

Myeloma Today

Supporting people *living* with myeloma

Blood Cancer
Awareness
Month

p.3

A *long road*

p.4

The team
with *support*
when you
need it most

p.7

plus
Support
directory

p.8



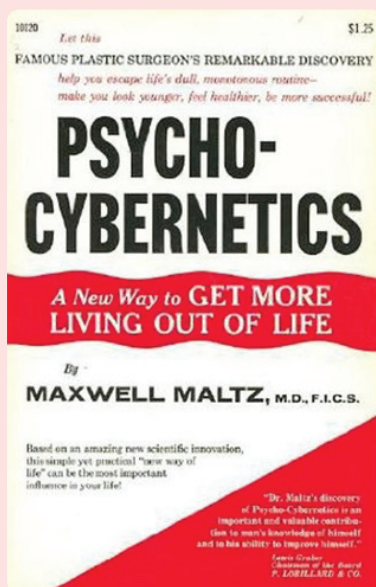
Inspiration corner

Recommended reading from patients and carers on the LBC Consumer Advisory Board.

Psycho cybernetics by Maxwell Maltz

"I have been big on healing and self-perception, particularly post-cancer." CAB member Mellisa Chesterman says.

"This is a fascinating book on the power of our subconscious mind and self-image. It teaches how to use the past positively, develop compassion and self-respect, as well as forgiveness. These skills are quite essential for any stage of life or journey."



“ You make mistakes. Mistakes don't make you.”

Maxwell Maltz

BLOOD CANCER PATIENT FORUM 2021

Leukaemia & Blood Cancer New Zealand is delighted to announce our upcoming Blood Cancer Patient Forum on Saturday, 4th September 2021, at the Rydges Hotel in Christchurch. The welcome evening will take place on Friday 3rd September 5-7 pm.



This year promises to bring a fantastic selection of new topics with experts across the haematology field, along with the latest updates on the various blood cancers and areas of survivorship. Topics will include survivorship and long term follow up for blood cancers, accessing unfunded drugs, self-compassion, understanding the palliative care pathway, foot care and peripheral neuropathy, and many more. We have something for everyone, even sessions devoted just to young adults and support people. There will also be a physio session on three ways to become a healthier, more energetic you.

To find out more about our programme and to register please visit here
<https://www.leukaemia.org.nz/forum/>



Get inspired, borrow a self-help book from the LBC library at your local support centre

Blood Cancer Awareness Month

You would be hard-pressed to find someone today untouched by cancer in one form or another.

While some types of cancer tend to be outwardly visible, blood cancer patients know that their journey is different. Cutting blood cancer out of your body, like a tumour, is not an option. It is an invisible disease for the most part and brings a range of vague symptoms that can be overlooked or misdiagnosed. This causes frustration and confusion when patients are advocating for themselves with their healthcare professionals.

Sadly, the hurdles do not disappear once a diagnosis is confirmed. After their hair grows back, the assumption is that a patient is cured. Many people reading this will know that struggle all too well. In some instances, the diagnosis of a blood cancer or blood condition is a life-long journey. How do you explain to your family and whanau that the "battle" you face is ongoing?

What are the symptoms of blood cancer?

Persistent fatigue	Regular & frequent fevers
Unexplained weight loss	Repeat infections
Itchy skin	Anaemia (tired, weak, dizzy)
Bone pain	Excessive night sweats
Swollen lymph nodes	Unusual bleeding/ bruising

Symptoms usually present as a cluster, if you are concerned visit your GP.

Did you know? While blood cancer symptoms are vague and could be easily misdiagnosed, most conditions can be picked up by a simple blood test.

On top of these specific challenges, our patients are still coming to grips with, and navigating, life with cancer. Wrapping your head around all of these touchpoints can be exhausting and seem impossible.

That is why spreading awareness and advocating for Kiwis living with a blood cancer or serious blood condition is crucial.

Historically, Leukaemia & Blood Cancer New Zealand (LBC) has recognised the patients we serve with Blood Cancer Awareness Week in November. However, this year, we are switching it up. We are moving to Blood Cancer Awareness Month in September, to align with the rest of the world and devote more time to increasing awareness of the symptoms and information surrounding life with a blood cancer.

Be sure to follow us on Facebook, Instagram, and Twitter to find out what we have planned for September. We will also be hosting our Blood Cancer Patient Forum in Christchurch from 3rd -4th September to kick everything off. If you want to learn more about the forum, refer to page 2.

