

LIFE IS GETTING IN THE WAY OF WENDY'S MYELOMA

Two years after being diagnosed with myeloma, Wendy Hampshire went on the holiday she had long dreamt about – her first trip to Europe.

She spent five weeks away, including a week in Paris and a month in Italy, travelling with friends and family.

"What was good about the travel is that I did it really easily and I realised that having myeloma doesn't stop me doing what I want to do. I can travel like anybody," explained Wendy, 45, who lives at Coffs Harbour.

In November 2009 Wendy holidayed in Fiji, and last September, she cooked in Paris, stayed in a "beautiful house in Umbria", caught up with friends in Rome, did all the touristy things and perused "the fabulous art galleries". She visited Lake Como, Venice, Verona, Pompeii, the Amalfi Coast, Florence, Cortina and Assisi and "did a spot of shopping".

"It was glorious," she says enthusiastically, although she admits to being nervous before she left, having ended up in hospital with pneumonia two weeks earlier.

She had no problems while she was away and was well prepared for the journey. She was fit, had a letter from her haematologist that explained her diagnosis, and a clear plan of action should the worst have occurred.

Wendy didn't get sick and now she's planning where she'll go for her next holiday!

Back in September 2008, Wendy was on study leave and was three months off finalising her PhD when she started feeling lethargic.

"I thought it was because I was doing so much, so I joined the gym to improve my fitness."

While exercising, Wendy had acute pain in her chest and within a few hours, swelling in her chest. She went to her general practitioner the next morning. At that time, she had a two-year history of chest discomfort.

"Despite having excruciating pain that was worse than the delivery of my 9lb baby boy, it was brushed off as a pulled muscle," said Wendy of this prior experience.

Following the more recent episode at the gym, Wendy's GP referred her to an orthopaedic surgeon. She had an MRI and other investigations and biopsies that discovered she had a large plasmacytoma that had destroyed her sternum.

Within 10 days she was diagnosed with myeloma – the same week her daughter, Lauren, was made college leader at her school and her son, Nick, was finishing year nine.

Unfortunately Wendy was away for the entire final school term



Wendy Hampshire in Paris last September

as she went to Queensland for radiotherapy and didn't return home until mid-December. During this time, she stayed with her mum who lives on the Gold Coast.

"My disease is currently stable. I'm in very good health and I feel really good," said Wendy, who has been treated with dexamethasone and for the last two years has taken thalidomide and has monthly zometa infusions.

"I got some toxicity and my memory was affected but since the dosage was cut in half, I don't have that anymore."

In May 2009 Wendy had a stem cell harvest, so she has the option of a transplant in the future if necessary.

"I feel very well cared for by the team looking after me and that's a big thing for me," Wendy said.

"I've seen three different haematologists and have three opinions – one in Coffs Harbour who I see regularly, one in Sydney who will head up the transplant, and another in Sydney. They talk to each other and are linked to experts all over the world.

"I am very comfortable with where I am and believe we have access to the best possible treatment."

Wendy's side-effects include some peripheral neuropathy, which she says is manageable with the shoes she wears, and some severe cramps which she manages with magnesium supplements.

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COPING WITH NAUSEA AND VOMITING

Nausea and vomiting can be a problem associated with treatment. Anti-sickness medications, called anti-emetics, can be prescribed to help and are often very effective. If you continue to have problems, mention this to your doctor or staff at the hospital, as they may be able to prescribe an alternative medication.

Here are some suggestions:

- Sit near an open window and keep surroundings pleasant, quiet and clean. Keep food smells to a minimum. Cooking in a microwave produces less aromas.
- Practise good mouth care. Rinsing your mouth with fizzy water between meals may help.
- Eating a cracker or dry biscuit before getting up in the morning can help.
- Keep a record of medication and when anti-sickness tablets are to be taken.
- You may be able to predict how your body responds following treatment. Ideally, take anti-emetics when you feel sickness coming on rather than waiting until you have been sick.
- Have small meals often. If possible, ask friends and relatives to prepare your meals or use ready-prepared meals.
- Cold foods served at room temperature are less likely to upset you. Avoid hot or spicy, fried or greasy, and sweet foods.

