

# Leukaemia Today

Supporting people *living* with leukaemia



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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. ”



**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](mailto: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](https://lbcnz.link/forum22)**



## 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

# Making new memories

**Teresa's leukaemia relapsed just days before her 50th birthday. It was devastating. "I almost cancelled my party that weekend. But then, I was like 'No, it's worth celebrating.' And I'm so glad that I did."**

Teresa hosted a party with all her loved ones around her, despite how raw the news of her relapse felt. It didn't spoil the night. *"I had the best time with all my favourite people around me. We danced, we cried and we had fun."*

*"Then, I went into hospital on Monday."*

Teresa's leukaemia journey isn't linear. Almost every challenging experience was followed by something positive. "I got out my journal last night, and I was reading what I went through...it was horrific. But in between, it was all about the people I met. The bad experiences blur as they are replaced with new ones."

One of those bad memories is her initial diagnosis in 2016. Teresa had a rash on her leg, which she thought was a spider bite. Her dermatologist took biopsies, and didn't find anything unusual. She wanted a second opinion and so she ordered blood tests.

*"And my blood counts were abnormal. So they did a bone marrow biopsy."*

The tests came back and confirmed that Teresa had acute myeloid leukaemia. It was a Friday, and so she was then sent home for the weekend. She was asked to return on Monday, the 18th of July; her daughter's birthday.

*"That Monday, my family went out for breakfast, and we ate together. It was this really special day, because it prepared us as a family for the next five months of treatment."*



Teresa on holiday with her family

The treatment was harrowing, but Teresa got through it, and was back at work within months. She was even well enough to travel to London and Paris.

But by the following year, Teresa's health took a downturn. She started to feel unwell just before her 50th birthday. She had relapsed.

*"I actually forgot that they had been testing me for months before I found out. I read that in my notes."* Perhaps this was another memory that has blurred.

*"Finding out I had relapsed was devastating. I didn't have this reaction the first time, I just went straight into survival mode. But, this time I felt deep pain."*

Teresa's daughter had planned to visit her in hospital, but as a student with a part-time job, she couldn't afford it. This is when Teresa's doctor referred her to LBC.

Teresa met with Sally, the LBC Support Services Coordinator for the Central Region.

*"I explained my daughter's situation to Sally, and she said, 'We can give her food and parking vouchers to make it easier on her'. She was so grateful for that."*

*"And when Nicki joined Sally's team, Nicki would ring me to check in. I find it hard to reach out, so I really appreciated that."* Teresa still has a great relationship with Nicki, and she regularly attends her support groups.

Next, Teresa decided that she wanted to make one last special memory before going through her stem cell transplant.

*"I went on a short holiday to Hawke's Bay with my son and husband. It was a special time for us to enjoy nature together, and to have a few days' reprieve from treatment."*

Teresa walked up Te Mata Peak, and she enjoyed a swim at Waihi Beach. She remembers watching her son playing in the sand, and contemplating how grateful she was for her family.

Soon, her gratitude would deepen.

*"If there could ever be a closer bond than what you already have with a sister...it's receiving her stem cells. My sister was nervous about the transplant...but she's the bravest in my family. She's got guts. She didn't even bat an eyelid about it."*

*"It makes me emotional. She gave me life."*

This experience also taught her the value of keeping the right people in her circle.

*"I didn't have the headspace for anyone who couldn't take me as I was. There was no 'being brave' this time. I knew how sick I could get and the humility one needs to have because you lose so much dignity in hospital with what your body is going through."*

👂 **Only certain people can cope with that. People who love you.** 🗨️

This is one of the lessons that Teresa has learned, now that she has fully recovered. But her biggest takeaway is this:

*"I will never again take for granted the little things. It's the taste of food, the hugs from your kids, and the conversations I had with people along the way - other cancer patients, doctors, nurses and of course friends and family."*

*"It's going down and watching the ocean. At every stage of my treatment, those were the things that had the most impact on me."*

## Fast Facts: Stem cell transplant

- There are 2 types of transplants – Autologous (using own stem cells) and Allogeneic (using a donor's stem cells)
- For an Allo transplant, people have to travel to either Auckland, Christchurch or Wellington hospitals.

# Getting through the scary bits together



Jacqui, Hayden and family at Taupo

**It's snowing in Taupo, it's July 2020, and Jacqui is with her family, enjoying a holiday away from their home in Auckland. But, her eldest son is not having a good time. He has typical flu-like symptoms, and he has a painful ulcer on his tongue.**

*"We all went into the snow to play – except Hayden. He was too tired, so he sat in the car. That wasn't like him."*

The following week, Hayden took Monday off school. And on Tuesday morning, after sweating through his duvet, and with a high fever, Jacqui took her son to the doctor, who ran blood tests.

Later that afternoon, Jacqui got the phone call. It was confirmed – Hayden had acute myeloid leukaemia and urgently needed to go to Starship. *"I was like, 'Excuse me? Is this a life-threatening disease?' And the doctor said, 'Yes, potentially.'"*

What followed was a whirlwind of emotions, introductions to doctors, and plans for all kinds of procedures and treatments. They were introduced to LBC Support Services Coordinator Tim, who provided information and a supportive ear at the beginning.

*"It was a very long five months. But Hayden had a good attitude about it all. That's the kind of person Hayden is at heart."*

A year later, in July 2021, Hayden relapsed and he had to go back to hospital for another four months. *"He took that very badly. He was quite depressed."*

But, having Tim there made an even bigger difference, this second time around.

*"Tim organised a Wi-Fi box for Hayden, to boost his internet because the signal in his hospital room wasn't great. He loves gaming, so that helped lift his mood."*

*"One time, Hayden wanted a specific pizza from this restaurant that couldn't deliver to*

*the hospital. Well, Tim drove and got it for Hayden, just to cheer him up."*

The lengths that Tim took to support the family meant that Jacqui could focus on being there for her son, supporting him on his journey and eventually helping him recover from his blood cancer.

*"Hayden went through a phase of watching horror movies in hospital. I spent five nights a week with him, so we'd watch them together, and he'd laugh when I got scared."*

*"Sometimes, I'd leave to use the bathroom... and I'd have to walk down the corridor, and I'd be gone for a few minutes. Then he would get scared, and he'd call my phone, just to say, 'Come back, mum!'"*

And, Jacqui would do just that. She would hurry back, join her son and they would get through the scary bits together, despite feeling scared herself.

This is how they continue to tackle Hayden's blood cancer journey, now that he is in recovery and Jacqui is aware of every moment they have together.

*"We grew close in hospital. He'd tell me that he really appreciated me being there, and I am so grateful for that."*

## Fast Facts: Acute myeloid leukaemia (AML)

- There are around 140 diagnoses of AML in NZ each year
- AML is an acute leukaemia that develops very quickly and requires immediate treatment
- AML is a cancer of the myeloid blood cells.

# 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](https://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](https://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](mailto:info@leukaemia.org.nz)

Visit: [www.leukaemia.org.nz](http://www.leukaemia.org.nz)

Mail: PO Box 99182, Newmarket, Auckland 1149

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