015. I am now making good progress on the current drugs. It is now almost seven years since I was first diagnosed and for me my journey has been about learning to live with myeloma.

Fortunately I am still able to attend most of the support group meetings in Tullamore. For me, it is truly a support; support from our shared experiences, from information given by experts, from the friendships formed and the goodwill of other members. I enjoy the social outings and I welcome a space where the mention of the word cancer doesn’t mean the end of the conversation! Another source of information and practical tips has often been from other patients, in the waiting room or in the treatment room.
PATIENT STORIES | Living with Multiple Myeloma

BOB MCCONNELL

I was diagnosed in 2012. There was a certain amount of disbelief in my case, as I didn’t feel particularly bad. I had some pain in my shoulder and some back pain but I could live with it. Blood, urine, and bone marrow tests proved inconclusive. It took about six months altogether. I underwent aggressive treatment, including a stem cell transplant, followed with triplet and later doublet therapy. I am doing well but I have had bone problems, including with my jaw, and I have severe neuropathy in his feet, which I am on medication for.

It affects everyone differently. Some people manage it better than others, my body seems to fight the treatments but everyone is different. I am really grateful that all the new drugs and research and technology is available. Before it was thought of as a disease with limited treatment options or with a poor outcome. The longer I live I feel there is even more chance that newer and better treatments will be developed. I would tell anyone who has been recently diagnosed to be positive. Don’t fall into a black hole of despair.

ANN MCCONNELL – THE CARER’S PERSPECTIVE

I took a career break to spend time with Bob during his treatment. When Bob was diagnosed, I had a choice: do I spend whatever time Bob has left with him, so he has a better quality of life, and so do I too, as I have a better quality of life when he is in my life, or do I spend time at a job? I chose my husband. We are in a fortunate position that we could afford for me to step back from my job, other people aren’t in that position. We do everything together. For me, one of the most difficult aspects was having to ask people for help. When you’re not used to having to ask people for help, it is hard, people have their own lives. I realised I had to get my confidence back and start driving. I bought a small Fiat Panda and now I feel very independent. I can bring Bob to his hospital appointments and bring him home again.

Bob’s myeloma has become a way of life now. My husband has a very good mental attitude but both of us are very much on our guard against depression, because if it creeps in, it saps all your energy and you are not able to get on with life. I keep an eye on myself. There are mornings I wake up and I can feel it creeping in, so I am very mindful of it. As a carer it is important to step back sometimes. You have to have a little something for yourself. I try to go away with my sisters around Christmas, and it’s so important to have something that you look forward to.