

SUMMER 2024

Leukaemia Today

Supporting people *living* with leukaemia



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Kia ora,

Welcome to your summer 2024 edition of Leukaemia Today.

In recent months, LBC has made strides in our advocacy efforts, with active and ongoing engagement with several key health decision-makers. As the Government progresses significant changes to the health system, including medicines access and health service delivery, we have ensured that the voices of our blood cancer community are represented.

Our advocacy has opened doors for meetings with Pharmac Chair Paula Bennett, the Minister responsible for Pharmac David Seymour, and Minister of Health Shane Reti. In these meetings, we have underscored the urgent needs of blood cancer patients and the importance of addressing these promptly. Pharmac's formal consultation process with patient organisations has provided an additional forum to emphasise the critical role of medicines for the blood cancer community.

The recent LBC Patient Forum was another highlight in our support of patients. It offered a platform for individuals to learn about important blood cancer topics and directly engage with Pharmac in a panel session. For many attendees, the opportunity to have their voices heard was invaluable. The Forum emphasised our commitment to bringing patients, health experts, and policymakers together with the shared aim of improving outcomes for the blood cancer community.

Ngā mihi nui,

Tim Edmonds
LBC Chief Executive



LBC's Patient Forum Pharmac Panel – Todd Stephenson MP, Hon Paula Bennett, and Dr David Hughes

Improving access to blood cancer medicines

The gap in access to blood cancer medicines between New Zealand and Australia has been highlighted in a recent report by the Cancer Control Agency. The report revealed that there are 24 blood cancer medicines funded in Australia but not New Zealand. This has sparked renewed interest in earlier political commitments to use the report's findings to address this disparity. Blood cancer patients have united to hold politicians accountable, with more than 700 patients co-signing an open letter to Rt. Hon Chris Luxon, urging action to fulfil these promises.

Progress through advocacy - stem cell transplant access

Earlier this year, LBC met with Health Minister Shane Reti to discuss critical issues impacting blood cancer patients – one being the capacity constraints in stem cell transplant services, which have led to long waitlists and patient harm. As a result, Minister Reti requested a formal briefing from the Cancer Control Agency on the state of the service.

Since then, expanding capacity for stem cell transplants has become a priority in the Government's efforts to meet its key health target for faster cancer treatment. Health NZ has now committed to recruiting additional specialist staff to help relieve these constraints and improve timely access to stem cell transplants.

CAR T-cell clinical trial support

LBC is providing travel and accommodation support for 60 lymphoma patients participating in the ENABLE-2 trial for CAR T-cell therapy.

This support ensures that patients outside the main trial sites can join the trial, and be accompanied by their whānau, without bearing the extra cost of travel and accommodation themselves.

Holistic wellbeing with blood cancer

Tokoroa local Vonda knows just how devastating a blood cancer diagnosis can be. In 2020, the primary school teacher had recently returned to in-person teaching after the COVID-19 lockdown when she noticed a spider bite on her hand that wasn't healing. A visit to the GP and some blood tests soon revealed why her hand wasn't healing – Vonda had leukaemia, and within a matter of hours, her life was turned upside down.

Vonda shares how she used Te Whare Tapa Whā, a holistic Māori health model, to advocate for herself and work towards wellness during this period.

Can you explain what Te Whare Tapa Whā involves?

Sir Mason Durie's Te Whare Tapa Whā model is based on a whareniui or meeting house. It commonly focuses on four sides of the whare – **taha wairua** (spiritual wellness), **taha hinengaro** (mental wellness), **taha tinana** (physical wellness) and **taha whānau** (family and social wellness). One more key to my recovery was the inclusion of the fifth element – **whenua** (land and identity wellness).

How did Te Whare Tapa Whā help you during your blood cancer journey?

