

MYELOMA FREED UP LOIS TO ENJOY LIFE, FAMILY & FRIENDS MORE

Casual attire is now the norm for Lois Booth, 64, of Fremantle. So is catching up with friends and family every week, spending special time with her six grandchildren and generally having a good time!

Gone are the long working hours, work stress, conferences and professional suits that were all part of Lois' job as a human resources manager at a Western Australian university.

"My life changed in an instant," said Lois about her diagnosis with aggressive myeloma in December 2006.

The first sign that something was wrong was six months earlier, in July, when Lois had a series of severe vomiting attacks. Over the following months she "didn't feel right", was constantly extremely tired and developed unexplained bruising on her left arm. But Lois, who was finishing a Masters degree as well as working, was too busy to take time off.

During her Christmas break, she decided to have a blood test. It was abnormal and another test showed she had myeloma.

"All I heard was that I had a cancer that was incurable but treatable. The GP was gently telling me a lot more, but I don't think I heard anything else."

Lois began treatment (bisphosphonate) the next morning and more blood tests and a bone marrow biopsy confirmed her paraprotein levels were extremely high and revealed she had holes in some of her bones.

She left her job because the chemotherapy required five to six days of hospitalisation each month for six to seven months. She managed to complete her thesis, with help from her lecturer, her sister who assisted with editing, and encouragement from her friends, and graduated from Murdoch University with a Masters degree in April 2007.

In August that year, Lois had a stem cell transplant using her own cells, which took three days to collect.

"Finally there was enough for two transplants. This means that a second transplant might be possible in the future when my condition changes," said Lois.

During the transplant Lois spent five weeks in hospital: "It was one of the most difficult periods in my life. But I'm amazed at the results. Thank goodness for medical research.

"I feel fortunate that I'm having treatment at this point in time rather than five to 10 years ago."



Lois Booth in March 2007 after beginning chemotherapy treatment

Lois' foreseeable future looks promising: "I am now in remission and my blood results and paraprotein levels are quite good.

"I still get occasional infections and experience regular bone pain and headaches, but these problems are manageable with medication.

"Like many myeloma patients, I take thalidomide and prednisolone and feel concerned about taking such strong medication," said Lois who also has bisphosphonate every three months and sees her haematologist every second month.

"I know my journey is not over but at least I now understand more about myeloma and I am encouraged by the progress made in treating this disease since I was diagnosed.

"I'm aware that at this stage of my journey I am more fortunate than many other myeloma patients and don't wish to undermine some of the difficulties they are facing.

"2007 was not the best year of my life, but I've made up for it since. Today I count every day as a blessing," said Lois who enjoys a good quality of life.

"This experience has taught me to really value life and my friends and to love my family even more.

"Although this diagnosis came at an inopportune time, in a way it freed me up for other things."

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COMBINATION THERAPY SUPERIOR

The large, international Phase III VISTA trial shows continued survival improvement for patients with previously untreated myeloma who were given Velcade® (bortezomib), melphalan and prednisone (VcMP).

Updated results reported at the 50th annual meeting of the American Society of Hematology (ASH) last December in San Francisco (U.S.) showed the Velcade combination demonstrated consistent efficacy in all patient sub-groups including those with poor prognostic characteristics such as advanced age, poor risk cytogenetics and renal impairment.

“The ultimate goal in treating multiple myeloma is to prolong the patient’s life,” said Professor Jesús San Miguel, M.D., Ph.D., Hospital Universitario de Salamanca (Spain) and Principal Investigator of the trial.

“The follow-up data from the VISTA study showed that the addition of Velcade to melphalan and prednisone continued to demonstrate a long-term survival advantage for patients with previously untreated multiple myeloma,” said Professor San Miguel.

The VISTA trial enrolled 682 patients with previously untreated multiple myeloma who were not eligible for stem cell transplantation. The first interim analysis was presented at ASH 2007. Data with a median follow up of 25.9 months were presented at last year’s ASH meeting.



