

BRODIE RIDING HIGH AFTER BEATING LYMPHOMA

A photo on his favourite show jump horse, Little Wick, is what got 19-year old Brodie Towns through his treatment for Hodgkin lymphoma.

And his mum, Cheryl, reckons his horse 'knew' and helped Brodie, looking after him when his balance wasn't good.

Before his diagnosis in August last year, Brodie's life was full on. He was a champion rider who'd won at Sydney, Canberra and Brisbane events.

He loved his job as a diesel mechanic in Moree and was three months shy of completing his apprenticeship.

He'd also just made a huge financial commitment, buying a six-horse float, and every weekend he'd head off to compete in showjumping events in different parts of Queensland, New South Wales and Victoria with his mum and two younger brothers, Ryan and Drew.

Brodie was looking forward to riding at last year's Ekka, Brisbane's Royal Show, when he felt a lump on his neck while shaving. Within three days it had grown to the size of a golf ball. An ultrasound showed it was on his gland, and when a biopsy didn't provide enough tissue for a diagnosis, he had the lump surgically removed.

After surgery, he was devastated at not being able to compete at the Ekka, and that's where he found out he had lymphoma – in the middle of the Brisbane Show.

Within days, Brodie had a specialist appointment in Tamworth, then flew to Sydney for more tests and days later, began treatment.

Cheryl said the doctors told Brodie to forget about working, riding or completing his trade qualification until he'd finished treatment because he'd be too sick. But Brodie had other ideas. He was determined to continue working, riding and studying, which he did, but it wasn't easy.



Brodie Towns competing in the 2010 Brisbane Ekka on Little Wick – 12 months after his diagnosis

Every fortnight from late-August until December 2009, he made the four-hour trip from Moree to Tamworth for chemotherapy. He'd lie on the back seat on the return trip home and spent the weekend recovering. But he was always back at work the following Tuesday.

He sat and passed his exams for his apprenticeship and every second weekend he'd try to ride.

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LOW COMMUNITY AWARENESS

To learn about community awareness of blood cancers, the Leukaemia Foundation commissioned a survey by Sweeney Research.

In April this year, 500 online responses were received from people, aged 18 to 80, from across Australia and the responses were weighted to the population using Australian Bureau of Statistics 2006 census data and showed:

- 13% of participants had not heard of lymphoma
- 42% of participants had heard of lymphoma but knew nothing about it
- 40% of participants had heard of lymphoma and knew only a little about it.

Participants ranked what they perceived as the most common lymphoma symptoms:

tiredness.....	47%	unexplained weight loss	37%
lumps.....	36%	infections.....	19%
bruising.....	18%	back pain	10%

Participants incorrectly identified that leukaemia was more prevalent and had a higher mortality than lymphoma.

The Leukaemia Foundation will use the survey results to help improve quality of life and to measure the effectiveness of its future programs for people with lymphoma.

WORLD LYMPHOMA AWARENESS DAY 2010



World Lymphoma Awareness Day is on September 15 and the Leukaemia Foundation is holding events in all capital cities and many regional centres across Australia.

These activities are listed on the back page of this newsletter and if you would like to hold your own event in your area, such as a BBQ lunch, please let us know. We'd love to hear about it.

The Leukaemia Foundation is conducting a national survey of people who have/had lymphoma, to learn more about your experience, what services you used, what worked well and what did not.

This survey will help the Foundation advocate for improved services for people with lymphoma.

If you would like to complete this survey and have your say, contact Cassandra Gauld by email, cgauld@leukaemia.org.au or phone 1800 620 420.

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"And he'd beg us to take him to a competition. He'd only ride in one event and we'd help him off his horse and he'd just about drop to his knees. Then he'd sleep." *

During the three weeks between finishing chemo and going to Brisbane for radiation treatment, Brodie took Little Wick to Toowoomba and he won the Young Riders Championship.

The following week he started radiation and his Nan went up from the Gold Coast to stay with him at the Leukaemia Foundation's new accommodation complex at Coopers Plains in Brisbane.

"The people at the Leukaemia Foundation, they are just fantastic and the villas are unbelievable. You have to see the facility and what they do," said Cheryl.

"It is so uncanny. You think of all the years you've made a donation to the Leukaemia Foundation to help people, and you never think it will be you."

While Brodie was staying in the Foundation's accommodation, he met other people who were in Brisbane being treated for various blood cancers.

"He rang me and said 'I'm not bad you know Mum. I've got a chance to beat this. There's a little baby here and a 17-year old girl and old people who say they're not going to make it'," said Cheryl.

Brodie had radiation five days a week for nearly six weeks and afterwards he was told to take two weeks off work and take it steady.

"Are you joking?" was Brodie's reaction.

"This company has kept my job and supported me and I'll be at work tomorrow at 8am," said Brodie who did front up



Brodie with his mum, Cheryl Towns

for work the next day, despite getting home from completing treatment in Brisbane at 9:30pm the night before.

In June this year, Brodie got the great news. He was told "your blood's as good as your mother's" and a year to the day after his diagnosis, Brodie was back in Brisbane, picking up where he had left off, competing at the 2010 Brisbane Ekka.

Cheryl said his attitude prior to his diagnosis, during treatment, and even more so now he has been given the all clear, is to "go out and live life to the fullest".

Brodie wants to let other young people know that it is possible to get through treatment and still get on with life.

"It can be very difficult at times and sometimes it seemed almost impossible, but you can do it," he said.

** always consult with your doctor before taking on physical activity during or after treatment for lymphoma*

AUSTRALIAN RESEARCHERS PURSUE EXCITING LEAD

The Leukaemia Foundation has awarded a 12-month Grant-in-Aid to Dr Christine Hawkins who is investigating a potential cause of lymphoma.

Based at La Trobe University in Melbourne, Dr Hawkins and her research team are working on a gene known as Caspase-2, which is believed to play a critical role in lymphoma development.

Discovered in 1992, the role of Caspase-2 is poorly understood, but it is believed to help the body prevent cancer by causing malfunctioning white blood cells to 'self-destruct'. Researchers also have found that when the gene was missing from cells, lymphoma developed.

However, a significant breakthrough was made recently by Dr Hawkins when she identified five potential proteins targeted by the gene, two of which are frequently mutated in lymphomas.

Funded by the Foundation, Dr Hawkins and her team are currently running a series of experiments to confirm that these five proteins are selectively targeted by Caspase-2, and the conditions under which the gene is activated.

"Very little is known about Caspase-2, so determining its key protein targets as well as the how and why, will give us some big clues into how Caspase-2 works and its role in lymphoma development," Dr Hawkins said.

"This is an incredibly exciting project because we have a real chance to make a substantial discovery about the cause of lymphoma and long term potential impact on patient treatment through new prognostic tests and drugs.

"Without the Leukaemia Foundation's funding, it would have been extremely difficult to take our preliminary findings



Dr Christine Hawkins, centre, with members of her lab group in Melbourne

forward. After only six months, we have more solid data and by the end of the year we will be in a position to apply for a three-year government research grant.

"Grants like the Foundation's are so valuable for giving life to projects with promising early-stage discoveries."

In 2011 and beyond, Dr Hawkins hopes to continue her research into Caspase-2 with more sophisticated experiments, including developing new models to examine the gene's cancer development link.

Any new lymphoma drugs to emerge from Dr Hawkins' research will not be available for many years. However, research groups internationally are developing a range of new drugs to target Caspase-2, which could potentially be used to treat lymphoma.

NEW MAINTAINENCE STRATEGY FOR FOLLICULAR LYMPHOMA

Recent results from an international Phase III study incorporating the use of rituximab (MabThera®) herald a new standard of care for improving overall survival in follicular lymphoma patients.

More than 1200 patients from 23 countries, including Australia, took part in the Primary Rituximab and Maintenance (PRIMA) study between December 2004 and April 2007.

Following three years of analysis, the PRIMA results were presented in June 2010 at the American Society of Clinical Oncology (ASCO) 46th Annual Meeting in Chicago.

The researchers found a significant benefit in continuing rituximab for two years in patients who responded to initial treatment with MabThera plus chemotherapy.

