leukaemia & blood cancer
NEW ZEALAND
Vision to Cure. Mission to Care.

WINTER 2025

LymphomaToday

Supporting people *living* with lymphoma

Kia ora,

Welcome to your Winter 2025 edition of Lymphoma Today.

Over the past 12 months, LBC's Support Services team has stood alongside nearly 1,700 people newly diagnosed with blood cancer, and their whānau, through one of the most challenging times in their lives. Every day, I see the care, commitment and professionalism our team brings to meeting the unique needs of patients across the country.

For some people, support means understanding their condition and knowing what to expect. For others, it means practical help, connection with others, emergency financial support or access to counselling during a difficult time. Our team takes the time to listen and then responds based on what matters most to each person. It's a personalised approach we take a lot of pride in.

As we continue to build our support capacity, LBC's goal is to connect with more patients across the country. If you or someone close to you is affected by blood cancer, please consider reaching out to our Support Services team – we're here to help.

While supporting the best possible outcomes for blood cancer patients diagnosed today, we're also ramping up our efforts to transform future outcomes. For some cancers, that means advocating for access to potentially life-saving treatments available overseas. For others, it's funding research that brings us closer to better therapies and, ultimately, cures. And in many cases, it's both at the same time.

Inside this edition, you'll find updates on our progress and stories from across the lymphoma community. Whether you're newly diagnosed, in treatment, or supporting someone who is, we hope these pages offer encouragement and reassurance.

Ngā mihi,

Tim Edmonds
LBC Chief Executive

Progress on bringing CAR T-cell therapy to New Zealand

At LBC, we're focused on making sure Kiwis can access the best global standard of treatment. One example is CAR T-cell therapy, a highly specialised treatment that has helped thousands of blood cancer patients around the globe, often leading to long-term remission or even a cure.

At the moment, Kiwis are travelling overseas to access this therapy. This can place a huge financial and emotional strain on them and their families. The exciting news is that a partnership between the Malaghan Institute and BioOra means this therapy is now being made here in Aotearoa at a much lower cost. It is currently being tested in a clinical trial called ENABLE-2, which is open to people with a certain type of lymphoma.

LBC is proud to support patients participating in this trial by assisting with travel and accommodation costs. As trial results emerge, we look forward to working alongside innovators and the health system to ensure that CAR T-cell therapy can be delivered here in New Zealand to the people who need it most.

State of the Nation

LBC is currently working on a State of the Nation report to capture a complete picture of the state of blood cancer care in New Zealand. The report aims to identify critical gaps, highlight areas for improvement, and detail a roadmap towards a future ambition of 'zero lives needlessly lost to blood cancer'. Central to achieving this is having a deep understanding of the real-life experiences and perspectives of patients. This is why we partnered with experts at Deloitte to develop a research approach that would capture detailed patient insights.

This comprehensive research includes surveys, focus groups, and in-depth one-on-one interviews. We received an incredible 785 responses to our patient survey, gained valuable insights through a focus group with parents of children diagnosed with blood cancer, and conducted detailed interviews with five individuals who bravely shared their personal experiences.

Many findings reinforced themes we were aware of but had not yet systematically documented or measured. Importantly, this research also revealed new insights into groups that are currently underserved and not meeting government targets for receiving timely, high-quality healthcare.

These findings clearly demonstrate the realities of blood cancer care and provide strong evidence to inform necessary policy changes. This ensures we can accurately and effectively represent patient voices when engaging with policymakers.

Thank you to everyone who has participated so far – we look forward to sharing the final report with you later in the year. For those interested in supporting future advocacy, there will be more opportunities to join us as we continue working towards meaningful, positive change for all those affected by blood cancer.

HSANZ Conference highlights

We were proud to have two presenters from LBC at this year's Haematology Society of Australia and New Zealand (HSANZ) conference, where clinicians, researchers, and advocates gathered to share progress in blood cancer care.

Tim Edmonds introduced LBC's role in advocacy and support, outlining how we work to shape the future of blood cancer care through strong partnerships and patient-focused initiatives. Rosie Shaw's presentation was on New Zealand's medicine decision-making processes. She used CAR T-cell therapy as a case study to highlight the urgent need for modernisation in access and funding pathways. Both presentations were well received, with strong engagement from attendees who appreciated the patient-centred perspective and practical insights into the challenges facing Kiwis with blood cancer.

