



leukaemia &  
blood cancer  
NEW ZEALAND

Vision to Cure. Mission to Care.

# MyelomaToday

Supporting people *living* with myeloma



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**Kia ora,**

Welcome to Myeloma 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 17-year journey

**Sue has been a nurse for as long as she can remember. She has two grown-up children and one grandchild, who all live in Christchurch. Sue moved from Christchurch to Auckland following the earthquakes and eventually settled in Whanganui, where she now lives with her wife, Jo.**

Sue has had a successful career, rising through the ranks in the healthcare sector. She's managed three retirement villages, worked as a regional manager for a home care company, and now works in a senior nursing leadership role. For all intents and purposes, she is active, fit and well – except that Sue has also been living with myeloma for the past 17 years.

*"It was an absolutely accidental finding,"* she says. It was 2007, and Sue had been to the doctor because she was feeling tired. She thought she might be iron-deficient, but to make sure nothing else was going on, her GP decided to run some other tests as well.

*"I had a whole myriad of tests done. With one of them, the lab came back and said, 'Actually, we think with this reading, you should probably have this new test for serum free light chains.' And just like that, they found it."*

Even with her nursing experience, Sue found it difficult to come to terms with a myeloma diagnosis. *"I think there's this thing when you're told you've got cancer – and especially 17 years ago – where you do sort of immediately start sizing yourself up for a box."*

One thing she found particularly difficult was telling her friends and family the news. *"It was devastating for them,"* she says. *"I just felt for them, because I couldn't make them feel any better about it."*

It was February when Sue was first diagnosed, and she was initially told that because her myeloma had been caught early, she might not even need to start treatment that year.



Sue as a bridesmaid at her friend's wedding, 4 months post-transplant

*"But by the middle of the year, I was on oral chemo and dexamethasone. That didn't work, so in September I was having my first transplant at the Bone Marrow Transplant Unit in Christchurch."*

After three weeks of strict isolation and a period of recovery, Sue was able to return to work and get on with life as usual. *"I got a five-year remission out of my first transplant, and then we had to start treating again. That was sort of year-on, year-off treatment, until my second transplant in 2018."*

Sue had three years in remission following her second transplant, and then had to look at what options were available to her. *"We tried chemo again, but my body doesn't seem to respond very well to boring old chemo! So they suggested a third transplant, which I've since learned is quite unusual."*

In the midst of preparing for her third transplant last year, Sue and her partner finally got married. *"We eloped to Coromandel and then came back to Whanganui. We had a family and friends party here – that was on the Saturday night – and on the Monday I started the transplant process. It was the big high before the impending low, but it was lovely to have that time."*



Sue with her wife on their wedding day

And she's not taking the time they've had for granted. *"We snuck off to the Coromandel again to celebrate our first anniversary. It was lovely and much more relaxed, as last time we weren't sure*

*there would even be an anniversary."*

Throughout Sue's 17-year myeloma journey, she's been incredibly well supported by her loved ones. *"I've got amazing friends and family – they've all been there when I've needed them... And sometimes just being there is the best thing they can do."*

Sue is also grateful for the support she's received from LBC. She attends her local support group and has had one-to-one support from Sally, an LBC Support Services Coordinator. *"Sally has been amazing. Particularly for my wife – just being around for Jo whenever she needed support."*

Sue has prepared herself for the likelihood of another relapse. *"This is the cancer that keeps on giving,"* she says. *"So it will come back. But at the moment it's behaving itself, and that's good."*

*"Certainly a fourth transplant is not going to be an option, I don't think. So we'll just have to keep an eye on what else is out there. But I'm absolutely positive there'll be something."*

## Fast Facts: Multiple Myeloma

- Myeloma is a form of plasma cell disorder, when plasma cells become abnormal and multiply
- The acronym CRAB is often used by doctors to describe the effect myeloma can have on different areas of the body:
  - ▶ Calcium elevation (hypercalcaemia)
  - ▶ Renal impairment and changes to kidney function
  - ▶ Anaemia, or bone marrow failure
  - ▶ Bone disease

