

## EXERCISE IS “INVALUABLE” TO MANAGING RECOVERY SAYS JOHN

**“It’s the best thing I’ve ever done” says John Castell about the exercise program he began in March 2007, almost two years after he developed myeloma.**

“I’d say my physical strength and stamina have improved by 50 to 60%. And it’s not just the exercise. It’s also about interacting with other people who have gone through the same thing, sharing experiences, comfort and support.”

Deb Hayes, the transplant co-ordinator at the Royal Adelaide Hospital told John about a cancer and exercise program and suggested it may help him develop more muscle support.

“I could hardly walk when I went to see Morgan\*,” said John, 58, who now lives at Gawler, 35 km outside Adelaide.

He has three collapsed vertebra and two major fractures in his lower spine and has lost 14cms in height: “I used to be 6’4½ and now I’m 5’11”. I’m shorter than my wife and the shortest person in my family!

“My muscle mass and strength had wasted away and I was in a lot of pain. Getting out of a chair was not an easy task.”

“Straight away I could feel the improvement,” said John about the results he achieved from regular exercise three times a week.

“Now I can comfortably do 30 minutes on the treadmill at five to six km an hour.

“It’s not high impact, but gently builds muscle strength. It really has made a difference and has made me realise the importance of exercise.”

John’s former job as a national account manager saw him spend a lot of time flying around Australia.

“I liked my fishing and had only been out on the water five times in my brand new fishing boat before my diagnosis,” said John who lost 13 kg the week he was diagnosed with myeloma, in July 2005.

At the time he was living in Newcastle and had planned to move back to Adelaide to live. He was “feeling a bit crook” the Saturday morning before he and his wife, Jeanette, were due to tow their boat to Adelaide.

He went to the doctor about chest pain and had a blood test before leaving Newcastle.

“I was feeling pretty ordinary and got as far as Gundagai four hours out of Sydney when I starting vomiting and had to pull over,” said John.

He couldn’t drive, so Jeanette took the wheel and despite having never towed a boat before, she drove straight through to Adelaide, arriving on Sunday night, to drop off the boat, then on to Melbourne, before the couple flew home to Newcastle that Monday night.



*John Castell enjoying a regular workout in the gym*

By this stage John could hardly walk and was suffering severe back pain. He called his doctor who told him he was “gravely ill” with hypercalcemia and needed to go straight to hospital.

At the time, due to a shortage of hospital beds in Newcastle, airlifting him to Sydney was being considered before a bed was found at the Mater Hospital. He took a turn for the worst the next day and was transferred to the John Hunter Hospital in Newcastle suffering renal failure and pneumonia.

When John came out of intensive care four days later he was told he had myeloma and began chemotherapy treatment.

John wasn’t able to work and spent a lot of time in bed over the following five months while the Castells sold their house in Newcastle. They moved to Adelaide in November 2005, where he continued his treatment at the Royal Adelaide Hospital and had an autologous stem cell transplant there in January 2006.

“My para-protein was zero for three years but it started to show its head again in July,” said John so he is back to having six-weekly blood tests. “I’m just hoping it’s not showing any increase. If it does, I’ll go back on treatment.”

“I’ve been given a second chance and if I have to go through it all again, I will. I’ve got too much to live for,” said John.

In July, he shared his disease experience with other patients when he told his story at a myeloma meeting held by the Leukaemia Foundation in Adelaide.

\* Morgan Atkinson, see pages 4 and 5.

# NEW DRUGS PERFORMING WELL IN PRE-CLINICAL TRIAL

**Myeloma cells are proving sensitivity to a promising new class of anticancer agents being trialled by Australian researchers.**

Known as histone deacetylase inhibitors (HDACi), they can cause cancer cell death with remarkably little toxicity. HDACi can also make cancer cells more attractive to the body's immune system as well as directly activating immune cells and increasing their activity.

To help progress research into HDACi, the Leukaemia Foundation awarded a \$100,000 Grant-in-Aid to Associate Professor Ricky Johnstone and Professor Mark Smyth from the Peter MacCallum Cancer Centre in Melbourne.

The pair initiated an advanced preclinical trial to test HDACi compounds and identify new therapeutic approaches for blood cancers, including myeloma.

The myeloma trials have progressed well, according to Associate Professor Johnstone.

"In laboratory experiments, we found that the HDACi compounds led to myeloma cell death, while a significant therapeutic benefit was delivered to mice," he said.

"We've been exceptionally fortunate to trial the compounds in a sophisticated and extremely relevant new mouse model of human myeloma," he said.

"The model was developed by our research collaborator Professor Leif Bergsagel at the Mayo Clinic in Phoenix, Arizona. We were the first group in the world outside his research team to use the mice and it's definitely given us a strong competitive advantage."