- Try sipping cold, clear fluids slowly through a straw and avoid drinking with your meal. Wait half an hour after a meal to have a drink.
- Avoid tight, restrictive clothing.
- Try relaxation techniques. These can be helpful for dealing with nausea. Relaxation also helps with anxiety and tension, which can make nausea worse.
- Avoid eating one to two hours before and after treatment.
- Acupressure has been said to help. This is the application of pressure to 'acupuncture points' and can easily be achieved with the help of wrist bands which are sold as aids for travel sickness and which are available from most good pharmacies. 'Sea-bands' or 'Travel-bands' are common brand names. Apply the bands to the wrists, about three fingers width from the base of the palm.
- Ginger and ginger beer can help when feeling nauseous and celery juice, or carrot and celery juice, has also been recommended.

If you are vomiting, keep a record of how often you are being sick, and if it persists or does not seem to be getting any better, contact your doctor.

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"I also get tired, but again that's manageable."

After the stem cell harvest Wendy went back to part-time work as a university research fellow but in May 2010 she reassessed her working life.

"I thought, hey, I'm not doing this anymore, so I took time out and I'm just doing some consulting work in research on an ad hoc basis."

Wendy keeps fit by going to the gym three times each week, she walks most days and does a gentle yoga session once a week.

"The Leukaemia Foundation has been just fantastic," she said.

"When I went to have a stem cell harvest in Sydney, coming from the county, they organised accommodation for us which was one less thing to think about. I thought it would be for only a couple of days but I had to stay two weeks."

Wendy also uses the Foundation's support networks at Coffs Harbour.

"I've been to some of the monthly support meetings and until I joined the telephone forums about 12 months after my diagnosis, I hadn't spoken to one person with myeloma. This made a huge difference. There are lots of people on the forums who are well and living with myeloma, which is encouraging and affirming.

"And the national myeloma co-ordinator is very good at getting the message across that myeloma is a very complicated disease that is different for everyone. Its presentation and treatment is different for everyone, so the outcomes are different for everyone too.

"Never give up hope," says Wendy.

"You can have lots of life after being diagnosed with myeloma.



Wendy with her children, Nick and Lauren in December 2010

"For me life is getting in the way of myeloma – I've been having too much fun with my travels and spending time embracing my family and friends."

WENDY'S TRAVEL MYELOMA TIPS:

I was keen to get really fit before I went overseas.

I did lots of stretching on the plane, wore my compression stockings and didn't get swollen feet or ankles.

I wore my one pair of Naot shoes every single day. The thick inner soles are super cushioned which helps my peripheral neuropathy.

I was fussy about keeping all my medication with me in my backpack, with a letter from my haematologist.

Having a clear plan of action gave me peace of mind. This included a list of who I'd get in touch with if I got sick while I was away.

MYELOMA RESEARCH A PRIORITY

The Leukaemia Foundation is a strong advocate for people affected by myeloma and has partnered with Cancer Australia for myeloma to be listed as a national research priority in 2011.

While treatments for myeloma are improving, and many potential new therapies are being tested all over the world, this type of blood cancer is still considered an incurable disease. The Foundation is dedicated to working with Australia's best researchers to help find this elusive cure.

This year, the Foundation will be a major funding partner in the government-run Cancer Australia's Priority-driven Collaborative Cancer Research Scheme, in conjunction with the National Health and Medical Research Council (NHMRC).

Research projects must have myeloma as the primary focus of investigation, with preference given to projects with the potential for short to medium use in a clinical setting.

Why do we believe the Leukaemia Foundation's research program is the best model for finding a cure for myeloma?

- We fund only the best research projects by drawing on the expertise of many leading Australian clinicians and researchers in the field of blood cancer.
- Our organisation works with highly respected agencies such as Cancer Australia to ensure we adhere to research best practice.
- We are an independent organisation, dedicated to meeting the needs of consumers, and can directly align research funding with the greatest area of need.
- As a national organisation, we can focus on funding the best research anywhere in Australia, rather than being restricted to a particular research centre or region.

For information about the Leukaemia Foundation's National Research Program, visit www.leukaemia.org.au/web/research

If you would like to donate to our myeloma program, please complete the attached donation form, or call 1800 620 420.

TREATMENT OF MYELOMA - ARE WE MAKING PROGRESS?

For the first time since 1960, there are drug treatment options to complement chemotherapy, radiation and stem cell transplant therapies for myeloma patients.

As previously reported in *Myeloma News*, the emergence of thalidomide (Thalomid®), lenalidomide (Revlimid®), and bortezomib (Velcade®) is providing a long-awaited breakthrough in myeloma survival rates.

