

LymphomaToday

Supporting people *living* with lymphoma



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Kia ora,

Welcome to your summer 2024 edition of Lymphoma 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?

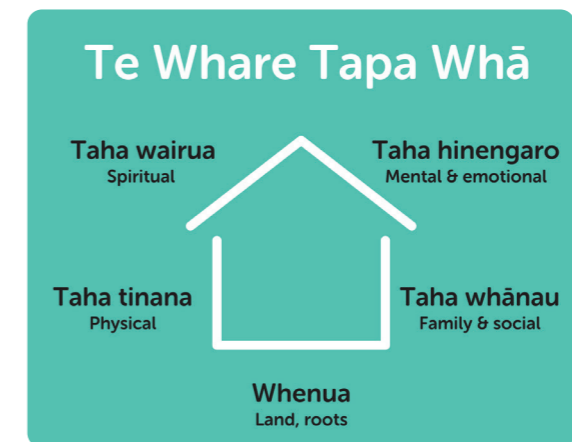
Te Whare Tapa Whā moved mountains for me. It was a way for me to communicate my needs with healthcare professionals. When I went into hospital, I had all these things swimming around in my head. I drew up the model and wrote down all the things that were bothering me, parking them where they needed to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

One page a day

"I'm 68, going on 69. I've got three daughters and five grandchildren. My husband and I moved up to Cromwell from Dunedin close to 20 years ago for a lifestyle change. We had lots of plans for retirement, but life got in the way quite severely there for a bit..."

In 2019, Ann was working as an administrator and, as she describes it, *"living an ordinary life"*. She and her husband have always been heavily involved in the New Zealand Rock 'n' Roll dancing scene and both enjoyed getting outdoors. But life changed quickly when Ann began experiencing health problems.

"I had severe stomach pain and vomiting," she says. *"I would be three or four hours over the loo. It started off during the night and then came during the daytime as well. Doctors couldn't find any rhyme or reason for it. I had none of the standard cancer markers."*

After seeing two separate GPs and a specialist who couldn't tell her what was going on, Ann was at her wits' end. *"I was getting sicker and sicker, and losing more and more weight. I was absolutely miserable."*

When a new GP started at the practice, Ann went to her and told her something needed to be done. *"I was still going to work, and I really don't know how I did because I was dragging myself around half dead."*

This GP ran a battery of tests and figured out that Ann had coeliac disease. After changing to a strict gluten-free diet, things were better for about six weeks. *"Then I woke up one night and I was vomiting and had these dreadful stomach pains again. That was a real low because, by that time, I'd lost about 20 kilos."*

Ann went back to the GP and told her she didn't feel she could carry on much longer – that every night she was going to bed scared she wouldn't wake up in the morning. After a scan at the local hospital, Ann was asked to come back that same afternoon.



Ann makes a point of getting out and enjoying her life



"The doctor said they found a mass, and it was cancer. And I said, 'Thank God. What are we gonna do about it?' I frightened her, actually. She rang me a couple of times in the next couple of days, making sure I was alright, because she said she'd never had anyone take a cancer diagnosis so well."

“I was so relieved because I knew once they found something, we could work with it.”

Ann and her husband headed down to Dunedin Hospital that evening. She was diagnosed with enteropathy-associated T-cell lymphoma (EATL), a type of lymphoma that occurs in people with coeliac disease. Five days later, she was in surgery to have the mass removed, and two weeks after that was started on R-CHOP chemotherapy.

While in Dunedin Hospital, Ann was visited by LBC Support Services Coordinator Deb. Deb told her about LBC's support groups, and Ann remembers thinking she didn't need a support group. *"But one of my daughters said to me, 'I'll be really cross with you if you don't go. You just don't know how helpful they'll be 'til you take part.'"*

So, she decided to follow her daughter's advice and give it a go. *"I thought, OK, I'll go along and see what it's like. And it's a great group. Really, really good people. We really support each other, and if someone's having a down time or has any questions, we all tell them about our experiences."*

Ann's family was another huge source of support. *"Throughout the whole thing, my husband has been an absolute rock. He's been with me the whole time."* Ann was also blown away by how her daughters showed up for her – one paid for somebody to clean her house for a whole year, another kept her



freezer filled with nutritious meals, and the third gave her a very special gift before she went up to Christchurch for her stem cell transplant. She gave Ann her laptop and told her there was a PowerPoint presentation saved on it. *"She said, 'You're allowed to open one page a day.'"*

"So, of course, the first day in there, I opened it up. My daughter had contacted people I'd worked with years ago, contacted my friends, the family, the in-laws, and she'd asked them to send me a message, preferably with a picture of something I'd be interested in. And it was lovely. People I hadn't even thought about in years, she'd found them and asked them to send me a message."

