

Lymphoma today



Leukaemia &
Blood Foundation
Vision to Cure - Mission to Care

Supporting people
living with lymphoma

www.leukaemia.org.nz

spring 08



01

'Lucky' Adam looks to the future

When Adam Gilshnan noticed a nagging pain in his lower back, the pub owner blamed the heavy beer kegs he moved around in the chiller. And when his trousers started feeling a little tight, the 29-year-old decided age and bad eating habits were taking their toll.

A short while later Adam was diagnosed with an aggressive form of non-Hodgkin lymphoma in the lymph nodes of his abdomen, a diagnosis that led him to move to Christchurch for 18 months of treatment and recovery, and sell up his share in the Railway Hotel in Greymouth.

Thankfully, Adam, now 35, is back to full health and this autumn he celebrated by marrying sweetheart Amber in a double ceremony – once on the West Coast surrounded by New Zealand family and friends and again in Cumbria, England, where Amber is from.

The couple now live in Greymouth and Adam has landed his dream job; cancer navigator for West Coast PHO, offering support to people diagnosed with all forms of the disease.

Adam, who was supported by the Leukaemia & Blood Foundation throughout his illness, says: "I'm so lucky. I've got a gorgeous wife and a brilliant job and now I have the opportunity to give back.

"What I went through with lymphoma was horrific – I wouldn't wish it on

anybody – but it does mean I can talk to people about my own experiences."

Adam's journey began when a physiotherapist he had visited for his back pain felt a large swelling in his abdomen.

Adam said: "He asked me if I was feeling OK and I said I was fine. He looked surprised and told me to go to my GP straight away, and if I couldn't get an appointment, to go to the hospital outpatient department.

"I was completely oblivious to any danger. I took the note he gave me to my GP who told me not to worry, it couldn't be cancer as I was feeling so well. He said it must be a cyst and that's what I told everyone at work. I was showing it off and they were poking it!"

A hospital scan followed, and then a call from his doctor which Adam says, "changed my life. I remember it was 6.50pm on Friday 31 May, 2002, when he rang with the diagnosis. I lived above the pub and I was just on my way down to the bar – we always had good fun on Friday nights."

Instead, Adam stayed put and phoned his business partner and father, who

both came upstairs to hear the news. "I think I still had it together," says Adam, "and then Dad said, 'you better call your mum.' Telling her was the worst thing I've ever had to do and I will never forget the look of absolute devastation on her face. My dad had been upset, of course, but she was just outwardly crushed."

Within days, Adam began a three-month course of chemotherapy at Christchurch Hospital then the decision was made to send him to Sydney for a PET scan to check on the lymphoma.

The scan confirmed lymphoma and back in New Zealand doctors tried five weeks of radiotherapy. Then, when he

CONT. ON PG 2



01 / Wedding at Woodland Glen, Hokitika. 02 / Amber and I in Barcelona, Spain, 2007. 03 / This was on my 2005 O.E standing by the river Thames, south London.

CONT. FROM PG 1

arrived for one of his regular hospital appointments, he found his haematologist waiting for him with the bone marrow transplant co-ordinator.

Adam remembers: “They said to me, ‘let’s sit outside, it’s a lovely day’, and I knew what was coming. The haematologist told me they weren’t sure they could do anything more for me and that was the first time I thought, ‘I’m going to die’. It took me a few years to tell my family about that day, at the time I didn’t want to worry them.”

Following more tests, the haematologist suggested a bone marrow transplant and Adam’s older brother Kelvyn was found to be a match. Adam says: “I wanted to have the chance to be a grumpy old man but that was a big thing to ask my brother to do. I knew if it didn’t work it would be very tough for him.”

However, in late 2005, Adam got the all-clear to head overseas for two months to Japan, the US and the UK, where he saw his beloved Liverpool Football Club play. But, he didn’t travel light. “I was still taking 30 pills a day so I needed a medical note to explain why there were 1,250 tablets stuffed in my sports bag.”

Adam returned home, still struggling against low energy levels – and then he met vet Amber at a rugby match in September 2006.

He says: “She encouraged me to walk and to push myself. I had no confidence after being out of work for so long but even if I took a step forward then two steps back, she encouraged me and believed in me, even when I didn’t. She is an amazing woman, and I am so very lucky that she has come into my life.

