

LymphomaToday

Supporting people *living* with lymphoma



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Inspiration corner

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

Mellisa Chesterman – *The High 5 Habit* by Mel Robbins



“ This pukapuka (book) resonated with me deeply. It speaks to being your own cheerleader in life, and incorporating small but effective strategies like giving yourself a high 5 in the mirror every morning. It may sound trivial, but it’s a strikingly simple way to rewire your brain and alleviate the stresses that can become habitual.

As a cancer survivor, this is one of my bedside treasures when I get bogged down and forget what I have been through; it is a game changer. ”

WIN!

We’re giving away 5 copies of this book!

To go in the draw to win, email your name and address to marketing@leukaemia.org.nz and we will select 5 winners.

Did you catch our patient forum?

We’ve Got Your Back

with Peter Browett, Peter Fergusson, Cushla Lucas and Raewyn Moss

Wellness & Identity

with Sean Bowler

Fear of cancer recurrence and managing mental wellbeing

with Philippa Croy

Mindfulness, compassion and mind-set changes

with Sean Bowler

Options to support you

with Carol Rose, Tracey Hancock and Emma Toy

This September, as part of Blood Cancer Awareness Month, we hosted our annual Blood Cancer Patient Forum online, with sessions every Thursday night, from the 1st to the 29th of September. We also welcomed visitors in each of our support centres around the country to watch the opening and closing sessions and share some food. **Missed the talks? Check out the recorded videos here: lbcnz.link/forum22**

“Today’s session was so inspiring and it made us feel like we’re in very good hands. I really appreciate all you do.”

“I have to compliment you on the Forum. If this is the standard of speakers, then I can’t wait to hear more. Keep it up!”

“We found it interesting and informative. It was great to meet some of the team that work hard for those of us who are living with a blood cancer.”

Ask the Chief Executive

Q. How do drug applications work?

A. This is a simple question with a complex answer. Submitting an application to Pharmac is actually the easy part – anyone can do this by producing the necessary documents and submitting to PHARMConnect online. The hard part is what happens after this – multiple committees, Pharmac, PTAC and suppliers are all involved. It can be years before the entire process is completed – whether a drug ends up being successfully funded or not.



Peter Fergusson, LBC Chief Executive

Q. What role does LBC play in all of this?

A. LBC is constantly pushing for the drug applications that we support, to receive funding, and this is a big part of our advocacy work. We know that there is a massive backlog of applications, with a huge amount of drugs just sitting there that could potentially save hundreds of thousands of lives. This is also where the government comes in, as the health budget determines what applications

are prioritised. We also keep the pressure on government from every angle we can to address this. And, I sit on working groups alongside haematologists where together we work hard behind the scenes to advocate for our blood cancer patients with Te Aho o Te Kahu, the Cancer Control agency, to keep their needs as a priority.

Q. What else is LBC doing to make a difference for blood cancer patients?

A. I am currently the chair of CANGO (Cancer Non-Government Organisations). This is a group consisting of 9 key cancer-focussed NGOs in New Zealand. One of our main priorities for 2022 and beyond is advocating for better access to medicine. While LBC has a strong voice in the advocacy space alone, it is even louder and more powerful when it’s amplified x9!

CANGO’s key advocacy priorities are:

- Better access to medicines
- The needs of those living with cancer
- Better access to clinical trial and investigator-led research
- Accuracy and speed of detecting and diagnosing cancer



Members from CANGO

I only want to deal with you

"I saw the doctor and I explained to her, 'I only want to deal with you.'"

"I said to her, 'I have talked to so many doctors in the last three months and I can't remember anyone's name – that's how many there's been. All I ask – can I just stick with you?' And she understood that, and she said yes."

"She took me into the room and she sat me down with a haematologist. And they said, 'Yep. You've got cancer. It's a blood cancer.' 'What type?' 'Hodgkin lymphoma', and I asked what stage – 'Stage 4.' 'OK, cool. Do I at least have a chance to live?' 'Oh, 50/50'"

"OK, sweet. That's a chance."

Coleman uses such casual words to describe this moment, but his feelings are written all over his face – this is a painful memory.

It began when Coleman started experiencing terrible fevers. He was drinking dozens of bottles of water a day and sweating right through his bed sheets. When he visited his doctor in Rotorua, he was given paracetamol and told to return home.