The pair now plans to combine HDACi with other agents, such as standard chemotherapeutics and bortezomib, to determine the most effective and safe combination of drugs.

Ultimately their preclinical work will be a precursor for more advanced clinical trials using HDACi in combination with chemotherapy.

## FIRST MEDICINE IN NEW CLASS OF TREATMENTS NOW PBS LISTED

**Revlimid® (lenalidomide), an oral medication for the treatment of myeloma, was listed on the Pharmaceutical Benefits Scheme (PBS) on 1 November for patients who have failed to respond to prior therapy.**

Revlimid is part of a new class of oral, immunomodulatory drugs (IMiDs) that modulate the immune system and affect multiple biological pathways within the cell.

Celgene has provided Revlimid through a compassionate access scheme to patients since approval by the Therapeutic Goods Administration (TGA) in December 2007 until August of 2009. Patients receiving compassionate supply Revlimid may now receive Revlimid through the PBS. Patients should see their healthcare professional to facilitate this change.

Phase III clinical trials demonstrated that patients taking Revlimid and dexamethasone therapy experienced significant

responses in refractory/relapsed myeloma compared to patients taking dexamethasone alone.

Patients taking Revlimid experienced a significant extension of median overall survival (29.6 vs. 20.2 months), more than double the overall response rate (60% vs. 20.5%), and more than double the time to disease progression (11.3 vs. 4.7 months)<sup>i</sup>.

As a result of its unique mechanism of action, Revlimid has a different side-effect profile to other available treatments. Revlimid is well tolerated in most patients due to low toxicity and does not increase peripheral neuropathy (side-effects) compared to dexamethasone alone<sup>ii</sup>.

i Weber D.M. et al NEJM 2007; 357 (21): 2133-42.

ii Dimopoulos M. et al NEJM 2007; 357 (21): 2123-32.

iii Current Approved EU Summary of Product Characteristics

## TELEPHONE FORUMS CONNECT PEOPLE

**The Leukaemia Foundation has launched a new support program for regional patients and families – Telephone Discussion Forums – which connect people with myeloma, wherever they live across Australia.**

It can be difficult for people who aren't living with myeloma to understand what it's like, and patients who live in regional areas may not meet other people with myeloma very often.

These telephone forums are designed to provide the opportunity for people with myeloma to share their experiences, to provide tips, education and to support each other in a relaxed forum. The facilitator is a trained Leukaemia Foundation health professional who is a member of the Support Services team.

Regional patients can make a free call to join the telephone discussion forums and for metropolitan patients, participation is the cost of a local call.

**Myeloma Phone Forum dates:** 1st Thursday of each month from 1-2:30pm (Vic). 5 November, 3 December, 4 February, 4 March, 1 April, 6 May, 3 June

Contact Kaye Hose, 03 9863 6951 or [myeloma@leukaemia.org.au](mailto:myeloma@leukaemia.org.au)

**Transplant Phone Forum dates:** 9 November, 12 January  
Contact Natasha Manoharan, 03 9863 6952 or [nmanoharan@leukaemia.org.au](mailto:nmanoharan@leukaemia.org.au)

*"Thank you for organising the phone forums. It has been so good to talk to other people with myeloma. Living in a rural area, it often feels like you are the only person with myeloma. Until the telephone forums I had not met one other person with myeloma."*

Myeloma telephone forum participant

# UK EXPERT AT SYMPOSIUM

**Professor Gareth Morgan from the Institute of Cancer Research and Royal Marsden Hospital in the UK presented an international perspective on myeloma management in Melbourne in July.**

He was a key speaker at a myeloma symposium, organised by the Leukaemia Foundation, chaired by National Myeloma Coordinator, Kaye Hose, and sponsored by Celgene.

Professor Morgan outlined the complexity of myeloma and the importance of further research into understanding how a normal plasma cell becomes malignant.

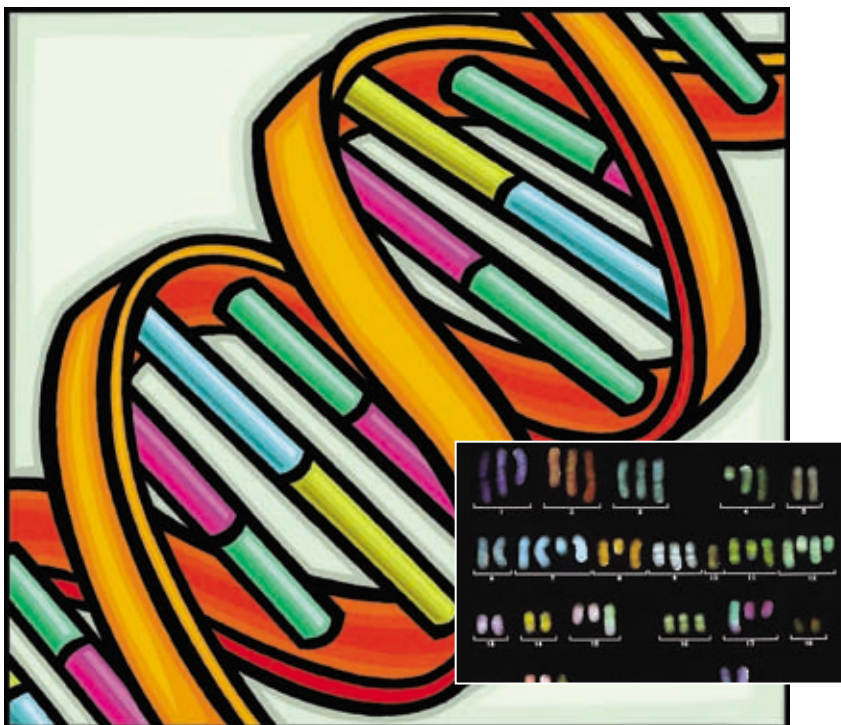
He described the concept of cytogenetics in myeloma. Cytogenetics involves the study of chromosomes which contain DNA – the basic building block required to form a human being. In myeloma, the chromosome is abnormal. This can be displayed by:

- gains of whole chromosomes and regions
- loss of whole chromosomes and regions
- bits that have moved from one chromosome to another – rearrangements.

These genetic changes can be measured using Fluorescence In Situ Hybridization (FISH) which provides researchers with a way to visualise and map the genetic material in an individual's cells, including specific genes or portions of genes. This is important for understanding a variety of chromosomal abnormalities and other genetic mutations. Unlike most other techniques used to study chromosomes, FISH does not have to be performed on cells that are actively dividing, which makes it a versatile procedure.

Professor Morgan clarified that it is useful to have these results but he also uses FISH results in conjunction with other tests. He emphasised the value in having these results and said that in the near future the particular characteristics of a person's myeloma would be used to determine the selection of their appropriate myeloma treatment. At this stage even if someone's myeloma has been identified as high-risk, standard therapy will still be selected based on the person's age.

Professor Morgan said a future approach in myeloma management would consist of determining the inherited genetic makeup of a person, which may predict the risk of potential treatment-related side-effects. This is not yet



*The DNA in the myeloma cell is abnormal*

available in the clinic situation. Targeted therapy, where the best treatment is selected using the genetic makeup or fingerprint of a person's particular myeloma gene, was another important point discussed. This involves using new, targeted therapies to switch off the abnormal gene (where the person has the abnormal gene). This approach is reliant on the development of new tests in the future that better identify people with that specific abnormal gene. These people then can be selected to receive the targeted therapy.

Many drugs currently are being trialed in myeloma and Professor Morgan believes patients will have access to many new drugs that may help control myeloma. He believes we will have the building blocks to achieve operational cures and further research is needed into how these drugs can be best used in combination. The real challenge is to apply them in the appropriate patient groups.

A DVD will soon be available from Professor Morgan's talk. If you are interested in a copy, please contact Kaye Hose: [myeloma@leukaemia.org.au](mailto:myeloma@leukaemia.org.au) or ph 03 9863 6951.

## PESTICIDE EXPOSURE AND MGUS

*From the International Myeloma Foundation's newsletter, Myeloma Today, Summer 2009 issue*

**As reported in *Blood* (18 June 2009, Vol. 113, No. 25, pp. 6386–6391), pesticides are associated with excess risk of myeloma, albeit inconclusively.**

The study looked at 678 men (ages 30 to 94) to assess the risk of monoclonal gammopathy of undetermined significance (MGUS).

Age-adjusted prevalence estimates of MGUS were compared with MGUS prevalence in 9469 men from Minnesota, and associations between pesticide exposures and MGUS prevalence were assessed by logistic regression models adjusted for age and education level.

Among 555 study participants older than 50 years, 38 were found to have MGUS, yielding a prevalence of 6.8%. Compared with men from Minnesota, the age-adjusted prevalence of MGUS was higher among male pesticide applicators. Increased risk of MGUS prevalence was observed among users of the chlorinated insecticide dieldrin, the fumigant mixture carbon-tetrachloride/carbon disulfide, and the fungicide chlorothalonil.

The prevalence of MGUS among pesticide applicators was twice that in a population-based sample of men from Minnesota, adding support to the hypothesis that specific pesticides are causatively linked to the origins of myeloma.

