

Lymphoma Today

Supporting people *living* with lymphoma



Blood Cancer
Awareness
Month
p.3

Mind over
matter
p.4

The team
with *support*
when you
need it most
p.7

plus
Support
directory
p.8

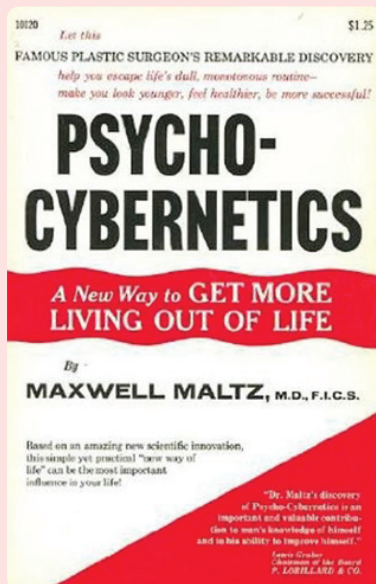
Inspiration corner

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



Mind over matter

Neil Brownlie has faced more hurdles at age 37 than most people encounter in a lifetime.

The first occurred ten years ago when he was diagnosed with Hodgkin lymphoma.

"I did some treatment, but I wasn't staying in hospital or anything like that. I went every couple of weeks to get some chemo and radiation."

Only five years later, cancer reared its ugly head once again.

"I got Burkitt's lymphoma, an aggressive form of non-Hodgkin lymphoma, and I had to stay in hospital to treat that. I was only getting chemo at that time, but I was in hospital for around six months. It was a pretty long stay."

After surviving two different cancers, Neil was facing issues with his employment.

"Before I got sick, I was working for myself. But now I'm not quite up to the physical rigours of what I had been doing."

When speaking about LBC, Neil says that this was an area where he could lean on Deb, the Support Services Coordinator in Dunedin, and the team for advice and support.

"With just my partner working, it was difficult, especially when I was the higher income earner. The financial support LBC gave to my family, like food and fuel vouchers, really helped."

In January of 2020 - Neil was back in Dunedin Hospital undergoing even more chemotherapy. This time, the diagnosis was different. Although he'd already overcome two forms of lymphoma, he was now being treated for acute myeloid leukaemia (AML).



Neil and his partner Jodi.

"I went in and had treatment for about four months, and then I had to go and get a stem-cell transplant. For the stem-cell transplant, I went up to Christchurch Hospital and stayed up there for just shy of four months as well."

While receiving treatment for AML, Neil encountered a unique problem. Throughout his three rounds of cancer, he had already had the maximum amount of a number of chemotherapy drugs that one person is allowed to receive in their lifetime. Yes, this is something that can happen in New Zealand.



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



The Brownlies are all smiles for a family photoshoot.

“They got rid of the cancer before I even went to Christchurch for the transplant. The problem was, because they couldn’t give me all of the chemo drugs; there was no way it was going to stay away.”

“They kind of just gave me what chemo they could but kept dropping them as I had reached their limit.”

On top of all that, Neil’s most recent treatment was happening during 2020 - the year COVID-19 spread around the globe.

“When the country went into lockdown for six weeks, I wasn’t allowed to leave my hospital room or have visitors, which included my wife and kids. Before that, I would walk around the hospital ward and go for a wander outside occasionally, but I wasn’t allowed to leave my room for those six weeks. So, that was an extra challenge.”

It was while the nation was facing the global pandemic that Neil underwent his stem-cell transplant.

“They got rid of the cancer before I even went to Christchurch for the transplant. The problem was, because they couldn’t give me all of the chemo drugs; there was no way it was going to stay away.”

Amazingly though, he has come out on the other side and is now only on the necessary post-transplant medication.

“I have had no sign of cancer coming back.”

Neil’s story is one of hope and focussing on the positive, but also thinking outside the box. During all of this journey, Neil had to re-evaluate what his next move could be workwise, as he could not work as a qualified electrician due to the physical nature of the job. This didn’t stop Neil. What he did was head back to school to upskill his knowledge and qualify to do something new.

“I’d looked into studying, not sure what I was going to do. I didn’t want to throw all of my electrical experience out the door. However, it just so happened that since there is such a shortage of electrical engineers in the country, the Government made it so that the course is free for the next two years. It saved me about \$10,000 a year in fees. So basically, when I saw that, I was like, this is my opportunity.”

Armed with a new lease on life, Neil says there is another major factor in tackling challenges as they arise.

“I believe that attitude has a large chunk to do with success. The worst-case scenario is always there, but if you dwell on it, it creates a lot of anxiety, whereas if you let things play out, it usually ends up not being as bad as you thought it was. You’ve got to try to stay positive.”

Connect with patients like you
on Facebook @LBC lymphoma



The waiting game

Naomi Stephenson was helping to care for her dying mum in June 2019, which would understandably be a stressful time in anyone's life. However, the hits kept coming when a lump appeared under Naomi's chin, and her journey with blood cancer began.



Naomi and her family on a sunny spring day in Akaroa.

"It's been a comfort to know that Mum never knew, as she would have been upset, but I ended up being diagnosed with follicular lymphoma. My mum died on June 26th, and I was diagnosed on August 2nd."

Naomi then underwent CT scans to determine how advanced her case was.

"I was either stage three or four, but they weren't sure. If it's in the bone marrow, it's stage four, but you need an invasive procedure to find that out."

Naomi's oncologist decided that because he would recommend the same treatment for stages three or four, the bone marrow biopsy was unnecessary. However, the CT scan could reveal the spread of the disease.

"It was above and below my diaphragm. The biggest one was tucked into my pelvic bone, and it was six centimetres in size."

Because follicular lymphoma is a slow-growing form of lymphoma, you may be placed on 'watch and wait', also called 'active monitoring'.

"That's hard for people to understand because you tend to think with cancer, that you take care of it, and that's it."

Naomi was curious about when treatment might be required, so she had a chat with her oncologist shortly after her diagnosis.

When pressed, he estimated she might need treatment in one to three years.

“That's hard for people to understand because you tend to think with cancer, that you take care of it, and that's it.”

Unfortunately, her cancer progressed quicker than that.

"Six months later, I had CT scans, and it had grown and spread quite a bit, so just into lockdown last year, he recommended treatment. The largest tumour was 8 cm."

Naomi says that going through treatment in a COVID-19 world was a double-edged sword. On the one hand, it was scary as she was immunocompromised during a pandemic. However, it was also protective, as she was not out in the community while at risk.

Thankfully, Naomi is now in clinical remission.

When asked about the support that she received during her cancer journey, Naomi says that much-needed information managed to come at the right time, and she is very grateful for the support from LBC.

"I received a link to a new fact sheet that had come out through LBC, and it was titled 'Chemo Brain'. It was just like reading a tick list."

When someone is diagnosed with cancer, it is not uncommon for people to want to share their knowledge and thoughts in the hope they are helping. This was no different for Naomi, but she shared a great takeaway from her journey that is worth noting,

"Many years ago, the first midwife that we had, had given me some advice that's been useful in lots of ways in life. She said, 'taste everything but only swallow what's good for you.'"



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

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)