## Let's get cracking

**It was a good deed that led to a shocking discovery. In 2021, mum-of-four Kelly decided to begin donating plasma. She was in her first year of midwifery studies and had been making the trip up to Hamilton from her home in Pātūtahi for block weeks of teaching. "I thought it was the perfect opportunity to donate whilst I was up there."**

Shortly after the donation, Kelly was contacted by the New Zealand Blood Service and told that something looked unusual in the tests they had done. *"They wanted to re-test. So I popped back in, did another test, and they said I should visit my GP when I got home."*

Kelly's GP referred her to a haematologist, who gave her the life-changing news she had myeloma. *"It was just surreal... I'd had absolutely no symptoms. So it was a shock. I'd never even heard of myeloma."*



Continue on the next page...



Kelly's myeloma was initially classified as smouldering. This meant that, for a while, she was able to carry on with normal life and keep an eye on it with regular blood tests. *"Then we got to June of 2022 and my haematologist wasn't happy with my blood results, and said we were going to start induction therapy. He spoke about harvesting my stem cells to do a tandem stem cell transplant."*

Her haematologist suggested that Kelly should have lenalidomide as her induction treatment. Unfortunately, lenalidomide wasn't government-funded for this use, and it was going to cost Kelly \$1000 a month to fund it herself. *"They wanted me to do five months of induction. I was studying and we only had my husband's income. But we wanted to go down the best route, and we decided to do the lenalidomide with the savings we had."*



*"But then our whānau and friends got together and had a massive garage sale. My Hawkes Bay midwifery sisters organised a Hangi to raise money too. With the amount of koha that came in, we ended up with enough to fund the five months. Although, in the end, the myeloma was so aggressive that my haematologist decided to cut the last one and only do four induction treatments before my transplant."*

In addition to the amazing support from her family and friends, Kelly knew she had LBC as backup. LBC Support Services Coordinator Sean was able to relieve some financial pressure by providing petrol vouchers to help the family with travel.

Kelly had her first transplant in January, 2023, followed quickly by a second transplant in March. It's clear from the way she talks about it

that this process was incredibly challenging. *"It was just mentally and physically draining."*

Kelly had put her midwifery studies on hold for a year, but by July she was ready to return. *"In the second week back, I brought a beautiful baby boy earthside. And then the next day I got a call for an appointment with my haematologist."*

Not thinking the appointment was about anything serious, Kelly went into it by herself.

*"I didn't know what she wanted to talk about. And then she gave me eight weeks to live."*

Kelly doesn't know how she made it through the rest of the appointment. All she could think about was how she'd tell her whānau that their world was going to come crashing down.

*"But then my haematologist said, 'There's a clinical trial, and I think you're the perfect candidate. But it takes six weeks to go through the screening process.' And I just said, 'Well, we'd better get cracking, because I've only got eight weeks!'"*

In September last year Kelly finally got the go-ahead to take part in the MAGNETISMM-5 clinical trial. *"Treatment was every week. I'd get a sub-cut injection in Waikato, so it was a matter of having to fly up there every week from Gisborne. That was so hard at the beginning."*

*"We're now six months into the trial and I had a bone marrow biopsy done last week. I got the preliminary results back on Thursday, and there are no myeloma cells present."*

Kelly's not taking this for granted and she can't wait to get on with living her life.

*"I've actually got an interview next Monday with the Head of Midwifery to start my studies again. So I'm gonna give it one more crack. Third time lucky!"*

#### Fast Facts: Tandem stem cell transplant (SCT)

- Tandem SCT is when 2 autologous transplants are done in a row
- The goal is to deepen the treatment response and prolong disease-free survival

# 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](https://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](https://lbcnz.link/kids_zone)

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 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)