

LymphomaToday

Supporting people *living* with lymphoma



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Kia ora,

Welcome to Lymphoma 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.

Living for today

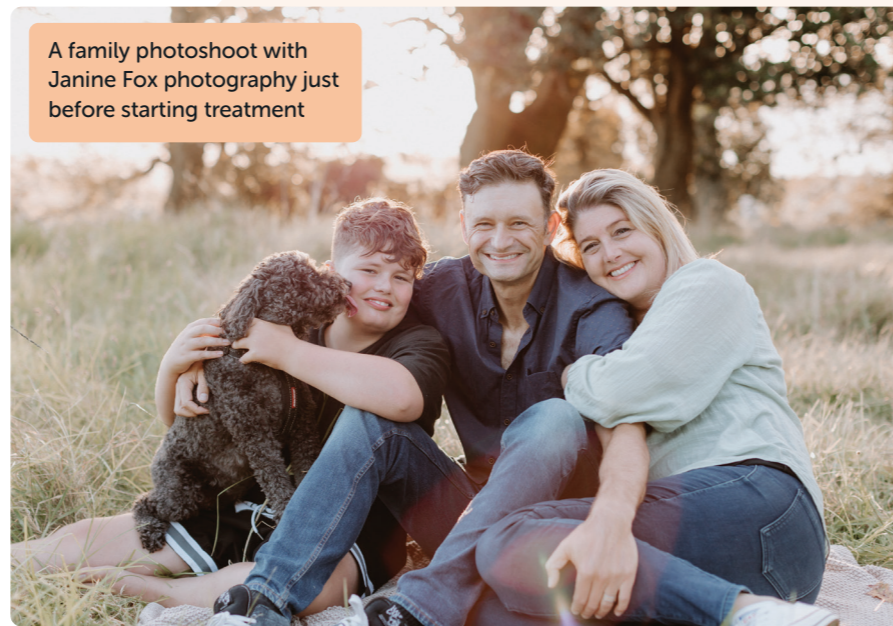
“Before I even got diagnosed, 2023 was always going to be my year of gratitude.” Helen is sitting on the couch in her Auckland home where she lives with her husband and son, reflecting on the past couple of years. “Life was awesome. I’d just scored a job in population health at the University of Auckland, and we’d done some travelling as a family to Australia and the South Island.”

It was at her new job that Helen first noticed something wasn’t quite right. “I was typing at work and my left hand started not working properly,” she says. “I realised I was just typing with one hand and texting with one hand, and I thought, this could be a stroke or something... I went to A&E and they said, ‘Look, we think it’s just a pinched nerve.’ But I knew in my gut that something wasn’t right.”

Helen called her GP and managed to get an appointment the next day. Her doctor was concerned enough to send her to the hospital, where she was rushed through to be assessed. After both a CT scan and an MRI scan, she was taken to a ward to wait for the results.

88 **Eventually, a doctor came in and said, ‘You haven’t been told, have you?’ and I said, ‘What?’ She said, ‘You’ve got a brain tumour.’ My husband burst into tears. I just lost it.** 99

Helen was booked in for brain surgery the very next week. It was explained to her that there were two possibilities for the type of cancer she had, but that this would only be confirmed after surgery and further testing: “It could either be a glioblastoma cancer which would need to be removed, and it would be terminal because of the size of it. Or it could be lymphoma, which would be the better of the two because there were options to potentially cure it.”



A family photoshoot with Janine Fox photography just before starting treatment



Helen in hospital during her stem cell transplant



Helen and her husband with their friends



First day of chemo

When Helen woke up from her operation, she was told that the surgeon had decided not to remove the tumour because it was quite deep down in an important part of her brain. But they’d taken some samples and sent them off for testing. “He said to me, ‘I think this is lymphoma. I can’t tell you for sure. We’re going to have to wait three and a half weeks.’”

After an incredibly anxious few weeks, the results came back and Helen received an official diagnosis – she had non-Hodgkin large B-cell central nervous system (CNS) lymphoma.

“We found out that they wanted to treat to cure, and I can’t tell you how happy we were. The second part was, ‘However, it will be a gruelling year.’ And I was like, ‘Whatever. Hey, there’s a chance I can live and see my son grow up.’”

Helen was started on MATRix chemotherapy at Middlemore Hospital. “I did one week in hospital, two weeks at home, and that rotated five times without stopping.”

Helen stayed at her mum’s place between rounds of chemo so she could be looked after while her husband worked and took care of their son. She had a stem cell retrieval after the first round, and when her chemotherapy was finally finished, Helen had a month’s break from treatment before her stem cell transplant. Then it was off to Auckland Hospital.

Helen found the stem cell transplant extremely gruelling. “Your bloods go down, down, down. Your emotions go down, down, down. A lot of the time I just thought, ‘Who am I? What have I become? I had an awesome job, a faith I felt connected to, and now I just feel like I have nothing.’ It was really hard.”

Despite the immense challenges she faced, Helen can’t speak highly enough of the support she’s received throughout her journey – from her mum, her family and friends, her healthcare team, and LBC. She says that everyone who helped her along the way is part of her whānau. “Without those people

around you, you can feel like you’re going to lose the battle. But I had these people telling me I could do it. I gained strength from people who cared, and it was so far-reaching.”

Natasha from LBC’s Support Services team gave Helen’s mum petrol vouchers to help cover the costs of driving her to appointments, and provided food vouchers for Helen and her family. “Money was so tight – it was really helpful.” Helen also felt relieved to have LBC at the other end of the phone whenever she or her mum needed help. “Just talking to LBC on the phone was really supportive – they were another part of the whānau.”

Helen is thrilled to now be in remission. “I’ve had four MRIs, and they’ve all been clear... Every single time that happens, I celebrate. It’s not just the physical healing, but the regaining of hope and faith, too.”

At this stage, Helen is taking time away from work to fully recover. But her experience of going through blood cancer has influenced her plans for the future. “I want to do something that’s really going to benefit people with disability.”

Although she’s looking forward to finishing her Public Health studies and getting back into work, she’s not in a rush. “I’m taking the time I need to heal, to understand the ‘why’, and to explore what might be. But also to just live and be grateful for today.”

Fast Facts: CNS lymphoma

- CNS lymphoma affects the central nervous system (the brain, spinal cord and eyes).
- It is an extremely rare and aggressive type of non-Hodgkin lymphoma.
- It is slightly more common in men and in those over the age of 50 years.



Taking back control

In 2022, Steve was working as a prison guard when he began noticing symptoms. He was losing weight, and he didn't know why. Then the pain started.

"I had severe pains in my legs, between my knee and hip... I called an ambulance and got to the hospital. They gave me fentanyl or morphine or something, then sent me home."

"The third time it happened, I said to the doctor, 'I can tolerate pain. But I can't tolerate this.'"

Two days later, I was diagnosed with cancer. It was the 25th of July, 2022.

The day Steve was diagnosed with Stage 4 Burkitt lymphoma is etched in his memory. *"The first thing I asked was, 'Is it treatable?' and they said that Burkitt lymphoma is aggressive, but it is treatable. I cried, because my wife had passed away from myeloma, and it brought back all those memories."*

This was the beginning of Steve's six-month hospital stay, where he received four days of chemotherapy each month, alongside other treatments.

"I don't remember the first month well, because I was hallucinating with all the drugs. At one stage, I had a caregiver sitting on my bed 24/7 just to stop me doing anything stupid. I didn't know what country I was in."

Steve also struggled with severe weight loss. *"I used to be 86 kilos, and at the peak of the cancer, I got down to 52 kilos. I was too scared to take my shirt off because I could count every rib."*

As he neared the end of his first month in hospital, Steve decided he needed to take some control back. *"I kept in the back of my head, 'The hospital's doing the medical stuff – I've got to do the physical.'"*

"Because I was in bed the whole time, I was wasting away. So I staggered out of bed and made my way to the patient lounge. There was an exercycle down there. I used to do it once or twice a day, just slowly, for five minutes."

Steve found it difficult to accept support while he was in hospital. But one person he did allow to help him was Nicki, a Support Services Coordinator from LBC. *"She used to come through the hospital every week or two, and she'd come and have a chat. That was probably more beneficial than the drugs, just having a chat to someone who talks to you with empathy."*

Steve was also grateful for the financial support he received from LBC while he was in hospital. *"LBC made sure I didn't have to pay for my hired TV, which was marvellous."*

Steve now lives on his house bus, and after more than 50 years of employment, his diagnosis has forced him to give up work for good. *"It's an awesome job, retirement, but the pay sucks!"*

Despite some remaining side effects of treatment, Steve is enjoying life and making the most of the time he gets to spend with his family. *"Every morning, I wake up and say to myself, 'You're alive.' I've got a picture of my wife in the bus, and I look at her and say, 'I'm alive.'"*

Fast Facts: Burkitt lymphoma

- Burkitt lymphoma is a rare type of non-Hodgkin lymphoma affecting around 15 New Zealanders each year.
- It is an extremely aggressive form of lymphoma requiring immediate treatment.
- It can affect people of any age, but it typically develops in children and young adults.

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)