*☹️ My sister gave me a call, and she was like 'Get your *** to hospital!' So I did. ☹️*

There was no improvement; by the next week, his condition had worsened. *"My temperature was still all over the place. My eyes were bloodshot as. That was scary. So my sister gave me a call, and she was like 'Get your *** to the hospital!' So I did. They gave me even stronger paracetamol...I took that for a while and it still didn't work."*



Coleman's children on the day of his wedding

When Coleman asked for medical help a third time, he explained that he'd never felt like this his entire life. His face had even started to swell up. His doctors were now very concerned, and they kept him there to do tests.

"They were trying to figure out what was wrong with me. Then it got even worse. I couldn't sleep, I was going to the toilet five or six times a night."

Coleman had a few CAT scans, MRIs, a biopsy and had his bone marrow tested. Still, nothing was found. *"I had a funny feeling about what they were looking for, but they were looking in the wrong area."*

The second time he had a biopsy, he had lumps all over his body. Looking back, he couldn't believe that he was still walking



Fast Facts: Hodgkin lymphoma

- Hodgkin lymphoma makes up roughly 10% of all lymphomas with about 120 diagnosed in NZ each year
- The majority of those diagnosed are aged between 15 and 35
- Hodgkin lymphoma is the name given to lymphomas that have a special kind of cancer cell, called a Reed-Sternberg cell.

around. *"I didn't want to lie down because I'd look like I was dead. I mean, I looked like I was dead anyway. I felt like giving up."*

By this point in 2020, COVID-19 restrictions meant that his hospital visits were limited. *"I just really missed my family. So I asked 'Can I at least go home to be with them? I don't want to be dying here.'"*

"My mum died here. I don't want to die here."

Ten years earlier, Coleman's Mum had passed away from cervical cancer. He and his siblings were only told about her diagnosis when she had a week left to live. *"That wasn't enough time. How can we prepare for anything, when we know we're about to grieve?"*

☹️ My mum died here. I don't want to die here. ☹️

Coleman didn't want this for his family.

He was thankfully allowed to go back home. Then on Friday night, he got a phone call. *"Ring, ring. 'Coleman, what are you doing on Monday?' 'I don't know, what am I doing on Monday? You tell me.' They said to come up to Hamilton, and from then on, I knew it. I prepared myself for it."*

This was when he was told he had Hodgkin lymphoma.

Coleman was put on different medications, given blood transfusions and finally chemo – over 20 pills a day. *"When I was in Hamilton, that was the best place I could have been. My face went down, and my body started to get better."* Suddenly, Coleman was in a completely different headspace than just six months earlier.

"The cool thing was finding a reason to live. I use my kids, pretty much, as a reason to stay alive. I don't think my kids realise how much they have impacted me."

"And Sean too, from LBC. Sean played a massive part in our lives. I've been to his support meetings and I like sharing my story and hearing other people's journeys."

"And when Sean gave us vouchers...I'm not a person who likes to get things for free, so that broke my heart. I'd never ask, but I put my pride away and accepted the help that I needed at the time."

Coleman not only accepted help, but he provided it too – to thousands of people. Coleman has a TikTok account where he posts videos relating to his blood cancer journey. He shares advice, and connects with his followers; many of whom are also patients.

"A lot of my followers know my journey and they've been there since day one."



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

Register for Blokes with Blood Cancer
group phone chat on 0800 15 10 15



A reason to fight!

"Someone said to me, 'It's amazing that you haven't had a break down yet.'"

It is. In just a couple of years, Marion has dealt with a lifetime of loss, all while coping with blood cancer.

"One day I had a really sore side. I got rushed to hospital because my doctor thought I had gall stones. After the scan, they thought I had a haematoma, so I was told to come back in six months."

Six months later, she returned and had her lymph nodes taken out of her arm to be tested. When the results came back, she was diagnosed with follicular non-Hodgkin lymphoma. However, this wasn't even the most challenging thing she was facing in life at the time.

"While going through all of that, I buried my brother and my father. And then my mum got sick, so I went to go look after her. She passed away before I started chemo."

Marion was devastated. Having lost both parents and her brother, she needed a reason to fight. She found that reason when she found out that she was going to become a grandmother. This kept her going through her chemo.

"I also volunteered at The Salvation Army. It was good for my wellbeing, even though I would get tired easily. But, my purpose behind it all was my grandson."

Being kind, helping people, and taking one day at a time is what has helped Marion cope with her lymphoma, as well as her small but very close circle of friends.