Members of LBC's Support Services team also attended the conference to showcase our patient resources, gather insights from haematology professionals to enhance our service delivery, and strengthen connections within the sector. The conference provided a valuable platform to ensure patient voices continue to inform research, policy, and clinical planning decisions.

LBC's stand at the HSANZ Conference

“She’ll be right”

It’s a stormy afternoon in Auckland, and Kelvin and his wife, Amie, are sitting on their couch. Their newborn baby is sleeping on Amie’s chest, and the couple are reflecting on the journey they’ve been on over the past five years.

It all began in early 2020, when their first child, Max, had just turned one. *“I’d been back at work from maternity leave for all of two weeks when COVID hit,”* Amie says. *“And then Kelvin was made redundant. So it was quite a stressful time!”*

Fortunately, mechanical engineer Kelvin was able to find another role without too much trouble, and before long, he’d started a new job at the same place that Amie worked.

Shortly after starting, Kelvin went to the GP complaining of increasingly bad headaches.

“I think with COVID as well as all the changes, we kind of wrote the headaches off as him being under a lot of stress,” Amie says.

Kelvin’s GP prescribed him a series of different painkillers to try and get the headaches under control, but nothing seemed to work. About three months after starting his new job, Kelvin decided to go and get his eyes tested to see if his vision might be the culprit.

“We went down to Specsavers,” Kelvin recalls. *“The guy there said, ‘Oh, there’s something wrong with your eyeballs, they’re really swollen.’”*

Kelvin was urged to go straight to the Greenlane eye clinic, and once there, he was told he needed to go to Middlemore Hospital. *“By this point, it was quite late, so we asked if we could nip home and grab a bag,”* Amie says. *“And they were like, ‘No, no. Straight there. Straight to ED.’”*


Kelvin with his son Max during treatment

Because of COVID restrictions, Amie had to drop him off outside the hospital and go home. *“That was really tough,”* she says. *“I wanted to be there to ask questions and understand properly, but I just had to come home and wait to hear what was going on. It was a very surreal feeling to not be able to support him.”*

At the hospital, Kelvin didn’t have to wait long to find out what the problem was.

“The doctors woke me up at 3 am to tell me I had a mass in my brain. I was mostly just annoyed they couldn’t have waited until 6 am to tell me the bad news!” Kelvin jokes.

In the morning, he was taken to Auckland Hospital in an ambulance. An MRI scan confirmed the exact location of the mass, and he had surgery to remove it.

“Even once they did the surgery, there was a two-week period where we didn’t know what the mass was,” Amie says.

During this wait, she found it hard not to turn to Google for information. She went into a panic reading about glioblastoma, an aggressive type of brain cancer with a poor prognosis. *“When we got the news that it was central nervous system lymphoma, I think we finally took a breath. Finding out it wasn’t glioblastoma was massive.”*

While Amie still worried about the diagnosis and what it would mean for the future, Kelvin reassured himself that everything would be fine. *“I’ve always worked with the saying, ‘She’ll be right!’”* he laughs.

Kelvin stayed positive right throughout his treatment


Kelvin and Amie were thrilled to recently welcome Dominic into their family

Although Kelvin took a relaxed approach to his diagnosis, his treatment was serious. *“Every three weeks, Kelvin would spend a week or so in hospital for chemo, and then have a week or two at home.”*

“That was really hard with a young kid at home,” says Amie. *“Max didn’t understand why Daddy was gone for a week every couple of weeks.”*

Fortunately, during Kelvin’s second round of chemotherapy, he met Natasha from LBC at the hospital. *“She’s been around from the get-go, and she’s been amazing,”* says Amie. *“She organised a play therapist so we could get some ideas on how to help Max process what was going on.”*

After he finished chemo, Kelvin spent a month back in the hospital for his stem cell transplant. When his small intestine became inflamed after the transplant, he wasn’t allowed to eat anything for two whole weeks.

“He was such a grump through those two weeks!” Amie laughs.

After some recovery time at home, Kelvin made a gradual return to work, and since then, life has been mostly smooth sailing. He’s had several clear MRI scans and now just has one each year to keep an eye on things.

Amie says, *“Every year when I know his annual MRI is due, in those few weeks leading up to it, I always have those recurring thoughts of, ‘What happens if it’s back? What do we do this time?’”*

“Kelvin doesn’t care though, he just sees the MRI as a chance to have a nap!”

