

Leukaemia Today

Supporting people *living* with leukaemia



Advocacy
Update
p.2

Getting through
tough times
p.3

I can
work with
this
p.6

Travel
insurance
Q&A
p.7

Whānau
Corner
p.8



Kia ora,

Welcome to Leukaemia Today.

Earlier this year, I started in the Chief Executive role at Leukaemia & Blood Cancer New Zealand (LBC) following Peter

Fergusson's retirement. It's been an exciting time to join LBC as we continue to extend our impact for blood cancer patients. Over the past 12 months, LBC has supported more patients and funded more research than any other year in our 47-year history.

Health charities play an incredibly important role in matching generosity with opportunities to improve patient outcomes. Throughout my career, I've been fortunate to see that impact realised across a wide range of health challenges, including mental health, cancer, rheumatic heart disease, and newborn and infant care. I'm delighted to now be working with the blood cancer community.

In addition to providing patient support and funding research, an important focus for LBC is ensuring that all New Zealanders with blood cancers have access to the best treatment and care available. We work towards this goal through collaborations with other cancer charities and ongoing conversations with Ministers, MPs, health officials and health-related bodies on issues that affect our patients. Our active advocacy programme includes several areas of focus, including access to medicines, clinical trials access, health system capacity & innovation, and the National Travel Assistance Scheme.

While we are encouraged by the opportunities for engagement and the progress made in recent months, our dedication to advocating for change remains unwavering. We'll continue to be a voice for change and ensure that the interests of blood cancer patients are top of mind for decision-makers.

Ngā mihi nui,

Tim Edmonds
LBC Chief Executive

Improving access to blood cancer medicines

In April, we mobilised a group of other blood cancer charities and leading haematologists to form the Blood Cancer Alliance. Together, the Blood Cancer Alliance is advocating for improved access to blood cancer medicines for patients in New Zealand. Our first undertaking has been a letter to Ministers seeking clarity on election commitments to bridge the existing gap in access to oncology medications. We joined other cancer NGOs at the Valuing Life Summit in Wellington at the end of April, where we met directly with Pharmac executives and Ministers to emphasise the role of modern medicines in blood cancer care, and the importance of providing timely, funded access.

A step in the right direction

We were pleased to see changes to the National Travel Assistance (NTA) Scheme following the Let's Drive Change campaign. The changes, which took effect at the beginning of April, include an increase in mileage rates and accommodation rates, and an easier process for making claims. This is a step in the right direction – however, we want to ensure that blood cancer patients' needs are adequately met, so LBC will continue to push for improvements and change alongside our NGO collective and our community.

Getting through tough times

Often, the best advice comes from people who have walked in your shoes and understand what it's like.

We asked people living with blood cancer to tell us their top tips for getting through the tougher moments, and here's what they said:

Share your journey with others – it can be a lonely time.

Break the day down into hours and get through one hour at a time.

Have a shower, get tidied up and go out for a coffee. It doesn't matter if you're alone or with company, just being out of the house and watching the world go by is good therapy.

I use meditation in lots of different forms.

Pop sticky notes in your makeup bag, on the mirror or on the jug, reminding yourself, "I'm okay. I'm still unwell but I'm doing okay."

Just concentrate on getting through the day; take a day at a time. Get on (as much as you are able) with living your very precious life.

Exercise – walk or run, as fast or as slow as you want.

Sometimes I am annoyed by the fact that I am immunocompromised but then I always think it could be worse! Kind of like, 'I thought I was poor when I had no shoes, but then I met a man with no feet.' I get through that annoyance by keeping myself active, eating well and generally taking care of myself.

Right at the beginning, ask to be introduced to someone with the same condition. It's such a relief to talk with others.

Buy a La-Z-Boy with electronic controls. I slept in one for three months until my bones started to heal.

My top tip for getting through tough times is creating a small space in the day, be it five or ten minutes, and sitting still, doing deep breaths, reminding myself of all the positive people and influences I have in my life.

Try to find a positive every day, no matter how silly it may seem to someone else.

In the really tough times, it helps to take time to just sit quietly and think of our life's joys and everything we have to be thankful for.

And remember, if you need extra support during your journey with blood cancer, LBC is always at the end of the phone – give us a call on 0800 15 10 15. Or to join one of our Facebook pages and connect with others going through the same thing, see the back page of this magazine for details.

A family's journey

"She's the most incredible little girl. She's a keen netballer – she got Junior Player of the Year last year! And she loves singing and music, and all things fashion. She's just your typical 9-year-old girly girl."

Hannah Whitehead is talking about her daughter, Frankie, from a room in Starship Hospital. It's the end of February, and little Frankie has been in Starship since November. She was admitted following her third relapse of acute lymphoblastic leukaemia (ALL) and has faced a string of serious complications after a recent bone marrow transplant.

Frankie was just three when she first became unwell. Hannah and her husband, Dylan, were a busy young couple juggling work and parenting their two little ones when Frankie's diagnosis came out of the blue.

"Frankie was sent home from daycare... She had a fever and was feeling lethargic, so we just thought she'd picked up a virus. That continued through the weekend, those high fevers, and she was just so, so tired. So that prompted us to take her to after-hours on the Sunday."

At the after-hours clinic, a doctor noticed some slight jaundice in Frankie's eyes. She was referred to the ED, where they ran some bloods, and could tell immediately that Frankie had leukaemia.

"Frankie was diagnosed with standard-risk ALL. She went through two years of standard treatment, which involved chemotherapy – intrathecal, oral, and IV. It was 800 days in total. It was a long process and it was really hard. But had we known what was coming afterwards, it would have felt easy by comparison."

After treatment, Frankie returned to kindy and eventually started school. Life was getting back to normal, and more than a year after the end of Frankie's treatment, Hannah and Dylan took a rare child-free trip down to Queenstown for Hannah's birthday. While they were away, Frankie seemed unusually tired, and was taken to the GP by Hannah's parents for an infection on her hand.



"Dylan and I got home that day. We only had to take one look at Frankie, and we knew exactly what was happening." A blood test at the hospital was all it took for Frankie to receive a relapse diagnosis.

From that point, we learned that her leukaemia was no longer completely responsive to chemotherapy alone.

Frankie underwent four months of immunotherapy to get her to the point where she was well enough to receive her first bone marrow transplant, followed by a week of conditioning chemotherapy. The donor cells came from her little brother, Leo.

"That all went really well. She was in remission and the transplant was deemed a success. And then life was back to normal. She was back at school, and we had 12 months before she unfortunately relapsed for a second time."



Team Frankie' at LBC's Step Up Challenge.

"But at this point, she's in remission, and outside of the GvHD, she's doing so well. We're just ready to get home."

Along their journey, Frankie and her family have had ongoing involvement with LBC. ***"We were introduced to LBC when Frankie was first diagnosed, when Tim came around on the ward,"*** Hannah

says. ***"He's popped in a few times since we've been here this time. And he very kindly organised a birthday cake for Frankie."***

"He connected her with the online children's group as well, and he did Monkey in My Chair for her school. She named her monkey Bananas. And then she's got Bananas Junior, which is the smaller one that hangs out with her. Her friends at school have loved that."

Hannah's focus now is on getting Frankie well enough to be discharged from hospital, so the family can return home to Northland and Frankie can be reunited with her schoolfriends. Although there's a lot to look forward to, Hannah knows it will be an adjustment.

"I think there's kind of the assumption when you have an experience like this, that treatment finishes and you just pick back up with normal life. But there's a lot to process and heal from."

With Frankie's second relapse diagnosis, Hannah and Dylan were presented with two options: Frankie could have a second bone marrow transplant, or she could try CAR T-cell therapy in Australia. It hadn't been long since Frankie's first transplant, and the team at Starship encouraged them to pursue the option of CAR T-cell therapy. They were fortunate to have government funding approved for the treatment.