"My friend Abe was there when my family died. He treated me like a big sister, and I know if I asked, he'd drop everything to help me. And there's Sharlene, my cousin. She's the one I talk to."

"I've also got Peter. We've got children together and he knows I'm sick, but we are still there for each other."



Marion at home with photos of her family

Marion was also supported by Nicki from LBC. ***"I knew that I could ring her up any time to talk to her. She advised me about quite a few things and put me in touch with a counsellor, which I needed."***

"To be honest, I just take one day at a time, like that Cristy Lane song..."

"I'm only human, I'm just a woman. Help me believe in what I could be, and all that I am."

Show me the stairway I have to climb. Lord for my sake, teach me to take one day at a time..."

Fast Facts: follicular non-Hodgkin lymphoma

- Follicular lymphoma makes up about 20% of all non-Hodgkin lymphomas with roughly 180 diagnosed in NZ each year
- Follicular lymphoma gets its name from the circular arrangement (follicles) of lymphocytes inside the lymph nodes
- Follicular lymphoma usually grows slowly over months or years.

We support Aotearoa

There are LBC Support Services team members based all over New Zealand, both online and in-person, and our support is more far-reaching than you might think!



"I love connecting with people in the far north, and helping them feel less alone"
Natasha Donovan, Northern Region



"I like writing resources that help people understand their conditions better."
Melody Bevan, Northern Region



"There's so much I love doing – presenting Monkey in My Chair to a classroom...getting coffee or dropping off groceries for patients...or just being a listening ear."
Tim Maifeleni, Northern Region



"I feel privileged to be welcomed into our patients' communities and whānau. The bravery and resilience of people in the Waikato region is really incredible."
Sean Reeves, Midland Region



"Walking alongside patients going through stem cell transplants, as they draw on everything they have to get through, is what I love about my role here in Wellington. It's a beautiful example of Te Whare Tapa Whā and holistic health. It humbles and inspires me."
Nicki Roy, Central Region



"I enjoy running peer support groups where patients can share their experiences, and learn from each other. It's very rewarding."
Sally Black, Central Region



"Whether it's making a difference for families with Kids' Club, or chatting with patients over a cup of tea – I love supporting whānau down here in the Southern region."
Helen McDermott, Southern Region



"I enjoy meeting patients and whānau throughout the lower South Island and taking our support to the more rural and remote areas."
Deborah Tomlin, Southern Region

Resources & Support Corner



Connect & Learn

For adults:

Join a personalised support group

and share your experiences, advice, and wellbeing tips and meet other people living with blood cancer.

Learn more at an education group with health professional speakers covering a variety of wellbeing and survivorship topics.

Get support with finding work at an Employment Workshop, designed for patients who are looking for new work, re-entering the workforce, or planning ahead due to gaps in employment.

More information for all of the above can be found at lbcnz.link/groups

For children and families:

Check out Kids' Zone for all the resources, support and programmes that LBC has to offer for children and their families affected by blood cancer.

More information: lbcnz.link/kids_zone

Get social:

Follow @LBCNZ on Facebook for updates on LBC's research, advocacy and awareness work, as well as support opportunities.

Join a closed Facebook group to connect with other patients or support people who understand the challenges of blood cancer.

Support for specific cancers and conditions

@LBCLymphoma
@LBCMyeloma
@LBCChronicLeukaemia
@LBCAcuteLeukaemia
@LBCBloodDisorders
@LBCHaemochromatosis
@LBCMPN

Support for young adults and parents

@LBCYoungAdults
@LBCParentsGroup

Further support pages

@LBCSupportPersonConnect
@LBCBereavement
@LBCNZConnect
(LBC & Health Professionals Connect)

Available online OR in-person



Read

Read our new factsheet on follow-up care after lymphoma treatment to help patients and their families understand what to expect after discharge from specialist care. lbcnz.link/care

[Anyone,
anywhere,
anytime]
is blood cancer
#ThisIsBloodCancer

This year's theme was
'This is Blood Cancer'

Blood Cancer Awareness Month

September was Blood Cancer Awareness Month. Here are three ways that LBC raised awareness about blood cancer.

1

Raised awareness with doctors, pharmacists & nurses about the importance of looking for symptoms and testing.

2

Explored the level of knowledge of blood cancer in Aotearoa and with global partners.

Only 2% of those surveyed named blood as a type of cancer.

3

Created an awareness video and campaign with our global partners to highlight the lack of knowledge and the challenge ahead.



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

Call us on: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin