

Living Well with Myeloma



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This guide is written for people who have been diagnosed with myeloma. It will also be helpful for their families, friends and health professionals. It provides information about how to live well with myeloma by explaining how to cope with the physical symptoms and side effects and practical implications of living with the disease. Being informed is a key step in learning to manage and cope. Sign posts to other useful resources and organisations are included throughout the book.

Myeloma Australia is a national nonprofit organisation dedicated to providing information and support for those affected by myeloma. Founded in Victoria in 1998 by three families living with myeloma, the organisation has grown to become a significant provider of services and support for the myeloma community.

Myeloma Australia:

- provides information and support to people living with myeloma, their family, friends and health professionals through its specialist myeloma support nurse led programs
- raises awareness of myeloma
- provides funding for research projects
- advocates to state and federal government for support regarding access to new therapies

To talk to someone about any aspect of myeloma, its treatment and management, call the Myeloma Australia toll-free Support Line on 1800 MYELOMA (1800 693 566). The Support Line is available 9am to 5pm (AEST) Monday to Friday and an experienced Myeloma Support Nurse will answer the call in confidence.



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Disclaimer

This guide is written to reflect the Australian health care system. While the advice and information in this guide is believed to be true and accurate at the time of publication, neither the authors, neither reviewers, nor the publishers accept any legal responsibility for the content. It is strongly recommended that advice is sort directly from medical professionals for the correct response for individual circumstances.



Introduction

Myeloma, also known as multiple myeloma, is a type of bone marrow cancer arising from plasma cells, which are normally found in the bone marrow. Plasma cells form part of our immune system.

Normal plasma cells produce antibodies (also called immunoglobulins) to help fight infection. In myeloma, the abnormal plasma cells release only one type of antibody known as the monoclonal (M) protein or paraprotein, which has no useful function. It is often through the measurement of this paraprotein in the blood, that myeloma is diagnosed and monitored.

Treatments for myeloma can be very effective at halting its progress, controlling the symptoms, and improving quality of life, but they are not able to cure it. Even after successful treatment, regular monitoring is needed for when the myeloma returns (relapse). If the myeloma is under control, people usually return to a good state of health which can last from months to years.

The outlook for myeloma is improving with many new developments in its treatment and management. These have had a significant positive impact on survival rates. Research is ongoing to develop new treatments and to use existing treatments in a better, more effective way.

Read more about myeloma and its treatments in our book *Myeloma a Comprehensive Guide*

People are living longer with myeloma and enduring more cumulative treatment than before. This means that side effects or toxicities are acquired that can impact negatively on QOL. There are a range of supportive care options to help prevent or moderate these effects. This guide gives information about the range of commonly used treatments to support anti-myeloma therapy.

This guide aims to provide most of the general information needed to live well with myeloma. There are notes within the guide to further reading and information resources available from Myeloma Australia and other organisations, for those interested in learning more.

**For access to other resources from Myeloma Australia go to
www.myeloma.org.au or call our toll-free Support Line to speak to an
experienced Myeloma Support Nurse – **1800 MYELOMA (693 566)**
Monday to Friday 9am – 5pm AEST**



Bone Health

What is myeloma bone disease?

Healthy human bones are maintained by a fine balance between bone breakdown (by osteoclast cells) and bone formation for repair (by osteoblast cells).

In myeloma, the balance is disrupted, bone breakdown increases, and bone repair slows. This leads to weak spots that easily break (fracture) or holes (lytic lesions) in the bones. If bone thinning occurs in the spine, a crush fracture may occur.

The imbalance of bone breakdown and formation can also cause calcium to be released into the blood. If this happens too quickly, a condition called ‘hypercalcaemia’ can occur.

Myeloma bone disease (MBD) affects over 80% of people living with myeloma and is common at diagnosis.

The bones most commonly affected are those in the spine, pelvis, ribs and skull. The upper ends of the long bones of the arms and legs can also be affected. The bones in the hands and feet are usually not affected.

How is myeloma bone disease diagnosed and monitored?

There are numerous radiological scans used to investigate and monitor myeloma bone disease. The type of scanning technique used will be determined by the location and type of symptom present.

Skeletal survey is a quick and commonly used technique involving a series of x-rays of the skull, spine, ribs, pelvis and long bones of the arms and legs to detect any lytic lesions or osteoporosis. If pain is reported but no fractures or lesions are detected on x-rays a more sensitive scan may be required.

Computerised Tomography (CT) provides a three-dimensional picture to evaluate the soft tissue as well as the bones. It is used to detect small areas of

bone damage or soft tissue involvement. Especially useful for detailed evaluation of small areas of possible bone damage or nerve pressure. Also called CAT (Computed Axial Tomography) scan.

Magnetic Resonance Imaging (MRI) a more sensitive scan that provides a detailed view of bone and soft tissue such as spine and / or brain. Can reveal the presence and distribution of disease in the bone marrow when X-rays show no bone damage. Can also reveal disease outside of bone, which may be pressing on nerves and/ or spinal cord

Fluro-deoxyglucose Positron Emission Tomography (FDG/PET) and sestimibi scans are less commonly used. FDG/PET scanning involves injecting a radioactive drug that highlights areas of rapid cell growth as ‘hot spots’ such as tumours. A sestimibi uses an injected radiolabelled isotope that may detect myeloma deposits not picked up on other scans. It may also be necessary to have a bone density test if osteoporosis is detected. These scans are useful when a whole body picture is required.

Availability of these scans are limited in some centres and as of now some of these are not Medicare reimbursed; however lack of these scans do not usually stop the myeloma from being managed.

Blood tests to monitor calcium levels can also give an indication of abnormal bone destruction.

Those with non-secretory myeloma, where there is no detectable paraprotein in the blood or urine, may rely on imaging alone to monitor the progress of their myeloma.

The treating team will recommend which type of scan is best for each circumstance. Investigations are carried out at the time of diagnosis and may be repeated after treatment, at follow up or when there is a new or increasing area of pain.

What are Bisphosphonates?

Bisphosphonates are a group of drugs used to treat and prevent myeloma bone disease. They work by restoring the balance of bone breakdown and formation that is upset by the myeloma cells allowing the opportunity for bone healing to occur.

Bisphosphonates have several beneficial effects, including:

- Preventing further bone damage
- Reducing bone pain and the need for pain killers
- Correcting and preventing hypercalcaemia (higher than normal levels of calcium in the blood)
- Reducing pathological fractures due to myeloma
- Improving the chance of healing and recovery of strength of the bone
- Possible overall benefit to disease control

Who benefits from bisphosphonates?

Bisphosphonates are recommended for anyone undergoing treatment for their myeloma. Unless there is a medical contraindication such as kidney damage.

It is not currently recommended for people with asymptomatic (smouldering) myeloma or a solitary plasmacytoma to have bisphosphonates.

Are there different types of bisphosphonates?

Several bisphosphonates are available to treat myeloma bone disease, they are tabled below.

Type	Other Names	Mode of Administration
Zoledronic Acid	Zometa	IV infusion over at least 15 minutes
Pamidronate	Aredia, APD	IV infusion over 90-120 minutes
Sodium Clodronate	Bonefos	Oral tablets

The treating team will make a decision about the preferred type of bisphosphonate and **how often** it should be given. After some time, they may adjust the treatment schedule or stop bisphosphonates all together depending on a person's risk of myeloma bone disease and their overall health.

What are the possible side effects of bisphosphonates?

Bisphosphonates are generally well tolerated and most people only encounter mild side effects such as:

- Fever and flu-like symptoms can occur shortly after the intravenous infusion. They are typically mild and last only for a few hours, paracetamol can be taken to prevent or treat this.

- Vein irritation may occur at the site of the infusion. It is usually mild and patients recover within one to two days.
- General bone aches and pains sometimes occur and are mostly linked to the onset of fever and / or flu-like symptoms. They can persist for a day or two after each infusion and can be managed with simple analgesics (pain relieving medication) such as paracetamol.
- Nausea that is mild and short lasting is quite common with oral bisphosphonates.

More serious side effects are not as common and include:

- Lowered levels of electrolytes in the blood, these are checked regularly by the medical team and they may prescribe supplements if they are very low.
- Damage to kidneys is more common if kidneys are also affected by the myeloma or other conditions. Kidney function is tested before each dose and the dose can be adjusted. Keeping a good fluid intake is important, drinking at least 2 litres of water a day and avoiding medications that can affect the kidney such as non-steroidal anti-inflammatory drugs, (e.g. ibuprofen). Ask the treating team if unsure which medications are safe.
- Osteonecrosis of the Jaw (ONJ) is a persistent, non healing wound in the mouth and occurs most commonly after invasive dental work (e.g. tooth extraction). It causes pain, can become infected and results in bone tissue death. While very rare, ONJ is a complication that can be quite serious if left too long without attention.

How to help avoid Osteonecrosis of the jaw (ONJ)

A full dental examination should be carried out before starting bisphosphonate therapy and any invasive procedures taken care of and allowed to fully heal. It is important to always discuss with your myeloma doctor, if significant dental work is being planned. If a person needs dental work after bisphosphonate therapy has commenced, it should be stopped for 2-3 months prior and withheld until complete healing has occurred. Good oral hygiene and regular dental reviews are essential and the best way to avoid problems.