# STRUCTURED EXERCISE PROGRAMS PEOPLE WITH MYELOMA

By Morgan Atkinson, Exercise Physiologist,  
Centre for Physical Activity in Ageing



**Physical rehabilitation and exercise training have become integral components in the treatment and management of chronic diseases such as diabetes, obesity, arthritis and cardiac disease.**

The potential health benefits of exercise are especially pertinent for cancer patients, for whom cancer and its associated treatments can bring about various physical and psychosocial side-effects that can not only impact on physical function but influence emotional, social, financial and psychological wellbeing of the person and family.

Structured exercise programs for cancer patients have been proven to:

- enhance muscular strength and endurance
- improve bone density
- maintain/achieve a healthy body weight
- improve joint range of motion
- reduce cancer-related fatigue (CRF)
- reduce nausea and improve appetite
- reduce duration of hospitalisation.

All these outcomes provide significant benefits for cancer patients in terms of their ability to integrate back into their daily life and peer groups while undergoing and after completing their cancer treatment.

## **Muscular strength**

Cancer treatments and drugs that treat side-effects damage healthy cells throughout the body and often cause nausea, vomiting, decreased nutritional intake and anaemia. These factors lead to higher levels of fatigue, decreased physical activity, reduced nutritional intake and lengthened bed rest which all contribute to muscular atrophy (muscle wasting).

Exercises that enhance muscle mass can be highly beneficial, preventing wasting, improving energy, increasing appetite and daily functional ability.

Patients should ensure a slow gradual progression when undertaking strength exercises so as not to aggravate fatigue, or cause excessive soreness or injury.

## **Endurance**

Endurance is the ability to persist with an activity for a prolonged time. Being able to sustain an activity for a longer

period is determined by the ability of the heart to deliver oxygen (fuel/energy) to working muscles. Cancer treatment affects the heart's ability to transport oxygen to working muscles, thus reducing the ability to maintain activity for a prolonged period.

Exercise is shown to improve cardio-respiratory function when undertaken regularly, even if the activity is low to moderate in intensity.

Typically, exercise that is repetitive or rhythmic in nature (such as walking or cycling) and that incorporates large muscle groups, is very effective and is easily monitored for intensity and progression.

## **Flexibility**

Flexibility is the ability to move a joint through its full range of motion.

Joint range is heavily dictated by the regular functional activities you engage in. Muscles and ligaments adapt to the postures/movements which we regularly undertake. Sedentary habits can reduce joint range and flexibility which can take considerable time and effort to later regain.

Maintaining regular movements and even undertaking a gentle stretching routine is worthwhile. Stretches are easily prescribed and can be done at home, taking up just a few minutes each day.

## **Bone health**

It is important to monitor bone health as cancer and its treatments can cause an increased risk for future bone complications such as osteopenia (and eventual osteoporosis), osteonecrosis and osteophytes.

Osteopenia results when bone mineral density decreases, but can be positively influenced by regular weight-bearing activity such as walking, jogging, or a supervised weights program.

Osteonecrosis occurs when bones lose their blood supply and eventually collapse. The support structures around the affected bone need to be maintained to ensure stability and avoid fractures where possible. Furthermore, balance exercises should be considered where there is a falls risk.

Osteophytes are protrusions of bone and cartilage that often cause reduced joint range of motion and pain depending on location. Exercise can gradually improve in joint range, circulation and joint stability.

## **Cancer-related fatigue**

Fatigue is a feeling of weariness, tiredness, or lack of energy that presents itself both physically and mentally. Persistent fatigue has been shown to be one of the biggest concerns for cancer survivors.

There are many factors that can trigger fatigue and some of the most common are pain, nausea, vomiting, diarrhoea, sarcopenia (loss of muscle mass) and anaemia. Some medications also can intensify feelings of fatigue.

A moderate exercise program can reduce fatigue by:

- building muscle mass (offsetting feelings of weakness)
- increasing appetite
- reducing side-effects of medication
- boosting energy levels
- increasing quality of sleep.

# HAVE SIGNIFICANT BENEFITS FOR

## Body image

Body image refers to the individual feelings we have about our appearance and physical state. These may include:

- weight loss/gain
- muscle loss
- appearance after surgery
- physical performance.

Exercise can be used as a means of countering negative feelings about our image in all of these areas. Further, where depression and anxiety play a part in influencing self-image, research supports a positive role for exercise as well.

## Anxiety and depression

Common causes of these conditions are lack of physical health, a sense of helplessness, pain and alteration in body image. If action is not taken to address these concerns, patients can experience further deterioration in outlook, functional ability and this can potentially influence treatment outcomes.