Internationally, numerous clinical trials are assessing the effectiveness of these drugs when used alone or in conjunction with chemotherapy in the treatment of relapsed or refractory myeloma or as an initial therapy.

Translating these findings into the best clinical practice requires individual trials to be "examined in the larger context of other emerging treatments and the results of other important trials", according to Los Angeles-based haematologist, Dr Brian Durie.

Dr Durie recently reviewed a clinical trial (bortezomib combined with melphalan-prednisone) and called for more uniform international standards in trials to allow for results to be compared. The review was published in the prestigious *New England Journal of Medicine*.

With 70% of patients who received the bortezomib combination therapy achieving a partial or complete response, compared with only 30% who received the traditional chemotherapy and steroid, there was no doubt the new treatment regimen was superior, according to Dr Durie.

He noted that the survival rates for myeloma patients had been similar in trials of thalidomide and lenalidomide used in combination with either low dose dexamethasone or melphalan-prednisone.

"[However, there is] no data available from randomised trials to compare these regimens against one another in a way that can be used to determine the best choice of therapy," said Dr Durie.

"We need prospective comparisons with other available options, valid uniform standards for those comparisons, and greater consideration of toxic effects and factors influencing the quality of life, along with outcomes."

In addition, bortezomib has also been trialled successfully with the alternative myeloma chemotherapy, cyclophosphamide, while promising results are emerging from a trial of bortezomib plus lenalidomide and low-dose dexamethasone.

Several new vaccine treatments and new drugs such as carfilzomib and sunitinib (similar in action to bortezomib) and RAD001, CNTO 328 and caelyx (a newer form of the chemotherapy drug, doxorubicin) are also undergoing clinical trials.

"For the foreseeable future, we are fortunate to have so many [myeloma treatment] options both in the clinic and in development. Our challenge will be to assess each patient on an individual basis and to identify and customise therapy for maximum long-term benefit," said Dr Durie.

From the Cedars-Sinai Outpatient Cancer Centre, Samuel Oschin Comprehensive Cancer Institute and Aptium Oncology, Los Angeles, U.S.

REGISTER FOR WORLD'S GREATEST SHAVE 2011

We are looking for thousands of brave Australians to register to shave or colour their hair to raise funds for the 13th Leukaemia Foundation World's Greatest Shave on March 10-12.

World's Greatest Shave is our biggest fundraiser. It generates almost half the income the Foundation needs each year for the National Research Program and to provide the free services that support thousands of people who are impacted by a diagnosis of leukaemia, lymphoma, myeloma and related blood disorders.

This is a seriously fun event and our fundraising tips make it easy. Raising \$120 is an easy goal and provides two nights accommodation at one of the Foundation's patient and family accommodation facilities for a regional Australian who has to relocate to a metropolitan centre for life-saving treatment.

So, get a team together at work, home, school or your sports club, and when the time comes, plan your own team event or head to one of many public shave events organised across the country. Sign up now at www.worldsgreatestshave.com or by calling 1800 500 088.

Q & A ABOUT TRAVELLING WITH MYELOMA

Here are some of the most common questions which members of the Leukaemia Foundation's support services team are asked about travelling with myeloma or one of the other blood cancers. The answers are by Susan Harper, Manager Infection Control & Staff Vaccination at Peter MacCallum Cancer Centre in Melbourne.

Q. Are there any precautions I need to take before I go travelling, to reduce the risk of getting an infection?

A. It is important that you discuss your personal travel plans with a health professional to ensure you have the correct vaccinations for your trip and any booster doses of childhood vaccinations you may need, so:

- make an appointment with your doctor or travel clinic at least six to eight weeks before your departure
- discuss the destination/s you plan to visit
- discuss the medications you should take with you, and
- discuss any vaccinations you should have, before you leave.

Q. What are the safer countries to travel in?

A. It is important to be well informed about the destination you're travelling to, so check the latest travel advice at www.smartraveller.gov.au to receive email notifications each time the advice for your destination is updated.

Q. Can a letter detailing my condition from my doctor help, if I get an infection and need to go into hospital?

A. It is recommended that if you are travelling and need to take any medications with you, that you:

- discuss with your doctor what medications you will need to take (including antibiotics in case you get an infection)
- carry a letter from your doctor detailing your medical condition, what the medication is, how much you will be taking and stating that it is for your own personal use, and
- ensure you leave the medication in its original packaging so it is clearly labelled with your name and dosage instructions.