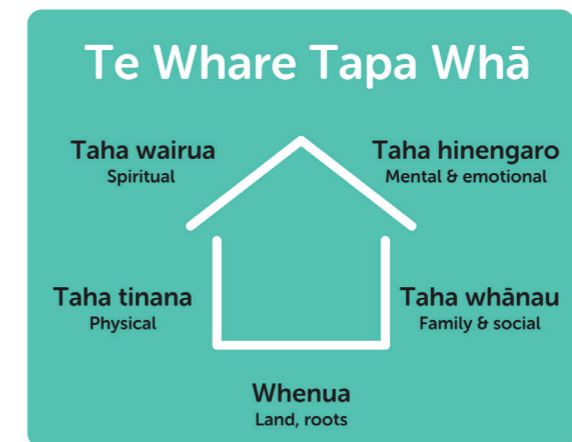
Te Whare Tapa Whā moved mountains for me. It was a way for me to communicate my needs with healthcare professionals. When I went into hospital, I had all these things swimming around in my head. I drew up the model and wrote down all the things that were bothering me, parking them where they needed to be. I utilised that model to negotiate my wellbeing, the way I needed it.

I remember feeling isolated from my friends and whānau. Physically, my body was weak and tired. Mentally, I was worried about finances. Spiritually, I had lost my faith in God. And I was confused about who I was, and where I belonged. Te Whare Tapa Whā helped me record all that fear and confusion into five key holistic elements.

How can other Kiwis living with blood cancer use this model?

Te Whare Tapa Whā is great because it empowers you to take control of your health and can also be a useful tool to communicate what support you need. I encourage people to take a three-phase approach when using the model to create change in their lives:

- The first phase involves getting honest and taking a snapshot of where you are right now. Look at each element and identify your feelings and worries.
- In the second phase, try to identify resources and solutions that could help you to improve your wellbeing in each of these areas.
- The third phase involves clarifying where you are heading.



Vonda's journey

- **Taha tinana (physical)** – Quit smoking, ate nutritional food and stuck to doctors' advice
- **Taha wairua (spiritual)** – Went to church and spoke to the hospital pastor
- **Taha hinengaro (mental/emotional)** – Withdrew Kiwisaver to reduce financial stress
- **Taha whānau (social)** – Chatted with family twice every day
- **Whenua (land and identity)** – Spoke to dad about whakapapa (ancestry)

Making memories

Invercargill hairdresser Diane is the type of person who just gets on with things. She's a mum of three and a grandmother to six, and for 30 years she ran her own hairdressing business. "I'm one of those people that's never had a sick day," she laughs.

But last year, at the age of 62, Diane was floored by something completely beyond her control.

"There was one day last year – June 15th, to be exact – where it took me three goes to make the bed. And I thought, honestly, I'm getting old, but not this bloody old!"

"I had noticed beforehand that I was bruising very easily, and I'd had bad fatigue. I would often come home from work and pretty much do dinner and go straight to bed – a late night for me would have been 8 o'clock."

Diane called her GP and was sent off for urgent blood tests. She didn't have to wait long for the results. *"My doctor rang me about 6.00pm that night. We'd just finished dinner, and she said, 'I want you to put some comfy clothes on and get down to Southland Hospital ASAP. They're waiting for you.'"*

Diane and her husband rushed to the hospital, where she received an urgent blood transfusion and some more tests. *"They pretty much decided then and there that I had acute myeloid leukaemia (AML). All my markers were at zero, everything was just depleted."*

☞ **One doctor told me that if I hadn't gone to get sorted when I did, I may have only had another fortnight, if I was lucky. That was a wake-up call.** ☞

Diane's husband was with her throughout her entire journey



The next morning, Diane was in an ambulance heading up to Dunedin Hospital. She was immediately started on intensive chemotherapy – every 12 hours for the first 10 days.

Diane spent the next four months receiving treatment in Dunedin – her husband stayed in a local motel and her kids drove up from Invercargill to visit her on the weekends. *"When I was allowed out during the day, all I wanted to do was sleep – so often we went to the motel, and I just slept. But I tried to do things with my husband, like we'd go out for lunch. It was just to be somewhere else, to try and be a bit normal."*

During her time at Dunedin Hospital, Diane was visited by Deb from LBC and was thankful to have that extra support. *"She immediately gave us a supermarket voucher and a petrol voucher."*

Diane's healthcare team told her that in the long term, she would need a stem cell transplant. *"They basically said, 'Without that, the AML is going to come back, and you'll die.' So that was just a given."*

In October, Diane was allowed home for three weeks before heading up to Christchurch to start the transplant process. *"So, we had an early family Christmas. We had fish and chips, and later we toasted marshmallows."*



Her kids had given her a voucher for a family photoshoot earlier in the year, so while she was back at home, they took the opportunity to use that too. *"I felt so good about that – in case things didn't pan out, I thought at least the kids would have those memories."*

Diane received her transplant on November 24th. It was initially supposed to go ahead a week earlier, but an infection delayed things. In a stroke of luck, during the delay, a better donor match was found.