Rituximab in combination with chemotherapy has been the first-line treatment of patients with stage III-IV follicular lymphoma for several years. However, in the PRIMA study, patients who continued to receive the rituximab maintenance therapy had twice the likelihood of progression-free survival with little additional toxicity, compared to those who did not receive maintenance.

Follicular lymphoma is a slow developing, incurable disease, which accounts for about 20% of all non-Hodgkin lymphoma cases.

The trial findings have provided new hope for the way follicular lymphoma is managed in patients, according to Principal investigator for the PRIMA study, Professor Gilles Salles, Centre Hospitalier Lyon Sud, France.

"Rituximab maintenance therapy is likely to become a new standard of care for these patients," said Professor Salles.

"(The PRIMA study) constitutes a new platform to further develop more efficient and well tolerated strategies."

FAST FACT

About 1000 more Australians were diagnosed with lymphoma in 2007 compared to 1997, yet there were 200 fewer deaths in 2007. Lymphoma research is making a difference.

YOGA IMPROVES SLEEP AND FATIGUE

Practicing yoga may improve sleep, reduce fatigue and boost the overall quality of life for people with lymphoma.

According to findings of the largest scientific study to examine the value of yoga specifically designed for cancer survivors, participants also reported reducing their need for sleep medication.

Once they began a yoga program, participants decreased their use of sleep medication by 21%, compared with the control group, who increased their use of sleep medication by 5% during the same time period.

The results of the study were presented at the American Society of Clinical Oncology (ASCO) 46th Annual Meeting in Chicago, Illinois in June.

"This is a readily applicable approach that improves quality of life and reduces medicine intake in cancer survivors.

This is a real positive," said George W. Sledge, Jr., MD, president-elect of ASCO.

As reported in the journal, *Medscape Oncology*, complementary medicine, including yoga, is common among cancer survivors, particularly women. Dr. Sledge pointed out that this study is "a creative application of scientific technique to complementary and alternative medicine approaches".

"Physicians frequently have trouble discussing these approaches with patients, but this study applies real science to the issue," he said.

The cancer survivors who participated in the study were enrolled in a specialised program known as YOCAS (Yoga for Cancer Survivors) which includes breathing exercises, gentle hatha and restorative yoga postures, and mindfulness exercises. The classes were 75 minutes long and participants attended twice a week for four weeks.

YOGA CAN PROMOTE COMFORT AND HEALING

by Alison Keane

There's growing interest in how the ancient eastern practice of hatha yoga – a gentle form of exercise and breathing – can support and soothe people with lymphoma.

Quantitative research is reaffirming a practice used for thousands of years – that yoga may ease fatigue, promote sound, restful sleep, and contribute to the healing process.

This is because in yoga we train ourselves to hold attention in the present moment. In so doing we let go of unhelpful thoughts about the past and anxiety and worry about the future. We do this by concentrating on the physical postures or *asanas* as they're known.

When we bring attention into the body, the mind can no longer cling to daily worries, and it begins to settle and to experience the present moment. Restful sleep patterns and elevated energy levels are the end result.

Yoga is sometimes called a moving mindfulness practice. The word 'mindfulness' translates from the term 'sati' which means 'to be awake'. When we are truly awake we are able to notice and appreciate so much more of each and every moment of our lives, not just physical pain, the inevitable life challenges and energy-draining worry.

Training ourselves to be mindful is not as easy as it sounds, believe me! Have you ever driven from point A to point B, and wondered how you got there? It's so easy for our busy and complex minds to multi-task. But it is not surprising that from here we slip so easily into stressful patterns where we seem to be constantly operating on 'auto-pilot'.

In yoga there is also a strong emphasis on breathing in a certain way. We are taught to breathe more deeply and at times, to lengthen the breath, particularly on the exhalation.

Practices such as this, under the instruction of a qualified yoga teacher, help to switch on the body's relaxation response. This again brings us back to the present and has a calming effect on the mind. As a result, a more relaxed brain demands less oxygen and this vital energy source is re-directed to the needs of the body, to rejuvenate and to heal.

Try this gentle yoga breath awareness practice. See if you can do it for about five minutes every day upon waking, for a week. Notice how you feel afterwards.

