

WENDY IS LIVING MEANINGFULLY AFTER SURVIVING MYELOMA

It's 14 years since Wendy Pfeifer was diagnosed with myeloma in April 1996 – the day of the Port Arthur massacre.

"When I was diagnosed I had one small granddaughter. She is 14 now and because of treatment I have 10 grandchildren who are a meaningful part of my life," said Wendy who has been para-protein free for seven years.

She's a survivor and has been since day one, despite being told "that's the one you don't survive".

"Getting the diagnosis was a relief because then I knew I wasn't going mad and I had something to fight," said Wendy, now 64, of Melbourne.

"I'd been frustrated, knowing something was wrong for so long, but nobody was listening. I thought I was imagining my condition."

A busy wife and mother of five at the time, Wendy and her husband, Robert, were also foster parents and she worked part-time. She had felt generally unwell for some time, had bone pain, and had taken antibiotics for numerous infections for more than 12 months. She also experienced fatigue to the extent that she'd fall asleep at the lights while driving home from work in the afternoon.

In April 1996 Wendy had a "system breakdown" following a fortnight of high temperatures that antibiotics couldn't control. Her immune system collapsed and she was admitted to hospital for pneumonia and wasn't expected to survive.

"One of the registrars gave me every test in the book and myeloma came out of one of those tests," said Wendy.

The treatment Wendy chose was a six-month trial for a new combination chemotherapy called PCAB*, but it was unsuccessful. Next she had five courses of VAD** which reduced her para-protein levels sufficiently so she could have her stem cells harvested for an autologous stem cell transplant in April 1997, the week after one of her daughters was married.

Wendy said her GP knew nothing about myeloma, there was no Internet at the time and she had very little access to information on the disease.

"I was lucky to have someone outside my family and hospitals who I could talk to about my fears and doubts about the disease and about surviving," said Wendy.

"This let me understand what I was feeling was real, but it could and would change. I did learn that although at times I might be disabled, I was also enabled to carry on living."



Wendy Pfeifer painting with grandson, Jacob Cuthbertson

She found waiting around for blood test results and bone marrow aspirations before treatment long and boring, so she decided to do some embroidery and started making a hand-stitched patchwork bear, never knowing if it would be completed. Now the bear sits in her bedroom to remind her to keep going.

"I believe success with my treatment depended on keeping a positive mindset regardless of what others around me said."

Because having myeloma was so demanding on her body and soul Wendy said she needed to join a myeloma support group "just to be with others who have this weird disease, so we can support each other".

"You're there listening to your own story and if I keep going I can show that there is something worthwhile at the end of treatment," said Wendy about being part of her myeloma support group.

Wendy's life has changed dramatically since her diagnosis and treatment. She came home from hospital in a wheelchair and it took her 12 months to learn to walk properly. She couldn't return to her previous busy life due to fatigue and bone pain and is restricted by a range of other medical problems - the side-effects of her myeloma treatment.

"I needed to find something that would fit around my fitness level, but would also challenge me mentally," said Wendy who started decorative painting (folk art) in 1998.

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NEW ANTI-CANCER DRUG HOLDS POTENTIAL FOR MYELOMA

The Leukaemia Foundation of Queensland has awarded a \$100,000 Grant-in-Aid to progress preclinical trials for a potential new drug to treat myeloma.

Bevacizumab (Avastin®) is an antibody targeting a chemical known as vascular endothelial growth factor (VEGF), which is produced by many tumours including myeloma.

Based at the Mater Medical Research Institute (MMRI) in Brisbane, Dr Slavica Vuckovic and Mater Adult Hospital Director of Haematology, Dr Laurence Catley, have spent the past two years investigating the role of VEGF in myeloma development.

They found that myeloma cells produce VEGF, which in turn suppresses the development of mature myeloid dendritic cells (DC) – specialised white blood cells which ‘train’ immune cells to destroy cancer cells.

With Foundation funding, the pair is looking at how VEGF-producing myeloma cells in the bone marrow affect myeloma-associated white blood cells as well as what happens when Avastin is used to block VEGF, according to Dr Vuckovic.

“Everyone is very excited about blocking VEGF in myeloma because if successful, we would be able to stop the myeloma cells growing, prevent myeloma cells from producing their own vascular system, and improve patients’ immune responses,” she said.