Introducing Kids' Zone

At LBC, we have services dedicated solely to supporting our paediatric patients, their siblings, and the children of older patients. These programs sit under our child-centric umbrella brand - Kids' Zone. Kids' Zone includes Kids' Club and Kids' Club Online (for both siblings and offspring) and Super Kids' Club, Battle Bus and Monkey in My Chair (for paediatric patients). So if you know any kids who could benefit from one or more of these groups then check out our website for all the details or get in touch with your Support Services Coordinator.



Phone 0800 15 10 15 for a catalogue of blood cancer resources



A long road

Nichola Oakenfull's journey with blood cancer started like so many others, with seemingly unrelated and vague symptoms. For about two years, she struggled to piece together the medical breadcrumbs that would lead her to a myeloma diagnosis.

She experienced extreme fatigue, headaches, shortness of breath, pins and needles in her hand, and chest and back pain throughout her path to an answer. She had been in touch with her GP, who didn't dismiss her symptoms and sent her to a couple of specialists, but she was told she was just a busy 40-year-old mum. While no news is usually good news, Nichola knew something was wrong with her body.

"I thought that I was going crazy and that I must be a hypochondriac. I had all these things that you can't make up. But they couldn't find anything, so I had been seeing a psychologist to try and make myself stop thinking that I had cancer."

It was after a back injury in October 2019 that Nichola's back pain got much worse.

"I couldn't move for a couple of days and then went to physio. But with physiotherapy, it got better really quickly, it improved, but then plateaued."

After family illness forced Nichola to take time off work and travel to Hawke's Bay, she had to stop going to physiotherapy.

"Then, in March last year, I tried running to pick up my little boy from athletics, and I couldn't run. It hurt too much. That was the Monday, and then on Thursday, I was at the supermarket, and I sneezed, and I couldn't move."



Nichola with her family visiting the beach, 6 weeks post stem-cell transplant.

Once she had healed enough to go to physio, the therapist thought she had a slipped disc. Again, the physiotherapy helped, but two weeks later, the country went into lockdown.

"My haematologist said that she would have been helping to relax all the tense muscles during our in-person sessions by massaging them. So then during the lockdown, when I wasn't getting that, the pain got progressively worse."



Share your story ideas.
Email info@leukaemia.org.nz



Nichola receiving bone strengthening medication.

“ I thought that I was going crazy and that I must be a hypochondriac.”

After the lockdown, the physio asked Nichola to get an x-ray of her back. This imaging showed that her back was broken, but there was a suggestion it was an old fracture. Simultaneously, she went to visit her GP for a long-lasting sore throat.

“I asked my GP to clear me to go to physio and asked her about my back. She said that she disagreed the fracture was old. ‘A 41-year-old doesn’t get a compression fracture for no reason.’”

Her GP ended up ordering more tests, which included an ultrasound due to extreme abdominal pain.

“I had an ultrasound and blood test on that Friday, then I saw on my ‘Manage my Health’ page on Sunday that the ultrasound had come back clear so I thought I was okay. But then, on the following Monday morning, my GP’s nurse called first thing. She asked if I could go for another blood test that morning.”

Later that day, her GP called her in and told her that she needed to see a haematologist.

“I saw the haematologist the next day. He said that there was a chance that my broken back showed up as inflammation, but he thought it was more likely than not Multiple Myeloma. Two weeks later, after an MRI and bone marrow biopsy, I was diagnosed. I’m so grateful that my GP took all of my symptoms seriously, which led to my diagnosis.”

Nichola says that she has had many touchpoints with LBC and values the Wellington team’s support of her and her family. She has participated in various services, including the Ladies Zoom support group, the Wellington Myeloma and haematological support groups, Kids’ Club for her now seven-year-old son. She was also grateful for the webinar series put on last year.

“The webinars were great because there was one on managing side effects of treatment. That was literally like my first or second week of chemo, and was really useful.”

Today, Nichola holds hope in the future of myeloma treatment, including clinical trials.

“The money that LBC gives to research, like the Malaghan Institute’s CAR T Cell trial, is significant. While that is for lymphoma patients, eventually, we may have Myeloma CAR T Cell trials or other similar treatments. I may not be gaining anything from it now, but maybe I might someday.”

**Register for Ladies Zoom
group phone chat on 0800 15 10 15**



Staying positive

Taranaki resident, Steve Roguski's cancer journey began in November 2013 with a commonplace symptom.

"I had back pain, and it turns out that I had myeloma."

While they sorted his back out, Steve says that it took around 20 days to diagnose him fully. He had surgery on his back, including adding screws to hold it back together. By February 2014, he was on his way to Palmerston North for radiation.

"I had to wear a body brace while the screws, and all that, healed for around three months."

Steve's blood cancer story does not stop there, however.