Professor Jesús San Miguel

To read the abstract: *Updated Follow-up and Results of Subsequent Therapy in the Phase III VISTA Trial: Bortezomib Plus Melphalan–Prednisone Versus Melphalan–Prednisone in Newly Diagnosed Multiple Myeloma*, visit: <http://ash.confex.com/ash/2008/webprogram/Paper8075.html>

CANCER PATIENTS WANT THE TRUTH AT ALL COSTS

From *Canberra Times*, 19 November 2008, p3; *The Age*, 19 November 2008, p12

Some cancer patients have learnt their oncologist did not tell them about a relevant drug because the treatment was too expensive, a study has revealed.

The finding reflects research showing up to 40% of oncologists would hesitate to inform a patient of a drug, which might cost up to \$1000 a week.

University of Sydney Associate Professor of medical oncology Fran Boyle said many oncologists felt it was kinder not to mention expensive drugs not subsidised on the Pharmaceutical Benefits Scheme.

Professor Boyle said some of these drugs might increase the chances of curing a patient or extend their survival.

“Oncologists are in a terrible dilemma,” she said. “If they say to the patient, ‘Here’s an option for your treatment, but the cost is going to be exorbitant’ - is that going to add so much to the distress of that patient, when they’re already in a vulnerable position?”

Professor Boyle, an oncologist at Mater Hospital in Sydney, spoke to fellow oncologists at a Clinical Oncological Society meeting in Sydney yesterday. She said cancer patients wanted

them to be more up front about available drug treatments.

Several participants in the study had found out about a drug after being treated, which they thought would have been useful in their recovery. They described this as a real breach of trust, Professor Boyle said.

“Almost all the women we surveyed, 96%, said they wanted to be informed about high-cost drugs, whether or not they could afford them,” she said.

Breast Cancer Network Australia chief executive Lyn Swinburne said the research sent a clear message from women: they wanted to be told the whole story.

“These results provide that knowing a treatment choice is far more important than any potential distress at not being able to afford the treatment,” Ms Swinburne said.

The survey, involving almost 50 breast cancer patients across Australia, was conducted by University of Sydney medical student Emily Kaser with Breast Cancer Network Australia.

People affected by myeloma who would like to know about all possible treatments regardless of the cost can contact the Leukaemia Foundation’s National Myeloma Co-ordinator, Kaye Hose, by email: myeloma@leukaemia.org.au or phone: 03 9949 5800.

MYELOMA BREAKTHROUGH

For the first time, a consistent genetic abnormality has been identified in myeloma development.

Canadian researchers have identified a key gene which could predispose people to developing myeloma and significantly reduce their survival.

University of Alberta researchers led by Professor Linda Pilarski have investigated hyaluronan synthase 1 (HAS1) gene, an enzyme that makes hyaluronan, a sugar molecule which is known to play an important role in cancer spread, including myeloma.

During patient-based investigations, they found patients with myeloma and Waldenstrom macroglobulinemia had a substantial number of inherited and acquired variations of the HAS1 gene which were absent in healthy people as well as patients with leukaemia. For any individual patient, the variations in the gene included as many as 20 very small

RESEARCHERS IMPROVING SCT SURVIVAL

The Leukaemia Foundation is pushing for better stem cell transplant (SCT) survival rates, funding ground-breaking studies into new treatment options for post-transplant complications.

Autologous SCT provides an important treatment option for many myeloma patients but the procedure leaves patients' immune systems severely weakened and vulnerable to attack from normally harmless infections.

Foundation-funded researchers at the Westmead Institute for Cancer Research in Sydney have successfully used donated immune cells to protect blood cancer patients post-transplant against potentially lethal viral infections.

Using donor cells, Dr Kenneth Micklethwaite successfully treated 21 patients for one of the most common post-transplant viruses, cytomegalovirus (CMV).

"Left untreated, cytomegalovirus can be lethal in transplant patients," said Dr Micklethwaite.

"To combat the virus, we took anti-CMV immune cells from each patient's bone marrow donor and grew these cells to

UNDERSTANDING CELL DEATH

Immortality and immunity to anti-cancer drugs is the secret to every successful myeloma cell.

Each day, 50 to 70 billion cells which have become old, damaged or stressed die in the average adult. Known as apoptosis, cell death is a normal, healthy process. Yet, understanding this process could be critical to effectively treating myeloma.

