

# MyelomaToday

Supporting people *living* with myeloma



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Kia ora,

Welcome to your summer 2024 edition of Myeloma 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 day at a time

***“Hairdresser, dance teacher, great life, really fit – and then this nasty little thing called myeloma showed up...”***

In December 2020, most Kiwis were enjoying the start of summer after a difficult year navigating COVID-19. But for New Plymouth dance teacher Chere, December 2020 was just the beginning of a journey that would leave her questioning everything.

*“I’d had an incredibly sore back and hips,”* Chere says. It was something she’d brought up with her doctor several times, but it had always been put down to her lifestyle – after all, she was a hairdresser and a dance teacher, so she was on her feet for most of the day.

But when she found out her old GP had returned from overseas, she booked in to see him for a second opinion. Over the next few days, he ordered blood tests, an MRI and finally a Bence-Jones test. Two days later, he asked Chere to come back in for the results.

*“He sat there and said, ‘I’m really sorry, but you’ve got multiple myeloma.’”*

It was 3 December when Chere received the news, and she had her dance school’s end-of-year show just three days later.

*“It was a real bolt, because I had the dance show coming up, and I’ve been told I’ve got cancer, and it’s not really on the ticket, is it?”*

Chere went ahead with the show, only telling one person there what had happened.

After that, it was straight into treatment with CyBorD. *“And then my back collapsed – that was just awful. I thought, what am I going to do now? I’m a dance teacher and I have a school of about 100 students. That was in January, and the studio opens in February, so it wasn’t looking very good.”*

***“But I was really determined, and I said to the haematologist right at the point of being diagnosed, ‘I’m going to live until I die. I’m not going to live like I’m dying.’”***

Chere managed to return to teaching dance classes with the help of a walking stick and a special chair. But she decided it was important to let her students’ parents know what was going on.

*“I told them what was happening and that I didn’t know what it meant. Was I going to die in a year? Was I going to live? What was going to happen?”*

*“I gave them all the opportunity to take their children elsewhere if they needed to, but none of them did. They all stood with me.”*

Chere also had LBC Support Services Coordinators Nicki and Sally standing with her. She was first introduced to them when she started going down to Palmerston North in the early days of her treatment.

*“LBC were incredible. We got petrol vouchers, vouchers for parking, and it just took all that stress away. Nicki and Sally really looked after me and were always just a phone call away.”*

The support from LBC was especially important in those early stages of navigating Chere’s diagnosis and treatment. *“You wouldn’t have known what you were supposed to do if LBC weren’t there – the haematologist says come back next week, we’re going to start you on that, and it’s like – your head’s fried. And then LBC steps in.”*

Chere went through 16 weeks of chemotherapy, only to find out she wasn’t responding to it as hoped. *“The difficulty of it was, I went through all of that, and it didn’t work.”*



Chere continued teaching dance throughout her myeloma journey

Her haematologist suggested they try a stem cell transplant. *“I remember walking out and just being quite bewildered – there’s no time to stop and breathe and think, now, is this what I want to do? Do I actually want to do this?”*

After some initial trouble harvesting Chere’s stem cells, the second attempt was a success, and the transplant was able to go ahead. But Chere wasn’t prepared for how hard the process would be.

*“I just got sick as a dog. I was so sick. I ended up at 55 kg after the stem cell transplant.”*

The thing she found the hardest throughout her journey was losing her hair. *“One day I went into the shower, and it just all fell out, spectacularly, all at once,”* she says. *“I cried like a baby – I think it was just the last straw.”*

*“You’re fighting this fight, and then it’s like, well, there goes the hair – that pretty much says it all now, doesn’t it? It’s pretty obvious what’s wrong with me.”*

Although Chere is now in remission, she still lives with terrible bone pain and fatigue, and life isn’t always easy. *“Do I love life? Some days I don’t love it at all, and I would rather not be here. But I’ve got to remind myself that I am here, and there are people who love me and want me around.”*

Chere’s strong faith in God is also a source of hope. *“Without Christ, the days would be difficult.”*

Chere is looking forward to this summer – to long days out on the deck and not feeling guilty about putting her feet up. She’s not sure what the future holds, but that’s okay.