“This is a unique and attractive idea, and because we have developed a humanised preclinical model with human DC we will be closer to replicating what will happen in the clinic with myeloma patients.

“We are definitely hoping to translate our laboratory work into the clinic within the next five years to design a new therapeutics for myeloma.”

Avastin has already shown promising trial results in patients with colorectal, lung and breast cancer patients, and Dr Vuckovic and Dr Catley are the only Australian group investigating its application in myeloma.

Their use of a humanised model puts them ahead of overseas projects. According to Dr Catley, in myeloma the bone marrow microenvironment provides a protective niche for the myeloma cells to thrive.



Research assistant, Dalia Khalil, with Dr Laurence Catley and Dr Slavica Vuckovic

“Our preclinical model reproduces this microenvironment, allowing us to study how this protection favours the growth of myeloma cells against the normal immune system as well as chemotherapy,” he said.

“We can also study the mechanisms by which myeloma cells migrate ‘home’ to the bone marrow.

“In this way, we may discover how to enhance the immune system to eradicate the myeloma, as well as overcome drug resistance when treating with chemotherapy.”

The Leukaemia Foundation does not receive many funding applications for myeloma research according to Dr Susan O’Brien, General Manager – Vision.

“Myeloma has to some extent been the forgotten disease. It is a challenging disease to investigate because it is very difficult to culture the disease cells in vitro, which is very important for preclinical research,” she said.

“We are very pleased to fund this project and look forward to the contribution Laurence and Slavica will make to our understanding of potential treatments for this terrible disease,” Dr O’Brien said.

WENDY IS LIVING MEANINGFULLY AFTER SURVIVING MYELOMA



Wendy Pfeifer with one of her youngest grandchildren, Oscar Whiteside

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She continues to meet with a “very special group of women” every Tuesday morning to paint, talk, listen or just sit.

“I love the different styles of painting. Some challenge me but with help I can achieve something worthwhile and beautiful. This is my special time and it doesn’t matter if I am sore, I can sit and ‘lose myself’ painting gifts or cards.”

Wendy has gradually worked out how to use her energy and has slowly returned to gardening, working within her church, volunteering for the Public Advocate’s Office and holidaying with her husband.

“All our daughters are now married and we have 10 beautiful grandchildren. I am able to spend time with my beautiful girls and their children, which was only ever a dream when I was diagnosed,” Wendy said.

“There is something worthwhile out there for all of us. We need that to keep connected with the world we live in. I needed to keep focused on living and being at peace.”

* PCAB, a combination of prednisolone, cyclophosphamide, adriamycin and BCNU (carmustine) that is no longer available.

** VAD, a combination of vincristine, doxorubicin (Adriamycin) and dexamethasone.

MAY 19 IS NATIONAL MYELOMA DAY

National Myeloma Day will be held by the Leukaemia Foundation for the first time this year, on May 19.

This special day aims to achieve three things:

- increasing awareness of myeloma among GPs, to support its early diagnosis;
- promoting awareness of this form of blood cancer within the wider community; and
- celebrating achievements including early access to the latest myeloma treatments in Australia.

Myeloma is the second most common blood cancer in Australia. It accounts for around 15% of all blood cancers and the incidence of myeloma is growing at the fastest rate of all the blood cancers. Around 1500 new cases will be diagnosed this year. In 2009 more than 600 people with myeloma contacted the Leukaemia Foundation for the first time for information and support. This number is on top of those people who have an ongoing relationship with the Foundation from previous years.

Myeloma diagnostic tool for GPs

Patient groups and health professionals have recognised that diagnosing myeloma is difficult and often can take many months, due to a limited awareness of the condition and its general unspecific symptoms. Myeloma usually occurs in the elderly and is incurable. Symptoms of the disease are often mistaken for other conditions, potentially delaying correct diagnosis and prompt treatment. In celebrating National Myeloma Day, a Myeloma Diagnostic Tool for GPs will be launched by the Leukaemia Foundation and distributed to GPs across Australia. This support tool, developed specifically for use within the Australian health care system, is based on the Myeloma UK Diagnosis Pathway and is inspired by the success of the Leukaemia Foundation's lymphoma diagnostic tool, developed in 2008.