"In 2017, I got a sore throat; they did a PET scan. Then I found out that I had lymphoma AND I learned the myeloma had started to spread."

He was being treated in Whangarei, where he was living at the time.

The first step, after learning this news, was to attack the lymphoma.

"They found out that it was double-hit lymphoma, so I had to go to Auckland for treatment. I did seven cycles, I think, and then I had a stem cell transplant. After that, I started treatment for multiple myeloma."

From there, he had two years of treatment. The treatment for his lymphoma was quite aggressive.

"You are on the drip for five days and nights. I lost all my hair; I lost my fingernails and toenails, but they did all grow back."



Steve enjoying life on his farm.

Steve says that he was first connected to LBC when he was in Auckland Hospital for treatment. He says that Tim Maifeleni's support sticks out in his mind.

"It's just knowing that he was there, which helped."

Sometimes, the most important gift you can give someone is showing that you care. This is especially true for caregivers when they are taking care of their sick loved

ones. Steve's wife, Joy, supported him through the process, and he recognizes that it must have been difficult for her.

"It must be hard on the carer to see how sick you are. Their entire life gets put on hold."

Today, Steve is done with treatment and says that his outlook on life is positive.

"I feel that you are better off to be happy as opposed to being sad. I leave the treatment and that for the doctors, that's their job to do, and my job is to be happy."

“ I had back pain, and it turns out that I had myeloma. ”



Connect with patients like you
@LBCmyeloma

The team with *support* when you need it most

Our Support Services team work hard every day to assist Kiwis living with a blood cancer, or serious blood condition, and their families. They travel across the country to help patients all over Aotearoa. Find your local Support Services Coordinator on the map below.



Annette Cody
Northern Region



Natasha Donovan
Northern Region



Tim Maifeleni
Northern Region



Sharon Verral
Northern Region



Sally Black
Central Region



Sheldon Kil
Central Region



Nicki Roy
Central Region



Rochelle Mills
Midland Region



Sean Reeves
Midland Region



Deborah Tomlin
Lower Southern Region



Matthew Eby
Upper Southern Region



Helen McDermott
Upper Southern Region

Find a support group near you
www.blood-cancer.online/support



Support Directory



Support Groups are hosted nationwide in a casual coffee and chat environment. Share experiences, exchange advice, get well-being tips and meet others in a similar situation. To find a group near you go to: <https://www.leukaemia.org.nz/support/education-support-programmes/>

Education Groups take place nationwide both online and face-to-face with health professional speakers covering a variety of well-being and survivorship topics. To find out more go to: www.blood-cancer.online/support

Blokes with Blood Cancer & Ladies Zoom are hosted group sessions via phone every eight weeks. Phone 0800 15 10 15 to register for either group.

Kids' Club is open to children ages 5–12 years, to help them cope with a parent or sibling who is living with blood cancer. Hosted by play therapists and psychologists in Auckland, Hamilton, Wellington and Christchurch. **Kids' Club Online** is available for children living in areas outside of the main centres.

LBC's Winter-Spring Webinar Series was created as an online alternative to our Blood Cancer Patient Forum during the COVID-19 Lockdown last year. We held weekly webinars on a range of disease-specific topics and relevant survivorship themes. These were recorded and are available to view on LBC's YouTube channel at www.blood-cancer.online/wsws

Employment Workshops are available either online or face-to-face and are designed for patients looking for new employment, to re-enter the workforce, or planning ahead due to gaps in employment because of treatment.

LBC General Facebook Page @LBCNZ is for everyone, including your friends, family and acquaintances. Keep up to date on recent news and blood cancer research, find out about LBC events, connect with patient stories, and much more.

New Resources available:

- ✓ Updated Blood Cancer information booklets translated into 7 different languages
 - ✓ Revised Sleep factsheet
 - ✓ New Chemo Brain factsheet
 - ✓ Revised Eating Well factsheet
- You'll find these and other resources online at <https://www.leukaemia.org.nz/information/information-booklets/>

The LBC Library located in every support office has many fiction and non-fiction books you can borrow. They are designed to educate, uplift and inspire those living with cancer.



Closed Facebook Groups allow you to connect online with others who understand the challenges of blood cancer. They are supportive and informative – there are groups for carers and young adults too.

- f @LBCSupportPersonConnect
- f @LBCLymphoma
- f @LBCMyeloma
- f @LBCCChronicLeukaemia
- f @LBCAcuteLeukaemia
- f @LBCYoungAdults
- f @LBCBloodDisorders
- f @LBCParentsGroup
- f @LBCMPN
- f @LBCBereavement
- f @LBCHaemochromatosis
- f @LBCNZConnect (LBC & Health Professionals Connect)