Research has shown that people who remain physically active have an improved quality of life and a lower incidence of anxiety and depression.

Consider that by undertaking exercise you are:

- **Empowering yourself** to combat losses in strength, endurance and mobility.
- **Doing something positive** towards controlling weight (loss/gain) and improving body image.

- **Deciding to take control** of a situation where many patients feel there is none.

## Social networking and support

Studies indicate that survivors who undertake exercise in a group setting have increased motivation, better functional improvement, improved body image and self concept, and lower levels of distress.

Group exercise sessions provide access to other patients/survivors with similar circumstances, treatment regimens and prognoses. Often these social bonds are valuable in establishing social connections and support whether it's during initial diagnosis, treatment, or in remission.

## Medical Consent (by GP, oncologist, haematologist)

Exercise is permitted before, during, after treatment for cancer, but it **must be medically safe to do so**. It is also important to seek professional advice either through an exercise physiologist\* or physiotherapist prior to starting any exercise program.

*\* An exercise physiologist is someone who is trained to deliver exercise programs for people with chronic disease and illness and they can be accessed through the Australian Association for Exercise and Sports Science website: [www.aaess.com.au](http://www.aaess.com.au). When you work with an exercise physiologist, the aim is to ensure that no harm is caused when you undertake exercise and that the prescription is appropriate for your medical circumstance and personal goals.*

**Exercise physiologist, Morgan Atkinson, manages one of the largest clinically-based cancer and exercise programs in Australia.**

**Morgan (right), who is a leukaemia survivor, started the cancer and exercise program for the Centre for Physical Activity in Ageing in 2006 after completing his Bachelor of Health Science Honours thesis.**

**In the last 12 months nearly 100 people have been through the program at the Hampstead Rehabilitation Centre, which is part of the Royal Adelaide Hospital.**

**“The program helps cancer patients regain their physical strength following treatment, and return to a normal life,” he said. “We’re getting really good feedback and there is some amazing improvement physically, especially by myeloma patients.”**

**The program begins with a 10-week intervention with two to three sessions a week and gradual progression of the exercises, followed by a reassessment to see if there has been any improvement.**

**“Participants also are empowered regarding overall better health and they are encouraged to take that knowledge out into the community and to continue for life,” Morgan said.**



## VELCADE (BORTEZOMIB) PBAC UPDATE

**At its July 2009 meeting, the Pharmaceutical Benefits Advisory Committee made a positive recommendation that Velcade® be approved for use at second line (after thalidomide) in patients with relapsed and refractory multiple myeloma.**

This change came into effect from 1 November 2009. This development now enables patients with myeloma to access

Velcade after only one prior therapy (thalidomide) instead of the two prior treatments (of which thalidomide was one) as previously required.

Janssen-Cilag also is working closely with the Federal government to find a timely way forward for the use of Velcade for patients with newly diagnosed (non-transplant eligible) myeloma.

# GITA'S STRONGER & MORE ACTIVE

**Gita Ramchand, who was diagnosed with myeloma in March 2006, now takes part in two gym sessions, an aqua aerobics class and a Latin American dance class every week.**

"Exercise has added so much to my quality of life," says Gita, 59, who also works one day a week.

Gita recommends everyone do regular weight-bearing exercise and she has converted some of her friends to take up this activity.

Side-effects of Gita's myeloma treatment included neuropathy in her feet, diabetes and muscle wastage. Two years ago she had difficulty getting in and out of her car, had to drag herself up and down her six front steps, and being extra cautious, she watched a lot of TV.

Now she's much more active, has lost weight, carries the groceries up the stairs and plays with her grandchildren: "I'm in a better frame of mind, have more confidence and I fit more into my day, even though gym takes up most of the morning."

In 2005 Gita travelled overseas four times, including a trip to India to visit her mother who was dying.

"There was so much happening in my life at the time," she said, describing the 12 months immediately before her diagnosis which included her son's wedding and painting the lounge and dining room at home.

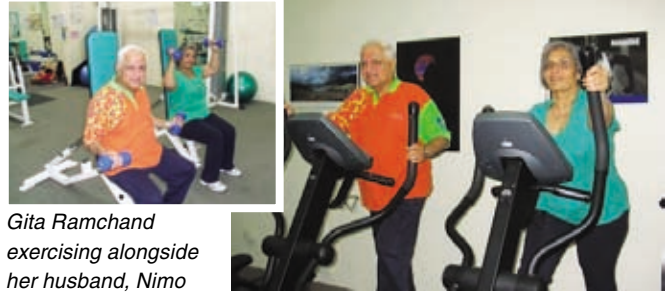
"I was so tired I could hardly stand, and when I went shopping I had to sit down every 10 minutes. I was so out of it and just like a robot."