It appears that cancers, such as myeloma, are able to live indefinitely, continuing to divide and multiply, because one or more of the mechanisms controlling cell death are switched off.

There is also increasing evidence to suggest that the genes controlling cell death and survival are damaged in cancer cells and that this could be a major cause of cancer cell resistance to chemotherapy treatment.

To help increase our understanding of apoptosis and its role in myeloma and other blood cancers, the Leukaemia Foundation has funded four research projects at the Walter and Eliza Hall Institute in Melbourne.

Dr Erinna Lee, a Postdoctoral Fellow, hopes to "untangle" the complex interplay between members of a protein family which

changes, as well as the insertion, deletion and substitution of genetic material, according to Professor Pilarski.

"We identified a large series of genetic changes in myeloma and Waldenstrom macroglobulinemia patients ... and showed that the variations to the HAS1 gene correlate with the production of abnormal proteins unique to the cancer," she said.

These abnormal proteins correlated with poor outcome in a small group of myeloma patients.

"This information has the potential for use in predicting the risk of developing myeloma as well as allowing us to partially control myeloma cells. It could also lead to a better understanding of disease progression, potentially leading to innovative therapeutic strategies," Professor Pilarski said.

The research was recently published in the prestigious journal, *Blood*.

large numbers in the laboratory before they were injected into the patient," he said.

"While anti-CMV cells will develop naturally after a transplant, it can take a long time for the body to produce the same number of cells that we injected.

"The benefit of the treatment appeared to be extremely beneficial as none of the patients in our trial have needed toxic antiviral drugs to treat CMV.

"We hope this approach will prevent CMV infection occurring after transplant, which would improve the survival rate of bone marrow transplant patients and make transplants a safer and more effective treatment for people with blood cancer."

The procedure is being refined and tested against additional viruses in a clinical trial run by haematologist, Dr Emily Blyth.

The Foundation is also funding clinical haematologist, Dr Siok-Keen Tey from the Queensland Institute of Medical Research, who is studying how the immune system rebuilds itself after a transplant, how this affects the risks of infection, and what can be done to improve a patient's ability to fight viral infection.

are important regulators of cell death.

"A better understanding of apoptosis is vital for identifying and understanding the best targets to develop therapeutic drugs to improve the treatment not just of blood cancers but also all other types of cancers," said Dr Lee.

PhD candidates, Lina Happo and Francine Ke, are studying specific genes which appear to play a role in allowing blood cancer cells to resist anti-cancer treatments. Their respective work has the potential to improve our understanding of the effectiveness of drugs and the design of new treatments.

Also looking to help identify new anti-cancer drug targets as well as understand the side-effects of current therapies is PhD candidate, Michael White. He is investigating the link between cell death, blood cell production, chemotherapy and the clearance of dying cells.



Dying white blood cells (photo courtesy of Science Photo Library)

MILESTONES IN MYELOMA THERAPY:

Several important developments in myeloma treatment were presented at the American Society of Hematology (ASH) 2008 annual meeting last December.

Dr Robert Orlowski, Director of the Myeloma Section, and Associate Professor in the Departments of Lymphoma and Myeloma and the Experimental Therapeutics Division of Cancer Medicine at the University of Texas M. D. Anderson Cancer Center in Houston (U.S.) said that the new drugs approved to treat myeloma in the last five years have had a dramatic impact — and there are many more promising therapies under study. Dr. Orlowski describes several of the emerging treatments for newly diagnosed patients and for patients with relapsed or refractory myeloma.

PROGRAM HIGHLIGHTS FOR PATIENTS WITH PREVIOUSLY UNTREATED MYELOMA

An important study finding for newly diagnosed patients is that a better response to treatment before transplant suggests that the outcome after transplant is also likely to be better. This finding is significant because there is now a lot of evidence that induction therapy with newer drugs, such as Velcade® and Revlimid®, offers patients a better response compared to the response from the older standard treatments, such as VAD (vincristine, Adriamycin® and dexamethasone) or thalidomide with dexamethasone. So, a good response to newer drug combinations — for example, Velcade with dexamethasone (VD) predicts for a better response after transplant.