Following the transplant, Diane struggled with terrible side effects, including mucositis in her mouth and swelling from excess fluid. She developed diabetes from taking steroids and was dealing with a persistent fungal infection in her lungs. *"It was just one thing after the other,"* she says. She's relieved that most of these issues have improved or resolved completely over time.

Diane attends LBC support groups in Invercargill, and although everyone has different types of blood cancer, she finds them a great way to connect with others – which is especially important now that she's closed her hairdressing business and doesn't get to spend her days chatting to clients.

"It was such a hard decision to stop working. When they told me it would be at least 12 months of treatment, and being the age I was, everyone said, 'Why don't you just live life?' And I thought, yeah, you're right."

Although she still gets quite tired, Diane is feeling well and has been spending lots of time with her grandkids. She's looking forward to a family holiday on the Gold Coast later in the year – something that her children have been planning since she was in Dunedin Hospital.

"It was pretty smart of them really. Going through the journey, on days when I wasn't good, it would suddenly pop up in our family messages: 'We're just booking the theme parks, or we're just sorting the rental cars.' Things like that really kept me motivated."

As well as preparing for her family holiday, Diane is also writing a book about her experience with leukaemia for patients and their support people to read. *"When I was first diagnosed, I tried to download or find a book at the library, and I found very little. It wasn't until I was actually in the leukaemia circle that I had access to more of those stories."*

Her advice for others facing leukaemia is to take each moment as it comes. *"Just get through this day – or this hour. When you're having those tough times, it's just about getting through the next hour."*

FORGOTTEN FACES OF BLOOD CANCER

We need your help to raise awareness of blood cancer. If you have blood cancer, know someone who has, or support someone who has, then please add your face to this campaign. Let's show New Zealand that blood cancer is more common and impacts more lives than many realise.