What other measures help bone health?

Staying active within personal limitations is important. Regular exercise helps strengthen muscles and bones, reducing the risk of bone thinning (osteoporosis) that can worsen the effects of myeloma bone disease. Maintain **a healthy balanced diet**, including three serves of calcium per day, with adequate fluid intake. In some cases, it may be necessary to take a calcium and **vitamin D** supplement to help improve bone health. **Ask the doctor if these supplements are necessary.**

Denosumab

Denosumab is a type of monoclonal antibody treatment that can also improve bone strength. It works by turning off a protein that is overactive in people with myeloma causing bone to break down faster than it can be repaired thus restoring the healthy balance of bone formation.

It is given as a sub-cutaneous injection (into the skin) once per month and is safe for people with kidney impairment.

Denosumab is commonly used in the treatment of osteoporosis and in people with bone metastasis in other cancers. Whilst not reimbursed by the Pharmaceutical Benefit Scheme currently, Denosumab has shown positive effects in some people with myeloma and will likely be more easily available soon. Some people may be able to currently access denosumab under special circumstances as directed by their doctor.

Bone disease is very common in people with myeloma. When untreated it can cause significant pain, lead to kidney problems and negatively impact quality of life. Carefully monitored bisphosphonate therapy alongside treatments for myeloma, is a safe way of managing myeloma bone damage.



Building a Team

Living well with myeloma is not easy in isolation. Building a support network of people that extends beyond the doctor can make life much easier. Members of an effective support network might include:

- The haematologist (or oncologist in some cases)
- The General Practitioner (GP) a good relationship with a regular GP is vital when living well with myeloma
- Close family or friends
- Local or hospital pharmacist
- Specialist nurse at the hospital (if available) e.g. Clinical Nurse Consultant/Coordinator or Nurse Practitioner
- Hospital day unit nurses
- Appropriate allied health professionals with an understanding of myeloma e.g. exercise physiologist or physiotherapist, podiatrist, psychologist or counsellor, dietician, social worker

In some cases, the above allied health professionals can be accessed via the hospital. Ask the treating team how to be referred to their services. If accessing allied health in the community, ask the GP about the Medicare funded Chronic Disease Management Plan as outlined below.

Chronic Disease Management through Medicare Australia

This initiative through Medicare enables General Practitioners (GPs) to plan and coordinate the health care of patients with chronic conditions (such as cancer) who require multidisciplinary, team-based care from a GP and allied health providers.

The GP can implement a GP Management Plan and Team Care Arrangements which allow access up to 5 allied health visits per calendar year for free or at a reduced rate.

The 5 visits can be used with one allied health provider or shared across different providers depending on individual needs.

The GP must refer to this program and allied health providers need to meet specific eligibility criteria and be registered with Medicare Australia.

Allied Health providers covered under the initiative include:

- Aboriginal Health Worker
- Aboriginal and Torres Strait Islander Health Practitioners
- Audiologist
- Chiropractor
- Diabetes Educator
- Dietician
- Exercise Physiologist
- Mental Health Worker
- Occupational Therapist
- Osteopath
- Physiotherapist
- Podiatrist
- Psychologist
- Speech Pathologist

If interested in a Chronic Disease Management plan, first speak with the GP.

More information and the referral forms can be found at:

www.health.gov.au – search for ‘Chronic Disease Management Plan’



Complementary Medicines

Complementary medicines are those used in addition to the prescribed treatment for myeloma. This is different to alternative medicines which are used instead of conventional myeloma treatment. For the purpose of the following information, complementary medicines will be the focus.

Many people look to complementary medicines to support them through their time on and off treatment for myeloma. They may be looking to control a side effect, gain better overall health or they may be hopeful that there will be some anti-myeloma effects.

The most important message here is that although some of these medicines are derived from natural substances, they may still have harmful effects on the body. In many cases they can also interact with other medicines causing more side effects or preventing the treatment from having its full effect.

It may be perfectly safe to take a complementary medicine but it is important to be honest with the treating team so they can make sure there are no risks involved. The hospital pharmacist can perform a cross check with the proposed complementary medicine and each conventional prescribed medication to ensure there is no potential for harmful interactions.

Here we will outline some of the complementary medicines that are more commonly requested by the myeloma community.

Plant based therapies

Curcumin

Curcumin is the active ingredient in turmeric, a plant-based spice commonly used in cooking. It has also been used for centuries as a traditional Indian medicine for its natural antioxidant, anti-inflammatory, antiseptic and analgesic properties. There is also some evidence to suggest that it may have an effect on cancer cells, including myeloma cells.

In laboratory tests, curcumin has been able to interrupt some processes known to help myeloma cells survive and increase the effects of some drugs used to treat myeloma. There has yet to be a clinical trial conducted that has proven these effects also applies when tested in humans. In fact, one clinical trial that investigated curcumin in people with myeloma noted the same interruption of the myeloma cell's survival but this did not have an effect on disease reduction.

Another study looked at whether curcumin could prevent the progression of Monoclonal Gammopathy of Undetermined Significance (MGUS) and smouldering (asymptomatic) myeloma to symptomatic myeloma. This study noticed small reductions in myeloma cell activity but not substantial enough to make any definitive claims.

Currently the evidence isn't robust enough to make any certain claims about the utility of curcumin in the treatment of myeloma. More research is required in this area.

If considering taking curcumin, always consult the doctor first and be mindful of the following;

- Curcumin can interact with many other medications, particularly cyclophosphamide which is a commonly used chemotherapy in myeloma. Ask the hospital pharmacy to cross check with each prescribed medication before use.
- Caution needs to be taken in those with bile duct obstruction, gallstones, kidney stones and gastrointestinal disorders such as gastric ulcers.
- Curcumin can cause an allergic reaction such as hives.

Medicinal Cannabis

Medicinal cannabis, also known as medicinal marijuana is often considered by people who find conventional treatments to combat the effects of cancer related pain, nausea, vomiting and weight loss insufficient or intolerable. Marijuana, the drug derived from the cannabis plant, is currently illegal in Australia but medicinal cannabis can be accessed in certain circumstances for medical reasons but only by registered practitioners and not currently in all parts of Australia.

There has been very little research into the use of medicinal cannabis in myeloma and it is a long way from it being recommended for use in the clinic. In fact, in most studies in other types of cancer, they found conventional treatments to be more effective.

Side effects

The extent and type of side effects will vary between each preparation of medicinal cannabis but can include:

- Fatigue and sedation
- Vertigo
- Nausea and vomiting
- Fever
- Appetite changes
- Dry mouth
- Diarrhoea
- Convulsions
- Altered moods
- Confusion
- Hallucinations or paranoia
- Psychosis or untrue thoughts

Medicinal cannabis can interact with other medications, particularly causing drowsiness. It is not recommended to drive or operate heavy machinery when taking medicinal cannabis.

More research is required to learn more about the potential benefits and risks of medicinal cannabis. More information can be found on the Therapeutic Goods Administration (TGA) website www.tga.gov.au

Complementary medicines that interact with chemotherapy

As previously mentioned, sometimes seemingly harmless natural substances can have detrimental effects on treatment for myeloma.

In particular, we know that green tea and high doses of vitamin C decrease the effect of bortezomib (Velcade®). Seville oranges (often used in marmalade) and grapefruit juice inhibit the action of venetoclax (Venclexta®).

The Memorial Sloan Kettering Cancer Centre (MSKCC) in New York, USA has compiled a database of commonly used herbs and dietary supplements, About Herbs. This resource outlines each product's traditional and proven uses, potential benefits, possible adverse effects and most importantly interactions with other herbs or medicines.

Access the **About Herbs** database as an app in the app store
or via the **MSKCC website www.mskcc.org**

Other forms of complementary therapy

There are many forms of complementary therapies that are not medicines but can enhance overall wellbeing in people with myeloma. These include: reiki, acupuncture, reflexology, aromatherapy, relaxation, meditation, art therapy, music therapy, yoga, massage and tai chi.

Always inform the treating team of any new therapy being considered as some physical activities are not recommended at certain times and in certain circumstances.

More information can be found about these
complementary therapies in the **Pain** section of this book

There will be some circumstances where it is perfectly safe to take a complementary medicine. To make sure it is safe,

- Always check with the treating team
- Be aware of where the substance is manufactured and make sure they have effective quality control systems
- Take as directed like any other medication. Correct dosing remains important in this setting too
- Weigh up whether the cost of the medicine is worth the benefit gained



Emotional Health

A diagnosis of myeloma almost always comes as a complete shock. It is very rare that someone has even heard of myeloma before they are diagnosed. These feelings are then further compounded when the information is relayed that there is no cure. The treatments for myeloma and survival rates have improved out of sight in recent years but having to comprehend living with such a disease for the rest of life can be very difficult.

Everyone has their own way to process such information and will do so in their own time. It is important to acknowledge when life seems overwhelming and seek appropriate supports. It is quite common for people with myeloma to experience depression and or anxiety at some point. Support can come in many forms such as, an understanding partner, family member or friend or from a professional such a psychologist, psychiatrist or counsellor. It might even be necessary to take medication to help stabilise thoughts and emotions for a period of time.