Within two weeks of Frankie's second relapse diagnosis, the family were on a plane to Australia. She went through treatment in Brisbane, and 30 days after she received the CAR T-cells, her tests came back clear – she was in complete remission.

Following this, her bone marrow was tested every month. After six months of clear tests, they were spaced out to every three months. It was on the first of these three-monthly tests that Hannah and Dylan's worst fear was realised – Frankie's leukaemia had returned for a third time.

"Then we were at the point we're at now, which was staring down our final treatment option – the second transplant."

This time, Frankie's bone marrow donor was her dad, Dylan. She was admitted to Starship in November to have the transplant and has been in hospital since then. ***"She's had every complication under the sun with this transplant... The biggest thing we're dealing with now is Grade 4 Graft versus Host Disease (GvHD). That has been so challenging."***

Fast Facts: Acute lymphoblastic leukaemia (ALL)

- Approximately 75 New Zealanders are diagnosed with ALL each year.
- Majority of cases are under 5 years of age but can be in adults too.
- ALL is an acute leukaemia affecting immature white blood cells. It usually requires immediate treatment.
- For more information on CAR T-cell therapy, visit lbcnz.link/CTC

I can work with this



In 2020, Tokoroa-based primary school teacher Vonda was adjusting to a whole new way of life amidst the COVID-19 pandemic.

After months of delivering lessons online, school finally opened again, and the teachers were encouraged to focus on the children's wellbeing. The school recommended they use Te Whare Tapa Whā, a Māori model of health Vonda had first learned about in the 1980s. The model considers four pillars of wellbeing: Taha tinana (physical), Taha wairua (spiritual), Taha hinengaro (mental and emotional), and Taha whānau (family and social).

Every day, Vonda checked in with the children to see what they'd been doing to support each of these areas. But at the same time, Vonda's own wellbeing was slipping.

She'd had a spider bite on her hand that wouldn't heal, so she made an appointment to see her GP. "I went to the doctor the next day. For some reason, I lost my breath walking up from the car park. I slumped over the counter." After initially being told to go home and take some Panadol, Vonda was asked to come back in to have some blood tests. "Three hours later, they called and told me it was terminal. They said, 'You need to get to the hospital – now.'"

At the hospital, the healthcare team explained to her that she had acute myeloid leukaemia (AML) and needed to start treatment immediately. "I said, 'Nah, I need to go home. I've got a son, a job... I've got rent to pay.'"

They said, 'If you go home, Vonda, you'll be dead in 72 hours.'

After a week of chemotherapy, Vonda was struggling. "I started to feel my strength fading away... I had a bit of a breakdown."

Vonda was given a mental health assessment form to fill out, and she noticed that it was split into the four headings of Te Whare Tapa Whā. "When I saw that, I was like, 'Oh my

gosh, this is what I've been talking to the kids about. I can work with this!"

Vonda realised she could use this model to communicate with her doctors. She asked to have two big pieces of paper brought to her, and immediately got to work.

"I wrote down all the things that were really bothering me and I put them into those categories. I labelled it 'Vonda's Treatment Plan' and put it on the wall. The next morning, the doctor came in and he looked at the poster and said, 'Vonda, how are you feeling spiritually today?'"

"It moved mountains for me, that model did. I utilised that model to negotiate my wellbeing."

Another great help to Vonda was the support she received from LBC throughout her journey. She received one-to-one support from LBC Support Services Coordinator Sharon and was provided with petrol and grocery vouchers along the way to help ease some of the financial burden of her diagnosis.

After three rounds of chemotherapy and a stem cell transplant, Vonda is now in remission. She's about to head to the World Indigenous Cancer Conference in Australia to present on the use of Te Whare Tapa Whā in hospital settings. And she's set up her own business as a holistic wellbeing facilitator.

"My dream is that there is a Te Whare Tapa Whā poster in every room in every hospital. That poster saved my life."