Study findings presented at ASH 2008 comparing VAD to Velcade + dexamethasone showed a 65% response rate in a group of patients treated with VAD compared to an 82% response rate in the group of patients treated with Velcade and dexamethasone. Both groups of patients went on to receive either a single or a double autologous stem cell transplant. The VAD group had a 47% very good partial response or better. The Velcade-dexamethasone group had a 68% very good partial response or better. Also, patients who received Velcade-dexamethasone plus transplant were less likely to have relapsed myeloma compared to patients treated with VAD plus transplant.

The VAD versus VD study results also showed that more patients who had VAD therapy had two transplants; fewer

patients treated with Velcade and dexamethasone needed two transplants.

In another study, the addition of Velcade showed a doubling of the best quality responses compared to the standard combination of thalidomide and dexamethasone for previously untreated myeloma. In this study, thalidomide and dexamethasone was compared with a combination of Velcade, thalidomide and dexamethasone (VTD), followed by transplant.

Patients in the VTD group had a better overall response rate, 94%, versus 79% for the thal-dex group. For the patients who had very good partial response or better, it was 29% for the thal-dex group versus 62% with VTD. Patients then typically went on to stem cell transplantation and again, patients who got VTD plus transplant were less likely to suffer disease progression than patients who got only thalidomide and dexamethasone.

Data was presented that updated earlier studies comparing the combination of Revlimid with high-dose dexamethasone versus Revlimid with low-dose dexamethasone. The findings indicated that patients can receive a lower dose regimen, tolerate it better, and probably because of that can stay on treatment for a longer period of time and ultimately have a better response. The two-year overall survival was 88% with low dose dexamethasone and 78% with the high dose dexamethasone.

If you have newly diagnosed myeloma and you're a transplant candidate, should you get a Velcade combination therapy or should you get a Revlimid combination therapy? One potential answer actually is that you may be able to do best with both — in the future, patients who are transplant candidates may be treated with Revlimid, Velcade and dexamethasone (RVD). A smaller study presented at ASH 2008 showed that RVD was tolerable and basically 100% of patients had a response. About one out of four had a complete response. Another one-third had a very good partial response.

Many patients ask, with all of the new drugs that we have now, do I still need to think about doing a stem cell transplant? At present, that question has to be answered individually for each patient, depending on their disease characteristics, their overall health and their personal preferences.

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Most summer days begin with walking and swimming at Port Beach in Fremantle and during cooler weather she walks near the Swan River or on other walking tracks.

Over the last two years Lois has had several holidays and in July she's off on a cruise to Asia and in October she's going to a wedding in Broome.

"My small superannuation fund is reducing quickly and I've jokingly warned my children that they may have to find me a spare room!"

After starting treatment, Lois learnt a lot about myeloma from the Leukaemia Foundation's "excellent publications" and from attending education seminars where she also found interaction with other myeloma and blood related cancers to be beneficial. "The staff at the Western Australian branch of the Leukaemia Foundation have

been wonderful and have taken a personal interest in my welfare and provided continual encouragement."

Last year Lois participated in the Foundation's fundraising event, Light the Night.

"It's reassuring to know the money raised will help to raise awareness about these cancers and contribute to worthwhile research for improving treatments and quality of life for patients."



Lois Booth earlier this year, all dressed up for a Bollywood party

AN UPDATE FROM ASH 2008

Melphalan with prednisone (MP), with an overall response rate in the 40 to 50% range, has been a standard of care for newly diagnosed patients who may not want a stem cell transplant, or who may not be candidates for stem cell transplant. A study presented at ASH 2008 updated data comparing melphalan and prednisone with the FDA-approved combination of melphalan, prednisone and Velcade (MPV). The update, with longer follow-up data, indicates that patients who got MPV are having better outcomes than patients in the MP group. The data from this trial also suggests that patients can safely get a more effective regimen for their initial treatment and expect that the treatment will continue to be effective if needed again to treat relapsed disease.

Another study for the non-transplant patient population compared Velcade, melphalan and prednisone (VMP) with Velcade, melphalan, prednisone and thalidomide (VMPT). This study showed that with VMPT there was an improvement in the complete response rate from 21% for VMP compared to 39% for VMPT. There were more very good partial responses. VMPT may cause more side-effects, so this regimen isn't necessarily for everybody. Longer term follow-up is needed on all of the combinations.