Gita regularly saw her GP, was prescribed three to four doses of antibiotics on two occasions that year to get over infections and had blood tests, but nothing was picked up: "I thought maybe it was the menopause."

Out shopping one day, Gita felt so exhausted she opted to have a free chiropractic assessment, just for the opportunity to lie down. She had a spinal X-ray and neurological tests and the radiologist's report noted an unusual gap between the bones in Gita's thigh and suggested further investigation.

Gita took this result to an appointment with her daughter's GP who ordered a general blood test. After further investigation this GP referred Gita to an oncologist who suspected she had Waldenstrom's macroglobulinemia – a rare form of cancer.

"I was in shock and now I understand that I had hypercalcaemia (too much calcium in her blood)," said Gita who was immediately



*Gita Ramchand exercising alongside her husband, Nimo*

admitted to hospital for bisphosphonates to treat this condition, followed by a blood transfusion. Gita also had a bone marrow biopsy and a blood test that showed she had a paraprotein reading of 69.

"It should have been zero," she said.

She was then diagnosed with myeloma and looking back, Gita realises she had several typical myeloma symptoms – "terrible backache, fatigue, exhaustion and I was a bit vague about everything".

Gita began chemotherapy treatment and six months later, in September 2006, after a successful stem cell harvest, she had a stem cell transplant.

Disappointed that her paraprotein level had not gone to zero as hoped, she began maintenance treatment and gradually over six months her reading steadily dropped from eight, until it became undetectable.

After the transplant, Gita said she started to consider her body "as precious". She began juicing fruits and vegetables, ate healthy food and started exercising, initially walking with her husband, Nimo, who is also a diabetic.

She joined Nimo at a community rehab centre where she began doing resistance training: "This helped me get a bit stronger and steadier on my feet."

It also gave her the confidence to join a Deakin University-run study, held at a gym two streets away from their home, that is assessing factors that successfully change a diabetic's lifestyle to incorporate regular resistance training at a gym.

Gita also discovered that the gym had a dancing class, which she "absolutely loves", and she has enrolled in a second weekly dance class that begins next term.

"It's important that you start exercising very slowly and have a supervisor – someone who knows your situation. And you need to persevere. It took at least six weeks for me to start noticing a difference."

## MYELOMA TIPS

**In future issues of *Myeloma News* we would like to include tips from our readers – both patients and carers – so we are asking for your input.**

These myeloma tips may relate to anything you have found useful in managing the experience of living with myeloma and any side-effects, navigating the hospital system, or something else you have learned along the way which you really would have liked to have known about earlier. We are also seeking tips from carers.

Keep in mind that your tip could help another member of the myeloma community.

The following tip is reprinted with permission from the Dana-Farber Cancer Institute in the U.S.

*When taking steroids your appetite usually increases. To fight the battle of the bulge, try increasing your intake of fruits and vegetables.*

*This can include:*

- *munching on carrots or celery sticks and other vegies*
- *crunchy fruits like apples may satisfy the need to snack*
- *try rice cakes or air-popped/light microwave popcorn, instead of high calorie snacks*
- *choose no-salt added pretzels and crackers*
- *try fresh fruit topped with low-fat yoghurt.*

Email your own personal tips to Kaye Hose, National Myeloma Coordinator on [myeloma@leukaemia.org.au](mailto:myeloma@leukaemia.org.au).

# MEDICAL IMAGING EXPLAINED

By Clinical Associate Professor Eddie Lau, Peter MacCallum Cancer Centre

**Medical imaging is the term applied to the area of medicine that deals with the various methods used to make pictures of the human body and the diseases which can affect it. The common imaging tests used in myeloma are X-ray, Magnetic Resonance Imaging (MRI) and sestamibi scan.**

## X-rays

X-rays use a beam of low-energy radiation that passes through tissues of the body to make a picture. The picture obtained depends on the tissue density. Bone is very dense and therefore stops particles from reaching the film and that is why bones appear white on an X-ray. Bones may be damaged by myeloma deposits and they may show up as holes (lytic lesions) or broken bones (fractures). If a myeloma patient has bone pain, an X-ray is often the first imaging test done.

## Magnetic Resonance Imaging

MRI uses radiowaves and a magnet to create an image of the body. The magnets used are powerful but very safe, except in patients with a cardiac pacemaker, or some other metallic foreign objects in their body. If you have any doubts about the safety of MRI for you, it is wise to check. MRI shows many tissues in more detail than X-rays and therefore can detect small myeloma deposits in the bone marrow. However, MRI is more expensive and its availability is more limited.