Although the future is uncertain, Kelvin and Amie are getting on with life. Back in 2020, just before Kelvin started treatment, he was able to get a last-minute fertility appointment to freeze some sperm. In March this year, the couple were thrilled to welcome their second son, Dominic, after three rounds of IVF.

It’s clear that Kelvin and Amie have been a huge source of support for each other during the past few years. Throughout all the anxiety, they’ve kept their sense of humour and managed to laugh together through the hard days.

“You’ve got to laugh at the small things,” says Kelvin. *“Throughout everything, I was laughing all the time. I spent more time laughing than I did crying.”*


Kelvin and Amie are now the proud parents of two little boys

Fast Facts: **Central nervous system lymphoma**

- CNS lymphoma is a rare lymphoma that develops in the central nervous system, affecting the brain, spinal cord, or eyes.
- It is a fast-growing cancer that causes symptoms like confusion, seizures, headaches, and vision problems due to brain involvement.
- It requires high-dose specialised chemotherapy that can cross the blood-brain barrier.

Looking ahead

Online Patient Forum

We're pleased to announce this year's Online Patient Forum, "Healthcare Compass – Haematology Updates in 2025".

Join us online this September for four informative sessions designed to empower patients throughout their healthcare journey. These webinars will explore patient rights, treatment landscapes, navigation of care transitions, and future directions in haematology care in New Zealand. Sessions will be held weekly throughout the month, providing valuable insights and practical guidance for patients and their families.

Registration details and final topics will be announced soon – we look forward to seeing you there!

Shine for a Cure

Do you want to shine a light on blood cancer? On Saturday, 20 September, you can join Kiwis in Auckland, Christchurch, and across the country as we light our lanterns and walk together to raise money for blood cancer research.

It's completely free to register and come along. There's no pressure to fundraise, but if you'd like to, you'll receive a free lantern when you raise $100 or more. The three lantern colours represent why you're taking part – teal symbolises a personal journey with blood cancer, gold is to remember those who are no longer with us, and white shows support for all those affected by blood cancer.

If you can't join us at Auckland Domain or Hagley Park this year, you're also welcome to hold your own lantern event wherever you are in the country and join the live stream online.

Keep your eyes peeled for more information on how to register!

Battle Bus Bonanza

We know that one of the hardest parts of a child's blood cancer journey is the feeling of isolation. That's why we created Battle Bus Bonanza, a special initiative designed to bring young patients together through the power of video game tournaments!

This isn't just about playing games – it's about building connections. Battle Bus Bonanza brings together kids, their families, healthcare teams, and fellow patients in a supportive, fun, and interactive environment. It's a chance for kids to take time out from their treatment to connect with others who truly understand, and have a blast while doing it!

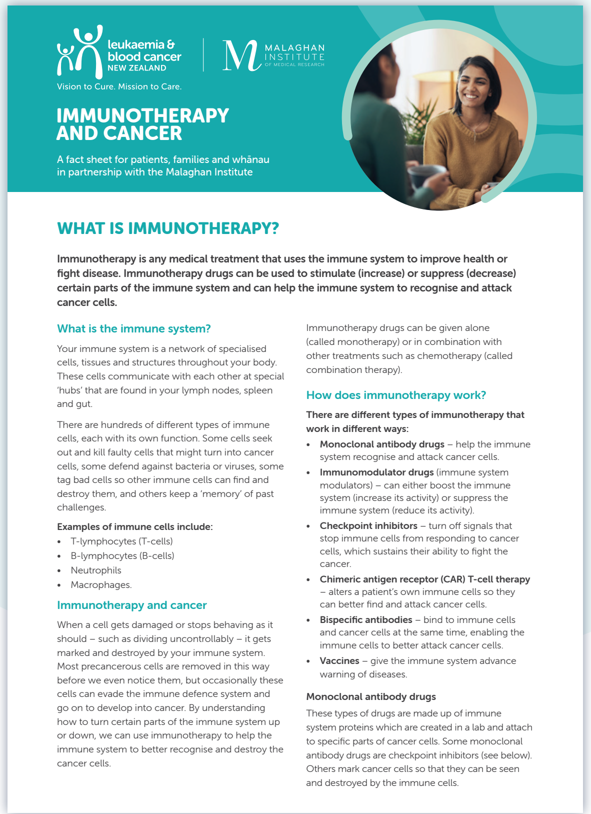
We have two exciting tournaments lined up later this year, and we'd love for your child to be a part of them. If you're a parent of a child living with blood cancer and want to get involved, reach out to Tim Maifeleni at **TimM@leukaemia.org.nz** for more details.