PROGRAM HIGHLIGHTS FOR PATIENTS WITH RELAPSED OR REFRACTORY MYELOMA

This year's ASH presentations about drugs being studied to treat patients with relapsed or refractory myeloma included:

Carfilzomib. This drug is related to Velcade (bortezomib) but may be more effective and does not appear to cause peripheral neuropathy, which is a side-effect for some patients treated with Velcade. A new study is looking at the combination of carfilzomib, Revlimid and dexamethasone to treat relapsed myeloma, including patients who have had prior treatment with Velcade. The results so far are encouraging for tolerance and response.

Pomalidomide. This drug may become an option for patients whose myeloma did not respond to thalidomide or Revlimid. The study findings indicated that pomalidomide with dexamethasone produced responses in 62% of patients, including one out of three patients with refractory myeloma who had prior treatment with Revlimid.



Revlimid plus melphalan, prednisone and thalidomide (RMPT). Among 40 patients with relapsed myeloma the response rate was 75%. The results of this study — where thalidomide with lenalidomide together led to good results — suggest a continued role for thalidomide at low doses in myeloma treatment.

Velcade with perifosine. Perifosine is a novel anti-cancer agent which blocks one of the pathways that reduces the effectiveness of Velcade.

Velcade with vorinostat (Zolinza®). Zolinza is already approved for one type of non-Hodgkin lymphoma and studies like this suggest that it may have a role in myeloma as well.

A monoclonal antibody therapy called **CNTO 328** (in early phases of study) which targets the IL-6 protein - a significant growth factor for myeloma. The potential treatment advantage is that not only does CNTO 328 slow the growth of myeloma cells, it also enhances the effect of some myeloma drugs, because IL-6 helps myeloma cells survive the effects of treatment. A presentation about the combination of Velcade and CNTO 328 showed it was well tolerated and it appeared that the combination was more effective than you would expect with Velcade alone. Future studies will look at CNTO 328 for the treatment of newly diagnosed myeloma patients.

NEXT FIVE YEARS EXCITING FOR ADVANCING MYELOMA TREATMENT

There are 40 drugs in development that are targeting myeloma according to Kenneth C. Anderson, MD, from the Harvard Medical School in Boston.

Chairing a symposium held during ASH 2008 in San Francisco last December, Dr Anderson said 2008 had been an "exciting year".

In the last 12 months there have been five new FDA approvals and three new drugs in Phase III clinical trials are expected to be available in the next few years.

In the introduction to the symposium, *Debating the Key Clinical Questions for the Management of Patients With Multiple Myeloma*, he said overall survival had significantly increased.

"Now we have novel therapies that allow a complete response," Professor Anderson said.

"The last five years have been fantastic, but the next five years will be even better."

According to the symposium abstract, the general consensus is that a patient with myeloma has the best chance for an optimal outcome if they participate in a clinical trial.

Enrolment in a clinical trial is an option at every stage of the disease, not just after all other options have been exhausted. Many Phase III trials investigate first-line treatments. The success to date with newer agents has stimulated efforts to expand the classes of agents used in the treatment of myeloma, as improved therapies are urgently needed. New treatments under investigation include second-generation proteasome inhibitors; inhibitors of heat shock protein 90, histone deacetylase, and mTOR; and agents that target the tumour microenvironment.

MOUTH CARE FOR PATIENTS

Information sourced from Myeloma UK info sheets.

Good mouth care is always important to help ensure your mouth is kept clean, moist and free from infections. When you have myeloma, it is essential to be extra vigilant with your mouth care as you may be more prone to problems including a sore or inflamed mouth, infections, bleeding gums and a dry mouth.