The knitting patterns, silly jokes and holiday photos were a welcome distraction through the transplant process. *"It was really, really, really hard,"* Ann says. *"But it gave me my life back again. It was a journey and a half, but it was well worth doing."*

When she returned home, she had to build her strength back up from nothing, starting with walks to the letterbox. Once she could walk to the end of the block and back, she started going further afield on her e-bike. *"I really credit that for my recovery – from then on, it was all upwards and I just got better."*

It's now been more than four years since her transplant, and *"life's good,"* Ann says.

"I was discharged back in May. I'm fully cured, which is amazing, because we didn't expect that. They told me that would probably never come, because with a blood cancer they can't be entirely sure. But she said no, I've been absolutely fine for four and a half years."

Going through lymphoma has completely changed Ann's outlook on life. *"Life is to be enjoyed. I make a real point of enjoying everything. It's given me such a positive perspective. There are so many really good things to do and enjoy – that's why I've taken up golf, because I always said I'd do it one day. But you don't know if one day's actually gonna happen – so get out there and do it!"*

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's in my blood

"I'm a half-Fijian indigenous woman – my mum's Fijian and my dad is Kiwi German," Daphne tells me. She's at the Wellington dance studio she runs with her partner, Pat. Music is playing in the background, and she moves to a quiet space so we can talk.

Aside from God and her family – including Pat and their two children – Daphne's biggest love is dance. *"I've been teaching dance for about the last five years, but I've been dancing for over 15 years."*

She and Pat run their studio part-time alongside other jobs. At Daphne's "day job", she's a healthcare assistant at the Wellington Blood and Cancer Centre – something she still finds pretty surreal, considering she was once a patient there.

"I'm really passionate about it – truly – I'm so grateful to go to work every day. I've only been there a year and have already had so many life-changing moments and get to work with the most incredible people."

Daphne knew for a long time that she wanted to make a difference for cancer patients (especially young people going through cancer), but after going through her own journey with blood cancer, it took time to process what had happened and clarify what exactly this might look like.

Now in her thirties, Daphne was just 25 when her journey with lymphoma began. *"I was really, really busy with dance at the time. I think the first red flag I noticed was when I was doing performances – I remember these two gigs where I was almost crawling off stage, just from those two-minute performances. I knew something was wrong."*

She visited her GP and was diagnosed with a sinus infection. But over the next six months, more unusual symptoms began to crop up. *"I was way more tired than usual. And I had these crazy night sweats – I remember one night when I woke up and had to change the whole bed. I was losing a lot of weight and dropped down to 52 kilograms."*

Although she hadn't been well, she managed to attend a friend's wedding in November. *"It was an amazing night. But I got home quite late and then started to feel a very severe pain in my side from the early hours of the morning."*

Daphne still made it to dance rehearsal that evening. *"All the dancers looked at me, like, 'Oh my God, what is wrong with you?'"* Her friends drove her straight to the nearest after-hours clinic. She had some blood tests done and was sent home with painkillers.

"I got home, and literally an hour later, I got a phone call from the Wellington Hospital Emergency Department. They said, 'We've just got your blood results and we need you to come straight here. We're waiting for you.'"