Introducing our newest factsheet

We're delighted to bring you our newest educational resource, "Immunotherapy and Cancer", developed in partnership with the Malaghan Institute of Medical Research. This factsheet explains how immunotherapy works by harnessing your body's own immune system to recognise and attack cancer cells. It explores the different types of immunotherapy treatments, including monoclonal antibody drugs, immunomodulators, checkpoint inhibitors, CAR T-cell therapy, bispecific antibodies, and vaccines.

Whether used alone or in combination with treatments like chemotherapy, immunotherapy represents an important advancement in cancer care, and we're pleased to be able to share this informative resource with you.

Head to www.lbcnz.link/immunotherapy or scan the QR code to read the full factsheet.



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MALAGHAN INSTITUTE OF MEDICAL RESEARCH

IMMUNOTHERAPY AND CANCER

A fact sheet for patients, families and whānau in partnership with the Malaghan Institute

WHAT IS IMMUNOTHERAPY?

Immunotherapy is any medical treatment that uses the immune system to improve health or fight disease. Immunotherapy drugs can be used to stimulate (increase) or suppress (decrease) certain parts of the immune system and can help the immune system to recognise and attack cancer cells.

What is the immune system?

Your immune system is a network of specialised cells, tissues and structures throughout your body. These cells communicate with each other at special 'hubs' that are found in your lymph nodes, spleen and gut.

There are hundreds of different types of immune cells, each with its own function. Some cells seek out and kill faulty cells that might turn into cancer cells, some defend against bacteria or viruses, some tag bad cells so other immune cells can find and destroy them, and others keep a 'memory' of past challenges.

Examples of immune cells include:

- T-lymphocytes (T-cells)
- B-lymphocytes (B-cells)
- Neutrophils
- Macrophages.

Immunotherapy and cancer

When a cell gets damaged or stops behaving as it should – such as dividing uncontrollably – it gets marked and destroyed by your immune system. Most precancerous cells are removed in this way before we even notice them, but occasionally these cells can evade the immune defence system and go on to develop into cancer. By understanding how to turn certain parts of the immune system up or down, we can use immunotherapy to help the immune system to better recognise and destroy the cancer cells.

Immunotherapy drugs can be given alone (called monotherapy) or in combination with other treatments such as chemotherapy (called combination therapy).

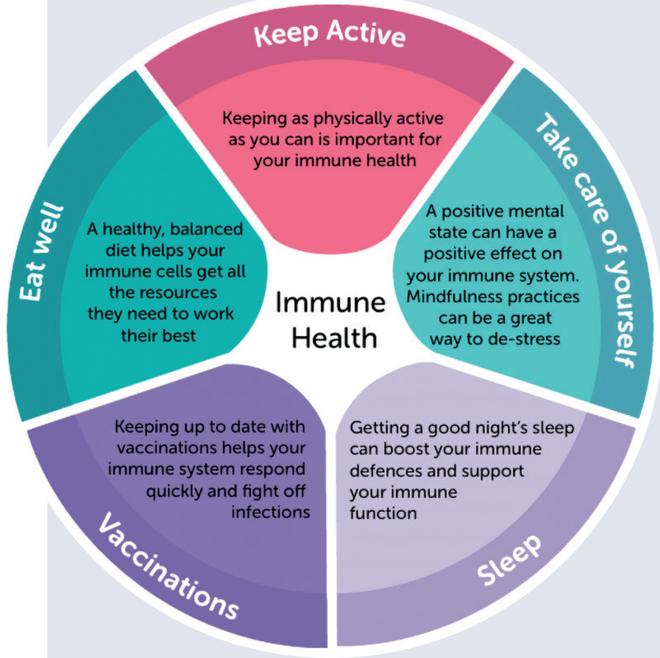
How does immunotherapy work?

There are different types of immunotherapy that work in different ways:

- **Monoclonal antibody drugs** – help the immune system recognise and attack cancer cells.
- **Immunomodulator drugs** (immune system modulators) – can either boost the immune system (increase its activity) or suppress the immune system (reduce its activity).
- **Checkpoint inhibitors** – turn off signals that stop immune cells from responding to cancer cells, which sustains their ability to fight the cancer.
- **Chimeric antigen receptor (CAR) T-cell therapy** – alters a patient's own immune cells so they can better find and attack cancer cells.
- **Bispecific antibodies** – bind to immune cells and cancer cells at the same time, enabling the immune cells to better attack cancer cells.
- **Vaccines** – give the immune system advance warning of diseases.