- Sit or lie comfortably. If possible, try to avoid lying in bed.
- Breathe in your usual way but pay attention to the feeling of the breath as it moves in and out of the nostrils.
- Notice when you become distracted with thoughts about something that happened in the past or something you imagine for the future. Notice even when you begin to have thoughts about whether you are doing the practice the right way, or even whether it will 'work'.
- Just keep returning your attention back to the breath.
- Be patient, gentle and kind with yourself.

Alison Keane, a Brisbane mindfulness educator, psychotherapist and hatha yoga teacher, trained in Mindfulness-Based Stress Reduction in the U.S. under Dr Jon Kabat-Zinn. www.alisonkeane.com.au



Alison Keane

FOUNDATION OFFERS FREE YOGA IN MELBOURNE

The Leukaemia Foundation has offered a regular yoga program for patients and families in Melbourne since early 2008. Held on the 3rd Wednesday each month, except during winter when patients are more susceptible to infections, the yoga classes are gentle, remedial hatha yoga classes taught by Support Services Co-ordinator, Natasha Manoharan who is a qualified yoga teacher.

Between six to eight people regularly attend the program with many benefits. "I am learning how to relax, how to be more aware and appreciate my body", commented a class participant. The yoga program is free. *For more information and to register, contact Natasha Manoharan, ph: 03 9863 6952 or email: nmanoharan@leukaemia.org.au*

LIFE AFTER TREATMENT - FOLLOW-UP APPOINTMENTS

After treatment finishes, you will have regular follow-up appointments for a period of time. The care and support offered during this important phase of your care is to aid your recovery and support you as you gradually return to normal life. This article describes what follow-up is, what it involves and how you might feel.

Before follow-up begins

Life after treatment can feel uncertain. It might be strange and a little frightening to be without the routine of going to hospital, without the regular attention of your doctors and nursing team. This period may be easier to manage if you prepare yourself with some information. You will need to know what to expect and what to look out for. It will help other health professionals, such as your GP, to have information about your treatment and the short and longer term implications for your health. Before you complete your treatment, ask for written information about:

- your exact diagnosis and what treatment you have had
- what symptoms to look out for
- what treatment side-effects to expect, how long they might last, and when you can expect to start feeling better
- what late-effects you may be at risk of in the future, when these effects might happen, and what symptoms to look out for
- when your follow-up appointments will be, and
- where to go for help, support and advice, if you need it.

Some treatment centres provide this information routinely, but you may have to ask for it. If you are not provided with written information, it might help to write down the answers to these questions. You might also want someone else with you for these conversations, to help you remember the important points.

What is follow-up for?

Follow-up is a two-way process. It is a chance for you to raise concerns and ask for help if you need it. It is a chance for your team to collect information and carry out routine tests. To start with, your follow-up appointments will be to monitor your recovery from treatment. You will have the chance to discuss any ongoing side-effects and plan what to do about them. You will have the chance to talk about how you feel in general – your health, your feelings, your gradual return to a normal routine. Follow-up appointments are also to check up on your lymphoma. They are an opportunity to investigate any worrying symptoms that might suggest relapse of your disease. If you have had high-grade non-Hodgkin lymphoma or Hodgkin lymphoma, relapse is most likely to happen in the first two years after your first course of treatment. If you have advanced low-grade non-Hodgkin lymphoma, relapse is more common and you are likely to need other courses of treatment in the future. As time moves on, your follow-up appointments will be to check for late-effects of treatment. Late-effects are the consequences of treatment that happen many months or even years after your lymphoma treatment. Your risk of late-effects will depend on a number of factors, in particular what kind of treatment you had, your age, your lifestyle and your general health. Collection of information about late-effects is an important part of follow-up.

This information helps to improve lymphoma treatments and reduce risks to long-term good health. Follow-up appointments will be a chance to make plans for dealing with late-effects. For example, you may wish to see another specialist for help with fertility, or speak to a counsellor for help with your feelings. Your team can arrange for you to see other specialists and arrange support as necessary.

How often will appointments be?

To start with, you will be seen every one to two months. Gradually, your appointments will become less frequent. They will go down to once every three to six months and eventually to once a year. If you have advanced low-grade non-Hodgkin lymphoma, your appointments are likely to remain regular for an indefinite period. Sometimes people with advanced low-grade lymphoma will be left to decide for themselves and will make a follow-up appointment when they need one.

How long will I be followed up for?

There are big differences in lengths of follow-up time, which will depend on:

- what sort of lymphoma you had
- your general health
- the usual practice in your area
- your choice and your doctor's advice.

Most hospitals will offer follow up for at least two years. This period is the most critical in terms of your recovery from treatment and the risk of your lymphoma coming back. Many hospitals will offer follow-up for five years, others for much longer periods, and some centres will leave it to you to decide. If you have been treated as part of a clinical trial, you will be followed up according to a set of instructions called the trial protocol. Clinical trials are often set up to monitor long-term health, so follow-up for trial participants may be longer than for others. If you have Hodgkin lymphoma, or high-grade non-Hodgkin lymphoma, there is no evidence to suggest that follow-up for longer than two years offers any benefit for your health, although many people will find prolonged follow-up reassuring. The Department of Health is currently developing guidance on follow up for people with lymphoma. People with advanced low-grade non-Hodgkin lymphoma are likely to be followed up for an indefinite period because the illness is likely to flare up at regular intervals.

How will I feel about follow-up?

Most people welcome follow-up appointments. They provide the opportunity to see familiar faces and supportive professionals who understand what you have been through. Getting back to normal can be difficult and follow-up can provide reassurance about problems and concerns. It can be good to be reminded that what you are experiencing is normal. People sometimes find follow-up appointments worrying, mainly because of fears about the lymphoma coming back: "my doctor will know something that I don't ... I'm scared of being given bad news". In fact, if your disease comes back, you are likely to be the first person to know something is wrong.

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LIFE AFTER TREATMENT - FOLLOW-UP APPOINTMENTS

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Your follow-up appointment is not likely to mean getting unexpected bad news. Some people find follow-up appointments frustrating or upsetting. You might just want to get back to normal, not want to be reminded of what you have been through, and you might find it distressing to go back to a place that's associated with bad memories. Talk to your team if you find follow-up appointments distressing. You may prefer to arrange appointments only if you feel the need for them.

What does follow-up involve?

You may see your consultant for your follow-up or you may see another member of the medical team. Some follow-up clinics are run by specialist nurses. Follow-up will combine a few routine tests with a physical examination and a talk about how you are feeling. The tests you have will depend on:

- What kind of lymphoma you have. Some lymphomas are more likely to affect particular parts of the body, which might mean a need for different tests.
- The parts of your body that were affected when you were first diagnosed. For example, if you had very large lymph nodes in your chest, your doctors might be keen to check that area in particular.
- What sort of treatment you had. Some treatments will mean you need to be monitored for particular side-effects or risks to your longer-term health.

Blood tests

Common blood tests will include the blood count, which measures the different levels of cells in your blood. It can give information about the function of your bone marrow and is a good measure of your recovery from chemotherapy, particularly in the early months following treatment. Other blood tests give information about your general health and organ function, including tests that check your liver function and how well your kidneys are working. You may hear of a blood test called 'LDH' or lactate dehydrogenase. LDH is a naturally occurring protein and levels of LDH can go up as a result of tissue injury or disease. There are many possible causes of raised LDH and it is sometimes seen in people with lymphoma. For some people, blood tests will provide more information about the behaviour of the lymphoma. For example, people with chronic lymphocytic leukaemia may have abnormal white cells in the blood stream. Some lymphomas might produce abnormal proteins that can be seen in the blood. But for the majority of people, blood tests are only an overview of your general health. Changes in your blood tests alone do not necessarily indicate that something is wrong – many changes to your blood happen as a normal response to something like an infection or an injury. Some changes in your blood might need further investigation if there are other causes for concern.

Your general wellbeing is the most important sign of your progress. Your doctor or nurse will want to know how you are feeling. This will include how you are recovering from the side-effects of treatment. It will also include how much energy you have and whether or not you can manage the things you used to do before treatment. Make a note of how you are feeling and tell your team about any concerns you have. You might want to keep a diary of your symptoms to help you identify whether certain problems are getting better or worse. Your doctor may carry out a physical examination. This might mean checking the lymph nodes that can be felt from the outside or seen in the throat. Your doctor or nurse may also check your weight, temperature and blood pressure. Your emotional health is also an important part of your recovery. It is common for people to struggle with moods, feelings and personal relationships following treatment for cancer. Some clinics use 'tools' to check on your emotional health. These are basic questionnaires that ask you to provide information about how you are feeling and can help to identify people who might need more psychological support.

Scans

Some people will be offered a CT scan following completion of treatment. In some cases, a scan will be repeated after a period of time. It is not common practice to offer regular scans following lymphoma treatment due to the radiation involved. Positron Emission Tomography (PET) scans provide information about the metabolic activity of cells – the way in which cells absorb compounds and make energy. They can help to distinguish between normal cells and cancer cells, and may be used for people who have residual 'shadows' on routine scans. PET scans are not in routine use for lymphoma follow-up. Clinical trials are testing ways in which PET scans might be used in the treatment and management of lymphoma.

Conclusion

Your follow-up marks the transition between your lymphoma treatment and your gradual return to normal life. For most people, follow-up will be a positive experience. It can provide a place to take your worries and concerns, and it can reassure you that you are on the right track. You may have come to rely on your medical and nursing team during the time of your illness, and it may be a little frightening to lose that regular professional support. The support you have in follow-up should help you to gradually regain confidence. Remember that the most important factor in successful follow-up is you. Be aware of how you are feeling and be sure to talk to your team about anything that is worrying you. With the right information to start with, you should feel prepared for the months ahead. Ask about what to expect, what not to expect, and where to go for help if you need it. With this information, your immediate future should feel more under control, and less uncertain.

For more information about anything you have read in this article, or if you would like to discuss how you feel about life after treatment, please telephone a Leukaemia Foundation Support Services Co-ordinator on 1800 620 420.

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TOP LYMPHOMA TIP

"Making friends with the nurses was one of the best things I did. They are full of useful practical information and made chemotherapy a bit of a social experience."

Craig Kelly, Queensland

JIM'S IN REMISSION AND FEELS GREAT



Jim Niemann has started playing his guitar again

If you wake up in the morning, it's another good day according to Jim Niemann who is in remission with mantle cell lymphoma.

"I feel great and it's good to be alive," says the retired operations manager who will turn 70 on Christmas Day.

But "things looked pretty grim" in mid-2007. Jim was doing some paving at his home in Adelaide and felt completely exhausted. Thinking he'd torn a stomach muscle shovelling sand, he went to see his GP.

After a month, when he hadn't improved, Jim's GP sent him to the Emergency Department.

"I had been feeling tired but put it down to just getting old. And I'd had some night sweats and shortness of breath, but what gave the doctor a clue was when he physically examined me and found my spleen was three times the normal size," explained Jim.

At hospital he had blood and urine tests and a CT scan and was told: "Mate, you've got cancer."

Mantle cell lymphoma stage IV was diagnosed after Jim had a bone marrow biopsy and more tests that showed he had a tumour next to his aorta.

Jim and his family thought about his predicament for 24 hours, then decided "to get on with it and beat this thing".

"And from that moment on the support I got from people was unbelievable including people I hadn't seen or talked to for 30 years who rang up, asked how I was going and offered me their best. It's mind-boggling where friends come from when you have a problem."

An oncologist started Jim on chemotherapy (R-CHOP 21*) but after two treatments, another CT scan showed it wasn't working.

"They told me I might have between six weeks and six months to live and suggested palliative care or a much stronger treatment that may have other side-effects. Have a guess which one I chose!"

He was referred to a haematologist who put Jim on a different treatment – hyper CVAD**. Every three weeks he went to hospital to receive this chemotherapy over five days.

In December 2007 Jim had a stem cell harvest and the following April he had an autologous stem cell transplant.

"I was in solitary confinement for four weeks, I had a couple of major infections including MRSA*** which were treated with lots of antibiotics, and I managed to lose almost 18 kilos," he said.

Jim has since had some 'top up treatments' of rituximab. The last one was in October last year and he hasn't had any treatment since. In June this year, a CT scan showed no evidence of any recurring disease and Jim only has to see his haematologist every six months.

"The only down side so far is a very low immunity level. I have to be careful of crowded places and I wash my hands much more."

Now Jim and his wife, Rae, who retired last Christmas, can make plans.

"We bought a caravan and plan to become grey nomads. So far we've only been on one trip. We went away for four days and ended up staying for 10 days but in the next few years, we're going all over the place.

"We're living day to day and we're having a good time," said Jim.

Jim and Rae have been together for 50 years. They met in Broken Hill during Jim's early days in the music industry. He was in several bands but hadn't played for 30 years, until recently.

"I get my guitar out of its case and practice a little every day," said Jim who loves his shed and spends several hours there nearly every day tinkering.

"If anything needs doing around the house, I try to do it myself. I do a bit of welding, carpentry and plumbing.

"During chemo I didn't go down to the shed for six months and in that time the door hinges rusted," said Jim.

"Mantle cell lymphoma can recur and if it does I'll have more treatment. I feel very positive about the next five, 10 or 15 years."

* R-CHOP 21: combination chemotherapy (rituximab, cyclophosphamide, doxorubicin, vincristine and prednisolone)

** CVAD: combination chemotherapy (cyclophosphamide, vincristine, adriamycin and dexamethasone)

*** methicillin-resistant staphylococcus aureus

ABOUT MANTLE CELL LYMPHOMA

Mantle cell lymphoma is an uncommon type of fast-growing non-Hodgkin lymphoma that affects the body's B-cells, a subtype of white blood cells that play important roles in the immune system. Median overall survival of mantle cell lymphoma patients has more than doubled in the last 20 years, but remains in the range of four to five years. Most patients eventually relapse and often develop resistance to the effects of their medication.

EDUCATION AND SUPPORT PROGRAMS

NEW SOUTH WALES / AUSTRALIAN CAPITAL TERRITORY		
4 Sep	10am	Haematology Support Group, Nurrabundah, Canberra (also 12 Oct, 16 Nov, 14 Dec)
9 Sep	2.30pm	<i>Life Beyond Cancer</i> information & support session, Wyong
28 Sep	10am	Blood Cancer Support Group, Liverpool (also 26 Oct, 30 Nov)
29 Sep	10am	Hunter coffee morning, LF office (also 24 Nov)
30 Sep	10am	Patient and Carer morning tea, Erina
8 Oct	10.30am	Grief & Bereavement Support Group Meeting, Artarmon (also 22 Oct)
14 Oct	10am 11am	Patient & Carer morning tea, Warnervale Eating well & dietician tips, North Wollongong (also 10 Nov)
21 Oct	TBA	GP breakfast, Murwillumbah
26 Oct	10am	Hunter coffee morning, Nourish café @ Shortland Wetlands
28 Oct	10am	Information & support session, Erina
4 Nov	2pm 6.30pm	Patient & carer support afternoon tea, Northern Rivers GP evening talk & dinner, Orange: Dr Scott Dunkley
11 Nov	2.30pm	Information & support session, San Remo
2 Dec	11am	Christmas party, Erina Fair
9 Dec	10am	Christmas morning tea, Warnervale
14 Dec	6.30pm	GP evening talk/dinner/open forum on haematological malignancies
TASMANIA		
7 Sep	11am	Blood Cancer Support Network, <i>Taking Control Part 2</i> , Hobart
21 Sep	11am	Blood Cancer Support Network, Launceston (also 19 Oct)
12 Oct	11am	Blood Cancer Support Network, <i>Taking Control Part 3</i> , Hobart
WESTERN AUSTRALIA		
13 Sep	TBA	<i>Look Good, Feel Better</i> , Bunbury (also 25 Oct, 29 Nov & Christmas get together 23 Dec)
24 Sep	10am	Carers' coffee morning, Northbridge (also 29 Oct, 26 Nov)
14 Oct	11am	Bunbury Support Group (also 9 Dec)
28 Oct	1:30pm	<i>Managing Pain</i> , Subiaco
24 Nov	11am	<i>Complementary Therapies</i> , Subiaco