It is also advised that you take along a spare pair of glasses and a copy of the prescription as these can be easily broken or lost.

Q. What are important considerations to help lower my risk of infection when travelling?

A. Strict adherence to hand hygiene, washing with soap and water when hands are visibly soiled, after going to the toilet, before eating or preparing food, and using a gel/foam or rub, in between.

Before you depart, find out whether the tap water and local food is safe to consume.

Continue to take anti-malarial medications (if prescribed). Avoid being bitten by mosquitoes by wearing light coloured, loose fitting clothing that covers your arms and legs. Regularly apply an appropriate insect repellent and stay in mosquito-proof accommodation.

If travelling overseas during summer in your destination, remember to use SPF30+ sunscreen, 20 minutes before you go outdoors and every two hours afterwards, wear a hat that protects your face, head, neck and ears, and seek shade. Carry bottled water.

Make up a small medical kit, including items such as headache tablets, antacids, antiseptic lotion, cotton wool, bandaids, a crepe bandage, SPF+30 sunscreen and an appropriate insect repellent.

Visit the following websites for information about safe travel tips:

www.smartraveller.gov.au/tips/travelwell.html

www.who.int/foodsafety/publications/consumer/travellers/en/index.html

www.sunsmart.com.au/ultraviolet_radiation/sunsmart_uv_alert

OTHER QUESTIONS

Q. I love gardening, is there anything I should be careful of when out in the garden?

A. Discuss gardening activities with your doctor, as it may be wise to limit some of these activities, depending on where you are with your treatment cycle. When gardening:

- wear thick gardening gloves to avoid any cuts or injuries while working in your garden

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TRAVELLING WITH MEDICINES

RESTRICTIONS ON TAKING OR SENDING PBS MEDICINES OVERSEAS

Under the Pharmaceutical Benefits Scheme (PBS) the Australian Government subsidises around 2500 prescription medicines. Exporting PBS subsidised medicines to people outside of Australia leads to a significant financial loss to both the Australian Government and the community. It is also dangerous for people to take prescription medicine that has not been prescribed for them.

The most common illegal export of medicines happens by the post or people taking them in their luggage. People caught illegally exporting medicines face two years imprisonment and/or a \$5000 fine. Therefore it is important to read the following information, to ensure you are meeting all the legal requirements.

PBS subsidised medicines

It is illegal to take or send PBS subsidised medicine out of Australia unless it is for your own personal use or someone travelling with you, such as a child.

The quantity of PBS medicines that you can take is restricted.

Before travelling you should contact the embassy of the country you are visiting to ensure the medicine is legal there.

You should also carry a letter from your doctor detailing what the medicine is, how much you will be taking and stating that the medicine is for your personal use.

You should leave the medicine in its original packaging so that Customs can see who dispensed it, for whom it was dispensed, and the cost. Customs can detain any medicine it suspects is being illegally exported.

TRAVELLING WITH A PRE-EXISTING MEDICAL CONDITION

Australians love to travel and increasing numbers of people are being inspired to travel overseas due to the strong Aussie dollar.

If you have a pre-existing medical condition (known as an EMC within the travel insurance community) such as myeloma, what are your options when travelling?

Your first consideration is your destination, then the level of medical support that can be provided in relation to your condition.

If you choose to jet off to Peru to walk the Inca Trail with your EMC, then you need to be fully aware that the availability of immediate comprehensive medical support is pretty low, even for those in peak health.

Travelling in the United States for a couple of weeks may sound great, but this is a very expensive destination when it comes to even the most basic medical care. If you can't prove you have insurance or enough funds in your bank account to cover a required procedure, you may be turned down and directed to another hospital, which is not ideal when you are in need of immediate care.

From a medical viewpoint, there are two ways to choose your destination.

Ask yourself if the country you are planning to visit has a level of health care that is appropriate for your condition, and what costs are involved if you travel to a country that isn't covered by your travel insurer. When travelling with an EMC, countries including South America, North America, Canada and Africa are considered 'high risk' areas in terms of appropriate care.

Most travellers are unaware that in the following countries, Australian residents are entitled to assistance with the cost of medical treatment under the Reciprocal Health Care Agreement (excluding elective or cosmetic surgery).

- New Zealand
- Republic of Ireland
- The Netherlands
- Italy
- Malta
- United Kingdom
- Sweden
- Finland
- Belgium
- Norway

Each of these countries provides care in different ways, so it is best to review the country you are thinking of visiting during

the travel planning stages and definitely before you commit to buying airline tickets and accommodation or embark on your travels. This means you have a fallback plan if travel insurance is turned down due to your EMC.