To add your face to the campaign, head to www.facesofbloodcancer.com



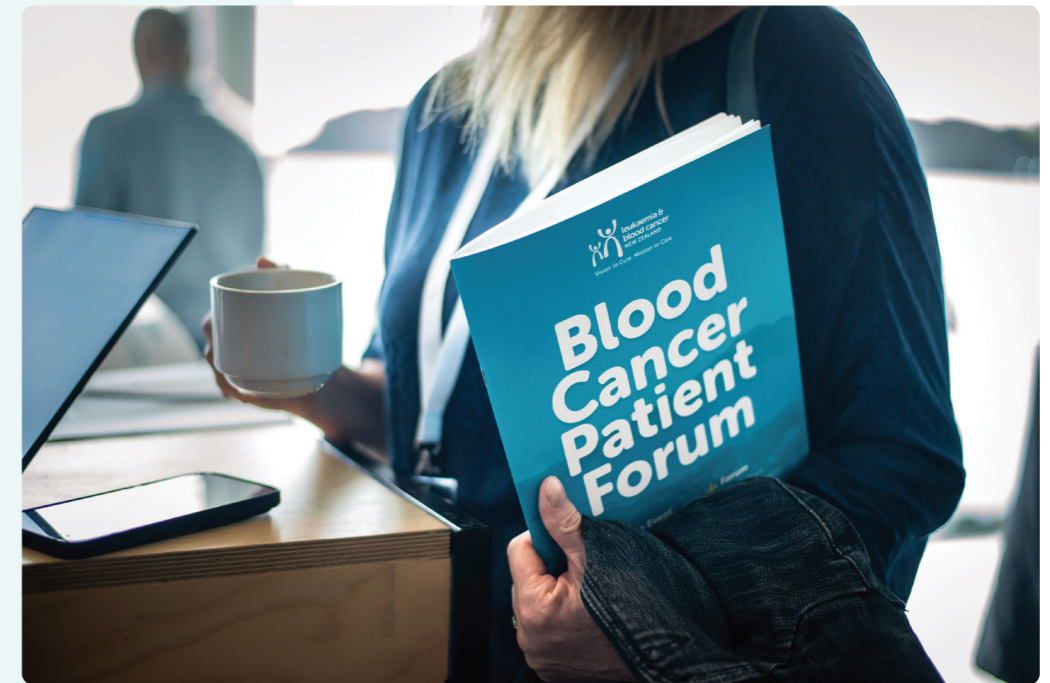
SCAN ME

LBC 2024 Blood Cancer Patient Forum

This September, we were delighted to host our Blood Cancer Patient Forum in Auckland. Nearly 180 blood cancer patients and their supporters came together on Auckland's waterfront to connect with other patients and hear a line-up of experts share valuable insights. Speakers presented on a range of blood cancer and supportive care topics, including immunotherapies, life after allogeneic stem cell transplant, the role of integrative oncology and use of complementary therapies, fatigue reduction strategies – and many more!

The day ended with a Pharmac panel discussion, hosted by Tim Edmonds and Rosie Shaw from LBC.

Many of the presentations were recorded and are now available to view on our YouTube channel. Scan the QR code or head to youtube.com/user/LBFNZ to view the Patient Forum playlist. Or read on to find out more about a few highlights from the day.



'The Power of Stories', from keynote speaker **Jehan Casinader**, was an inspiring journey through his career as a TV journalist – and his experience of depression and suicidal thoughts. Jehan explained how he tried a range of mental health tools, before discovering the power of **"narrative psychology"**. He explained how each of us is the "main character" in our own life story – and we're also the author of that story. Even though we can't change the events that occur in our lives, we can choose how to interpret them, which can have a huge impact on our wellbeing. Jehan shared some powerful questions:

- Who is writing your story right now? Are you willing to be the "author"?
- If your life was a movie, what character would you be playing?
- What would a good character do – in the scene you're currently in?
- How can you tell a different story, using the same facts?
- If you change your story, what impact could that have on your wellbeing?

Professor Judith Lacey, Director of Supportive Care and Integrative Oncology at Chris O'Brien Lifehouse, Sydney, gave a very informative presentation on **'Medicinal Cannabis and the endocannabinoid system, and their role in cancer symptom management'**.

In this, Judith discussed the use of medicinal cannabis in the context of supportive cancer care. She led with the idea that it is not just controlling the cancer that is so important but also supporting the whole person to live well with cancer. During her presentation, Judith spoke on:

- A history of cannabis and medicinal cannabis use.
- The human endocannabinoid system and the cannabis plant.
- Requirements for prescribing and using medicinal cannabis.
- The interest in and research happening about the possible anti-cancer effect of cannabis.

It was a really interesting presentation, all leading to the understanding of where medicinal cannabis can fit in cancer care, noting it is a rapidly growing space.

Professor Ian Morison gave a fascinating presentation on the role of **genetics in blood cancer**, starting with a 101 on chromosomes and genes. Did you know that 26 trillion of the 37 trillion cells in our bodies are blood cells? Professor Morison talked about how cell divisions cause genetic mutations – this is normal, and these mutations are usually harmless, but sometimes they aren't and can end up causing blood cancer. He gave a great explanation of the JAK2 mutation and chromosomal translocations, and spoke about how identifying translocations can aid in diagnosis and treatment decisions. He mentioned there has been incredible progress in genomic technology and the ability to sequence DNA. Some interesting points were also raised about familial predisposition to different blood cancers. Although blood cancers are mostly not from inherited genes, a person's overall genetic background can have a small effect on the risk of getting a blood cancer.



The panel discussion titled **"The Future of Pharmac"** featured insights from **Paula Bennett**, Chair of Pharmac; **Todd Stephenson**, MP and private secretary to the Minister of Pharmac; and **David Hughes**, Pharmac's Chief Medical Officer. Each panellist addressed the current state and future directions of Pharmac, particularly concerning cancer and haematology. Todd Stephenson began by outlining his vision for Pharmac and its potential impact in these areas. David Hughes followed with an update on the assessment process and the status of funding proposals for blood cancer treatments. Paula Bennett wrapped up with a discussion of the constraints Pharmac faces and realistic near-term goals.

The presentations were followed by a panel discussion that tackled key pre-submitted questions, including issues related to New Zealand's exclusion from clinical trials due to limited access to standard treatments, the need for clarity on funding timelines for blood cancer medicines, and ethical concerns surrounding extended price negotiations. The session concluded with a brief Q&A with the audience, exploring potential models and approaches for accelerating access to critical treatments.



It's giveaway time!



We're giving away four copies of of keynote speaker Jehan Casinader's book, ***This Is Not How It Ends: How Rewriting Your Story Can Save Your Life***. In his book, award-winning TV journalist Jehan chronicles his four-year battle with severe depression. He shares how the power of storytelling helped him survive and gives readers some helpful tools to reshape their own life stories.

If you miss out on a book, we also have four beautiful water bottles from Chunky up for grabs, with designs by Cass Urquhart and Eddie Botha.

To be in the draw to win, tell us the title of a story you loved as a child, or one that's particularly special to your family. Email your entry to marketing@leukaemia.org.nz along with your name and postal address. Winners will be randomly drawn on Tuesday, 7 January. Good luck!

It feels like something else

"I went into shock after hearing 'leukaemia'. It's not something you ever think you'll get."

Tanya is speaking from the United States, where she's currently staying with family. She's recounting the day she was first diagnosed with acute lymphoblastic leukaemia.

It was 2013 when she realised something was going on. Tanya was just 23 at the time. She had a supportive partner and a job she found fulfilling, but she'd been feeling exhausted and seemed to be waking up with new bruises every day.

"I did a lot of Googling around then," she says. *"But your mind doesn't automatically go to the worst-case scenario."* She'd had problems with anaemia in the past and thought her symptoms might be related to that.

Then the bleeding started – first from her nose and gums, and then from her legs after shaving them. *"One day at work, my gums wouldn't stop bleeding... My teeth were all red – I just felt horrible."*

She decided it was time to visit her GP. *"I thought, my legs are bleeding, I've got bruises everywhere, my gums won't stop bleeding – I think it's about time that I actually go find out what's happening. Because now it doesn't feel like anaemia. It feels like something else."*

The GP ran some blood tests and sent Tanya home, telling her that if anything concerning came through, they'd call her to come back in.

"They called me back within two hours."



Tanya knew it was time to visit her doctor when her gums wouldn't stop bleeding

Tanya was urged to go to the hospital that evening for further investigations. As it got late, she felt sorry for her aunt who was falling asleep on the chair next to her hospital bed. Tanya told her to go home. *"My auntie went to leave, and then she came back. I asked, 'What happened?' She didn't tell me until afterwards, but one of the nurses came after her and told her she needed to stay with me because this was something serious."*

Tanya was transferred to Auckland Hospital, where she had a bone marrow biopsy and was eventually given the news that changed everything. *"They told me to pull in my support people first. I felt like I would be a burden on my partner and aunt who already had a lot on their plates and trying to put myself in front of their needs was difficult to consider. So I decided to go in on my own."*

"I went from being shocked I had leukaemia, to feeling overwhelmed by the information I was being given. That's when I understood why it's so important to take someone in with you."

Tanya was told that she had 94% blast cells and needed to begin chemotherapy straight away. *"I was in hospital for a month or two while we went through the induction phase. I was concerned about not being able to have kids after. That was a major thing for me. But it was quick – they said we had no time to freeze eggs before the first round."*

Her medical team advised her to stop working so she could focus on treatment. *"I didn't realise how intense the treatments were going to be. Throughout the whole thing, I just felt constantly sick. Nausea, vomiting – it was awful."*

Once she was in remission, Tanya returned to work. Maintenance treatment continued but life was getting back to normal.

But then it came back in 2020.

"Again, I had fatigue, I had bleeding. And the constant headaches that just would not sort themselves out. I was also having infections – I felt very feverish and nothing was helping to sort the fever." When her gums began bleeding again, Tanya went to her doctor for a blood test – and just like that, her fears were confirmed.

Tanya admits she questioned whether or not to go ahead with treatment the second time around. This time, she knew what was in store. *"But after telling those closest to me that I had relapsed, they all wanted me to fight. A difficult choice to make, but I chose to do the treatment. It wasn't for me, though - it was for them."*

The first time Tanya was diagnosed, she had been living with family and was grateful to have them take care of her while she took time off work. *"The second time, I worked throughout the whole process. I felt as if I didn't have much of a choice. My partner had just lost his job because of COVID. Getting a job proved to be difficult, so I made the choice to work. Thankfully, my boss was supportive of my request to continue working."*

Again, Tanya faced horrendous nausea during chemotherapy. *"It was hard. Especially when you're trying to manage to be online, do the work, as well as coping with the side effects of treatment."*

Realising she needed some extra support, Tanya's nurse specialist told her about LBC and made a referral.