It is a good idea to also seek peer support throughout life with myeloma. Myeloma Australia facilitates Information and Support Groups across Australia so that like-minded people can share experiences and feel connected to people in similar situations.

Professional emotional support can be accessed through the hospital or with a mental health plan from the GP.

Find the closest Information and Support Group
via our website www.myeloma.org.au or call our

toll-free Support Line – 1800 MYELOMA (693 566)

Monday – Friday 9am – 5pm AEST

There is also a Telephone Support Group available co-facilitated
by Cancer Council NSW and Myeloma Australia

– for more information call 1300 755 632

Coping while myeloma is stable

It is often assumed that during the periods of time when myeloma is stable that life will be worry free. In many cases there is still a level of stress associated with the unknown time until myeloma returns. Many people report coping reasonably well during periods of disease stability until they have their disease monitoring blood test taken and need to wait a week to see the doctor for the results.

Some people also express feelings of unrest on days when they may not have necessarily achieved anything due to a new awareness of mortality or uncertainty about how much life is left and feeling as though they have ‘wasted a day’.

It is important not to bottle up these emotions. They are rational feelings and fears that may never go away but sometimes just sharing them is enough to provide some relief.

Some people, especially long-term survivors of myeloma, might have achieved an excellent response to treatment and their myeloma is under control but over time side effects have accumulated. These side-effects can be just as life-limiting as the myeloma itself and sometimes people struggle with being grateful that their treatment had a lasting effect and resentful that they have not returned to their pre-diagnosis level of function.

There is often a need to become accustomed to a ‘new normal’. Again, Myeloma Australia’s Information and Support Groups, family, friends and health professionals can all be utilised to help come to terms with the ‘new normal’.

Coping when myeloma returns

After going through the initial shock of diagnosis, then treatment and a period of stability for most people at some point the myeloma will return or relapse. It is quite common for people to have a more heightened reaction at this point than at diagnosis. This could be due to myeloma and all it encompasses being unknown in the beginning and having some prior experience with treatments and hospital appointments at relapse.

Depending on how long it's been since the first line of treatment, a lot may have changed in the way myeloma is monitored and treated meaning the education and coping process may need to start all over again.

If one on one peer support is more appealing there are two options:

Cancer Council's Cancer Connect Program
call 13 11 20 or www.cancercouncil.com.au

The Leukaemia Foundation's Blood Buddies Program
call 1800 007 343 or www.leukaemia.org.au

Don't be afraid to speak up if feeling overwhelmed during this time. Emotional support is available at any time and should be utilised if needed.

Forgetting things and lost concentration

Many people with myeloma notice a significant change in their ability to remember things, find words in conversation and a diminished level of concentration that might prevent them from being about to do such tasks as reading a novel. We often refer to this as 'chemo brain' or 'brain fog' in jest but it can be quite a distressing experience especially if it is an unexpected side effect. The formal term for this phenomenon is cancer-related cognitive impairment.

What is cancer-related cognitive impairment or chemo brain?

The exact cause of chemo brain is unknown but there seems to be a strong link between a cancer diagnosis and symptoms of cognitive impairment. Some possible causes of chemo brain include treatments for myeloma, medications to manage side effects, sleep disturbances, stress or inflammation in the body.

In addition to those mentioned above, chemo brain might also manifest as difficulty multitasking, following directions, trouble shooting and learning new skills. It may also contribute to fatigue.

What can be done to help?

Some people notice an improvement once treatment has finished although improvements might take some time to be noticed. Other people are on continuous therapy and need to learn to manage the effects.

It is important to acknowledge chemo brain and try to lower expectations. This might help lessen the associated stress by reducing the pressure on oneself. To help those nearest and dearest understand, it is also a good idea to let them know that memory and concentration is a problem.

Some people find keeping their mind active by regularly doing crosswords, puzzles or Sudoku helps. Letting the mind rest through mindfulness and meditation may also provide some relief. Some people enlist a health professional such as a psychologist to participate in cognitive rehabilitation, a more intense and targeted form of brain training. It is possible to receive Medicare rebates to see a psychologist by accessing a mental health plan via the GP.

For more information see the Cancer Council's fact sheet –

Understanding changes in thinking and memory

www.cancercouncil.com.au or 13 11 20

Sexuality and intimacy

Just like any other part of our being, myeloma can also have an impact on sexuality and intimacy. This can come in the form of altered body image, reduced libido and sexual function due to side effects of treatment, changed physical and emotional connections with people and self-esteem. If any of these issues are causing distress or concern, confide in a trusted member of the treating team who can refer to the appropriate health professional.

A comprehensive resource is available via the Cancer Council

Sexuality, Intimacy and Cancer

– a guide for people with cancer and their partners

Caring for the Carer

Living with a diagnosis of myeloma not only pertains to the person with the disease but their support network members too. Those caring for someone with myeloma carry quite a heavy load and often place high expectations on themselves to be a constant support. Living with myeloma is a marathon, not a sprint and carer's fatigue is a real risk.

The carer usually takes on the responsibility of taxi driver, medication manager, chef, appointment coordinator, researcher, home nurse and family spokes-person.

If the carer does not take time to take care of themselves, there is potential for them to also fall ill, making life even more difficult. There is a great analogy from the safety message on airplanes, 'fit your oxygen mask first before helping others'. There are a few strategies to implement to help prevent carer's fatigue.

- Form a support network of close family and friends to share the responsibility of driving to appointments, cooking meals and generally keeping each other company
- Make sure the carer has a good relationship with their GP and keeps their own health in check including seasonal vaccines
- Utilise social media or messaging apps to communicate information to a group at the same time. It can be exhausting repeating the same information to concerned family and friends multiple times
- If keeping on top of contacting family and friends is too much, even using a group messaging service, nominate a trusted person to be a spokesperson
- Make sure the carer takes time each week to do something that is only for them, no one else. This could be as simple as going for a walk in the fresh air
- Seek independent professional counselling or psychology support. Having someone neutral to offload thoughts and feelings can be a really effective way to keep on top of a stressful situation
- Ask the doctor if the consultation can be recorded to take the pressure off trying to remember everything and settle disputes when there are disagreements about what was said

For support specifically for the carer contact:

Carers Australia – www.carersaustralia.com.au or 1800 242 636

Carers Couch – www.carerscouch.com

Most importantly, if life begins to feel like it's getting too much, speak up. The health professionals looking after the person with myeloma are also there to support the carer. They will gladly direct to appropriate services.

Maintaining emotional health is just as important as the physical when living with myeloma. Taking care of oneself with a healthy diet, regular exercise, a good sleep routine, connecting up with social networks, connecting with activities that give a sense of purpose and meaning in life and being mindful are all really important.



Exercise

Exercise is an integral part of a healthy lifestyle for everyone. It can help lessen fatigue, improve general well-being and weight management and help prevent health issues associated with a sedentary lifestyle.

People with myeloma experience many physical and psychological effects associated with the disease and its treatments which are often long lasting and complex, making exercising more challenging. Therapy associated changes in muscle strength for e.g. from long term corticosteroid use can affect mobility and these changes often involve the proximal muscles like the quadriceps ('quads') and the shoulder muscles.

Over the last decade, it has been found that people with myeloma who participate in prescribed exercise programs experience improved overall quality of life.

Other benefits of exercise include increased self-esteem, improved mood, regained independence, increased stamina for walking, standing and general daily household tasks and a possible shorter hospital stay. It is often said that if we could manufacture a medicine with all these benefits, it would fly off the shelf.

Which symptoms can be relieved with exercise?

Physical

Pain and discomfort, fatigue, weakness, loss of appetite, weight loss, weight gain, fluid retention, peripheral neuropathy, loss of muscle tone, strength, endurance, reduced flexibility.

Psychological

Disturbed sleep, anxiety, stress, depression, decreased motivation, reduced concentration span (chemo brain)

How often to exercise

Exercise on as many days of the week as possible without increasing symptoms such as pain, cramps or fatigue. Start small and increase a little bit each time. If it takes more than 10-15 minutes to recover after exercise, the activity was too much for that time. Reduce the length or intensity until recovery time decreases. It may be as simple as walking across the room 3 times per day or walking around the block daily. Aim to build this up to minimum 30 minutes of activity on most days.

The intensity should be enough to increase breathing and heart rate, but not enough to cause pain, gasping or a struggle to recover. The ability to talk comfortably should be retained whilst exercising.

Acknowledge a feeling of accomplishment after exercise and use this for motivation next time. It may help to make a regular commitment to exercise with someone, or in a group.

Types of safe exercise

After a long period of immobility, an accredited exercise physiologist or physiotherapist is the best person to get the body moving safely. Exercises are tailored for myeloma bone damage, muscle weakness, pain, balance, motivation and fatigue.

See the **Building A Team** section of this book for information on how to access an exercise physiologist or physiotherapist through the **MediCare Chronic Disease Management Plan**. To locate an accredited exercise physiologist see the **Exercise And Sports Science Australia Website** www.essa.org.au . To locate a physiotherapist see the **Australian Physiotherapy Association website** www.physiotherapy.asn.au .