*“One day at a time – that’s my philosophy. One day at a time.”*

## 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](http://www.facesofbloodcancer.com)



SCAN ME

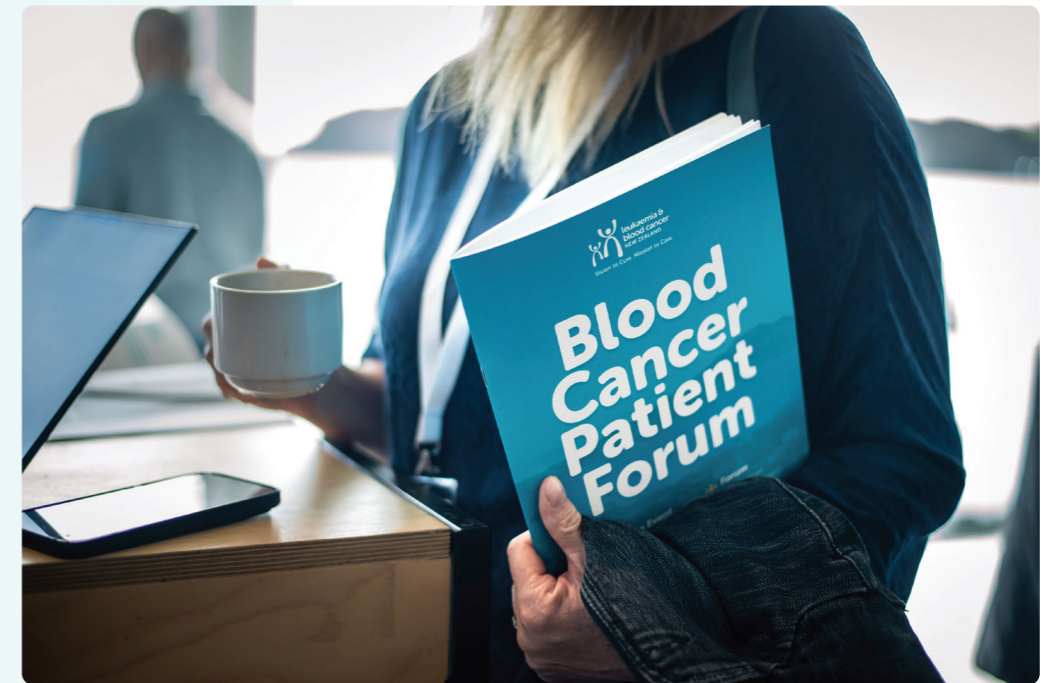


# LBC 2024 Blood Cancer Patient Forum

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](https://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](mailto:marketing@leukaemia.org.nz) along with your name and postal address. Winners will be randomly drawn on Tuesday, 7 January. Good luck!



# Every day is different

**Sixty-four-year-old George is an engineer who lives in Auckland with his wife. "I have two daughters," he tells me. "I'm originally from Sri Lanka, but I've been living here for 26 years."**

George has had an exceptional life. He's travelled all over the world for work and has been heavily involved in community work. *"I was President of the New Zealand Tamil Society – that's a Sri Lankan group – and was involved in the Tamil community for around 10 years."* He's worked with refugees and migrants and is now the Director of International Projects at his local Rotary Club, supporting healthcare and education in Vanuatu. He's been awarded the New Zealand Order of Merit to recognise his contributions.