CAUSES OF MOUTH PROBLEMS

Having a weakened immune system because of the myeloma itself and as a result of common treatments (eg. chemotherapy) means you have an increased risk of picking up frequent or recurring infections. Common mouth infections include the fungal infection known as thrush (or candidiasis) and the viral infection herpes simplex (which often results in cold sores). Some chemotherapy drugs can cause a variety of mouth problems, especially inflammation or ulceration of the lining of the mouth (known as mucositis) because chemotherapy attacks the rapidly dividing cells throughout the body, such as those in the lining of the mouth. After high dose chemotherapy and stem cell transplantation mucositis can be extremely painful and can make eating and drinking very difficult. Some myeloma treatments can temporarily lower your platelet count and you may bleed more easily, especially from your gums or the corners of your mouth. This can lead to painful cracks around your mouth. Another common side-effect is a dry mouth, as many drugs can interfere with saliva production. Though unpleasant and uncomfortable, remember that most mouth problems are usually temporary and treatable.

WHAT TO LOOK OUT FOR

It is a good idea to get into the habit of inspecting your mouth every day to detect any visible changes. Look closely at your gums, tongue and the lining of your mouth and let your doctor or nurse know if you experience:

- unusual dryness of the mouth
- redness or swelling of the tongue, lips, gums or the lining of the mouth
- gums that bleed easily or are inflamed
- sores on the lips or at the corners of the mouth
- mouth ulcers
- altered taste or sensation in mouth
- white plaque coating the tongue and the lining of the mouth (this may indicate oral thrush)
- pain or numbness in the jaw or surrounding area
- loose or damaged teeth.

MOUTH CARE TREATMENTS AVAILABLE

It is important to inform your doctor or nurse as soon as you notice any changes to your mouth so appropriate treatment can be prescribed. Treatments may include:

- anti-bacterial mouthwash (to reduce the risk of infections)
- anaesthetic mouthwash (to relieve pain)
- anti-viral medication (to treat or prevent cold sores)

- anti-fungal lozenges, drops or mouthwash (to treat and prevent oral thrush)
- artificial saliva spray (to help relieve the discomfort of a dry mouth)
- painkillers, eg. codeine or morphine may be required, often in liquid form or via a syringe driver (for severe mucositis).

Try to be routine with your mouth care and ensure you comply with any treatment your doctor has given you. If your mouth is sore, ensure you take painkillers or an anaesthetic mouthwash before you eat. If you do need any invasive dental treatment, it is important your dentist knows about your myeloma and any treatment you are receiving. It is advisable to discuss any proposed dental treatment with your haematologist prior to undergoing the procedure.

SELF-MANAGEMENT TIPS

Preventative measures

- Keep your mouth clean by brushing your teeth at least twice a day. Use a soft toothbrush and brush very gently around your gums.
- Avoid flossing your teeth unless you know your platelet count is normal.
- Keep your mouth moist and fresh and try to drink at least three litres of clear fluid a day.
- Use Vaseline or lip balm to help keep your lips moist.
- Keep your dentures clean.
- Visit your dentist regularly, especially prior to the start of any new treatment.
- Avoid smoking and take alcohol only in moderation.
- Inspect your mouth daily and inform your doctor or nurse of any changes.

Coping with a sore, dry or infected mouth

- Take painkillers regularly throughout the day (do not wait until you are in pain).
- Avoid spicy, acidic or salty foods as they can increase irritation in your mouth.
- Avoid alcohol and tobacco as they also can irritate your mouth.
- Eat soft or pureed foods or moisten foods with gravy, melted butter or sauces to make them easier to chew.
- Try to keep drinking as much as possible (use a straw if necessary).
- Eat ice cubes or boiled sweets (to soothe a sore mouth and help with dryness).
- Avoid wearing dentures for a while if your mouth is very sore or inflamed.
- Ask to be referred to a dietician if you are having problems eating (they can prescribe supplements to boost your nutritional intake).
- Use water-based mouthwashes regularly as they can provide temporary relief.

The information in this article is not meant to replace the advice of your medical team. Ask them if you have questions about your individual situation.

BISPHOSPHONATES AND ONJ

For the first time, guidelines have been developed to help Australian clinicians manage bisphosphonate use in treating myeloma.

The bisphosphonate class of drugs can prevent bone mass loss and are used to help manage bone deterioration, bone pain and hypercalcaemia in myeloma patients. However, clinicians had been carefully reconsidering how they

prescribed the drugs, following the recent realisation that their ongoing use could lead to osteonecrosis of the jaw (ONJ) in 1.2% to 15% of myeloma patients.