Fast Facts: Acute myeloid leukaemia (AML)

- There are approximately 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.

Travel insurance Q&A



The world of insurance can be tricky to navigate at the best of times – and having a blood cancer diagnosis can sometimes add to the confusion! One type of insurance we get a lot of questions about is travel insurance. We asked Sandra Grant, a travel insurance broker, to explain how it all works.

Can I get travel insurance if I have a blood cancer diagnosis?

Travel insurance is generally available to all travellers, unless deemed medically unfit to travel, or travelling against medical advice.

For conditions where a terminal diagnosis hasn't been declared, insurers will consider the following:

- whether treatment is recent or ongoing;
- whether the condition has caused or is linked to other medical events/ complications;
- any other underlying medical conditions.

Most travel insurers now use algorithms to calculate risk, and will either approve cover if the 'score' falls within their pre-determined risk parameters, or decline to cover the condition/s if the assessment score falls outside the parameters. Regrettably, most insurers do now use this as their 'last word' and don't offer an option for a full review by a medical professional. We can still request this but we do find that most reviews don't change the original algorithm outcome. It's always worth a try though!

What if my diagnosis is terminal?

Travellers who have received a terminal diagnosis may still be eligible for cover, but there would be no cover for any event linked directly or indirectly to the terminal condition. This is something that travellers need to consider carefully when deciding if they're prepared to travel with no cover in place.

What are the benefits of using an insurance broker for travel insurance?

Insurance brokers work closely with our insurers to be able to offer a level of comfort wherever possible. While we cannot guarantee cover, we have established strong relationships with some very empathetic insurers and can give assurances that while financial costs may not be covered, there will be options for non-financial support should things go wrong while travelling. And, of course, our team are here to advocate for and support the insured as our client and act as an independent voice when dealing with insurers.

If you have questions about travel insurance, you can visit lbcnz.link/insurance to find out more about what Sandra offers and how to contact her.

Blood Cancer Patient Forum

Save the Date

Welcome Event
5.00pm to 7.00pm
Friday 27 September

Forum
8.30am to 4.30pm
Saturday 28 September



Hyundai Marine Sports Centre
8/10 Tamaki Drive,
Orakei, Auckland

Whānau Corner

Introducing our new booklet for young people

LBC has recently published an updated information booklet for adolescents and young adults (AYA) facing blood cancer.

This booklet has been written specifically to help AYA navigate their blood cancer diagnosis, treatment, recovery, and everything that goes along with it.

To read the booklet, scan this QR code, or ask your LBC Support Services Coordinator for a print version.



Factsheet: Supporting a child through a loved one's cancer diagnosis

A blood cancer diagnosis can affect the entire family in different ways. Helping children to understand cancer and how it might impact them can help them to cope with the changes and challenges.

Of course, it can be difficult to talk to children about a sensitive topic like this.

We have a factsheet that contains a few tips to help support you with these conversations. Scan the QR code to read this resource on our website.



Kids' picture books

Did you know that LBC produces a number of picture books for children?

We have four books that have been written especially for kids who have been diagnosed with a blood cancer, or who've had a family member diagnosed. The books, available in both English and te reo Māori, have been designed to help explain the diseases, their treatments and survivorship information to young children and their families.

Scan the QR code to download an e-version of the books, or contact a Support Services Coordinator to order a hard copy.



Check out Kids' Zone for more resources, support and programmes that LBC offers for children and their families affected by blood cancer. You can find all of this at lbcnz.link/kids_zone

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 finding work at an employment workshop.

You can also follow @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
@LBCMyloma
@LBCChronicLeukaemia
@LBCAcuteLeukaemia
@LBCBloodDisorders
@LBCHaemochromatosis
@LBCMPN

Support for young adults and parents

@LBCYoungAdults
@LBCParentsGroup

Further support pages

@LBCSupportPersonConnect
@LBCBereavement
@LBCNZConnect
(LBC & Health Professionals Connect)