Daphne was shocked. She headed straight to the hospital and was met with

a barrage of tests. *"It was just this blur – I got admitted, and for the next four days, all I remember was that they were ruling out one thing after the other, trying to get to the bottom of what it was."*

An ultrasound and CT scan revealed three large masses, and after a biopsy was taken, Daphne was sent home to await the results. *"I still didn't know at that point that it could be cancerous."*



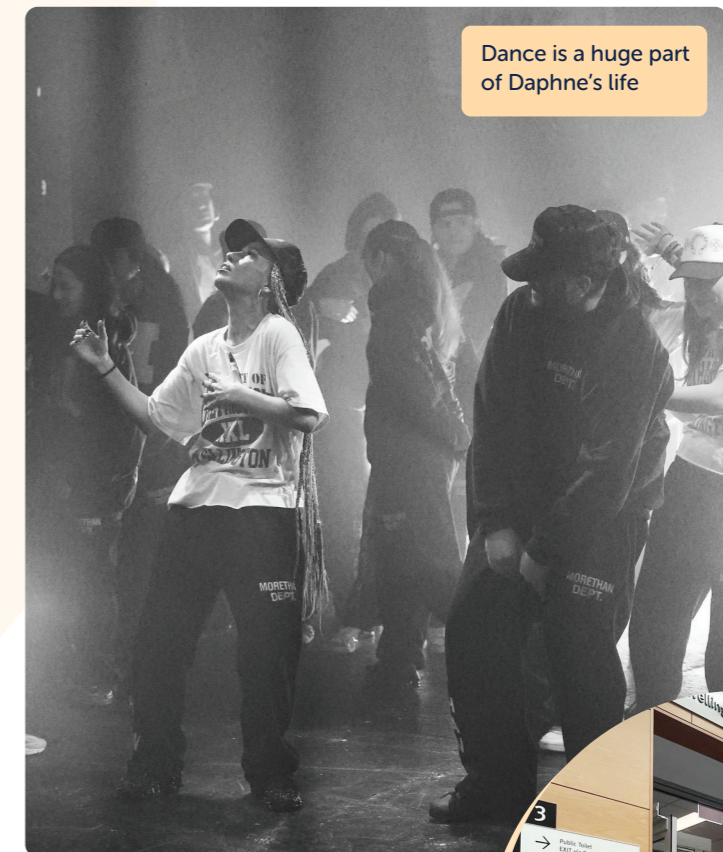
Daphne was only 25 when she came down with a mysterious illness

In January, Daphne was back at Wellington Hospital for an appointment with a haematologist. *"She said, 'You probably don't know why you're here. We got the results back and we have a diagnosis for you, and it's cancer.' But she explained about the type of lymphoma it was – nodular sclerosing Hodgkin lymphoma – and that it's one of the more treatable ones."*

After a couple of weeks of more tests, Daphne was started on six months of ABVD chemotherapy. Knowing she would probably lose her hair, Daphne took control and ran a fundraising event where she and her loved ones all shaved their heads. *"So, I did that before my hair could fall out. But I did get really bad nausea, and I had bad skin problems with folliculitis."*

Daphne was supported through this difficult time by her local LBC Support Service Coordinators. As well as visiting her in the hospital and inviting her along to her local LBC support group, they also helped to connect Daphne with some other young blood cancer patients, including a young man with leukaemia called Kurt. The two became good friends, but Kurt tragically passed away in 2010 after relapsing. *"He actually made a documentary about his blood cancer before he passed – it's called 'In My Blood'. It's very powerful."*

And although treatment was tough, Daphne attributes a big part of her recovery to her partner, mum and friends – as well as her love of dance, and the fact she continued with it throughout her journey. *"I remember I asked my haematologist, 'Am I still gonna be able to dance?' And she said, 'You do what is going to make you happy. As long as you feel up to it and you have time to recuperate after chemo days, then absolutely.'"*



Dance is a huge part of Daphne's life

Photo by Manny Okan (MANFRD)



Daphne now works at the unit where she once received treatment

“Dance saved me – it's in my blood, just like Kurt said.”

Now more than a decade on, Daphne is healthier than ever and is grateful for the opportunity to support others going through cancer. She's particularly passionate about supporting young people and has been helping out at one of LBC's support groups for young adults. She's also eager to increase awareness of blood cancers, particularly in Pasifika communities. *"I honestly believe that's why I went through my journey – I got a second chance to live because I was meant to serve people, and to help in the places I love and care about the most."*

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

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.



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



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)