Myeloma awareness

An awareness survey will be conducted to assess awareness of myeloma and its impact in the wider community and information that will be used as a benchmark to measure future programs.

ON-LINE SUPPORT FORUM FOR YOU

Talk Blood Cancer* is a moderated on-line information and support forum for patients and families living with myeloma and other blood cancers.

Being diagnosed with myeloma and undergoing treatment can be confronting, at times overwhelming, and presents patients and their families with many challenges. Being in contact with other people who have experienced or are going through similar, complex feelings associated with the disease can help.

Talk Blood Cancer is designed to help you understand and manage the practical and emotional issues that are part of the journey through diagnosis and treatment.

It is a safe, supportive and informative environment that is moderated by experienced haematology nursing and allied health professionals from the Leukaemia Foundation. The on-line forum enables participants to share ideas, opinions, helpful and practical advice, and personal experiences.

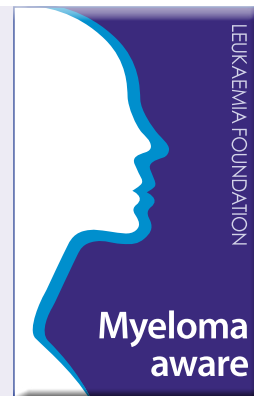
Talk Blood Cancer also is an alternative source of support and

Celebrating early access to new treatment

In the last 12 months, myeloma patients in Australia were granted earlier access, through the PBS system, to various drugs used to treat myeloma. The Leukaemia Foundation would like to celebrate this with people who are affected by myeloma all around the country in a series of activities.

Three ways you can get involved

- 1. Promote community myeloma awareness by buying a limited edition 'Myeloma Aware' badge (pictured right).** Celebrate National Myeloma Day with this special commemorative badge, \$7, which can be worn by people with myeloma, their family and friends. Badges can be ordered using the enclosed donation slip, or are available at our Leukaemia Foundation office in your state, ph: 1800 620 420. Proceeds also support our Vision to Cure and Mission to Care.
- 2. Support others with myeloma by attending a National Myeloma Day event in May.** A range of planned activities are listed on the back page of this newsletter, and if you aren't physically able to attend, register for the myeloma telephone forum on May 6.
- 3. Promote GP myeloma awareness through the myeloma diagnostic tool.** Copies are available from Leukaemia Foundation offices and education sessions during May and June. We encourage you to take one with you the next time you visit your GP, to reinforce the need of early myeloma diagnosis.



For more information, or if you would like to hold an event to commemorate National Myeloma Day, please contact your local Support Services Co-ordinator on 1800 620 420.

information and is particularly helpful for people who live in regional and rural areas, and those who are not able to attend the Foundation's face-to-face support groups.

Registration is free and you can remain anonymous if you prefer. To participate is easy. Simply:

1. Visit www.talkbloodcancer.com
2. Click on 'register'
3. Provide a username (for public viewing) and your email address and a password (not public)
4. Take part by posting messages, participating in polls and reading on-line discussions.

The *Talk Blood Cancer* website is part of the Foundation's commitment to providing world-class support to patients and families free of charge.

* *Talk Blood Cancer* was established with financial assistance from the Australian Government through the Cancer Support Groups Program.

COMMON NUTRITION ISSUES IN MYEL

It is important for people with myeloma to eat a well balanced diet to maintain muscle strength, increase energy levels, aid recovery after treatment and help the immune system function effectively.

What is a well balanced diet?

A well balanced diet includes a wide variety of foods, from all the food groups, to ensure you obtain all the nutrients you need. Protein is essential to build healthy new cells and is found in lean meat, chicken, fish, eggs, dairy foods, nuts and legumes. Carbohydrates, including bread, rice, pasta and cereals, provide the body with energy. Fats also provide the body with energy. Healthier fats are the poly and monounsaturated fats in nuts, fish, seeds, and plant-based oils such as olive oil. Saturated fats are found mainly in animal foods and should only be eaten in small quantities. Fibre maintains a healthy digestive system and is sourced in fruits, vegetables and wholegrain breads and cereals. A healthy diet aims to include two serves of fruit and five vegetable serves each day. Vitamins and minerals perform a variety of functions, including maintaining healthy tissues and nerves, and have a role in energy release and resistance to infection. Ensure an adequate fluid intake of two to three litres per day for healthy kidneys. Drink a variety of fluids each day, limiting coffee and alcohol as these can cause dehydration. Drink at regular intervals throughout the day and carry a water bottle with you, if necessary.