Monoclonal antibody drugs

These types of drugs are made up of immune system proteins which are created in a lab and attach to specific parts of cancer cells. Some monoclonal antibody drugs are checkpoint inhibitors (see below). Others mark cancer cells so that they can be seen and destroyed by the immune cells.



Immune Health

Keep Active

Keeping as physically active as you can is important for your immune health

Take care of yourself

A positive mental state can have a positive effect on your immune system. Mindfulness practices can be a great way to de-stress

Sleep

Getting a good night's sleep can boost your immune defences and support your immune function

Vaccinations

Keeping up to date with vaccinations helps your immune system respond quickly and fight off infections

Eat well

A healthy, balanced diet helps your immune cells get all the resources they need to work their best

Supporting your immune system

Want to give your immune health a boost? Here are five key things to focus on:

- Eating well
- Keeping active
- Taking care of yourself
- Getting enough sleep
- Keeping up to date with your vaccinations.

The fight to be heard

Ollie and her partner, Chris, live in a small rural town in Southland. The couple have a big, blended family, with five kids and 13 grandchildren between them. Ollie has worn a lot of hats throughout her life – solo mum to two boys, taxi driver, fish and chip shop owner – and for the past 11 years, Ollie and Chris have run the local pub in Balfour, only selling the business recently to focus on the next stage of life.

Last year, Ollie began to struggle with severe back pain. *"I'd spend nights on my knees, with the top half of my body and tummy lying across a chair, because that was the only thing that gave me some sort of relief."*

It got worse and worse over a period of months, to the point where she was struggling to do anything. *"I just had a constant backache all the time,"* she recalls. *"I couldn't walk very far, I couldn't sit for long, I couldn't sleep."*

She had also lost her appetite and dropped more than 30 kilograms. Despite frequent visits to her GP, she wasn't given a clear explanation for her symptoms. At one point, she visited the doctor seven times in five weeks. *"I'll be honest,"* she says. *"That was probably the worst part of my whole journey."*

One day, fed up with feeling like she wasn't being taken seriously, Ollie put her foot down.

> "I said to the doctor, 'I'm sick. I know I'm sick. There's something wrong with me. I'm not leaving here until you do something.'"

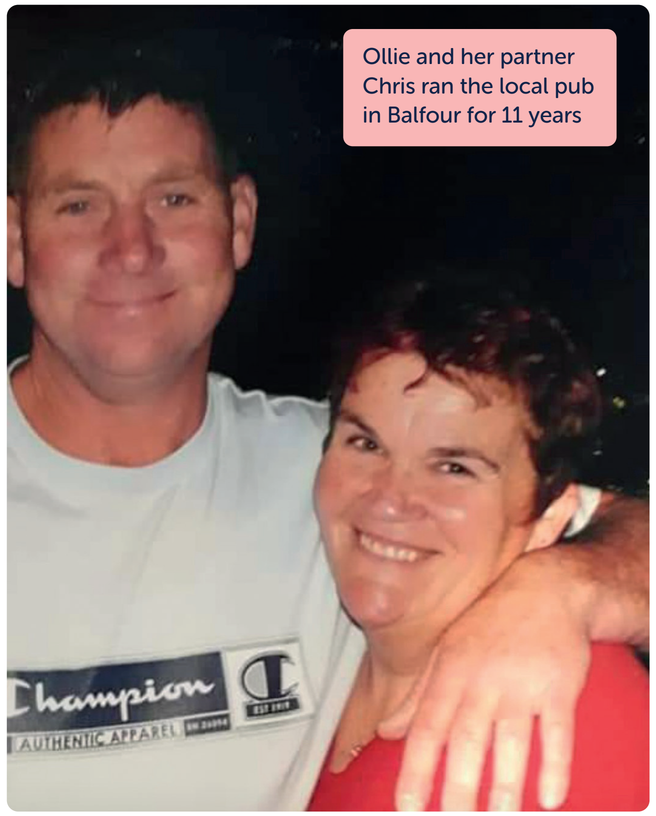
This time, her doctor sent her off for a scan. *"Four hours later, I got told I had a 28-centimetre mass on my back."*

Ollie finally knew what had been causing her such severe pain. She was diagnosed with diffuse large B-cell lymphoma (DLBC lymphoma), an aggressive form of non-Hodgkin lymphoma requiring urgent treatment.