Slow breathing and gentle, big limb movements

When the body is out of condition, simple movements can help the body regain some fitness and feel better. Sit or stand in a position that is comfortable. Try gentle swimming actions with the arms and sliding the feet forward and back over the floor.

Chair exercises

Sit with feet flat on the floor and knees bent at right angles. Some movements to try include: chest stretch, hip marching, ankle rotation and neck stretching. Examples of these exercises can be found online https://www.nhs.uk/Tools/Documents/NHS_ExercisesForOlderPeople.pdf

Tai Chi, Yoga and Pilates

Improves balance, posture, strength and flexibility and reduces stress and fatigue.

Walking

Wear footwear that provides stability, use a walking aid if necessary and avoid uneven ground. Wading through shallow to thigh deep water adds resistance and lessens falls. Walking uses large muscle groups and helps circulation. Nordic walking uses poles for stability and focuses on technique to maximise stride. Joining a Nordic walking group is an excellent physical and social activity.

Swimming

Builds strength without putting stress on joints. Sidestroke, backstroke or walking in water are best as prolonged swimming face down puts stress on the lower back.

If there is a central venous access device such as a PICC or Hickman line in place, it is not recommended to swim. Also, if the white blood cell counts are low, the doctor may advise to avoid public, heated swimming pools due to an increased risk of infection. Public pools should have a regular cleaning schedule. Try to visit soon after the pool has been cleaned.

Stationary bike

Helps build strength and can be performed in any weather whilst watching TV or reading. Also, a much safer option than riding outside.

Exercises to avoid

Heavy lifting

Avoid overhead exercises. Lifting heavy loads and extreme ranges of motion such as deep squats, leg press or bench press increase the risk of fracture or injury. However, light resistance training guided by a professional can be beneficial.

High impact exercises and sports

Activities that place stress on the bones and joints should be avoided such as jogging, tennis and squash. Even golf needs some consideration due to the severe rotating motion of the golf swing. Also avoid contact sports such as football, basketball and boxing if there is bone damage.

Things to consider before exercising

Pain

Do not keep exercising if pain starts or increases. Ensure the doctor is aware of any new or worsening pain.

Low white cells

Myeloma and its treatment can cause the white blood cells to drop (neutropenia). If neutropenic the risk of infection is increased. During this time, activities such as swimming in a heated public pool, large gym classes and gardening should be avoided.

Low platelets

Myeloma and its treatment can cause the platelets in the blood to drop. In this case the risk of bruising and bleeding is increased therefore caution should be taken during any physical activity.

Low haemoglobin

Myeloma and its treatments can cause low levels of haemoglobin in the body. This means the capacity to carry oxygen around the body is less and can lead to shortness of breath, fatigue and increased heart rate. Therefore, overexertion is not recommended.

Peripheral neuropathy

Myeloma and its treatments can cause damage to the nerve of the peripheral nervous system and the autonomic nervous system. If present, peripheral neuropathy causes symptoms of pain, numbness, burning or tingling in the extremities and can also affect balance, blood pressure and cause dizziness. If low blood pressure or dizziness is a problem, start exercising slowly, avoid holding the breath and stand from a seated or lying position slowly.

Exercise is encouraged. It has many health benefits both for people with myeloma and healthy individuals. It is important to listen to the body and

to build up the exercise routine gradually, do a little often. Set realistic goals, aim to feel better and enjoy a sense of accomplishment. Don't be disheartened if today's effort is less than yesterday. Consistency is key.

If at any time exercise causes a negative effect, stop the activity and consult a health professional.

For more information see Myeloma Australia's book

Peripheral Neuropathy – a guide for people with myeloma
www.myeloma.org.au or call 1800 MYELOMA (693 566)



Fatigue

Cancer related fatigue (CRF) is defined as a ‘distressing, persistent and subjective’ feeling of physical, mental or emotional tiredness related to cancer and/or cancer treatment interfering with usual functioning. This tiredness is not proportional to recent physical activity and is unrelieved by sleep and rest. Fatigue is recognised as one of the most common and debilitating symptoms of myeloma. Understanding the cause and adopting strategies to manage fatigue can help improve quality of life.

Symptoms of Fatigue

Physical

Unrelenting tiredness, weakness, feeling sluggish or slow, heavy limbs, difficulty completing routine tasks or participating in recreational hobbies.

Mental

Impaired concentration and memory, absentmindedness, difficulty understanding simple instructions, difficulty processing information, irritability, forgetfulness, negative or unpleasant emotions, brain fog.

Social

Limited ability to socialise, unable to fulfil usual role within the family or friendship group, impaired relationships, feelings of isolation.

What causes fatigue?

Fatigue in myeloma can be caused by the disease itself and thought to be heightened by symptoms such as pain, infection, low haemoglobin (anaemia) and reduced kidney function, all of which can become more severe during myeloma treatment.

Other contributors include reduced activity, inadequate diet and fluid intake, psychological stress such as depression or anxiety, insomnia, nausea and treatment side effects.

Assessing for other conditions like underactive thyroid, adrenal gland insufficiency might be beneficial in case other interventions fail to help improve fatigue.

How do treatments for myeloma cause fatigue?

As myeloma cells die, they release cytokines, which are substances that upset the normal chemical balance in the body, thus using more energy. This effect can be amplified when treatments accelerate the rate of myeloma cell death.

Chemotherapy targets any rapidly dividing cell, both cancerous and healthy. This requires a significant amount of energy. It can also cause nausea and in some cases mouth ulcers, making it difficult to maintain adequate nutrition. Chemotherapy can also cause anaemia related fatigue and a profound decrease in muscle strength.

Targeted agents such as immunomodulators, thalidomide (Thalomid®), lenalidomide (Revlimid®) and pomalidomide (Pomalyst®) are associated with notable fatigue, as are proteasome inhibitors, such as bortezomib (Velcade®) and carfilzomib (Kyprolis®). These treatments may also help relieve fatigue as the myeloma activity reduces.

Steroids may cause insomnia and muscle weakness that can lead to fatigue. They are also known to cause changes in mood and energy levels. It is recommended steroids be taken early in the morning to avoid insomnia. However, some people find that the effects of steroids take some time to kick in therefore taking steroids in the evening might provide more opportunity for sleep.

Stem cell transplants are associated with fatigue due to the intensity and duration of the treatment. The fatigue usually improves with time as general wellbeing and fitness return. However, some people report experiencing residual fatigue up to one year after their transplant.

Radiotherapy related fatigue can develop over time and is the effect of the body repairing damaged cells. It usually lasts 3 to 4 weeks after the completion of radiotherapy but may last up to 3 months.

Other medications given for pain management (opioids), anxiety (anxiolytics), depression (antidepressants), nausea (antiemetics), insomnia (benzodiazepine, hypnotics) can cause medication related fatigue and enhance the effects of fatigue from other causes.

What can be done to lessen fatigue?

Exercise

Regular exercise programs to improve muscle strength are a very effective way to reduce fatigue. Particularly those that include stretching, aerobic and resistance exercises.

See the **Exercise** section of this book for more information on how to exercise safely

Psychological and emotional health

It is quite common for people with myeloma to experience stress, depression and anxiety which can also lead to increased levels of fatigue. A psychologist can be engaged to use cognitive behavioural therapy (CBT) to positively manage thoughts, behaviours and emotions associated with a certain goal. CBT is a very effective way to manage fatigue.

Other interventions include relaxation techniques, meditation, spiritual practices, talking with others, and counselling. These self-help techniques can provide a sense of control of the situation.

Social support and information and support groups including those run by Myeloma Australia are also an effective way to lessen the burden of fatigue, as well as a useful place to learn from the experiences of others and share management strategies.

See the **Emotional Health** section of this book for more information

Food and fluid intake

If nausea or loss of appetite prevents adequate food and fluid intake, the body will not have enough energy to perform usual activities. A balanced diet that includes foods that supply iron and energy, such as green leafy vegetables and red meat, is recommended.

It is a good idea to cook when energy levels are highest, freeze extra food and accept help from family and friends to maintain nutrition. If cooking is challenging, consider home meal providers such as Meals on Wheels or consider private home meal provider companies.

Maintaining adequate fluid intake is also important to flush through the toxins and waste products that can also cause fatigue. Keeping a water bottle close by and taking frequent sips will help maintain hydration throughout the day. Aim for 2-3 litres/day unless the kidneys are impaired, and the doctor has enforced a fluid restriction.

See the **Food and Fluid Intake** section
of this book for more information

Rest and Sleep

It can be useful to keep a diary to record fluctuating energy levels. This will help in planning activities for the time of day when energy levels are typically higher and to know when to conserve energy when levels are low.

When tired, the body is most likely requesting a rest. If thoughts are worrying, set aside time during the day to deal with them if they are preventing sleep at night. Avoid caffeinated products such as tea, coffee, chocolate, and energy drinks in the afternoon or evening. Napping can be beneficial for some people. It is important to limit naps to around 30-60 minutes to avoid interfering with night sleep patterns.