The effects of myeloma and its treatment can make it difficult to maintain a balanced diet all the time due to fatigue, loss of appetite and nausea, diarrhoea or constipation, which can all contribute to muscle loss.

Here are some tips on how to manage some of the dietary challenges you may experience, particularly during treatment.

Loss of appetite

Loss of appetite can be the result of fatigue, anxiety, pain and some treatments including chemotherapy. Here are some tips:

- try eating several small meals throughout the day
- use high protein high energy snacks, eg. cheese and biscuits, crackers and dip, yoghurts, fruit and nuts
- use a small plate and serve small manageable portions and

add tasty accompaniments such as cheese or chutney or even some nuts or crisps

- a breath of fresh air can stimulate your appetite and light exercise such as a walk can also help
- nutritional fluid supplements such as Sustagen® and Ensure® can be useful in between meals and are available from chemists, or make your own fruit smoothies
- avoid strong food smells and fried, greasy foods.

Nausea

Nausea and vomiting can be a side-effect of some treatments for myeloma.

If you feel nauseous try:

- sips of cool fluids such as flat lemonade or dry ginger ale, and try icy poles or slushies
- carbohydrate foods such as crackers, toast, noodles, plain rice and clear soups with noodles
- cool, light, bland foods such as sandwiches, wraps and stewed fruits
- ginger-based foods and fluids can help nausea including ginger ale, candied ginger or ginger biscuits
- avoid strong food smells and fried greasy, foods.

Diarrhoea

Diarrhoea is another potential side-effect of myeloma treatments. To manage diarrhoea try:

- plenty of clear fluids such as clear soups, diluted juice, and oral rehydration solutions such as Gastrolyte® or Hydralyte® (available from chemists)
- easily digested foods such as toast, crackers, noodles or pasta and rice, stewed fruits, mashed potato and lean meat, chicken and fish
- avoid most dairy foods if lactose intolerant
- avoid fried, spicy or greasy foods
- avoid caffeine and alcohol, as they are gastric irritants
- dilute sweetened beverages such as juices and sodas
- as your symptoms settle, gradually reintroduce a wider variety of foods.

MYELOMA AND OCCUPATIONAL RISKS

Occupational exposure to chemicals and allergens in jobs as diverse as painting and baking could play a role in people developing myeloma.

Farming - and exposure to certain pesticides - has long been associated with myeloma, and last year, four studies published by international research teams have shed new light on occupational risks.

Swedish researchers found an “excess risk” associated with exposure to chemicals and sensitising agents, including agricultural pesticides and flour, which affected farmers, bakers and pastry cooks. Dental technicians, stone cutters/ carvers, metal workers and paper/paperboard product workers also had an increased risk.

University College Dublin-based epidemiologist, Dr Carla Perrotta, has been analysing the role of occupation and occupational exposures (mainly pesticides and organic solvents) in myeloma development.

In an analysis of five studies from the U.S. and Europe, published at the 2008 InterLymph conference, Dr Perrotta observed a statistically significant increased risk of myeloma only among painters, with no association evident in farmers.

However, in a separate, systematic review of case-control studies of myeloma from numerous countries published from 1970 to October 2007, Dr Perrotta found consistent, although weak, association between working on a farm and myeloma.

While she cautioned the results could be biased by a lack of consistency between the studies, Dr Perrotta concluded there was a link to exposure to pesticides such as DDT, chlorophenols and phenoxy-acetic acids as opposed to working with animals.

A French research group reported an increased risk of myeloma from exposure to UV radiation during adulthood.

Sometimes alternate diets such as the BRAT diet (bananas, rice, apple sauce and toast) are recommended, however, these are unnecessarily restrictive and are likely to lead to nutritional deficiencies in protein, fat, fibre and critical micronutrients.

Constipation

Constipation may be caused by reduced mobility, treatment and certain pain relief medications. An adequate fibre and fluid intake will usually achieve a response, however, occasionally a gentle stool softener may be required.

Ways to increase the fibre in your diet:

- choose wholegrain breads and cereals and add bran to cereals
- add legumes such as kidney beans, lentils or chickpeas to soups, casseroles and salads
- aim for two fruit and five vegetable serves each day
- add nuts and seeds to salads or include as a healthy snack through the day
- drink two to three litres of fluids each day
- try pear or prune juice as a bowel stimulant.

Weight gain

Weight gain or elevated blood sugar levels can be caused by steroid medications such as dexamethasone, which is often used in the treatment of myeloma. To help manage your weight, try the following:

- choose lean cuts of meat and trim the fat before cooking
- remove the skin from chicken
- use low fat cooking methods such as grilling, roasting on a rack or stir frying rather than deep-frying
- choose low fat dairy products
- limit high sugar and high fat foods such as cakes, pastries, lollies, chocolate and soft drinks
- choose wholegrain foods as they make you feel full for longer
- choose healthy low fat snacks such as air popped popcorn, crunchy apples, rice cakes, yoghurt and fruit, or small amounts of nuts and dried fruits
- Include regular gentle exercise such as walking*

* Remember to seek medical advice before starting an exercise program

For more food ideas to help manage symptoms and maintain a healthy weight, contact a dietitian at the hospital where you are treated, or look for an Accredited Practising Dietitian (APD) at your local community health centre or on the Dietitians Association of Australia, website: www.daa.asn.au



Jacqueline Osborne

MYELOMA TIP

"I have osteoporosis caused by myeloma and it is quite severe. It is mainly in my back and when the pain becomes difficult to bear, I use a heat pack and belt that I bought. I put the heat pack in the belt that sits around my waist, so the heat is on my lower back. It gives me the most amazing relief."

Sandra Finlayson, Sydney

NEW COMBINATION TREATMENT OPTION FOR RELAPSED MYELOMA

A new drug, Caelyx (Doxil®), in combination with bortezomib (Velcade®) is proving to be an important new treatment option for relapsed myeloma.

At the time of relapse, newer agents are frequently used to achieve a further response. Revlimid® (lenalidomide) is used in this setting, as is Velcade.

Doxil* is a different form of the chemotherapy agent doxorubicin and is made by coating doxorubicin with lipid (fat) to create a fat bubble called a liposome. This in turn is surrounded by another layer of a rubber-like material, called methoxypolyethylene glycol (MPEG). The MPEG layer may increase the time that Doxil circulates in the bloodstream by protecting it from detection and destruction by the immune system.

The United States Federal Drug Authority has approved Doxil

in combination with Velcade to treat patients with myeloma. Patients who have not previously received Velcade and have received at least one prior therapy and who have also already undergone or are unsuitable for bone marrow transplant can access this treatment.

A large clinical phase III study looked at the safety and efficacy of Doxil in combination with Velcade in 646 patients with myeloma who had not previously received Velcade and whose disease had progressed during or after at least one prior therapy.

The median time from treatment to disease progression for patients treated with Doxil and Velcade was 9.3 months compared with 6.5 months for patients treated with Velcade alone.

*Doxil is not yet PBS-listed in Australia.

WARM UP, BE GENTLE AND DON'T DO ANYTHING STUPID SAYS STUART

Stuart McMaster, who was diagnosed with myeloma in December 2000, went back to playing golf within months of his first stem cell transplant in 2001.

He'd get up early to play "a nice leisurely game" on a nine-hole golf course with his wife, Jude, or he'd go for 45-minute walk near the beach on the Gold Coast every day.

"I'd go at 6am before the crowds and I never played golf to win – I did it for the exercise and for something to do to fill in a few hours," said Stuart, now 67, who has always been physically active.

"I don't belt the ball like I used to and I have a different way of holding the club," said Stuart who is no longer able to lift anything heavier than 15kg because he is missing a third of part of his spine.

"I have a nice gentle swing and I hope I hit the ball 100 yards straight. I aim down the centre and if you keep your head down until after you've hit the ball, it goes straight.

"It does relax you being out in the open," said Stuart.

Based on his own personal experience, Stuart has some suggestions for other people with myeloma who are looking at being physically active.

- If you've always been sports active, be sure to drop the intensity down a few notches. Start out at 50% of your former pace and if you can, push it up a bit, but gradually.
- If you've played tennis or squash in the past, try a sport that's less abrasive.
- If you used to play 18 holes of golf, try playing nine holes with friends.
- Before you tee off be sure to warm up first with some stretching exercises for the arms and neck so you are loose when you first hit the ball.



Stuart McMaster enjoys being physically active

- Don't push yourself past your limit. If you overdo it, it'll put you back 50%. It's better to start out slowly.
- And finally, don't do anything stupid.

MYELOMA TIP

"I take a second set of ears with me – my wife or my daughter - when I go to my doctor, a specialist or anyone who is going to give me information, in case I'm concentrating on one thing and thinking about it when something else has been said, or there's something someone else has picked up that I haven't."

Ian Cooper, Drouin

EPIGENETICS NEW FRONTIER IN BLOOD CANCER RESEARCH

New ground-breaking drugs and diagnostics are being touted for treating blood cancers with the emergence of a new research frontier – epigenetics.

In the past decade, researchers have shown a clear link between cancer development and acquired changes in cell epigenetics – a term used to describe the mechanisms which control the way DNA in individual cells is packaged and 'flagged' for expression.

(Despite all cells containing the same DNA, a range of mechanisms that operate within the cells enable the DNA to promote different activities and allow the cells to perform various roles – hence the same DNA that creates a liver cell can also create a brain cell.)

In many cancers, such as lymphomas and myeloid leukaemias, the epigenetic mechanisms have been altered, possibly through aging, environmental carcinogens or diet. Without any changes occurring to the underlying DNA sequence, these acquired changes are passed on to new cells through cell division.

Unlike genetic mutations, which cause cancers, researchers

have found that the damaging changes to cell epigenetics can be reversed with tailored pharmaceutical therapies.

Internationally, numerous blood cancer research groups have been working on developing new treatments and diagnostics based on the epigenetic changes to cancer cells.

To date, the United States Food and Drug Authority has approved the use of three new epigenetic drugs for treating blood cancers: Zolinza® (vorinostat) for cutaneous T-cell lymphoma, Dacogen for myelodysplastic syndrome, and Vidaza® (azacitidine or mylosar) for myeloid leukaemias.

Research in the field should dramatically increase with the United States National Institutes of Health committing US\$190 million in epigenetics research over the next five years.

The Leukaemia Foundation has funded an epigenetic research project led by Associate Professor David Ashley from the Children's Cancer Centre at the Royal Children's Hospital in Melbourne. The Foundation's commitment of \$100,000 to the project enables the epigenetic factors involved in childhood leukaemia to be investigated, with a report due soon.

RAY AND ROZE SAID “I DO” AT MYELOMA SUPPORT MEETING

Ray and Roze Mellor surprised fellow members of the Leukaemia Foundation’s myeloma support group in Hobart by getting married during a meeting.

On 19 August last year, the meeting started out as usual with a 15-minute presentation by a guest speaker, a psychologist, and Ray, who was diagnosed with myeloma in July 2006, was among the 30 people there that day.

Then the Foundation’s Support Services Co-ordinator, Jane Anderson, made an announcement: “We have a special treat today – Ray and Roze are getting married!”.

“We didn’t want people to know,” explained Roze, so it was a complete surprise for the other members of the group who were delighted to be a part of the celebration. One of Roze’s daughters was there too.

“I’d bought a dress with a bit of bling on it and I had a bouquet of 10 red roses - one for every year I’ve known Ray.”

The couple was married by a celebrant, followed by a small luncheon and photos.

“So far, so good,” said Roze who is Ray’s full-time carer.

“We haven’t had a honeymoon but it’s just wonderful. We’ve just carried on the same, although Ray hasn’t had to go to hospital,” said Roze who popped the question to Ray while he was in hospital in February last year.

“It was a leap year and I was reading the paper out loud to Ray about how the female can ask the male to marry them. I said - what do you think? And he said: ‘are you asking to marry me?’ and said ‘yes’.”

“Later, when we were talking, he said he was going to ask me before he got sick, but then he hadn’t got around to it.

“We could have spent a lot of money on a wedding but we couldn’t plan anything because Ray was always in and out of hospital. That’s when we thought maybe we could have the wedding at one of the support meetings.

“If it hadn’t been for the Leukaemia Foundation we’d be lost – we couldn’t have got through this on our own. Jane’s always there and she says: ‘let’s talk it through’.

“We go to all the education activities and talks about exercise, meditation and relaxation, understanding your emotions and new treatments, and the support network gets Ray out of the house. We’ve made some really good friends and it’s really good how we all support each other.



Ray and Roze Mellor cutting their wedding cake



Newlyweds, Ray and Roze Mellor, with members of the Hobart myeloma support group

“It really helps to be with other people who are going through the same things.”

In mid-2006, Ray mentioned a stiff back after doing some gardening which would prove to be the first sign of myeloma. Roze knew something wasn’t right when she visited Ray the next day and found him in bed. They were due to go to Ray’s granddaughter’s first birthday, so Roze headed off alone, but half way there she had a feeling that Ray wasn’t himself so she decided to go back and take him to hospital.

“He was in a lot of pain with backache and that just wasn’t Ray - he never complained and everything was always fine, so I called the ambulance,” Roze said.

On the way to hospital Ray was given two bags of fluid because he was dehydrated and morphine for the pain. At one stage during the trip the ambulance stopped at the side of the road.

“They couldn’t find his blood pressure, it was very low,” said Roze.

Ray went straight to emergency, then to intensive care and the next day Roze was told Ray had myeloma and may have only five to six weeks to live. Roze took time off work to be with Ray who was in the intensive care unit for five weeks. During this time, Ray had a tracheostomy and he could only communicate using a whiteboard. Afterwards, Ray had to learn to walk again.

Over the next six months Ray had thalidomide, chemotherapy, steroids and bone strengthening medication. He also kept developing pneumonia every four months.

“They’d fix him up and send him home again for a few weeks before he’d go back to hospital,” Roze said.

In April 2007, Ray was put onto a new treatment, Velcade®, which Roze said picked him up a bit, but he had problems with neuropathy and went on to have a stem cell transplant in July 2008. He continued to be treated with lenalidomide but he was still in and out of hospital with pneumonia.

“We practically lived there,” said Roze.

“It seemed a non ending vicious cycle but Ray just kept battling on, thanks to the staff at the Royal Hobart Hospital and the Leukaemia Foundation who came into talk to us.”

In October last year Ray had a second transplant and at the time of writing it had been four months without a return to hospital.

EDUCATION AND SUPPORT PROGRAMS

| NATIONAL MYELOMA DAY | | |
|----------------------|---------|---|
| 19 May | 10:30am | National Myeloma Day, Rydges, North Sydney National Myeloma Day morning tea, Coffs Harbour |
| 19 May | 11:30am | National Myeloma Day seminar, Dr Peter Wood, Sth Brisbane |
| 19 May | 12noon | Nationa Myeloma Day, Assoc. Prof. Andrew Zannettino & Dr Cindy Lee, Adelaide |
| 19 May | 11am | National Myeloma Day Details: Jo Beams ph 03 6331 5479 |
| 19 May | 10:30am | National Myeloma Day, Dr Simon Harrison & Dr Louise Purton, Preston |
| 19 May | 10am | National Myeloma Day, Darwin |
| 20 May | 1:30pm | National Myeloma Day: <i>Current & Future Perspectives</i> , Subiaco |

| NEW SOUTH WALES | | |
|-----------------|-----------------------------|--|
| 28 Apr | 10am | Community legal, estate planning & guardianship, Erina Fair |
| 11 May | 9:30am 10:30am 6.30pm | Myeloma Education Seminar, Dr Peter Presgrave, clinical haematologist, Gwynneville Complementary Therapies, Coffs Harbour GP evening talk, Dr Rob Lindeman, Bathurst (also 12 Oct) |
| 13 May | 2:30pm | Community legal, estate planning & guardianship, San Remo |
| 18 May | 11am | Myeloma morning tea, Albury Complementary Therapies, Port Macquarie |
| 27 May | 2pm | Myeloma information & education afternoon, Alstonville |
| 2 Jun | 10am | Myeloma Oncology Clinic, Tamworth |
| 4 Jun | | <i>Taking control of your finances</i> , Granville Library |
| 8 Jun | 10:30am | Bone Marrow Transplants, Coffs Harbour |
| 9 Jun | 11am | Carers' Health & Wellbeing, Rockdale |
| 15 Jun | 11am 6.30pm | Bone Marrow Transplants, Port Macquarie GP evening talk, Dr Joy Ho, Dubbo |
| 30 Jun | | <i>Taking control of your finances</i> , St Leonards |
| 5 Aug | 6.30pm | GP evening talk, Dr Scott Dunkley, Orange (also 4 Nov) |
| 30 Aug | 9:30pm | Myeloma for GPs & health professionals, Griffith |

| QUEENSLAND | | |
|------------|---------|---|
| 13 Jul | 11:30am | <i>Making My Life Better with Exercise & Nutrition</i> , exercise physiologist & dietician/nutritionist, Sth Brisbane |
| 5 Aug | 3pm | <i>Allogeneic Transplants</i> , Dr James Morton, Sth Brisbane |
| 10 Aug | 11:30am | <i>Getting My Life in Order</i> , solicitor, Centrelink officer & financial counsellor, Sth Brisbane |

| SOUTH AUSTRALIA | | |
|-----------------|---------|---|
| 22 Apr | 12 noon | <i>Chemobrain – Strategies for Managing the Condition workshop</i> , Adelaide |

| TASMANIA | | |
|----------|---------|--|
| 20 Apr | 11am | <i>A Guide to a Healthy Heart</i> , Launceston |
| 27 Apr | 10:30am | <i>Understanding the Role of Complementary Therapies workshop</i> , Invermay |
| 4 May | 10:40am | A day in the country, Hobart |
| 15 Jun | 10.45am | <i>Preparing for Winter Blues</i> (Taking Control, Part 5), Hobart |

| VICTORIA | | |
|----------|-----------------|---|
| 21 Apr | 10:30am 10am | Yoga, Preston <i>Living with Blood Cancer</i> , Bendigo (also 28 Apr; 5 May; 12 May) |
| 22 Apr | 1pm | Medications: Q & A session, Lee Belcher, pharmacist, Ballarat |
| 29 Apr | | Complementary Therapies Workshop, Traralgon |
| 6 May | 10:30am | Myeloma Education & Support Network, Preston (also 1 Jul; 2 Sept; 4 Nov) |
| 13 May | 10am | Mornington Coffee Morning |
| 11 May | 10am | Latrobe Blood Cancer Support Network, Traralgon (also 8 Jun) |
| 20 May | 10:30am | Baw Baw Blood Cancer Support Network, Warragul (also 17 Jun) |
| 27 May | 10am | Horsham Blood Cancer Support Network |
| 2 Jun | 10:30am | <i>What is on the Horizon in Myeloma</i> , Kaye Hose, Mildura |
| 3 Jun | 10am | Transplant Education & Support Meeting, Preston |
| 24 Jun | 10am | <i>Introduction to Art Therapy</i> , Ballarat |

| WESTERN AUSTRALIA | | |
|-------------------|------|--|
| 28 Apr | 11am | Advance Planning, Bunbury |
| 17 May | | <i>Look Good, Feel Better</i> , Bunbury (also 9 Aug; 25 Oct) |
| 17 Jun | 1pm | <i>Managing Fatigue</i> , Subiaco |
| 10 Jun | 11am | Bunbury Support Group, Bunbury (also 12 Aug) |
| 23 Jun | 11am | <i>The ABC of Myeloma & Treatments, Research & Clinical Trials</i> , Bunbury |

| TELEPHONE FORUMS | | |
|------------------------|---|---|
| Myeloma Phone Forum | Facilitator: Kaye Hose Ph: 03 9863 6951 | 6 May; 3 Jun, 1 Jul, 5 Aug, 2 Sept, 7 Oct, 4 Nov, 2 Dec |
| Transplant Phone Forum | Facilitator: Natasha Manoharan Ph: 03 9863 6952 | 27 Apr, 22 Jun, 26 Aug, 28 Oct, 23 Dec |

**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 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 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, 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.