## Sestamibi scan

Sestamibi scan is a type of nuclear medicine imaging test which uses a very small amount of radioactive material (radiotracer). The radiotracer emits gamma-rays (a form of X-ray) and is administered into a vein. The distribution of the radiotracer in the body is then detected by a gamma camera that moves over the patient, generating an image of abnormal tissues. Sestamibi is trapped by active tissues, such as active myeloma deposits, and the areas that are positive on the scan are often called 'hot spots'.

Less common imaging tests include Computed Tomography (CT), bone scan and Positron Emission Tomography (PET) scan.

## Computed Tomography

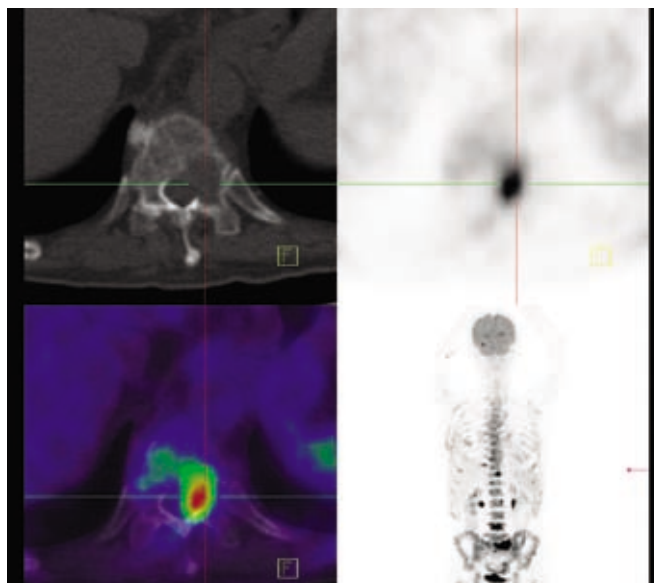
CT scan is simply a fancy X-ray that uses a tubular ring of X-ray detectors that encircles the patient to create cross-sectional views of the patient.

## Bone scan

Bone scan is another nuclear medicine imaging test. It uses a bone-seeking radiotracer that shows up abnormal tissues with a high bone turnover. It can be useful in detecting myeloma deposits which are large enough to cause significant bony destruction, therefore causing higher bone turnover. Bone scan is however not very sensitive for detecting all myeloma deposits because early deposits may not destroy enough bone to show up as 'hot spots'.

## Positron Emission Tomography scan

PET scan is a new type of nuclear medicine imaging test that uses a special group of radioactive materials that give out (emit) positively charged particles called positrons. Nearly all clinical PET scans use a positron emitting material that is tagged to a sugar, called Fluoro-Deoxy-Glucose (FDG). Because sugar is used, areas that are metabolically active or 'use sugar for fuel' show up as 'hot spots'. Things that grow



*PET/CT images of a patient with newly diagnosed myeloma (top); MRI machine (centre); Clinical Associate Professor Eddie Lau (above)*

more quickly, like cancer cells and this includes myeloma deposits, can take up sugar quickly and will show up as 'hot spots'. Therefore PET scan also has been labelled somewhat inaccurately as a 'cancer scan' in the press. PET scan can be used to assess the distribution and activity of myeloma disease. It may also be useful in the evaluation of treatment response. The modern PET scanners are often combined scanners that incorporate both PET and CT, called PET/CT scanners, which allow more accurate localisation of the abnormal active tissues in the body. The number of PET scanners in Australia is limited – just over 20 – and Medicare funding is not available for performing PET scans on myeloma patients.

**Acknowledgement:** Special thanks to Associate Professor John Seymour, head of haematology at Peter MacCallum Cancer Centre, for his input.