Getting up and going to bed at the same time each day helps the body maintain a regular sleep pattern. Eating rich food or exercising too close to bedtime can make sleeping difficult. Make sure the sleeping environment is not too hot or cold and avoid watching television, using electronic devices, e.g. iPad or iPhone, or reading in bed. This helps the body to associate the bedroom with sleep.

If sleep does not come easily, get up and do something quietly distracting until tiredness is experienced again. Most importantly, do not get concerned if sleep is being evasive. Just lying quietly in bed can be beneficial.

The doctor may also recommend a sleeping tablet if chronic insomnia is a problem.

If considering taking a natural supplement to aid sleep, speak with the treating team. Some of these medications interrupt the effect of myeloma treatments.

What medical interventions might help lessen fatigue?

Myeloma and its treatment can cause a drop in haemoglobin level called anaemia. Haemoglobin is responsible for carrying oxygen around the body and if levels are low can cause symptoms of fatigue, shortness of breath and dizziness. Our body can adjust to low levels of haemoglobin but if symptoms are a problem, a blood transfusion can be given to restore haemoglobin levels and provide relief.

People with myeloma have an increased risk of infection. A common sign of infection is fever, which is a temperature of 38°C or above. Having an infection can also contribute to fatigue therefore taking medication to treat the source of the infection can help improve energy levels.

If the temperature is 38°C or above, medical attention must be sought immediately

See the **Infection Prevention section of this book for more information about infections and how to prevent them**

If depression or anxiety is a problem, a medication can be introduced to improve psychological health and increase energy levels.

If myeloma itself is the cause of the fatigue, sometimes simply reducing the disease burden with treatment can be accompanied by increased energy levels.

Unfortunately some people find that no matter how well they look after their mind and body, fatigue is still a problem. Acknowledging fatigue as a part of life with myeloma and trying to accept a new level of functional ability can go a long way towards coping with fatigue.



Food and Fluid Intake

Maintaining adequate food and fluid intake is vital when aiming to live well with myeloma. Eating a well-balanced diet will help preserve muscle mass to maintain strength, increase energy levels and promote recovery after periods of treatment.

It is possible that appetite and dietary requirements will vary and there may be times, especially when receiving treatment for myeloma, that eating, and drinking may be more difficult.

What is a well-balanced diet?

A well-balanced diet is one that will supply the body with all its nutritional needs so that it functions well. It should consist of foods from each of the major food groups and should be rich in all the essential vitamins and minerals.

Any food allergies should be taken into account when considering the information provided below.

Protein to help build new cells and replace old ones. Foods that contain protein include meat, dairy products, nuts and fish.

Carbohydrates provide an ideal source of energy. There are two types of carbohydrate; complex and simple. Complex carbohydrates are often referred to as starch and simple ones as sugars. Foods that contain carbohydrates include bread, pasta and rice.

Fats are a valuable source of energy. Fats are also needed to transport some vitamins around the body. A healthy diet includes more fat from fish, nuts, seeds and olive oil (monounsaturated and polyunsaturated fats) than from meat, dairy, cakes, biscuits and chocolate (saturated fats).

Fibre helps the digestive system work efficiently. Foods that are high in fibre include bran, whole wheat bread and cereals, as well as most fruit and vegetables. It is recommended to eat five portions of vegetables and two portions of fruit each day.

Vitamins and minerals; are essential nutrients, they work together in many of the body's systems. They help strengthen bones, maintain healthy nerves, heal wounds, and support the immune system. They also convert food into energy, and repair cellular damage. Vitamins and minerals can be destroyed in the cooking process, so overcooking food should be avoided.

Fluids are essential to keep the kidneys functioning well to eliminate waste products. Drinking at least 2 litres of fluid each day (unless on a fluid restriction enforced by the doctor) is recommended.

Most type of drinks are acceptable with some exceptions:

- Coffee and alcohol should be drunk in moderation, in excess they can contribute to dehydration
- Sugary soft drinks and juices, especially when on steroid therapy which can increase blood sugar levels
- Green tea interferes with the action of Velcade® (bortezomib) so should be avoided during the course of treatment.

What makes a well-balanced diet difficult to maintain?

Myeloma and its treatment may have side effects that make maintaining a balanced diet difficult. These include:

- Loss of appetite many medications reduce the appetite as well as enjoyment of food
- Taste and smell changes decreased or a metallic taste after treatment
- Sore, dry mouth especially after high-dose chemotherapy
- Nausea and vomiting
- Tiredness or fatigue
- Diarrhoea or constipation (often caused by myeloma treatments) – an alteration in normal bowel habit can temporarily put people off food
- Anxiety and depression
- Steroids – these can increase appetite, lead to weight gain and cause heartburn

Tips to maintain a healthy diet when appetite is low

- Eat small amounts regularly throughout the day
- If the smell of hot food is off putting, switch to cold meals. Be sure to adhere to safe food handling practices as outlined below
- Squeezing lemon juice on to food can help enhance the flavor
- If experiencing a sore mouth or taste changes, ask the treating team about topical treatments that can be used
- Some people experience a metallic taste when having treatment. Using plastic cutlery can help minimise this at meal times
- Keep the mouth fresh and clean by using a non-alcohol-based mouthwash
- Light gentle exercise (e.g. walking) may stimulate the appetite and improve fatigue
- Ask to see a dietitian to advise about diets and supplements as needed to ensure an intake of all the essential vitamins and minerals.
- When not fatigued try cooking larger portions and freezing some for another day; seek help with cooking and shopping.
- When food intake is low, it is important to drink enough fluid. A good way to achieve this is to have a drink bottle nearby and take sips often. A squeeze of lemon juice in the water can help make it more palatable.

Is a special diet necessary?

Besides following a well-balanced diet, there are no specific diet recommendations for people living with myeloma.

During periods where the immune system function is especially low like during treatment, it may be necessary to avoid certain foods to reduce the chances of picking up a foodborne infection. These foods include:

- Raw or undercooked eggs, meat, fish or shellfish
- Unpasteurised dairy products
- Soft or blue cheeses
- Pâté
- Takeaway foods or foods that have not been freshly prepared (e.g. from a buffet)

- Safe food handling practices are recommended such as washing hands and cooking utensils thoroughly with soap before eating and not mixing raw meat with other foods on the chopping board
- Adhere to 'best before' and 'use by' dates.
- Food should be stored in the refrigerator or freezer and if eating leftovers ensure they are reheated to hot.

When taking steroids, it may be necessary to seek specialist advice from a dietitian or diabetes educator if the blood sugar levels become very high. Especially if diabetes is already an identified issue. It might be useful to seek advice from a dietitian who is a health professional and uses evidence-based recommendations to help people modify their diets to help treat symptoms, maintain a healthy weight and get the most out of their food. Dietitian services can be accessed through the hospital, community health centre or in private practice.

To locate an accredited dietitian who specialises in cancer or has experience with myeloma patients please contact the
Dietitians Association of Australia (1800 812 942).

If accessed in the community, many private health funds will provide a rebate for this service. It is also possible to access 5 free visits to a dietitian by utilising the Medicare funded Chronic Disease Management Plan via the GP

See the **Building a Team** section of this book for more information about the Medicare Chronic Disease Management Plan

Changes in bowel habits

Constipation

A decrease in the normal frequency of bowel movements may occur whilst having treatment for myeloma. It may be accompanied by gas, pain, or pressure in the stomach. Constipation is usually easier to prevent than to treat.

To relieve the symptoms of constipation, eat a healthy diet which is high in fibre. Fibre absorbs water making stools softer, bulkier and easier to eliminate. Drinking plenty of fluids (aim for about 8 glasses of water a day) helps the fibre work. Pear or prune juice may also help. Regular gentle exercise keeps the

bowels more active to help move things along. Gentle laxatives, (consult nurse or pharmacist) may be needed but if constipation continues to be a problem, talk with the doctor.

Diarrhoea

Whilst usually mild and easily manageable, diarrhoea can become problematic in some cases but easily managed with simple treatments. It is important to determine if the diarrhoea is being caused by an infection or medication. The doctor will ask for a stool sample before recommending any medications to manage diarrhoea so that the correct advice is given.

If experiencing diarrhoea, it is important to maintain good fluid intake and alert the doctor as soon as symptoms commence as there is a risk of dehydration when experiencing diarrhoea.

Oral health

Taking good care of the teeth and mouth is very important for people with myeloma, especially when the immune system is at its lowest during periods of treatment or active disease.

Some treatments for myeloma can cause the lining of the mouth and throat to dry out or develop sores (mucositis). It is important to use a non-alcohol based mouth wash, such as sodium bicarbonate, after every meal to help keep the mouth clean. Mouth washes that contain alcohol can further dry out the mouth. If the dryness causes discomfort, speak to the pharmacist, nurse or dentist about special gels and creams that can be used.

Flossing is a good way to remove plaque buildup between the teeth. However, there may be times during treatment or when myeloma is active that the blood cells that cause the blood to clot are low. During these times, flossing should be avoided as it may cause the gums to bleed.

It is also important to attend regular dental checkups to ensure any issues are prevented or treated quickly. Most people with myeloma are given a bone strengthening medication called a bisphosphonate. A rare complication of bisphosphonate therapy is osteonecrosis of the jaw (ONJ) which is a persistent, non healing wound in the mouth and occurs

most commonly after invasive dental work (e.g. tooth extraction). It causes pain, can become infected and results in bone tissue death. ONJ is a complication that can be quite serious if left too long without attention. Ensure the dentist is aware of any bisphosphonate therapy before any examination takes place.

Taking responsibility for food and fluid intake and oral health is an excellent way to feel more in control of well-being when much of life with myeloma is unpredictable. Family and friends often want to help but don't know how. Asking for help with meals is a great way to make them feel useful and reduce the effort required to maintain.

See the **Bone Health** section of this book for more information bisphosphonates and ONJ



Infection Prevention

We rely on our immune system to fight and prevent a range of infections. As myeloma affects different parts of the immune system and weakens it, the risk of infection is increased. The treatments for myeloma are very effective but some types of treatment such as steroids can add to risk for infection.

There are different steps people can take to avoid and prevent infections during this time.

General measures to avoid infection

Where possible, avoid contact with colleagues, friends and family members who are unwell with symptoms such as cough, runny nose, sore throat, diarrhoea and rashes.

It is important to maintain good hand hygiene at all times. This can be done through regular hand washing, especially after using the toilet or using an alcohol-based hand sanitiser.

There are certain activities that could potentially increase exposure to an infection. When performing activities that generate dust or in dusty environments, wear a mask to reduce exposure to organic dusts that can carry bacteria and fungi, which can then lead to infection. When looking after pets, use gloves to handle pet waste and during cleaning.

Specific measures to avoid infection

Preventative medications

Some treatments for myeloma can increase the risk of certain types of serious infections. Medications to reduce this risk during treatment for myeloma or after a stem cell transplant are usually prescribed by the treating team. These could be an antibiotic (e.g. Bactrim), an antiviral

(e.g. valaciclovir) or an antifungal tablet (e.g. fluconazole). It is vital they are taken regularly according to the provided instructions. If side effects are noticed from these medications, it is important to discuss these with the doctor before stopping them. Often, there are alternative tablets that can be taken to maintain protection from infection. As these medications are often taken long term, it is important to ensure the prescriptions don't run out.

Vaccination

Vaccination can be an effective way to protect from certain types of serious infection. If offered a vaccine, it is important to check if it is a 'live' or 'inactive' vaccine. During treatment for myeloma, all 'inactive' vaccines are safe to be given. 'Live' vaccines such as the measles, mumps, and rubella vaccine are not safe unless advised by the doctor in certain circumstances.

People with myeloma are recommended to have the influenza vaccination every year. It is an 'inactive' vaccine so it is safe. These vaccines become available around late April every year before the winter season begins. There are specific stronger influenza vaccines for patients older than 65 years. In addition, vaccination for pneumococcal infection, the bacteria that causes serious pneumonia and meningitis is recommended. Vaccines for other infections such as meningococcal infection may also be helpful. Ideally, these should be given before starting treatment for myeloma. Please ask the doctor to recommend the most suitable influenza and other vaccines to have.

Chemotherapy given as part of stem cell transplantation can reduce some of the protection or immunity from childhood vaccinations. The transplant team will often recommend revaccination against a range of infections starting at 6 months after transplant. This is often given either through the transplant centre or general practitioner using a standardised schedule. Over the course of 2 years, the same vaccines are given several times as boosters to ensure a higher level of protection. Only 'inactive' vaccines are given for the first 2 years after the transplant. Live vaccines may be given after 2 years if the doctor has determined it is safe to do so.

Overseas travel

If planning to travel overseas, it is important to check with the doctor if any additional preventative tablets or additional vaccinations are required. This may be dependent on the intended destination. As it takes up to 2 weeks for

vaccines to take full effect, it is important to discuss travel plans early. Certain travel vaccines (e.g. yellow fever) are live vaccines and should be avoided. There are travel health clinics that can help recommend preventative tablets and vaccines. If the trip involves being on the plane for long hours, talk to the doctor about ways to prevent blood clots. Remember to pack enough medications, including preventative tablets to cover the trip and a recent summary of myeloma treatment can be helpful in case of emergencies.

See the **Practical Help** section of this book for more information about travelling with myeloma

Early recognition of serious infection

Despite attempts to prevent infection, serious infections can still occur, and it is important to recognise some key symptoms that should prompt a review with a doctor or a visit to the closest emergency department.

If feeling unwell, check the temperature. Key signs of infection include fever (38°C and above) and uncontrollable shivering. If experiencing these symptoms, it is important to present to a doctor or the emergency department for assessment. Do not wait until the fever/shivering resolves, as it can be an early sign of a serious infection which can be life threatening.

If the temperature is 38°C or above, medical attention must be sought immediately

Colds and flu

During winter, it is important to see the doctor if unwell with a cough, runny nose or sore throat. A viral infection can develop into a more serious infection involving the lungs like pneumonia. If experiencing cold or flu symptoms, with productive sputum and/or shortness of breath, urgent medical attention is required including taking a nose or throat swab to check for influenza. Specific anti-influenza treatment can be started to prevent the infection from getting worse.

Shingles

If infected with chicken pox as a child, the virus i.e. varicella-zoster, remains in the body and can reappear again later in life as shingles. Shingles can cause nerve damage and long-lasting pain. The risk of this happening is higher with certain types of myeloma therapy such as bortezomib and after stem cell transplantation. The risk is reduced by the use of preventative antiviral tablets but shingles can still occur. It is important to be alert for symptoms of shingles such as burning pain and red spots with a clear centre that generally occur in a fixed area on the skin in a band like pattern such as a single side of the face or back. It is important to seek medical attention as soon as these symptoms are noticed, as the antivirus treatment is only effective when used early. Currently the only available shingles vaccine is a live vaccine and is not recommended for people with myeloma but newer killed vaccines may be available soon.

Being aware of infection risk and instituting strategies into daily life to prevent exposure to infections can make a great deal of difference to quality and longevity of life for people with myeloma.



Pain

What is pain?

Pain is an extremely common symptom experienced by people with myeloma with it affecting 80% of patients at some point. Pain occurs when pain receptors in the nerve endings send a signal to the brain that there has been some damage. The brain responds by telling the body to protect itself, minimising the potential harm to the body. Most pain is resolved once the cause of the pain is removed, though some pain can persist after the body has healed.

Pain can be caused by both physical factors such as illness, inflammation, surgery or injury and by emotional factors such as experiences, memories and emotions. It is a subjective and individual sensation the response to pain varies from person to person.

In myeloma pain can have a significant impact on quality of life, especially if it is not managed effectively, making it difficult to undertake basic activities, maintain relationships and cope with other symptoms.

Pain control therefore is an important part of myeloma management.

Types of pain

Pain is generally described as acute, chronic or breakthrough

Acute pain comes on quickly and lasts for a relatively short time period. An example is a headache or cut finger.

Chronic pain does not go away or comes back often and may persist for months or years. An example is arthritis pain and back pain.

Breakthrough pain is an abrupt, short-lived spike in pain which overrides the persistent chronic pain. It may be a sign that the body is becoming resistant to the pain relief or that the cause of the pain is worsening.

Pain can also be described according to where it originates in the body

- Somatic / musculoskeletal pain: comes from joints, muscles and bones and is often described as dull or achy.
- Visceral pain: originates in the internal organs and is often difficult to locate as is described as a pressure, squeezing
- Neuropathic pain: is as a result of pressure on or damage to the nerves and is described as sharp, burning, electrical shock or shooting.

Causes of pain in myeloma

There are many potential causes of pain in myeloma it can be caused by the disease itself or because of the side effects of treatment.

Bone disease

Bone disease is very common and often the most debilitating feature of myeloma. Although any bone may be affected, the areas usually involved include the middle or lower back, the hips, the rib cage and the long bones of the upper arms and legs.

Bone disease occurs as a result of myeloma cells producing a protein that causes the bone to be broken down faster than it can be repaired. Sometimes the bones can become so weak that they can break without undue force or injury – this is called a pathological fracture.

The thinning of the vertebrae (bones of the spine) can also result in fractures. They tend to collapse and become compressed. This is known as a vertebrae compression fracture and can be very painful.

Sometimes, a group of myeloma cells can collect on a bone or tissue forming a tumour called a plasmacytoma, which may be associated with pain.

**More information can be found in the
Bone Health section of this book.**

Peripheral neuropathy

Peripheral neuropathy is the term used to describe damage to the nerves that make up the peripheral nervous system which includes the hands, feet, arms or legs. Peripheral neuropathy is the most common cause of nerve pain in myeloma. This can be as a result of the myeloma itself whereby the paraprotein

from the myeloma cell deposits on the nerves causing damage to them. It can also be caused by the treatment for myeloma drugs such as bortezomib (Velcade®) and thalidomide (Thalomid®) can cause toxicity to nerve cells. Other factors such as diabetes, vitamin deficiency and high alcohol consumption can contribute to peripheral neuropathy.

Peripheral neuropathy pain can be described as altered sensation, tingling, numbness, pins and needles, cold sensation.

**For more information see Myeloma Australia's book
Peripheral Neuropathy
– a guide for people with myeloma
www.myeloma.org.au or call 1800 MYELOMA (693 566)**

Infection

Myeloma and/or its treatments increase the likelihood of an infection, some of which can be accompanied by pain.