While the cause of ONJ – an incurable, disfiguring and painful jaw wound – is unknown, the condition is known to be associated with poor dental hygiene and dental work such as the removal of teeth.

KERRIE IS POSITIVE AND LIVING DAY TO DAY

Two years ago, Kerrie Ryan was a physically fit, active and confident 48 year-old who was never sick.

"I was a 'real perfectionist'," said Kerrie, who takes pride in having an immaculate house and a beautiful garden.

"I was always on the go and never sat down and watched tellie. I was in control of everything and I was the boss."

Then, in November 2007, she collapsed at the bakery where she worked and her life came crashing down.

"I went to the GP because I thought something was seriously wrong and I was just exhausted," said Kerrie, who lives at Albury in NSW, with her husband, Peter, and son, Jamie, 15.

A blood test showed something was wrong and Kerrie was referred to a physician. Her appointment was several weeks ahead but the pain got so bad that Kerrie went to Emergency and was admitted to hospital.

After more tests Kerrie was diagnosed with myeloma: "It didn't mean anything to me. I'd never heard of it."

Looking back Kerrie believes she may have had myeloma for years, but she'd put the nagging back pain down to hard physical work and household duties.

Her myeloma treatment began with radiotherapy and at first Kerrie spent a lot of time in hospital.

"Everything seemed to go wrong at the start and I just seemed to lie in bed for what seemed like months," she said.

Kerrie's spine was full of fractures and her mobility was severely limited but she graduated from her bed or sitting in a chair to a walker. Then she dispensed with that and just managing the 16 stairs in her home was a huge achievement.

Peter, encouraged Kerrie to get out of the house, going for coffee on Sunday mornings.

"Eventually I had the well-being to go shopping as long as I had someone with me."

She started on thalidomide early last year but it didn't have any real effect on her paraprotein count, so she went on to have chemotherapy, then a stem cell harvest in May.

Kerrie was also accepted for the Revlimid® trial in June and this drug brought down her count and made her feel a lot better in the lead-up to a stem cell transplant in October 2008.

"I got through this procedure without too many dramas which enabled me to start doing more around the house –



Kerrie Ryan, centre, with Jamie and Peter

cooking, ironing, washing clothes, etc."

She also pushed herself and was able to negotiate their steep driveway to take Stanley their pug dog for short walks.

"Then hallelujah, I finally got the gumption up to drive the car, even though only for short distances," said Kerrie.

"I felt I'd got some real independence back. Just being able to go and see Mum or get to the supermarket is special when you haven't been able to do that for such a long time."

After the transplant Kerrie went back onto Revlimid, which she continues to take along with Zometa (bone strengthening treatment), painkillers and medication for anxiety.

For Kerrie, what was even worse than the extreme physical pain she suffered and the disease itself, was the anxiety that set in early after her diagnosis.

"I just didn't know what was going on with me," said Kerrie about the first anxiety attack she had while in hospital.

"It's settled down, but I still feel agitated, uptight and shaky, and my memory has deteriorated. Now the back pain is the worst thing and my real wish is to beat some of this pain and to be independent.

"I haven't come across anyone who has been in the terrible pain I'm in.

"But I'm positive. I live day to day, and every day is different. This morning I was teary and I was really down and then I bounced back this afternoon.

"I couldn't have got through all this without the support of the palliative care nurses and I found the prompt response and assistance of the Leukaemia Foundation amazing, but I especially appreciate the help, love, and support of all my family.

"This time last year I didn't think I'd make my 50th," said Kerrie about her landmark birthday which she will celebrate quietly with her family next month.

The Myeloma Foundation of Australia's Myeloma Scientific Advisory Group has developed a series of bisphosphonate guidelines, including a thorough oral health assessment before patients begin bisphosphonate therapy; vigilant dental care and six-monthly dental reviews while on the therapy; as well as avoiding tooth extraction and invasive surgery.

Specific dosage reductions and alternative therapies were advised, as was a course of antibiotics in conjunction with a mouthwash prior to any invasive dental surgery.

In the case of patients who develop ONJ, the Advisory Group warned against the current practise of 'debriding' (or removing diseased tissue and bone) and recommended stopping bisphosphonate therapy for at least three months.