She was soon visited by LBC Support Services Coordinator Tim. Tanya was relieved to hear that LBC had a support group for young adults – something she felt like she'd been missing.



Tanya struggled to balance work with treatment after she relapsed

"It was really nice having LBC support groups the second time round. Because I just felt really lonely for such a long time, after losing the friends I made while in hospital. The people at those groups just understood me."

LBC also provided Tanya with vouchers for petrol and groceries, which helped take off some of the financial pressure she was under.

"As soon as I finished treatment, I was discharged from hospital and then got straight on a plane to the United States to visit my family. I felt like I needed to do that – I think I earned a holiday after doing treatment and working full time."

"I came here and got to hang out with my family, and it felt great. It reminded me of why I chose to stay alive - for my partner, family and friends I love dearly."

Although she's in remission now, Tanya struggles not to think about the possibility of her leukaemia coming back. The fear of relapse is something she's been able to talk about with others at LBC support groups, and she knows she's not alone in feeling like this. She's doing her best, but admits it's hard: *"We can tend to focus on relapse rather than on living life."*

Whānau Corner



Blood cancer doesn't only affect adults – it also impacts children of all ages, who have their own support needs. That's where LBC's Kids' Zone comes in.

Whether a child in your whānau is living with blood cancer, or they're impacted by a family member's diagnosis, we have plenty of support and resources available to help you through this time, including:

Kids' Club

LBC runs Kids' Club to support children aged between 5 and 12 who have a family member with blood cancer. The group focuses on the needs of the children and supports them



A recent Kids' Club session at LBC's Auckland office

to successfully cope with the diagnosis and treatment of their loved one.

In a safe, friendly, and fun environment, children can take part in activities and talk about their feelings, learn a little bit about cancer and treatment and meet other kids who are in a similar situation.



Our Kids' Club whānau were delighted to receive their new hoodies recently

In-person groups are held in our main centres, and there are also online sessions available.

Super Kids' Club

We also run Super Kids' Club, which is a group to support paediatric patients who have been diagnosed with a blood cancer or blood condition.

The sessions are run by a professional therapist who specialises in workshops for children. Kids can take part in creative activities, discuss their feelings, learn more about blood cancers and their treatment while meeting other young patients going through a similar experience. These virtual Zoom sessions are available for children at home or in paediatric wards around New Zealand. Activity packs are sent out prior to each of these virtual sessions.

Plus much more...

Head to lbcnz.link/kids_zone for more info on what we offer.

And if you're an adult living with blood cancer, check out lbcnz.link/groups for information about joining a support group, attending an education group, or getting support to navigate life with and beyond blood cancer.

You can also follow [@LBCNZ](https://www.facebook.com/LBCNZ) on Facebook for updates on LBC's research, advocacy and awareness work, as well as support opportunities. Or join one of our closed Facebook groups to connect with other patients or support people who understand the challenges of blood cancer.

Support for specific cancers and conditions

[@LBCLymphoma](https://www.facebook.com/LBCLymphoma)
[@LBCMyeloma](https://www.facebook.com/LBCMyeloma)
[@LBCChronicLeukaemia](https://www.facebook.com/LBCChronicLeukaemia)
[@LBCAcuteLeukaemia](https://www.facebook.com/LBCAcuteLeukaemia)
[@LBCBloodDisorders](https://www.facebook.com/LBCBloodDisorders)
[@LBCHAemochromatosis](https://www.facebook.com/LBCHAemochromatosis)
[@LBCMPN](https://www.facebook.com/LBCMPN)

Support for young adults and parents

[@LBCYoungAdults](https://www.facebook.com/LBCYoungAdults)
[@LBCParentsGroup](https://www.facebook.com/LBCParentsGroup)

Further support pages

[@LBCSupportPersonConnect](https://www.facebook.com/LBCSupportPersonConnect)
[@LBCBereavement](https://www.facebook.com/LBCBereavement)
[@LBCNZConnect](https://www.facebook.com/LBCNZConnect)
(LBC & Health Professionals Connect)