# EDUCATION AND SUPPORT PROGRAMS

NEW SOUTH WALES		
SYDNEY METROPOLITAN		
Dates & Time	Topic / Speaker	Venue
18 Nov	South-east Sydney Metro <i>Taking Control</i> program	Leukaemia Foundation Boardroom, Level 2, 42-44 Chandos St, St Leonards
November (TBC)	Education Seminar: <i>Bone Marrow Transplants / Annabel Horne, Bone Marrow Transplant Clinical Nurse Consultant</i>	Leukaemia Foundation Boardroom, Level 2, 42-44 Chandos St, St Leonards
CANBERRA & SURROUNDS		
3 Dec	<i>Caring for the Carer</i>	Woden Public Library Meeting Room
CENTRAL WEST		
1 Dec 6:30-9:30pm	GP Evening Talk, <i>Myeloma</i>	Dubbo
3 Dec 10:30am-12noon	Patients' Morning Tea & Christmas Party	Suite 5, Anson St Plaza, Orange
8 Dec 10.30am- 12noon	Patients' Morning Tea & Christmas Party	Daffodil Cottage, Bathurst
16 Dec 10.30am-12noon	Patients' Morning Tea & Christmas Party	Alan Coates Cancer Centre, Dubbo
RIVERINA AND SOUTH WEST NSW		
19 Nov 2-4pm	<i>Radiotherapy FAQ</i>	Murray Valley Private Hospital boardroom
GOSFORD		
21 Nov; 28 Nov 10am - 1pm	<i>Looking After You</i> , six-session course	Narra Community Centre, 2 - 12 Pandala Rd, Narara
26 Nov 10-11.30am	Haematology Support Group	Cancer Council Community Hub, The Hive
10 Dec 2.30-4pm	Haematology Support Group	San Remo Neighbourhood Centre, 28 Brava Ave, San Remo
WESTERN AUSTRALIA		
PERTH METROPOLITAN		
27 Nov	Carers' Coffee Morning	Tart's Café, 212 Lake St, Northbridge
10 Dec	<i>Complementary Therapies</i>	Level 3, Conference Room, St John of God Hospital, Subiaco
VICTORIA		
MELBOURNE METROPOLITAN		
18 Nov; 16 Dec 10.30am-12 noon	Yoga session	Leukaemia Foundation Bell City, Event Centre, 205 - 215 Bell St, Preston
25 Nov	<i>Introduction to Meditation</i>	Leukaemia Foundation Bell City, Event Centre, 205 - 215 Bell St, Preston

GRAMPIANS		
25 Mar 10am-12noon	<i>Understanding Myeloma &amp; Lymphoma</i> DVD viewing	Horsham Library
22 Apr 10am-12noon	<i>Medications: Q &amp; A session</i>	Ballarat Library
24 Jun 10am-12noon	<i>Understanding Myeloma &amp; Lymphoma</i> DVD viewing	Ballarat Library
GIPPSLAND		
23 Nov 1.30-3pm	East Gippsland Support Network	Riversleigh Comfort Inn, Bairnsdale
GEELONG		
November (TBC)	<i>Traditional, Complementary &amp; Nutrition Management</i> , Dr Craig Hassed	Mecure Geelong Hotel, Cnr Gheringhap & Myer Sts, Geelong
TASMANIA		
18 Nov 11am-1pm	<i>Taking Control: The Role of Exercise</i>	Tamar Yacht Club, Park St, Launceston
19 Nov 11am-1pm	<i>New Horizons in Myeloma Management</i>	Devonport
2 Dec	Gala Christmas Lunch	Tamar Yacht Club, Park St, Launceston
25 Feb; 29 Apr; 24 Jun	Myeloma Support Group	Northern Tasmania, TBC
SOUTH AUSTRALIA		
18 Nov; 16 Dec 10:30am	QEH Carers' Coffee Group	North East Ground Seminar Room, QEH Hospital
25 Nov 10:30am	Friends of the Foundation, Northern Metro Support Group	Sainsbury East Neighborhood Centre, 28 Smith Rd, Salisbury East
27 Nov 10:30am	Carers' Coffee Group	Palais Café (Opposite RAH)
TELEPHONE FORUMS		
Myeloma Phone Forum	Facilitator: Kaye Hose Ph: 03 9863 6951	1st Thursday of every month; 1-2:30pm (Vic). 5 Nov; 3 Dec; 4 Feb; 4 Mar; 1 Apr; 6 May; 3 Jun
Transplant Phone Forum	Facilitator: Natasha Manoharan Ph: 03 9863 6952	9 Nov; 12 Jan

More information: visit [www.leukaemia.org.au](http://www.leukaemia.org.au) (education & support programs section)

**LEUKAEMIA FOUNDATION SUPPORT SERVICES**  
PH: 1800 620 420 (FREECALL)

**NATIONAL MYELOMA COORDINATOR**  
**KAYE HOSE PH: 03 9863 6951**  
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## OUR VISION TO CURE AND MISSION TO CARE

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation provides emotional support, accommodation, transportation and practical assistance for patients and their families. It also funds research into cures and better treatments for leukaemias, lymphomas, myeloma and related blood disorders.

The Foundation receives no direct ongoing government funding and relies on the continuous support of individuals and corporate partners to provide its services and to fund its research programs.

To find out more about the work of the Leukaemia Foundation and how we can help, phone 1800 620 420 or visit [www.leukaemia.org.au](http://www.leukaemia.org.au).

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Disclaimer: No person should rely on the contents of this publication without first obtaining advice from their treating specialist.