Symptoms of ONJ can include tooth, jaw or facial pain and difficulty eating or speaking.

Painful exposed bone or infected and swollen flesh around the jaw, and loose teeth can also be signs of the condition.

NEW MYELOMA CO-ORDINATOR

This year, approximately 1200 people will be diagnosed with myeloma in Australia and it is estimated that another 6000 people are living with the disease in the community.

The Leukaemia Foundation works hard to ensure its services are known and are available to Australians who are affected by this disease and to facilitate this outcome, more than 50 myeloma education and support programs will be held nationally in 2009.

This is an amazing effort by Foundation's support service staff and the establishment of a new position – National Myeloma Co-ordinator - further cements the Foundation's commitment to helping people affected by myeloma.

Kaye Hose has been appointed to this role and is responsible for co-ordinating the myeloma program across Australia.

The Leukaemia Foundation's National Myeloma Co-ordinator, Kaye Hose, grew up in country Victoria before moving to Melbourne to study nursing.

She completed her nursing degree in 1989 and started working in haematology in 1992 which has remained her area of interest. Kaye selected myeloma as the topic of her major project while studying for her Graduate Diploma in Advanced Nursing in Oncology and Palliative Care.

Her interest in myeloma has continued to be sustained by the professional roles she pursued.

"In the clinical setting on the haematology ward I enjoyed being the myeloma resource person," said Kaye.

Then, when she became Myeloma Support Nurse for the Myeloma Foundation of Australia in 2002, her many responsibilities included helping people affected by myeloma and educating health professionals about the blood cancer.

"I was also very passionate regarding setting up avenues of support for people and their families who are affected by myeloma," Kaye said.

She will work with patient and community groups and health professionals to ensure the Foundation effectively and efficiently provides the best support services to myeloma patients.

Having identified that myeloma services and research are severely under-resourced in Australia, the Leukaemia Foundation wants to work with everyone who is affected by myeloma, whether as a patient, carer, friend or loved one, to advocate for improvements in treatments, access to treatments, and services.

To assist Kaye in the development of the Leukaemia Foundation's myeloma program or if you have any questions about the program, please contact Kaye via email: myeloma@leukaemia.com.au.

"This led to helping facilitate myeloma support groups in Melbourne and the greater region and being involved in many myeloma workshops and seminars for people in regional Victoria."

Kaye is looking forward to developing her role as National Myeloma Co-ordinator at the Foundation: "I will be the main resource and will co-ordinate the many myeloma programs delivered by 45 Support Service staff based in all Australian states and territories."

"Myeloma research and support requires much more assistance in Australia and the Leukaemia Foundation is dedicated to helping to rectify this current situation which is greatly under-resourced. I look forward to working with various groups and people who have been affected by myeloma across the nation to ensure that together we can make a difference."

Kaye is married, has two young children and many interests that help her keep family and work in balance.



EDUCATION AND SUPPORT PROGRAM ACTIVITIES

Understanding myeloma	Apr 24	Alstonville, NSW
Understanding myeloma	Apr 28	Adelaide, SA
Understanding myeloma	Apr 30	Erina, NSW
Understanding myeloma	May 15	Sydney, NSW
Myeloma discussion group	May 20	Adelaide, SA
Myeloma munchies	May 29	Parramatta, NSW
Understanding myeloma	Jun 17	Sandy Bay, Tas
Understanding myeloma	Jun 17	Launceston, Tas

For more information and a complete list of education and support programs for myeloma patients and families in your state, visit the education and support programs section on www.leukaemia.org.au.

LEUKAEMIA FOUNDATION SUPPORT SERVICES

Ph: 1800 620 420 (Freecall)

National Myeloma Co-ordinator

Kaye Hose Ph: 03 9949 5800

New South Wales / Australian Capital Territory

Ann Schiller Ph: 02 9902 2223

Queensland

Barbara Hartigan Ph: 07 3840 3840

South Australia / Northern Territory

Steve Marshall Ph: 08 8273 3515

Victoria / Tasmania

Samantha Schembri Ph: 03 9949 5824

Western Australia

Katey Stewart Ph: 08 6241 1020

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.



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