A fever, which is a temperature of 38°C or above, is a sign of infection. It is recommended that patients have a thermometer at home and check their temperature if they feel excessively warm or hot or develop the shakes (rigors).

If the temperature is 38°C or above, medical attention must be sought immediately

Some common types of infections are:

Lung infections e.g. pneumonia can cause chest pain usually located on one side of the chest, sharp in nature and worse on coughing or breathing.

Urinary tract infections can cause pain on passing urine usually described as burning or stinging sensation which can sometimes be accompanied by lower back pain.

Skin infections such as shingles can cause severe pain and sensitivity on the skin near the shingles rash. Shingles is caused by the chicken pox virus travelling down the nerve causing pain. Intermittent sharp,

stabbing pain can continue for a long time after the rash has disappeared. Early detection and treatment may minimise the pain associated with shingles.

Mouth infections such as oral thrush may cause pain and difficulty swallowing. In some cases, prophylactic antibacterial and antiviral medication may be prescribed to prevent infections. It may also be appropriate to have the flu and pneumococcal vaccinations. The doctor will advise if any of these measures are necessary.

See the **Infection Prevention** section of this book for more information about infections and how to prevent them

Treatment side effects

The treatment that destroys myeloma cells can also damage healthy cells leading to unpleasant side effects including pain. Some of these common side effects include:

- Diarrhoea and constipation causing abdominal bloating, discomfort and stomach cramps
- Sore mouth and throat (mucositis) a side effect of chemotherapy, especially from the high dose melphalan given as part of an autologous stem cell transplant. This results in the breakdown of the lining of the mouth and throat causing inflammation or blisters resulting in pain. This may make it difficult to eat or drink
- Peripheral neuropathy due to nerve damage

Most of the pain associated with side effects are short term and can be either avoided or well managed and usually improve or resolve once the treatment is completed.

Investigations and Procedures

There are numerous tests and investigations required before, during and after treatment for myeloma. These include blood tests, bone marrow biopsies, insertion of central venous access devices (for stem cell collection and transplant) all of which may inflict short-term pain. If pain is not easily resolved with paracetamol, let the treating team know so they can assess for any complications of the procedure.

Describing pain

For the treating team to help effectively manage pain it is important that they have a good understanding of the impact the pain is having on the ability to function normally. Being honest about the level and frequency of the pain will ensure the appropriate management is advised.

Questions that may be asked during an assessment include:

- Where is the pain?
- When did it begin?
- Does it move anywhere else?
- What does it feel like? Is it sharp/ dull/ throbbing / burning?
- Does it prevent the carrying out of daily activities such as showering, dressing?
- Does anything make it worse?
- What pain relief has previously been used?
- What else makes the pain better?
- Is the pain constant? If not, when does it occur
- Are there any other symptoms?

The palliative care team

Complex pain is often managed by the palliative care team, which can be comprised of doctors, specialist nurses, psychologists, physiotherapists and occupational therapists. This team can assist pain management and provide advice and guidance on which treatments should be given. They can also provide holistic support for someone with myeloma, their family and caregivers. There is often a misconception that the palliative care team is purely to provide care at the end of life, however they can provide specialist care in pain management and symptom control at all stages of illness. A patient can be referred to a palliative care team at any time.

Treatment of Pain

The aim of treatment for pain is to provide adequate, constant relief, with as few side effects as possible. Often myeloma pain can be relieved by the treatment of the disease; therefore a response to treatment is a large contributor to reduced pain and improved quality of life.

Every person's experience of pain is different and because of this, pain control requires an individual approach so that the best treatments can be used to achieve the most relief. Sometimes, treatments prove ineffective at pain relief and a process of trial and error is required to find the best plan to control pain.

There are many different pain relief options available for myeloma related pain. These strategies are outlined below.

Anti-myeloma treatments

If the pain is caused by the effects of myeloma, starting treatment and reducing the burden of the disease in the body can provide effective pain relief. It may be necessary to take pain relieving medication until enough disease response has occurred.

Pain relieving medication (analgesia)

There are many types of pain relieving medications (also known as analgesia) available and often more than one type is prescribed at the same time for maximum effect.

Pain relieving medications take many forms, such as tablets, liquids, medicinal lollipops, nasal sprays, skin patches or injections.

Non-steroidal anti-inflammatory drugs (also known as NSAIDS such as ibuprofen) are a type of pain relieving medication NOT recommended for use in myeloma due to the risk of kidney damage. A list of drugs that are commonly used for myeloma pain are listed below.

As with any type of medicine, pain relieving medications can cause side effects. Common side effects include constipation, drowsiness and nausea and these can often be well managed or prevented by the treating team or palliative care team. It is important to report any side effects as it is usually possible to make small changes to the medication regime to maintain pain control while reducing side effects.

It is important to remember that everyone is different and sometimes it takes a few attempts to settle in a good pain relieving regime. Discussion with the treatment team and/or palliative care team is important to find the best pain relief plan.

Common pain relieving medication (analgesia)

Class	Examples	Comments
Simple non-opioid analgesics	Paracetamol	Useful in mild to moderate pain.
Weak opioids	Provide effective pain relief for moderate pain, e.g. panadeine forte, tramadol.	Confusion and drowsiness may be experienced initially: can cause constipation: caution required in renal impairment.
Strong (natural) opioids	Provide effective pain relief for moderate to severe pain. Morphine as liquid or tablets can be converted to slow release preparations when daily requirements are established e.g. MS Contin	Can cause confusion and drowsiness, may also cause constipation, nausea and vomiting.

table continues on next page

Synthetic Opioids	<p>Provide effective pain relief for moderate to severe pain; some can be less toxic than natural opioids. Include:</p> <ul style="list-style-type: none"> -Oxycodone may be given orally (immediate or slow release formulations) e.g. Oxycontin, targin, endone, hydromorphone -Fentanyl or buprenorphine given as slow release patches or lollipops 	Can cause confusion and drowsiness, may also cause constipation, nausea and vomiting.
Others	<p>Gabapentin and pregabalin, amitriptyline, carbamazepine (neuropathic pain) Steroids e.g. dexamethasone.</p> <p>Medicinal Marijuana</p>	<p>Can cause drowsiness; discuss side effects with the treating team. Commonly given as part of antimyeloma treatment. Can cause gastric irritation, mood changes, difficulty sleeping.</p> <p>Evidence for use is still emerging and availability varies around Australia. Consult treatment team to discuss best options available.</p>

Other medicinal treatments

Bisphosphonates

Bisphosphonates are a group of drugs that help to minimise the extent of or prevent bone damage. Bisphosphonates are effective at reducing the chance

of pathological fractures but are also highly effective at relieving bone pain and can reduce the need for other pain relieving medication to be taken.

Bisphosphonate medication is explained further in the Bone Health section of this book.

Radiation Therapy

Radiation therapy can be effective in reducing the myeloma cells present in bones and soft tissue and can be helpful in the treatment of localised bone pain. It is also effective at relieving the pain caused by a condition known as spinal cord compression, where myeloma cells press on the spinal cord, often presenting as unexplained back pain (often feeling like a tight band) that gets gradually worse, which may radiate down to the buttocks and legs. Spinal cord compression may also present with incontinence (uncontrolled bowel or bladder function). It is important for radiation therapy to be commenced as soon as possible in this case to prevent permanent spinal cord damage and paralysis.

Surgical procedures

Sometimes it is necessary to surgically repair and stabilise an area of the spine to help with pain and mobility through the injection of surgical cement. There are two types of surgery used in myeloma, percutaneous vertebroplasty and balloon kyphoplasty. Ask the doctor if either of these procedures might be appropriate.

Non-medical treatments

There are a range of non-medical interventions to help relieve pain, some are listed below. It may also be useful to enlist the help of allied health professionals such as an occupational therapist, physiotherapist and psychologist to help manage pain.

It is important that the treating team are aware of any non-medical interventions to ensure no inadvertent harm is caused.

Transcutaneous Electrical Nerve Stimulation (TENS)

TENS machines deliver small electrical pulses to the body through electrodes placed onto the skin. These machines are thought to affect the way that pain signals are sent to the brain, resulting in the brain releasing endorphins, a hormone which acts as a pain killer in the body. TENS machines can be bought or hired from most physiotherapists or pharmacies.

Acupuncture

Acupuncture is part of traditional Chinese medicine and uses the balance of the body's own life force to restore wellbeing. Acupuncture can be used to alleviate pain and to relax muscles, but it is important to discuss the use of acupuncture with the treating team as the use of acupuncture needles can increase the risk of infection and bruising.

Massage

Gentle massage can be useful in relieving muscle pain and tension. It is important to tell the massage therapist about the diagnosis of myeloma and that forceful massage can cause bone damage and bruising.

Hot and cold packs

Heat packs and ice packs can be effective in providing short term pain relief. Often alternating between hot and cold works best. It is important to avoid applying hot or cold directly to the skin especially if peripheral neuropathy has caused numbness or altered sensation to an area, to minimise the risk of damaging the skin.

