

SPRING 2022

MyelomaToday

Supporting people *living* with myeloma



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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 can rebuild myself

Twenty years ago, Peter was involved in a serious car accident that could have ended his life. He remembers being trapped in his car, his leg at a crazy angle. His femur in his left leg had been smashed.

But Peter survived that car crash, and while it took some time – he recovered well, apart from some lasting issues with the muscles in one leg. He knew that at some point he would need surgery.

This is why, in July 2020, when Peter was called to schedule a meeting with his doctor after a series of blood tests – Peter thought that he was finally getting the surgery he needed on his leg.

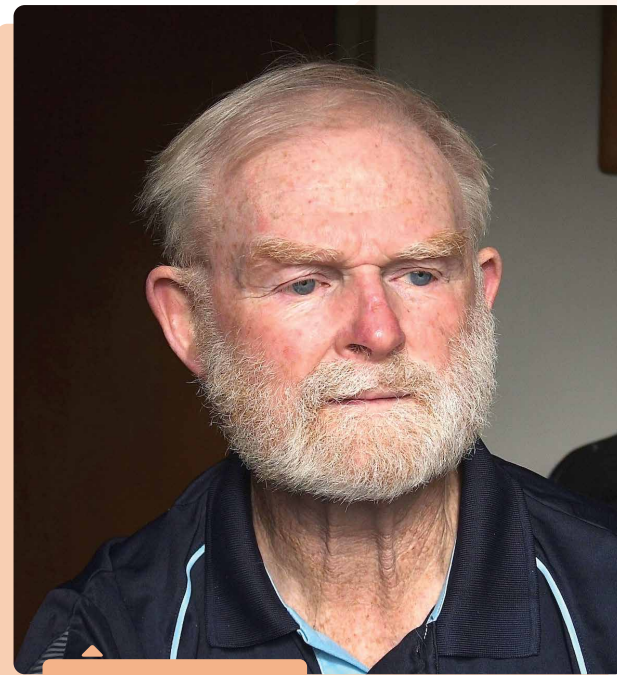
“And that’s why I was alone when I drove up for that appointment. I didn’t have my wife with me because I didn’t think anything was wrong,” says Peter.

But there was something wrong. Peter knew that he had hip and back issues. He was often in pain, which he had become used to. But he was not expecting to be told that he had myeloma.

“It’s hard to put into words how it felt. But I can tell you one thing – I do this crossword every day in my local paper. Every single day. I brought it with me to pass time during my appointment. Well...”

Peter turns to his side and stares at the floor. His voice goes a little wobbly as he says, *“The only time I’ve not been able to do the puzzle was that day.”*

Suddenly, his life was turned upside down and he entered a new world of chemotherapy, doctor appointments, treatments and even a stem cell transplant. His wife and family joined him at his side, as well as Natasha from LBC.



Peter at his home in August, 2022



“At some point, I don’t remember when, but Natasha visited me in hospital, just to check in and see how I was doing. And I really appreciated that. I went to her support meetings.”

After his transplant, Peter started to recover slowly. He was told that regaining his mobility would be a long and gradual process. *“So I set myself goals, and I said, right – I’m gonna do this. I never wanted to climb Mount Everest or swim across the Cook Strait. I just wanted to do the things I enjoy.”*

One of those things that he enjoys is lawn bowls. *“I told Natasha this funny story about when I started back at the club and I met one of the new guys who looked like a good player. So I contacted him, and it turned out that he had been living with leukaemia for years.”*

“Then we found a third guy to join us, and I said to him – ‘Hey, this is like a rugby scrum. We’re the two props – one’s got leukaemia, one’s got myeloma – so as the hooker in the middle, you’ve got to keep us together!’”

“And he looked at me and said he’s going through treatment for bowel cancer.”

Peter laughs as he says, *“So it was the three of us old cancer survivors! We played together, and you know what, we almost won the club champs.”*

Peter has learned to be kinder to himself this time around. *“You’ve got expectations about how you perform, and when something like this happens, it shakes you about a bit. And you hope to bounce back. But you’re also getting older.”*

“Back when I was a young rugby player, the local newspaper picked up this photo of me at a game and called me the hairiest rugby player in New Zealand.”

“So when I had my treatment, my hair started falling out. And one of the people at the hospital helped me to cut my hair. I said to this woman – at one point, I was one of the hairiest men in New Zealand. And look at the remnants on the floor now!”

This was not the only memory that has come back full circle. After the car accident in 2000, Peter’s attitude toward life changed. *“I was determined that I would go to this conference in Christchurch. And my boss knew how important it was to me – it was my goal. I had to use a crutch at the airport, and needed to be wheel-chaired to my flights, but I got there.”*

And similarly to his blood cancer journey, Peter is again determined to get his energy back.

“One of my daughters noticed that I had improved recently, and it wasn’t until I thought about it that I thought, yes I have! It’s the small things – the way you roll in bed, the way you might reach out for something. I was quite limited back then.”

“But, I’ve been to this movie before – I’ve had to rebuild myself in the past and I’m doing it again now. I know I can do it.”

Fast Facts: Multiple Myeloma

- Around 450 New Zealanders are diagnosed with multiple myeloma each year
- In multiple myeloma, the overgrowth of plasma cells in the bone marrow can crowd out normal blood-forming cells, leading to low blood counts
- Fractured bones are a major problem in people with myeloma.



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

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



Everything just felt hollow

"My mum would drive me to my hospital appointments, and we'd go past the university. I'd see other people in their 20s, studying and hanging out. Meanwhile, I was here fighting for my life."

In 2020, at age 22, Massey University student Toby began feeling unwell. *"I was really breathless, weak and throwing up a lot. I turned up at hospital to find out that I was running low on blood counts, and later learned that I had a plasmacytoma."*

The plasmacytoma required all kinds of tests, biopsies and finally, radiation. Afterwards, Toby felt well for a while, until three months later, when he had a PET scan and new tumours had shown up. More surgeries and biopsies were booked, and that's when it was confirmed that Toby had multiple myeloma.

"There was this song playing when we showed up at the hospital that I really like; Black Magic Woman by Santana. So I was thinking in my head, oh this will be a good time! But it wasn't."

📖 **My doctor gave us the news, and...everything just felt really hollow. It was a big shock.** 📖

By now, Toby had put his studies on hold, left his flat and stopped working. He moved back home to Wellington where his parents could support him through treatment.

"Every single doctor visit, my mum was in the room writing things down, and that really helped me out. She'd pick up on something that I missed, or vice versa. It's been a dream. As much as I feel like I shouldn't be at home at my age, I think it's been one of the best decisions."



Toby with his family in Wellington

And Toby was also supported by Nicki from LBC. *"She was awesome. She met me one day at hospital and explained what LBC does. She pointed me to some of the online resources about blood cancer. As a student, I like to do my research on stuff, so I appreciated that."*

"She also offered me a TV card so I could watch TV in my room without having to pay for it."

Toby has recovered well, and as of August 2022, he is tumour free. He's grateful to be healthy, and back on track with his studies. He's back doing what he loved before – getting outdoors, going for walks and cycling. He's also back studying, and has almost finished his degree.

"It's just about changing your mindset."

Fast Facts: Plasmacytoma

- Plasmacytoma is a type of cancer that begins in plasma cells (white blood cells that produce antibodies)
- When only one lesion is found it is called a plasmacytoma but may turn into multiple myeloma, and is often thought of as early multiple myeloma.

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

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.

[Anyone,
anywhere,
anytime]
is blood cancer

#ThisIsBloodCancer

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



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