“Now I’ve joined a gym, I eat healthily and life is good. And the one big lesson I have learned, is that if you want to do something, do it now - there are only so many tomorrows.”



Support Services Team Update

The Support Services team is made up of trained haematology nurses who are here to help patients, family and friends of people living with blood cancers or conditions.

BRIAN AMOS NZ TOUR

We were fortunate enough to host Brian Amos on a NZ tour in May. Brian hails from Queensland and has an extensive nursing background, previously working as the National Support Services Manager at the Leukaemia Foundation of Australia. Brian gave presentations to health professionals and patients alike about the emotional impact of living with a blood condition.

NEW LBF REGIONAL OFFICES NOW OPEN

We are pleased to announce that we have new premises open in the Central and Southern Regions. The Support Services Coordinators are available at the following locations:

Lisa Speedy
Central Region
15 Riddiford Street
Newtown
Wellington, 6021
Phone: 04 389 3774

Christine Kerr
Southern Region
Ground Floor
68 Oxford Terrace
Christchurch, 8011
Phone: 03 365 0367

If you would like to pop in to visit, please phone Lisa or Christine for an appointment. The Northern Region Support Services staff are available at the National Office in Auckland. We’d love to see you!



NEW SUPPORT SERVICES COORDINATOR IN THE NORTHERN REGION

Debbie Murphy has joined us as the newest member of the team, covering Auckland and Northland. Debbie comes from Auckland City Hospital with a wealth of haematology nursing experience. With her arrival, the team expands from three coordinators to four, which allows us to increase the availability to patients and look at ways we can continue to improve current services.



SHARON VERRALL

Sharon has been a part time member of our Patient Support team for three years, assisting the Support Services Coordinators in the Northern Region. We thought it a good time to introduce Sharon, who has a small caseload of patients that she works with.

World Lymphoma Awareness Day

Fatigue

The focus of this year’s World Lymphoma Awareness Day (WLAD) is fatigue. The LBF will be running patient education sessions around the country to discuss these issues and offer advice, guidance and information.

Fatigue is very common experience with any cancer and its treatment. As many as three quarters of people living with lymphoma feel fatigued at some point. Feeling excessively tired or exhausted all or most of the time can be frustrating and overwhelming. Fatigue may be due to the cancer itself, or a result of symptoms caused by the cancer. It can also be a side effect of treatments including chemotherapy, radiation therapy and stem cell transplant.

Research has shown that people with cancer find that fatigue is the symptom which is most disruptive to their daily life.

Fatigue can affect the way you think and feel. You may find it difficult to concentrate on work, socializing and even day to day activities such as housework.

Fatigue can affect your relationships with family and friends. It is important to talk to people close to you about how you’re feeling as they can help. Take up offers of assistance, even if they are as small as making some meals to put in the freezer or some help with the garden.

The education sessions will have speakers discussing how to cope and how exercise can play a role in your wellness. They will be giving hands on help and in-depth advice on the practical day to day strategies to manage and mitigate the effects of fatigue.

Although the sessions are held in conjunction with WLAD, they are open to patients and families living with any blood condition.

For more information on these workshops either visit us on www.leukaemia.org.nz or call us free on 0800 15 10 15.

By Phil Kerslake
Lymphoma survivor; author & speaker on navigating cancer
www.lifepaths.co.nz
phil@lifepaths.co.nz



*psychosocial corner

Keep doing what you enjoy!

A novelist friend contacted me recently with bad news. Her cancer had recurred so she was facing more treatments and of course, more uncertainty and distress. In despair she asked me for a suggestion to help her re-gather and cope. In her case my response came immediately: “write, write, write!”

So often when diagnosed with cancer, we put our lives on hold pending recovery. We reduce involvement in or withdraw altogether from the pursuits that brought us most joy and fulfillment when we were well.

Physical debilitation is often not a factor. Deciding we should be focused and single-minded about our recoveries, we mistakenly surmise that life’s pleasures can play no part in this – they may even be detrimental distractions. So we start to turn down social invitations; stop writing, painting, having our card evenings, playing bowls – whatever we usually did for rest and recreation gets shelved.

Here’s the problem with this strategy. With our pleasurable pastimes abandoned, we can find ourselves with nothing to be preoccupied with but the cancer and our mortality. Between treatments we worry about whether the disease is responding. We dread every test result. We are haunted by the ‘psychological cancer’ every moment of the day.