VICTORIA		
1 Sep	10am	Lymphoma Education & Support Meeting, Preston (also 6 Oct, 3 Nov)
7 Sep	11am	Hobart Blood Cancer Support Network, (also 12 Oct)
9 Sep	10am	Mornington Education & Support Program, Frankston (also 11 Nov)
14 Sep	10am 10.30am	Latrobe Blood Cancer Support Network (also 12 Oct) <i>Meditation Part 1</i> (Part 2, 28 Sep; Part 3, 12 Oct), Preston
15 Sep	10.30am	Yoga, Preston (also 20 Oct, 17 Nov, 15 Dec)
16 Sep	1pm	Baw Baw Blood Cancer Support Network (also 21 Oct)
23 Sep	10am 1.30pm	Horsham Blood Cancer Support Network East Gippsland Support Network
7 Oct	10am	Transplant Education & Support Meeting, Preston
19 Oct	2pm	<i>Surviving Carer Stress</i> , Preston
28 Oct	10am	Ballarat Blood Cancer Support Network
16 Nov	10.30am	Taking Control Seminar, Preston

SOUTH AUSTRALIA / NORTHERN TERRITORY		
8 Sep	10am	Friends of the Foundation patients & carers' coffee morning, Noarlunga (also 13 Oct, 10 Nov)
9 Sep	10am	LMB Support Group morning tea, Darwin (also 14 Oct, 11 Nov, 9 Dec)
21 Sep	10.30am	Friends of the Foundation coffee morning, North-east metro (also 19 Oct)
23 Sep	10am	Carer's Connect morning tea, Darwin (also 28 Oct, 25 Nov; 16 Dec)
24 Sep	10.30am	Friends of the Foundation, carers' coffee group, Adelaide (also 26 Nov)
5 Oct	12noon	<i>Dealing/coping with dexamethasone</i> , Adelaide
6 Oct	10am	Friends of the Foundation coffee morning, Victor Harbor
26 Oct	12noon 1.30pm	<i>Access to super and insurance</i> , Adelaide <i>Supports through Centrelink for blood cancer patients & carers</i> , Adelaide

WORLD LYMPHOMA AWARENESS DAY ACTIVITIES

NEW SOUTH WALES		
9 Sep	2pm	Lymphoma patient education: Cathy Paine, St Bartholomew's Anglican Church, Alstonville
15 Sep	6.30am 6.30pm	GP/Practice nurse lymphoma breakfast, Newcastle Lymphoma seminar for GPs, Wollongong: Prof. Peter Presgrave
21 Sep	1:30pm	Lymphoma Day event: Kerry Wagland, Tea and Treasures Café, Port Macquarie
27 Sep	10am	St George Area Lymphoma Support Group, Kogarah (also 29 Nov)
SOUTH AUSTRALIA / NORTHERN TERRITORY		
14 Sep	12noon	<i>Exciting new drugs for lymphoma</i> : Associate Prof. Nick Wickham, Hilton Hotel, Adelaide
15 Sep	10am	National Lymphoma Awareness Day morning tea: Eat at Martin's Café, Darwin
WESTERN AUSTRALIA		
8 Sep	11am	Lymphoma Education Session, Bunbury
30 Sep	1pm	<i>Lymphoma Update</i> , Subiaco

QUEENSLAND		
15 Sep	1:30pm	Lymphoma Education Day, <i>Emerging research</i> : Dr Jason Butler, & patient forum, South Brisbane
VICTORIA		
22 Sep	TBA	<i>New Trends and Treatments in Lymphoma</i> , Melbourne
23 Sep	11am	<i>Know Your Nodes</i> , Hobart

NATIONAL TELEPHONE FORUMS

Lymphoma and transplant telephone forums are held regularly for patients in regional and remote areas, and metropolitan patients who have difficulty accessing the Leukaemia Foundation's regular education activities. To find out more and to register, contact your local Support Services Co-ordinator on 1800 620 420.

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 and 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's free services include 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.

Roche proudly supports the Leukaemia Foundation in its educational activities through an unrestricted education grant.

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 you, phone 1800 620 420 or visit www.leukaemia.org.au