*"That's my background,"* George says. *"That was before I was diagnosed with cancer."*

Every year, George would have a routine blood test. *"My GP usually asked me to do the blood test every January, but last year I was a little bit lazy and thought, 'I don't have anything wrong with me – I don't even take Panadol!' So, I was postponing and postponing it until the doctor called me, and then I went and got the blood test on the 28th of March."*

That date has stuck in George's mind, because the very next day, he received a phone call while he was at work. *"The doctor called me, and he said I have multiple myeloma."*

George says he went straight into planning mode, thinking about what needed to be done. *"I didn't get scared – I immediately thought, whether or not we have myeloma, there's always a possibility of dying, so why should I worry about that? I had to go and write a to-do list!"*



George ended up in the ICU after his second stem cell transplant due to problems with low blood pressure

He thinks the diagnosis was harder on his family. *"It was very hard for my daughters. Initially, they were scared, and they couldn't accept it."*

After more tests and some checks to make sure he was fit for treatment, George began 16 weeks of chemotherapy. *"Then, during that period, they told me they're going to do a stem cell transplant."*

In August, he had six days of injections to boost the stem cells in his bone marrow and move them into his bloodstream, and then they were harvested. *"Fortunately, they were able to capture enough for two transfers."*

*"Then in October, they admitted me to the hospital and gave me high-dose chemotherapy to destroy all my bone marrow. The next day, they put the stem cells into my body. During that period, I didn't have any immunity, so I was given a separate room. They looked after me very well in the hospital – the doctors, nurses, everyone."*



George and his family at the ONZM investiture ceremony in May 2022, prior to his myeloma diagnosis

While he was in the hospital, George was introduced to Tim, a Support Services Coordinator from LBC. Tim kept in contact with George over the phone and would visit him in the hospital to offer support.

In the weeks after George's transplant, he struggled with terrible side effects including a high fever and diarrhoea. After 28 long days, he was able to return home. He took another four weeks off work while he regained his strength.

Then, in February, he was back in hospital for a second transplant – and went through the whole process all over again. *"This time it was bad, because my body was already weak. I was in ICU for four days because my blood pressure was down. Everything was different. My diarrhoea was much worse."*

Again, after 28 days, he was allowed to go home. *"I was so tired. I couldn't even walk 50 metres. For two weeks I stayed in bed, and then I slowly started walking about 50 metres with a hockey stick, and slowly, slowly, slowly improving. This time, I had to take eight weeks of rest."*

George is now on maintenance therapy. He was part of a clinical trial for a new treatment, but the trial was cancelled, so he now takes lenalidomide.

After working from home for most of the year, George recently started going to the office three days a week. *"That's been okay. It's not the same every day – sometimes I'm very tired."*

George and his wife have regularly attended LBC's support groups. *"When we go there, we meet people who have already had multiple myeloma, so we can talk and ask them things. We have become friendly with one or two people. One of the guys is also from Sri Lanka, and he's now 20 years on from his stem cell transplant – so I used to call him and get advice."*

George says he is now feeling well – both mentally and physically. Life is getting back to normal, although some days are better than others. *"But everyone says that's how it is – every day is different."*

Earlier this year, George was extremely proud of his daughter when she honoured her dad's journey by climbing the Sky Tower to raise money for LBC. *"She wanted to do it for me,"* he beams. George helped her fundraise through social media and was there to support her on the day. It's clear that even in the midst of his own struggles, this is what makes George tick – giving back and making a difference in his community.



Connect with patients like you  
@LBCmyeloma

Find a support group near you  
[www.blood-cancer.online/support](http://www.blood-cancer.online/support)





# 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



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

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](https://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](https://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

[@LBC Lymphoma](#)  
[@LBC Myeloma](#)  
[@LBC Chronic Leukaemia](#)  
[@LBC Acute Leukaemia](#)  
[@LBC Blood Disorders](#)  
[@LBC Haemochromatosis](#)  
[@LBC MPN](#)

### Support for young adults and parents

[@LBC Young Adults](#)  
[@LBC Parents Group](#)

### Further support pages

[@LBC Support Person Connect](#)  
[@LBC Bereavement](#)  
[@LBC NZ Connect](#)  
(LBC & Health Professionals Connect)