To gain access to care you will need your passport and a current Australian Medicare card. For more information visit: www.medicareaustralia.gov.au. (Use the search facility by entering Reciprocal Health Care)

For other destinations not covered by the agreement, look into the state of medical care in each country because under the terms of your travel insurance, you may have to personally cover the cost of any treatment you require. For example, Japan doesn't come under the Reciprocal Health Care Agreement but is very medically advanced, so you need to look at the cost of care to ensure you can afford this cost, if required.

Communication is another consideration. Is not having an English-speaking doctor/surgeon cause for concern and would this worry you or your travel partner, should the worst happen? If the answer is 'no', go ahead, but if you have reservations, consider another destination.

Your chosen travel insurance provider will always ask you to submit a Pre-Existing Medical Assessment. Based on that assessment, they will either turn you down, and the fact is - you may be turned down, or they will accept coverage at an additional premium payment. The premium is often based on the number of days away, but can vary between travel insurers. If you are denied travel insurance, you have to ask yourself if you really want to travel.

While travel is a marvellous experience, you do need to know all the facts first so you are fully informed when making decisions.

For more information and guidance, contact Leisa Burdette, Travel Managers Australia. Ph: 0405 100 095 or email: leisab@travelmanagers.com.au

Would you like to contribute an article or a helpful myeloma tip to this newsletter? Please contact the national myeloma co-ordinator by email: myeloma@leukaemia.org.au

Non-PBS medicines

Medicines that have not been subsidised by the PBS can be taken or sent overseas. However, you should still contact the embassy of the country you are travelling to, to ensure the medicine is legal there.

You should also carry a letter from your pharmacist stating the medicine has not been subsidised. Some overseas countries will require a letter from your doctor for any prescription medicine.

You should leave the medicine in its original packaging so Customs can see who dispensed it, for whom it was dispensed, and the cost.

Reciprocal health care agreements

The Australian Government has signed Reciprocal Health Care Agreements with several countries. This means

Australian residents are entitled to assistance with the cost of medical treatment in New Zealand, UK, Ireland, Sweden, Netherlands, Finland, Italy, Malta, Belgium and Norway. (See the website address below for information on individual countries.)

For more information

Medicare Australia has a 24/7 information line to answer all your queries. They advise getting your information from them earlier rather than later as a phone call from the airport can be too late.

Travelling with PBS Medicines enquiry line: 1800 500 147

Translating & Interpreting Service: 13 14 50

www.medicareaustralia.gov.au/public, then Migrants & travellers> Travelling overseas

ONJ AND BISPHOSPHONATES – DENTAL IMPLICATIONS



By K. David Hay, BDS, FDSRCS, MDSc – Oral Medicine Specialist, Greenlane Clinical Centre

WHAT ARE BISPHOSPHONATES?

Bisphosphonates are drugs of choice in managing a variety of bone disorders including tumour deposits in bone. They act by inhibiting the cells that are responsible for normal bone resorption (osteoclasts) and thus reduce further bone damage and allow an opportunity for the bone to heal.

WHAT ARE THE CONCERNS?

There have been increasing reports of a possible relationship between bisphosphonate therapy for bone cancer and osteonecrosis* (bone death) of the jaws (ONJ). ONJ may occur following extractions or dental surgery and, in some cases, may appear spontaneously.

Because of the potentially serious nature of these complications and the failure of the exposed bone to heal, dentists and doctors must be aware of recommended precautions for the management of patients taking bisphosphonate medication.

The drugs which are principally involved are intravenous pamidronate (Aredia®) and zoledronate (Zometa®). A further bisphosphonate medication – alendronate (Fosamax®) – used commonly for osteoporosis has only rarely been reported as being associated with osteonecrosis of the jaws.

HOW DOES OSTEONECROSIS DEVELOP?

The bisphosphonates are concentrated in bone and internalised by osteoclasts where they interfere with the cell membrane ruffled border by which the cell makes contact with the bone. With the ruffled border compromised, the osteoclast cannot function properly and dies, thus stopping bone resorption.

It is interesting that there have been no reports in the literature of osteonecrosis associated with bisphosphonate use in bones other than the jaws. It is thought that because the jaws have a greater blood supply than other bones and a faster bone turnover rate, bisphosphonates are highly concentrated in these tissues, the direct result of which is a significant reduction of the daily re-modelling and replenishment of the bone. This, in turn, compromises the ability of the jaw bone to heal normally in the presence of dental disease or following invasive dental treatments and bone death results. The problem is that once osteonecrosis has occurred, it cannot be treated.

Bisphosphonates persist in bone for at least up to 12 years – probably much longer. This implies that the potential for bisphosphonate-related osteonecrosis to develop in the jaws may remain for many years even after the drug has been discontinued.

WHAT PRECAUTIONS/ORAL CARE SHOULD BE TAKEN?

Doctors who are intending to prescribe bisphosphonate therapy must refer the patient for a dental evaluation. The dental surgeon's role can be summarised as follows:

Patients prior to beginning bisphosphonate therapy

A thorough dental and X-ray examination should be undertaken in order to detect potential dental and periodontal problems.

- Teeth with poor prognosis or poor periodontal health should be removed and other dental surgery completed prior to the initiation of intravenous bisphosphonate therapy;
- Dental prophylaxis, dental decay control and reasonable rehabilitation of the remaining salvageable dentition** should be undertaken;
- All dentures should be checked to prevent soft issue trauma;
- Patient education should emphasise the importance of home care and regular review and the importance of potential problems relating to bisphosphonates.

Patients receiving bisphosphonate therapy

For these patients, dental care should include:

- Maintenance of the dentition to avoid risk of dental or periodontal problems;
- Maintenance of dentures to eliminate risk of soft tissue trauma;
- Management of dental infections non-surgically, for example by endodontia; decoronation of the tooth and endodontial on the retained roots;
- Avoiding the need for tooth extraction;
- Avoiding any elective dental procedure that will require bone to heal.

SUMMARY

The recent problems that have emerged with bisphosphonate therapy as described in the international literature present a new and serious challenge in the management of patients who are taking, and who have taken in the past, bisphosphonate medication.

In the face of these new and serious complications, there must be measured and scientific investigations into the reasons for bisphosphonate-related osteonecrosis and the development of more suitable pharmacological use of the medication. This may lead eventually to a reduction and elimination of the problem.

It is clear that dentists must obtain a history of usage of these drugs as part of the patient's medical history, be aware of the dental conditions which could predispose to osteonecrosis, avoid dental extractions and dental surgery, and manage any problems conservatively in accordance with the present recommendations.

The Leukaemia Foundation recommends all people with myeloma who are prescribed bisphosphonate therapy as part of their treatment plan, speak with their haematologist about the risk of osteonecrosis of the jaws.

* Osteonecrosis is a term derived from 'osteo' meaning bone, and 'necrosis' meaning cell death

** Dentition is defined as the makeup of a set of teeth including their kind, number and arrangement

This article adapted in part from the New Zealand Dental Journal 102, No. 1 4-9 March 2006 and reproduced with permission from the Leukaemia & Blood Foundation, New Zealand

RETIRED BOTANIST CONTINUES TO TRAVEL EXTENSIVELY

Botanist, Lyn Craven, was in Papua New Guinea on fieldwork in mid-2006, aged 61, when he started having trouble with his back.

It began after a mishap while crossing the Huon Gulf en route to a field location in a small boat in choppy seas. His condition progressively deteriorated and by the time he was due to return home to Canberra, he was having difficulty scrambling around the forest.

By August, Lyn's pain was extreme and a CT scan revealed its cause - a tumour in a collapsed vertebra.

He was admitted to hospital in October for pain management and radiation therapy for the tumour. The following month, he was referred to a haematologist and began chemotherapy. The combination therapy CID* regimen was used.

After dealing with a massive deep vein thrombosis that developed in his right leg in January 2007, he had a procedure to stabilise his fractured vertebra in February. The vertebroplasty successfully ended his back pain and since then Lyn has been careful "not to overdo things".

In April that year Lyn had an autologous stem cell transplant and was lucky to survive an infection that saw him spend several days in intensive care. This left Lyn quite helpless physically and his wife, Kirsty, organised a hospital bed and walking frame at home for him and a range of support and care.

"It took me 18 months to recover from the transplant but the myeloma resurged after only 10 months. If one wished, one perhaps could be justified in feeling cheated," Lyn said.

He went on to a combination of thalidomide and dexamethasone in March 2008 and 12 months later, when his myeloma was no longer detectable, he went off this treatment after developing slight neuropathy.

Lyn said he was fortunate to receive strong clinical and patient support from the ACT health system (at Canberra Hospital and Community Nursing) and Palliative Care.

Lyn's remission continued throughout most of 2009 before the paraprotein gradually reappeared and in July 2010 he went back onto thalidomide and dexamethasone. He is thankful that his neuropathy has not worsened.

Throughout his career classifying plant species, Lyn travelled extensively within Australia and the south-west Pacific and these travels continued after his diagnosis with myeloma.

In mid-2008 he went to New Caledonia for a month doing fieldwork on rainforest trees.

"Our son, Ross, went with me to climb trees and pull down branches, etcetera while I stayed on open, level ground," Lyn said.

He and Kirsty spent a fortnight in New Zealand in March 2009 and six months later they went to France for five weeks.



Lyn Craven in Yunnan, China, in May last year

On their return, Lyn formally retired but has continued his research in an honorary capacity.

This saw him go on a plant-focused tour to Yunnan in China for three weeks in mid-2010 to see northern hemisphere rhododendrons in the wild. Not long after this trip, Lyn and his daughter, Cathy, went to visit Ross on Tarawa atoll in the Gilbert Islands, which straddle the equator, three hours by jet north of Fiji.

Lyn said travel insurance hadn't been a major issue for him. He isn't concerned about not being covered for myeloma per se, as he has no complications that could see him suddenly needing to be admitted to hospital, such as pneumonia.

He does however want insurance for standard reasons such as accidents, flight cancellations, illness, lost baggage or family emergencies, etc.

"In view of having cancer I get quotes from three insurance providers, which enables me to select a value-for-money policy as some companies still offer cover for conditions I have flagged as being related to my myeloma, such as DVT."

Lyn, now 65, said he and Kirsty were planning another trip to New Zealand in early-2011 and he was keen to go back to France.

"Ten days in Singapore and peninsular Malaysia seems like a good idea for mid-winter and the New Caledonian rainforest is calling me, but I need a volunteer to collect the specimens. Any takers?"

** cyclophosphamide, oral idarubicin and dexamethasone*

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- ensure that your tetanus vaccinations are up to date
- during warm weather remember to slip, slop slap, taking extra care between 10am and 3pm when UV Index levels are most intense
- wear a sun hat.

Q. Are there any ways I can help prevent infections?

A. Discuss having the influenza vaccination with your GP.

Follow good hand hygiene practices at all times.

Ask your family and grandchildren and other relatives, friends and carers not to visit if they have cold or flu-like symptoms.

EDUCATION AND SUPPORT PROGRAMS

NEW SOUTH WALES / ACT		
February 2011		
1 Feb (also 1 Mar; 3 May; 7 Jun)		Port Macquarie Tuesday Chats
2 Feb (also 2 Mar; 4 May; 1 Jun)		Tamworth Wednesday Chats
3 Feb (also 7 Apr; 2 Jun)		Thursday Chat, Port Macquarie Haematology Support Group, Wilders Bakery, Booroowa St, Young
8 Feb (also 8 Mar; 10 May; 14 Jun)		Coffs Harbour Tuesday Chats
8 Feb (also; 8 Mar; 12 Apr; 10 May)	10am- 12noon	Haematology Support Group, St Benedict's Parish Centre, Narrabundah ACT
10 Feb (also; 10 Mar; 14 Apr; 12 May)		South Coast Haematology Support Group
22 Feb 22 Feb (also 22 Feb; 31 May)		Myeloma Update, Professor Chong, Rockdale City Council Conference Room, 2 Bryant St Rockdale Taree Tuesday Chats

NORTHERN TERRITORY		
February 2011		
11 Feb		Leukaemia, Lymphoma, Myeloma & Related Blood Disorders Support Group, Eat at Martins Café, Coconut Grove, Darwin

SOUTH AUSTRALIA		
January 2011		
24 Jan (also 28 Feb; 30 May; 27 Jun)	10-11am	QEH Carers' Coffee Group, QEH main building, 2nd floor dining room, Adelaide
28 Jan (also 25 Feb; 25 Mar; 29 Apr; 27 May; 24 Jun)	10.30am- 12noon	Carers' Coffee Group, Palais Café, opposite RAH, Adelaide
February 2011		
10 Feb (also 10 Mar; 14 Apr; 12 May; 9 Jun)	10.30am- 12noon	Southern Metro Coffee Group, Reynella Youth Centre, 10 Main South Rd, Reynella
15 Feb (also 15 Mar; 19 Apr; 17 May; 21 Jun)	10.30am- 12noon	North East Metro Coffee Group, Salisbury East Neighbourhood Centre, 28 Smith Rd, Salisbury East
March 2011		
17 Mar (also 21 Apr; 19 May; 16 Jun)	10.30am	Strathalbyn Coffee Group
23 Mar		Patient Education Session: <i>Blood Products</i> , presented by Bev Quested (Red Cross), BioSA Incubator Conference Centre, 40-46 West Thebarton Road, Thebarton

NATIONAL MYELOMA DAY	
18 May	National Myeloma Day seminar, Sydney National Myeloma Day GP seminar, WRD, 2/26 Ralph Black Dve, North Wollongong National Myeloma Day seminar, Adelaide National Myeloma Day GP event, Albury National Myeloma Day seminar, Melbourne National Myeloma Day seminar, Bellerive Yacht Club, 64 Cambridge Rd, Bellerive, Hobart

VICTORIA		
January 2011		
27 Jan (also 24 Feb; 31 Mar; 28 Apr; 26 May)		Blood Cancer Support Network, Geelong West Town Hall, 153 Pakington St, Geelong West
February 2011		
9 Feb (also 9 Mar; 13 Apr; 11 May; 8 Jun)	10.30am- 12noon	Bendigo Myeloma Support Group, Bendigo Club, 22 Park St, Strathdale, Bendigo
10 Feb (also 8 Apr; 9 Jun)	10- 11.30am	Mornington Peninsula Blood Cancer Information & Support Forum, Mornington Library, Vancouver St, Mornington
15 Feb (also 19 Apr)	11am-1pm	Shepparton Blood Cancer Support Network
24 Feb (also 24 Mar; 21 Apr)	10- 11.30am	Horsham Blood Cancer Support Group
	10am- 12noon	Barwon Blood Cancer Support Group
24 Feb (also 31 Mar; 28 Apr; 26 May)	2-4pm	Blood Cancer Support Network, Geelong
March 2011		
3 Mar (also 5 May; 7 Jul)	10.30am- 12.30pm	Myeloma Education & Support Network, Leukaemia Foundation office, Bell City (Event Centre), 205 - 215 Bell St, Preston
24 Mar	10am- 12noon	Ballarat Blood Cancer Support Group

TASMANIA		
February 2011		
15 Feb (also 15 Mar; 19 Apr)	11am-1pm	Launceston Blood Cancer Support Group, Leukaemia Foundation office, Lower Ground Level, office suite, 4/216 Charles St, Launceston
16 Feb (also 8 Mar; 23 Mar; 5 Apr)	11am-1pm	Taking Control seminars: <i>Centrelink</i> , Bellerive Yacht Club, 64 Cambridge Road, Bellerive, Hobart (8 Mar, <i>Emotional Support</i> ; 23 Mar, <i>Perpetual Trustees</i> ; 5 Apr, <i>The Role of the Social Worker</i>)

WESTERN AUSTRALIA		
February 2011		
11 Feb (also 11 Mar)	10am- 12noon	Bassendean coffee morning, Blue Dog Café, Bassendean. Support for patients & carers
21 Feb	1.30-3pm	Patient support group, Monastery, Leederville
25 Feb (also 25 Mar)	10am- 12noon	Tarts coffee morning, Northbridge. Carer support group
March 2011		
31 Mar	11am- 2pm	<i>Taking Control and Getting Back Into Life</i> , psychologist, Perth
April 2011		
9 Apr	9:30am- 4:30pm	WA Patient Conference , The Boulevard Centre, Floreat, Perth

TELEPHONE FORUMS		
Myeloma Phone Forum	Facilitator: Kaye Hose Ph: 03 9863 6951	3 Feb; 3 Mar, 7 Apr; 5 May; 2 Jun; 7 Jul; 4 Aug; 1 Sep; 6 Oct; 3 Nov; 1 Dec
Transplant Phone Forum	Facilitator: Natasha Manoharan Ph: 03 9949 5847	Dates: TBC

To register for all education and support programs, contact:
LEUKAEMIA FOUNDATION SUPPORT SERVICES
Ph: 1800 620 420 (FREECALL)

For more information, visit: www.leukaemia.org.au
 (education & support programs section)

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 people affected by leukaemias, lymphomas, myeloma and related blood disorders.

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

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

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.