The focus we were trying for is not the one we get and this has consequences

for the quality of our life. We lose the art of living for the moment and of experiencing the joy of life – both of which may have therapeutic benefits.

Fact is, our favourite pursuits are distractions of sorts – but not in the negative way we can anticipate. Any psychologist will tell you that positive distractions are both life-affirming and a healthy respite from the many stresses of life.

Consciously not focusing on your cancer encounter for periods can provide valuable interludes during which you can re-gather equilibrium and re-charge your energies. Resulting benefits also include better decision-making and problem solving and a greater capacity for self-advocacy within the medical system – all valuable coping enablers.

Perhaps most compelling though – these kinds of activities are a big part of what makes life worth living. In that sense, engaging in them can underpin your resilience, increasing your resolve to hang in there when times are toughest. In my experience this can make a difference.

I often paraphrase Nietzsche on this latter count: ‘We can cope with any how if there’s a why.’ Being a focused and active patient is beneficial in coping with cancer; giving up life’s joys and pleasures is not.



Patients flock to hear lymphoma specialist

Professor Volker Diehl's ground-breaking research into lymphoma has earned him a place in the annals of medical history.

So when the German oncologist and self-acclaimed 'lymphomaniac' visited New Zealand earlier this year, he was understandably in hot demand.

But despite a hectic touring schedule, the professor still found time to present to a packed patient and family meeting of the Leukaemia & Blood Foundation's lymphoma education and support programme in Auckland.

According to Amy Munro, Support Services Manager for the LBF, it was one of largest patient events the LBF has ever held.

She recalls: "There were so many patients interested we had to start a waiting list - around 40 people attended, that's twice the size of our usual meetings."

"A couple of patients even travelled up from Hamilton because they had heard

Volker Diehl speak the night before and enjoyed it so much."

Amy believes the professor's appeal lies in his, "real passion for the subject and his ability to share his expertise in a way that has a relevance to patients' everyday lives.

"For example, he didn't just focus on advances in medical treatment, but on the psychosocial aspects of living with the disease, like the health benefits of practicing Tai Chi."

During his presentation, Volker Diehl spoke about the 'enigma' of Hodgkin lymphoma and the mysteries surrounding its cause.

He also spoke on the doubling of incidence of non-Hodgkin lymphoma in the US and Western Europe in the last 20 years – right in line with New

Zealand Ministry of Health data for this country. He also touched on theories around the reasons for that rise, including increased exposure to pesticides, solvents and hair dyes.

The professor also shared 'Diehl's theory about NHL and allergy increase in the Western world'. He told the group: "Is it that we are brought up too sterile in the first years of our life, not allowing the thymus* to decide who is friend or enemy?" He talked about the dangers of late exposure to pathogens / antigens / allergens and pointed out that Albania, the poorest country in Europe, has one of the lowest incidences of non-Hodgkin lymphoma.

He was also able to reassure the patients and family members present that the treatment provided in New Zealand is on a par with the rest of the Western world.

Amy said: "He was so enjoying answering patients' questions we regrettably had to intervene so he wouldn't be late for his next meeting.

"He did say to me afterwards that talking to our patients was one of the highlights of his trip (it was the only patient group he presented to on his Roche Products-sponsored tour), and that all around the world, patients have the same questions."

The professor also admired the LBF's information booklets on non-Hodgkin and Hodgkin lymphoma and took away copies of each.

* The thymus is an organ located in the upper part of the chest cavity just behind the sternum. Hormones produced by this organ stimulate the production of certain infection-fighting cells. The thymus is of central importance in the maturation of T cells.

transformation and immortalisation of B-lymphocytes with Epstein Barr-Virus (EBV) and he cultured the first in vitro Hodgkin cell lines (L428, L540, L591, L1236). His main clinical achievements include the remarkable improvement of outcome rates for patients with Hodgkin lymphoma.

Professor Diehl sits on a number of professional bodies including the European Society for Cancer Research, the German Society of Haematology and Oncology and the German Cancer Society. He has also co-edited several national and international journals including the New England Journal of Medicine.

Who is Volker Diehl?

One of the world's most esteemed medical oncologists, Professor Dr. Volker Diehl is Chairman of the German Hodgkin Lymphoma Study Group, which he founded in 1978. For 20 years, he was Chief of the Department for Internal Medicine and Head of the Division of Haematology and Oncology at the University of Cologne, Germany. From 2003 – 2006, he was Founding Director of the Comprehensive Cancer Center in Heidelberg, Germany.