"I was upset, of course, because I didn't know what was going to happen to me," she says. *"But at least I finally had a diagnosis."*

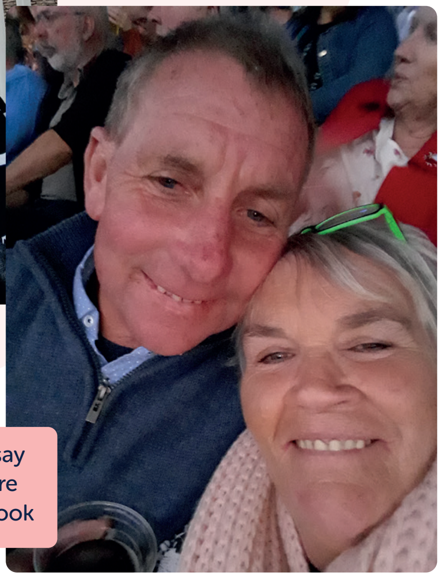
Within weeks, Ollie had met with her haematologist at Dunedin Hospital. *"It was very inspiring going to see her, because on the form I had to sign where they put down everything that would be happening to me, at the bottom, it said 'cure'."*

> "I just burst into tears, and I said, 'Really? This isn't going to kill me?' And she said, 'Not if you don't let it.'"



Ollie and her partner Chris ran the local pub in Balfour for 11 years

Ollie is feeling well after finishing treatment



The couple say that the future is an open book

Over the next several months, Ollie was back at the hospital every four weeks for chemotherapy. She was meant to have six rounds in total, but in the end, she was too unwell to receive the last one.

"I just had nothing left in me. I was in and out of hospital quite a bit because I got neutropenic."

Although treatment was difficult, Ollie says she counts herself lucky when compared to some of the people she's connected with during her journey. *"The people I've met and the stories I've listened to in the last six months – they just break your heart."*

And she was relieved to have the support of her local LBC Support Services Coordinator, Deborah, throughout her lymphoma journey.

"Debbie talked me through lots of things and answered my questions. She sent me some brochures with information about all the different things."

"She also sent me some fuel vouchers," says Ollie. *"While I was sick and in hospital, we weren't making any money, and things were really quite tight for quite a while. So that was absolutely amazing for me."*

Now that they've sold the pub and she has more time, Ollie is looking forward to heading along to the LBC support group in Invercargill so she can connect with others who are on a similar journey.

That's not to say she'll be slowing down, though – *"Retiring is not a word in my vocabulary!"* she laughs. She says she and Chris would love to get away and do some travelling, and she likes the idea of taking on a part-time job where she can continue to connect with people in her community.

These days, although she's well, Ollie still gets very tired. She's trying to regain some of the muscle she's lost, but her haematologist has told her it can take up to two years to feel "normal" again after treatment. Despite this, she's happy to be alive and feels optimistic about what's to come. In May, she travelled up to Auckland to speak about her experience at the awards dinner for LBC's annual Firefighter Sky Tower Challenge.

"You know, we're not here for a long time, and you've got to make the most of it. The world's our oyster and the future is an open book."

Fast Facts: **DLBC lymphoma**

- Around 400 people are diagnosed with DLBC lymphoma each year in NZ.
- DLBC lymphoma is one of the more common types of non-Hodgkin lymphoma.
- It is an aggressive type of blood cancer requiring immediate treatment.

Healing after treatment

Annette Cody works as a Support Services Coordinator in the Northern region. She is both a registered nurse and a counsellor, and holds a Masters of Health Science focusing on the psychological and spiritual impact of disease. Here she reflects on the process of healing after treatment ends and gives some advice on how you can support yourself through this time.

Your feelings are normal

After successfully completing treatment, we usually expect to feel better. There may be an expectation that we feel grateful. Yet some people feel depressed, anxious, lost and emotionally worse than before the diagnosis. Medical interventions can only take us so far on the road to recovery and wellbeing. We also need psychological support to process and adjust to changes.

Watch your thoughts

Notice if you have intrusive or disturbing thoughts that repeat. An example is ‘the cancer will come back’. When thoughts create an emotional charge like fear, we tend to believe them. We need to be aware of these thoughts, challenge them, and counteract them. They are just thoughts.