Relaxation techniques

Relaxation techniques can ease muscle tension and help people to cope better. Mindfulness meditation and visualisation exercises can also be effective. Distraction therapy such as watching TV, reading, listening to podcasts or the radio can help by taking the mind off pain for a short period of time.

Correct positioning

Often body positioning, including sitting or lying down can alleviate pain. Moving to get comfortable and using supportive pillows or cushions can be useful to assist positioning, whilst occupational therapists or physiotherapists can help with positioning options to try.

Exercise

Moderate gentle exercise such as walking can strengthen the muscles to support the area of pain, elevate mood and help to provide distraction from pain. It is important to find a balance between regular activity and rest, allowing the body time to recover.

Pain affects the majority of patients with myeloma at some point: however, with open and honest communication with the treating team about pain, and using the correct pain management interventions, it can be controlled, allowing for an improved quality of life.

With an individual pain control plan in place, regular review of pain killers and their effectiveness will increase the chance that pain will be managed well whilst reducing side effects. When starting to take pain killers, often a mild pain killer will be prescribed first and gradually increased in dose before a different or stronger type of medication is offered.

See the **Exercise** section of this book for more information about how to Exercise safely



Practical Help

In addition to the impact myeloma has on health and wellbeing; there are also many practical implications as the impact of the disease extends further than just the physical attributes.

To help navigate and relieve some of the issues hospitals may have social workers available in varying capacities to assist. A social worker's role is to provide emotional and practical support to patients and families in their care. Ask the treating team if there is a social worker available.

Getting financial, legal and medical affairs in order

Financial and legal

When people are diagnosed with myeloma, the stress associated with a new uncertainty of the future can be amplified by financial stressors. Often people are still working and the main providers for the family. Therefore, taking time off work for treatment can result in huge financial pressure.

There are a few ways to ease these financial pressures. We recommend exploring eligibility to entitlements such as:

- Approaching the employer about any leave entitlements
- Taking advantage of income protection policies. These are often attached to the superannuation policy
- Exploring any Centrelink entitlements
- Early or compassionate access to superannuation
- Contacting organisations such as the Cancer Council and Leukaemia Foundation which may have small grants available to help with bills

If unsure of available Centrelink benefits, make an appointment to speak to a Financial Information Officer at Centrelink. If in hospital or unable to make it to a Centrelink Office personally, nominate a trusted person to deal with

Centrelink by completing an 'authorising a person or organisation to act on your behalf' form.

Most employers are very understanding of a diagnosis of myeloma but may require documentation from the hospital. The treating team are always happy to provide letters with as much or as little diagnosis information as an individual is comfortable to share. The Cancer Council are also able to provide free advice to small business owners as outlined below.

It may be possible to modify working hours or conditions so that some income can still be generated and most importantly some normalcy can continue. Talk to the employer about any possible changes that could be made to help achieve this balance.-

In some cases, the person with myeloma may have dependent children. This adds another level of complexity when it comes time to be in hospital. If earning capacity is reduced, usual child care services may become too expensive. Centrelink can often help in these situations with either child care subsidies towards fees of child care provided in a centre or in the home. Contact Centrelink, a childcare provider or speak with a social worker at the hospital to explore this option.

It is also recommended to review any legal affairs as being organised for future circumstances helps relieve stress for all involved.

Completing or updating a Will is recommended as is consideration of appointing an Enduring Power of Attorney (EPOA). An EPOA can act on behalf of the person with myeloma regarding any financial or legal matters should they be unable to do so themselves. Further information can be found via the Office of the Public Advocate.

Many of the points mentioned above require professional advice. The Cancer Council have a raft of different professional volunteers able to provide pro-bono advice in their field. These services are:

- Legal referral service
- Financial planning service and financial counselling
- Workplace advisory service
- Small business advisory service

For more information on how to access these services, call the Cancer Council on 13 11 20 or visit www.cancercouncil.com.au

Medical

There may be times where the person with myeloma is unable to make decisions about their medical care. It is important to consider who medical staff would liaise with in these circumstances and whether formally appointing someone or completing an Advanced Care Directive (ACD) is appropriate. Considering these matters in advance can assist if stressful situations arise.

An ACD, sometimes called a living will, is recognised by common law or specific legislation. The directive records preferences for future care including values, life goals and preferred outcomes. It can also include instructions about preferred treatments.

If the next of kin (NOK) is not a suitable medical advocate, then a substitute decision maker can be appointed in the ACD.

If the situation is unexpected and there has not been a substitute decision maker appointed, consent for treatment will be obtained from the first in the following list of people who have been in a close and continuing relationship with the patient. If more than one is appropriate, the oldest will be chosen:

- a. the patient's spouse or domestic partner
- b. the patient's primary carer (an adult who is in a care relationship with the person and has principal responsibility for the person's care)
- c. an adult child of the patient
- d. a parent of the patient
- e. an adult sibling of the patient.

The person needs to be reasonably available, and willing and able, to make the decision.

If there is no one who meets the criteria for this, the law recognises the Public Guardian as the statutory health attorney.

The ACD will provide direction and guidance and should be discussed, reviewed and updated regularly in consultation with the substitute decision maker, NOK or statutory health attorney.

Please visit Advance Care Planning Australia's website www.advancareplanning.org.au for state-based information and forms. National Advisory Helpline: 1300 208 582

Please note different states and territories in Australia have different laws and differing terminology regarding advance care planning. A substitute decision maker may be legally appointed as an 'enduring power of attorney' 'enduring guardian,' 'guardian,' or 'agent.' An ACD may also be called an Advanced Care Plan or Advance Health Directive depending on the jurisdiction.

Travelling with myeloma

For most people with myeloma it is completely feasible to go on holidays both within Australia and overseas. It just requires a little more preparation and planning than before diagnosis.

As the nature of the disease is to have periods of being active and in control, the doctor will be able to advise the safest time to travel. For example, if the myeloma is active and requiring treatment, the immune system will be at its lowest. This would not be the best time to travel due to the increased risk of infection and commitments to hospital appointments.

However, it may be possible to travel during periods when the disease is under control and there is either no treatment being prescribed, or treatment is in tablet form and can be continued on the holiday. Pain and fitness levels should also be considered when planning a holiday.

It may also be possible to arrange for infusions for supportive care such as bisphosphonates and intravenous immunoglobulins to be given by hospitals at the holiday destination. The treating team will advise if this is a possibility.

If there is a desire to head overseas, it is advised to choose countries where there is a reciprocal health care agreement with Australia such as New Zealand, the United Kingdom, Italy and Sweden.

A full list of countries and more tips for travelling overseas can be found on the Smart Traveller website www.smarttraveller.gov.au

Being prepared

It is important to be well prepared before heading off on the trip so that if a medical situation arises, the associated stress is minimised. It may be useful to arrange the following things:

- A letter from the specialist with a brief medical history, list of current medications and any allergies. This will help any new health professional quickly assess and diagnose the problem
- Take enough medication for the duration of the trip and pack repeat scripts if necessary
- Ask the doctor if it is appropriate to pack a course of broad-spectrum antibiotics to take at the onset of fever
- Make sure there are enough funds available for an emergency flight home if needed
- Ask the doctor if there are vaccines required for the destination and when is safe to have these.

See the Infection Prevention section of this book for more information about vaccinations

Travel insurance

It can be very difficult to find a travel insurance policy to cover a person with myeloma beyond baggage, theft, flight changes and unforeseen medical issues not related to the myeloma. Some companies have a finite number of 'higher risk' policies available per year that may cover myeloma related expenses.

These are often not advertised online. Calling each company and asking them directly if they can cover myeloma will provide the best chance of success. It is a good idea to confirm if travel partners are also covered for expenses if there is a medical emergency.

It is advisable to disclose the diagnosis of myeloma to ensure cover is provided where possible.

Even after being well prepared and planning a trip during a supposed 'good period', myeloma may still get in the way. It is sometimes possible to obtain refunds or defer bookings even if there is no travel insurance. The treating team can provide documentation to support the case and are always happy to help.

Australian Support Organisations

Myeloma Australia

www.myeloma.org.au
1800 MYELOMA (693 566)

Leukaemia Foundation

www.leukaemia.org.au
1800 620 420

Cancer Council

www.cancercouncil.com.au
13 11 20

Carers Australia

www.carersaustralia.com.au
1800 242 636

Carers Couch

www.carerscouch.com

Palliative Care Australia

www.palliativecare.org.au



International Support Organisations

International Myeloma Foundation

www.myeloma.org

Myeloma UK

www.myeloma.org.uk

Multiple Myeloma Research Foundation

www.themmrf.org

Useful Websites

Medicare and Centrelink Australia

www.humanservices.gov.au

Dietitians Association of Australia

www.daa.asn.au

Australian Physiotherapy Association

www.physiotherapy.asn.au

Exercise and Sports Science Australia

www.essa.org.au

My Aged Care

www.myagedcare.gov.au

Advance Care Planning Australia

www.advancecareplanning.org.au

Memorial Sloan Kettering Cancer Centre (USA) About Herbs Database

www.mskcc.org

National Centre for Complementary and Alternative Medicine

www.nccam.nih.gov

Smart Traveller

www.smarttraveller.gov.au



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