To date, he has published more than 500 papers and articles in clinical and basic scientific journals. His valuable scientific contributions include the first

ANOTHER OVERSEAS VISITOR SHARES EXPERTISE

New Zealand was also on the lecture tour itinerary of America's Dr Myron Czuczman, who is a recognised expert on the biological therapy of lymphoma and related cancers.



Dr Czuczman arrived on our shores late last year on his way to an annual haematology conference in Australia.

During his visit, he presented to haematologists and nursing staff around the country presenting on *The changing landscape in the treatment of follicular lymphoma: 2007 and beyond*.

The group heard about Dr Czuczman's clinical research, which contributed to the US Food and Drug Administration's 1997 approval of the first monoclonal therapy rituximab (MabThera) for non-Hodgkin lymphoma.

He told the group his research interests focus on:

- Monoclonal antibodies, either alone or in combination with other agents in the treatment of lymphoma
- Evaluating novel target-specific molecules active against lymphoma in the clinic and laboratory
- Studying the mechanisms-of action and resistance pathways involving monoclonal antibodies currently used in lymphoma therapy.

New booklet

Look out for two of our brand new patient information booklets coming soon. The first one is entitled "Understanding Allogeneic Transplants" and the second is, "Understanding Autologous Transplants"

For your free copy please contact the LBF on 0800 15 10 15 or email lbf@leukaemia.org.nz or alternatively these booklets will also be stocked at major treatment centres around New Zealand.

Rochelle's touching tribute to mum Marie

Hundreds of brave New Zealanders willingly went under the razor for our April fundraiser, Shave 08.

And just like Feilding mum-of-four, Rochelle Lancaster, many had a very special reason for taking the plunge.

In Rochelle's case, she sacrificed her shoulder-length hair as a tribute to her mum, Marie Bragger, who died of non-Hodgkin lymphoma at the age of 56.

And once Rochelle's head was bare, she took a few moments to make up a little pony tail of the hair scattered on the floor of North End Playcentre, where she had shaved with a friend.

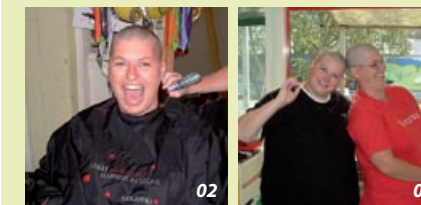
She reveals: "I tied the ponytail up with a nice piece of white string and I put it on mum's grave. She had shaved her head when her hair started falling out during chemo, so I thought, well this is something I can do for mum."

Doctors initially believed Marie was suffering from an allergic reaction to her dentures when she told them about the severe itch on her body, which was keeping her awake at night.

By the time her lymphoma was diagnosed in 2002, it was quite advanced.

Rochelle remembers: "The day they told her there was nothing more they could do, I found out I was pregnant with my second child Tessa-Marie (now four). We had been trying for a baby for a year because we knew mum was seriously ill and she really wanted another grandchild."

Rochelle, 32, looked after her mum whilst struggling with debilitating morning sickness. Rochelle says: "I was exactly three months pregnant when she died. Mum



01 / Rochelle (right) and pal Kerrie Hardgrave, get ready for the big shave with the help of Rochelle's twins Cori and Ella, 2. 02 / There's no going back for Rochelle. 03 / Kerrie (left) and Rochelle show off their new look.



had a real thing about your pregnancy not being safe until you reached 12 weeks – so she waited."

Rochelle decided to get involved in Shave 08 after watching our television advert, starring 10-year-old Leukaemia & Blood Foundation patient, Ryan McGregor.

She admits: "I loved it. It brought me to tears every time I saw it. I remember saying at the time, 'I'm going to do that', and my husband, Steve, said 'no way' – he could understand why I wanted to get involved, but he didn't want me to do it."

Rochelle was determined though and when she next dropped her three-year-old twins, Ella and Cori, at the North End Playcentre, she told fellow mum Kerrie Hardgrave about her plans.

Kerrie had seen the advert too and decided to join her and with only a week to go until their shave on Monday 14 April, the two started fundraising hard.

Between them, the mums hit their target of \$500 and then surrounded by family, friends and playcentre youngsters, they were shaved by local hairdressers Advance Hair, who also donated \$50 to the campaign.

She adds: "Mum was very self conscious about her hair loss and covered up her head whenever she went out. It's strange, when I went to the bank with my Shave donations, a woman there said I was brave, that she couldn't go outside bald.

"But I think brave is when you don't have a choice. This is something I chose to do and a lot of people don't have that option."



IN THIS EDITION WE TALK TO MELANIE BURFITT, CHIEF EXECUTIVE OF THE UK'S LYMPHOMA ASSOCIATION.



Lymphoma Coalition

The Leukaemia & Blood Foundation is a proud member of the Lymphoma coalition, a global alliance of 30 countries representing the interests of people living with lymphoma.

WHEN WAS YOUR ORGANISATION ESTABLISHED?

It was set up in 1986 as a telephone helpline operated from the dining room table of a patient named Tim Hilder and his wife Felicity. Tim wanted to offer other lymphoma patients something he had found lacking at the time of his diagnosis and treatment – information and support. Although Tim is no longer with us, Felicity remains a trustee. Tim and Felicity's philosophy of 'going the extra mile' for patients still holds true to this day.

WHAT IS YOUR VISION AND MISSION?

The role of the Lymphoma Association is to provide accurate medical information and emotional support to those affected by lymphomas, be they patient, family member, friend or carer.

Our mission is to ensure that those affected by lymphomas have access to relevant, accurate and timely information and support.

Our vision is that one day our services will no longer be needed as the outcome and services for patients gradually improve.

WHAT SERVICES DO YOU PROVIDE FOR PATIENTS AND THEIR FAMILIES?

We offer support and information through:

- A free phone patient helpline which deals with more than 5,000 calls and 1,000 emails a year.
- A wide range of free patient literature on the different types of lymphoma treatments.
- A Clinical Nurse Specialist project which has so far established five nursing posts within haematology units across the UK.
- A telephone buddy scheme where individuals concerned about issues relating to lymphoma can discuss these with another person who has experienced a similar situation.
- 29 support groups throughout the UK.
- An interactive website www.lymphomas.org.uk containing valuable information for patients, their friends and family along with a message board and chatroom.

HOW MANY PEOPLE ARE DIAGNOSED WITH LYMPHOMA EACH YEAR IN THE UK?

In the UK an estimated 9,500 new cases of non-Hodgkin lymphoma each year and 1,500 cases of Hodgkin lymphoma.

ARE THOSE FIGURES TYPICAL OR HAVE YOU WITNESSED CHANGE OVER THE LAST FEW YEARS?

The incidence of non-Hodgkin lymphoma is rising steadily year on year but the incidence of Hodgkin lymphoma seems to have plateaued.



HOW WOULD YOU RATE THE UK'S PROVISION OF HEALTH SERVICES AND DRUGS FOR LYMPHOMA PATIENTS COMPARED WITH OVERSEAS?

By the end of the 1900s it was clear that the UK was lagging behind many other countries in terms of survival rates and quality of life for cancer patients. In a bid to improve this situation the Cancer Plan was launched in 2000 to introduce the government's comprehensive national programme for investment in and reform of cancer services. The Cancer Reform Strategy in December 2007 set out the next phase of the governments commitment to the delivery of world class cancer services.

In theory, treatments for lymphoma should be available to all eligible patients once they have been approved by the National Institute for Health and Clinical Excellence. In the past there has been something of a 'postcode lottery' but the government is trying to stop this. However funding can be more problematic with new drugs particularly those that will only be effective in a small patient group.

The provision of PET scanners can be patchy, according to where you live in the UK, although the government has put a lot more money into the service recently in a bid to reduce inequalities.

HOW LONG HAVE YOU BEEN A MEMBER OF THE LYMPHOMA COALITION?

Our organisation was one of the original four founding members in 2002.

DO YOU BELIEVE COALITION MEMBER-SHIP HAS IMPROVED THE SERVICES YOUR ORGANISATION OFFERS?

It has helped to raise our profile and enhance our reputation internationally and has given us publicity opportunities such as World Lymphoma Awareness Day.

In terms of service development, we are always open to sharing best practice and are happy to share and use ideas that have worked elsewhere. For example the Lymphoma Coalition member group in Brazil has translated some of our literature into Portuguese.

RAISING AWARENESS OF LYMPHOMA IS A CHALLENGE. WHAT DO YOU THINK HAS BEEN YOUR MOST EFFECTIVE CAMPAIGN?

Probably the launch of our young peoples' website which won a Communiqué Award for the best patient education project in 2004 and created a good deal of press interest.

HOW WILL YOU BE MARKING WORLD LYMPHOMA AWARENESS DAY THIS SEPTEMBER 15TH?

We will be holding a reception to present the Beacon of Hope awards to people who have made a real difference, whether it's from their fundraising efforts, giving support, raising awareness of lymphoma or because they deserve a special commendation. We will also be promoting the 'Know Your Nodes' campaign to increase awareness of lymphatic cancer and the lymphatic system.

Is it safe to exercise when you have been diagnosed with lymphoma?

BY KAREN ANDERSON, EXERCISE PHYSIOLOGIST FROM BODY MAINTENANCE

Exercise physiologists can help people with lymphoma to become functionally fit. Research shows that exercise is beneficial and starting a physical activity program when you are first diagnosed will help you through your treatment phase.

EXERCISE CAN:

- reduce fatigue
- increase the quality of your sleep
- reduce risk of developing secondary cardiovascular complications
- increase your self-esteem and independence
- regain your independence
- reduce the length of your hospital stay
- help walking, standing and general daily household tasks
- give you something fun to do with your carer
- build your muscle strength
- reduce the side effects of your medication

Fatigue is a more common problem experienced by people with cancer than pain and nausea. Despite the common saying, "I feel too tired to exercise," you need to exercise through the fatigue barrier. The way to do this is to start slowly and increase the quantity of exercise gradually so you reduce your level of fatigue rather than increasing it.

Exercise may be the last thing you feel like doing when you have no energy and feel sick but it does not have to be a 10km run. There are several simple ways to increase your fitness and there will be days when you won't feel like doing anything and that is absolutely okay.

SPECIAL CONSIDERATIONS BEFORE YOU EXERCISE

An important consideration is for the activity to improve your functional fitness and daily living activities. Loss of leg strength is the most common

problem for people who are sedentary for periods of time. This can affect standing, sitting, walking, the ability to carry out household chores and most importantly, your balance. It is recommended that you get out of bed and do a few simple exercises to prevent loss in leg strength.

- Do not exercise in the heat, use an air-conditioned room
- Do not exercise if you have a high fever
- Choose exercises that you can do at home or at hospital. Start doing a few exercises a day which will only take a few minutes and slowly build up as you become stronger
- Avoid direct sunlight
- Avoid busy gyms and swimming pools (a low neutrophil count means high risk of infection)
- Use good equipment (a low platelet count increases your risk of bruising and bleeding)

- Do not exercise if you feel the following:
 - Increased pain
 - Breathlessness
 - Severe nausea or dizziness

EXERCISE IS IMPORTANT FOR YOUR CARER

While exercise is very beneficial for the patient, it is also extremely important for the carer to stay fit. Exercise is a great distraction for both the patient and carer during and after treatment. The carer can spend endless hours at the hospital in support of the patient and this sedentary lifestyle affects their aerobic capacity and muscle strength. It is advisable that the carer starts their exercise program at their current level of fitness and gradually improves. The carer's exercise program can be designed to be carried out with or without the patient.

Here are some basic exercises to get you started at home.

Remember, start slowly and build gradually by increasing distance not intensity.

Aerobic activities for cardiovascular health

Walking or riding a stationary exercise bike are good for helping your aerobic system.

Chair squats help strengthen leg

Sit on a chair with your feet shoulder width apart and try to stand without using your hands. Do not let your knees come over your toes. Continue to stand and sit for a number of repetitions. Start by doing two chair squats and build up to 15 times. When you have mastered 15, repeat for two sets of 15, then three sets of 15.

Wall push ups help to strengthen the muscles in the arms and chest

Stand facing the wall with your arms straight and place your palms on the wall at chest height. Keep your body straight and bend your arms so your face comes closer to the wall. Start by doing two wall push ups and build up to 15 times. When you have mastered 15, repeat for two sets of 15, then three sets of 15.

Upward row helps to strengthen the back muscles

Use two dumbbells, one in each hand. Stand upright with a dumbbell in each hand. Lift your elbows up past your shoulders keeping your hands at chest height.

Stand on one leg to help improve your balance.

Practice standing on one leg. To be safe initially, hold onto a bench then as you build your confidence, try letting go of the bench and closing your eyes.

Clinical Trials

The LBF supports participation of patients with lymphoma in clinical trials. It has been shown that involvement in clinical trials improves quality of care for patients and may allow them access to cutting edge, potentially life-saving and life-enhancing treatments.

The following are trials in lymphoma either currently recruiting or still underway in New Zealand:

A phase II trial of Apo2L/TRAIL with rituximab in patients with relapsed follicular non-Hodgkin's lymphoma

This is a study looking at the effectiveness of a new drug APO2L/TRAIL given in combination with Rituximab (MabThera) in patients with follicular and other low-grade, CD20+, B-cell non-Hodgkin lymphomas that have relapsed following previous Rituximab (MabThera) therapy.

An intergroup randomized trial of rituximab versus a watch and wait strategy in patients with advanced stage, asymptomatic, non-bulky follicular lymphoma

Currently patients with advanced stage, asymptomatic, non-bulky follicular lymphomas are managed with a watch and wait strategy until they become symptomatic. This study compares this conventional strategy with early intervention using the monoclonal antibody Rituximab (MabThera).

A phase III randomized study Avastin +/- R-CHOP in patients with newly diagnosed, previously untreated diffuse large B cell lymphoma.

Current treatment for patients with diffuse large B-cell lymphoma is 6-8 cycles of chemotherapy and Rituximab (R-CHOP). This trial compares conventional therapy (R-CHOP) with a second monoclonal antibody Bevacizumab (Avastin) (RA-CHOP).

ALLG HD4 study: BEACOPP (4 cycles escalated + 4 cycles baseline) versus ABVD (8 cycles) in stage III & IV Hodgkin lymphoma

6-8 cycles of ABVD chemotherapy has been the standard approach for patients with advanced stage Hodgkin lymphoma. The aim of this study is to compare conventional therapy with a more intensive

regimen (BEACOPP) which has been developed and by the German Hodgkin lymphoma study group.

ALLG NHLLOW5 study: A Randomized Multicentre Trial of Involved Field Radiotherapy Versus Involved Field Radiotherapy Plus Chemotherapy In Combination With Rituximab (Mabthera) For Stage I – II Low Grade

Conventional therapy for patients with localized low grade lymphoma is involved field radiotherapy. The aim of this study is to determine whether addition of chemotherapy and MabThera to radiotherapy improves outcomes.

ALLG NHL16 (Prima study): A multicentre, phase III, open-label, randomized study in patients with advanced follicular lymphoma evaluating the benefit of maintenance therapy with Rituximab after induction of response with chemotherapy plus Rituximab in comparison with no maintenance therapy

This study has now closed to accrual but many patients remain on the trial. It will provide important information as to whether there is a benefit for maintenance therapy with the antibody MabThera following initial induction treatment in newly diagnosed patients with follicular lymphoma.

Target study: A Phase III, Randomized, Double-Blind Study of Galiximab in Combination with Rituximab Compared with Rituximab in Combination with Placebo for the Treatment of Subjects with Relapsed or Refractory, Follicular Non-Hodgkin Lymphoma

This is a study looking at the effectiveness of a new antibody (Galiximab) given in combination with Rituximab (MabThera) in patients with follicular lymphomas that have relapsed following previous Rituximab (MabThera) therapy.

For more information on these or other clinical trials please speak to your specialist.

Our vision to cure and mission to care

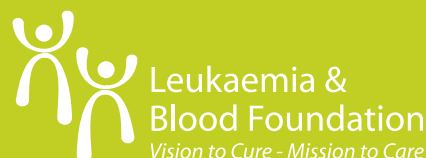
The Leukaemia & Blood Foundation (LBF) is New Zealand's leading resource of information specifically for patients and families affected by leukaemia, lymphoma, myeloma and related blood conditions.

We provide emotional support and a range of practical assistance, as well as information for patients, family members and friends affected by these diseases. The LBF also works to raise public awareness,

funds research into cures and better treatments, and represents the needs of patients and their families to the Government, related agencies and other relevant bodies.

The LBF receives no government funding and relies on the generous support of individuals, companies, trusts and grants, as well as support in kind.

To find out more about the work of the Leukaemia & Blood Foundation, and how you can help, call 0800 15 10 15 or visit www.leukaemia.org.nz.



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