Accept your emotions

It is important to allow our feelings. Sometimes we benefit from naming the emotion, for example anger, and acknowledge that other people in our situation might also feel angry. If we can accept the feeling, without acting it out, there may be a softening, a releasing of that feeling.

Mourn and acknowledge your losses

We don’t have a choice about feeling symptoms of grief, but we do have a choice about how we acknowledge and process our grief. Losses may include the financial cost, the loss of trust in our body, the impact on our vitality. Remember that the symptoms of grief can manifest in a variety of ways, in our bodies, thoughts and feelings. So, it is important to be kind to yourself. Cancer is an uninvited and sometimes overwhelming intrusion on our wellbeing. It can take courage to acknowledge the impacts and find new ways to engage in life.

You’re not alone

LBC offers a range of support groups and closed Facebook groups where you can connect with others. For more details on these and our other resources, refer to our website or contact your local coordinator.

Meet our new support services staff

Tina

Last year, we welcomed Tina Stewart as a Support Services coordinator in the Midland Region. She has previously worked as a health professional and has broad experience across the New Zealand health sector. Tina is passionate about supporting the quality of life of blood cancer patients and their whānau. Her goals for 2025 include expanding existing services where needed and improving equity across the regions she covers, including Waikato, Tauranga, Whakatane, Thames, Coromandel and Whitianga.

Melody

A familiar face to some, Melody has returned from parental leave and is working alongside Sally and Nicki in the Central Region. She has a background in nutrition and dietetics and has previously worked as an oncology and haematology dietitian in both New Zealand and the UK. Melody works part-time, looking after LBC’s private Facebook groups, developing high-quality patient resources with the health literacy team, and helping the Wellington team with patient support. She is passionate about helping patients and families to feel supported and empowered in their journeys.

Vanessa

Vanessa recently joined the Support Services team as the Support Services Administrator. She has a strong administration background, having worked for one of New Zealand’s largest retirement villages as well as running her own business. Vanessa works full-time in the Auckland office and assists the Support Services team nationwide. She prides herself on ensuring things run smoothly behind the scenes so that the team can focus on delivering support to patients and their families.

A day in the life at LBC

Tim, Annette and Natasha from our Auckland office recently helped make a short video about what the Support Services team get up to day-to-day. In it, they share a glimpse behind the scenes and discuss the different ways they provide support to patients and their families.

“I love my support groups. I love being part of an environment where there’s space for the difficult feelings to arise and be held by everybody, and there’s space for the love, and there’s space for the optimism. It feels like humanity at its best.” – Annette, Support Services Coordinator (Northern Region)

Head to **www.lbcnz.link/dayinthelife** to watch the full video.

Resources and support *corner*

Education and support programmes

We host support groups for patients and their whānau across the country. Groups are held both in-person and online, and they allow you to meet and connect with others facing similar challenges. The programmes aim to help you make informed choices about your condition, treatment and lifestyle. To find a patient support group near you, head to **lbcnz.link/groups or scan the QR code.**

Educational materials

We produce a wide range of patient information resources, including booklets and factsheets. These are designed to help you understand your condition, its treatments and other topics like managing fatigue, chemo brain, eating well, and sleep – plus many more! Head to **lbcnz.link/info or scan the QR code** to view our full library of information resources, or contact your local Support Services Coordinator to order printed copies.

Kids' Zone

LBC also offers a range of services and programmes for young people affected by blood cancer. We run Super Kids' Club for children living with cancer, and Kids' Club for children who are affected by a family member's diagnosis. These groups are facilitated by play therapists and psychologists, and give children space to talk about their feelings, learn a bit about cancer and treatment, and meet other kids going through a similar experience. We also offer picture books for kids, as well as a range of other initiatives. To find out more, go to **lbcnz.link/kidszone or scan the QR code.**

Facebook

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
- @LBCMyeloma
- @LBCChronicLeukaemia
- @LBCAcuteLeukaemia
- @LBCBloodDisorders
- @LBCHaemochromatosis
- @LBCMPN

Support for young adults and parents

- @LBCYoungAdults
- @LBCParentsGroup

Further support pages

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

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

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Call us on: 0800 15 10 15
Email: info@leukaemia.org.nz
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Mail: PO Box 99182, Newmarket, Auckland 1149
LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin