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

WINTER 2025

Myeloma Today

Supporting people *living* with myeloma

Kia ora,

Welcome to your Winter 2025 edition of Myeloma 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 myeloma 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

"I'll give it a good shot"

"When you're a farmer, you're used to hearing the worst and hoping for the best..."

Farming is in Peter Morton's blood. Born and bred in Dunedin, he finished school in 1972 and moved to his family's farm in Central Otago to work alongside his uncles. They had taken over the farm from Peter's grandfather, who first began farming the land in 1921. Now, after running the farm for much of his life, Peter has passed the baton to his own kids.

Although he still likes to help out around the farm (in Peter's words, *"there's nothing nicer than getting out with some dogs and shifting some sheep"*), he and his wife, Sue, are finally enjoying their retirement together. But it's looked a bit different to how they'd imagined it – in 2023 Peter was diagnosed with myeloma, although his health journey started well before that.

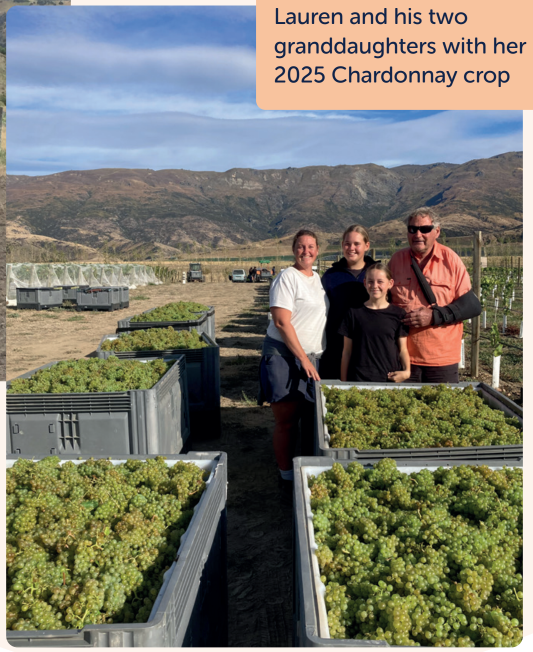
"When Sue and I were first together, I had my 50th birthday and she sent me along for a WOF to make sure she was going to get longevity out of me," Peter laughs.

Tests picked up unusually high protein levels in his blood, and he was diagnosed with monoclonal gammopathy of undetermined significance (MGUS), a benign condition that doesn't require treatment. For the next 20 years, he was sent for annual blood tests to keep an eye on his protein levels, but otherwise carried on with life as normal.

"During that time, I seemed to end up with every cold and flu that came around. When we went on holiday, I'd invariably pick up either a sinus infection or a flu bug, and twice I've had pneumonia while I've been overseas."

This second bout of pneumonia happened during a trip to Canada in 2023. When Peter got back from the holiday in August, he was due for his annual blood test to check his protein levels. *"My numbers were elevated at that stage,"* he says. *"But I thought it might have had something to do with the pneumonia."*

Peter's son, Brad, has taken over farm operations



Peter's daughter Lauren and his two granddaughters with her 2025 Chardonnay crop

Peter with three of his four grandchildren

In November, Peter headed down to Dunedin for some more tests and a haematologist appointment. *"We went to the specialist, and he handed me a whole plan for how I'm going to attack the myeloma I've got, and I'm thinking, 'No one's even told me this – I've only come here for a test!' That was one hell of a shock."*

Not long after his diagnosis, Peter was out splitting wood with his son. Slabs of wood that he'd been able to lift just days prior were suddenly impossible to pick up. *"The next day, I couldn't even get out of bed. I was locked up between my shoulder blades and in my lower back, and I couldn't do anything."*

An X-ray revealed he had three fractures in his spine.

"After all that happened, the myeloma really started to take off. So my haematologist said it was time for us to do something. No argument."

With more free time, Peter has enjoyed getting out on his bike

Peter was advised that due to his age, a stem cell transplant wasn't recommended. Instead, he was entered into a clinical trial where he could use lenalidomide as a first-line treatment, along with steroids and chemotherapy.

Last winter was tough going. Twice, Peter became extremely unwell and needed to be rushed to the hospital. He missed a special dinner celebrating 100 years of the family farm and couldn't make it on a trip they'd planned for Sue's birthday. He was dealing with severe back pain and struggling to get out of the house.

During this time, he leaned heavily on his local LBC support group in Cromwell. Peter and Sue had started attending the group, run by Deb from LBC, even before Peter's diagnosis had progressed to active myeloma. They say it has been a huge source of support as Peter has navigated this new stage of his condition.

"There was one guy in particular who got diagnosed with exactly the same thing as me, and he's gone through hell, but now he's out the other side – no treatment, no nothing. When you're at your lowest point, you look for the highest thing to aim for. So I think, 'If he can do it, I'll give it a good shot.'"

Peter and Sue travelling in Scotland

Peter has also been astounded by the support he's received from his community when he's been too unwell to work on the farm. Last year, when all the ewes needed to be scanned for pregnancy, a big group of local guys turned up to help. *"There were 4000 sheep to go through, and it was cold. It was wet. It was miserable. And I was sitting here in front of the fire."*

Peter recently finished his last round of chemotherapy. He's still taking lenalidomide and a steroid, and will continue with regular monitoring. *"The protein level is still going down at this stage. If it starts to elevate, then that's a bit scary, and the doctor has said the outlook's not great if that happens. We should know where we are by Christmas time."*

In February, Peter ended up back in the hospital – this time after being trampled by a cow and breaking multiple bones. While this might've been the last straw for many, Peter is unlikely to stop helping on the farm any time soon.

"You can tell that farming is his passion," says Sue. *"He lives for the farm, and for trying to leave it in good hands for the ones coming up."*

Fast Facts: **MGUS**

- MGUS is characterised by abnormal protein (M protein) in the blood without symptoms or organ damage.
- Only 1% of people with MGUS progress to multiple myeloma or related blood disorders annually.
- Regular monitoring is recommended, but no treatment is needed unless progression occurs.

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!

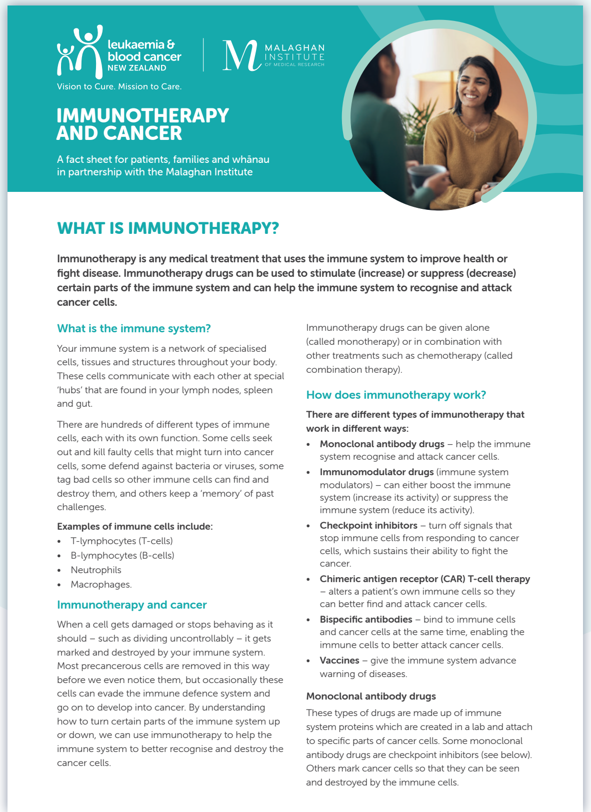
We have two exciting tournaments lined up later this year, and we'd love for your child to be a part of them. If you're a parent of a child living with blood cancer and want to get involved, reach out to Tim Maifeleni at **TimM@leukaemia.org.nz** for more details.

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.

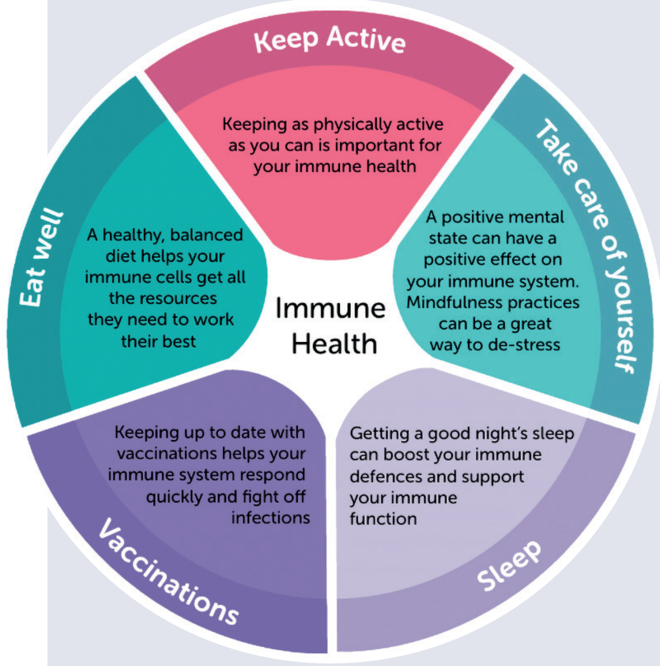
Monoclonal antibody drugs

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.

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.



That's just *life*

Retired teachers Barbara and Gary spent much of their careers moving around the North Island, teaching at small-town schools with their two daughters in tow. *"I was a teacher for probably 40 years,"* Barbara says. *"I've taught at all levels, from five to 14 years of age. The kids were different in every single place we went."*

The pair eventually settled in Taupō, and as she approached retirement age, Barbara decided it was time to say goodbye to teaching. *"I thought I'd step back and let somebody younger do it!"*

By this point, she'd been struggling with aches and pains for several years. *"I'd been going to the doctor at least twice a year because my bones hurt. My joints and muscles hurt. And I was tired. But I'd thought, 'Oh, that's just life.'"*

Then, in 2019, Barbara was alerted to the fact that there might be something else going on. After being turned away from donating blood due to low iron levels, she made an appointment to see her GP.

"I had some blood tests, and some more blood tests, and some more blood tests..."

She was referred to a specialist, who decided she needed B12 injections. *"Back in 2019, B12 was pretty fashionable,"* she says. *"So I was having these B12 injections three times a week. I thought, 'This is just silly.'"*

In the meantime, Barbara had been doing her own research. *"I had gone through our good friend Doctor Google, and after looking at all the info there, I had already decided I had myeloma."*

She discussed this possibility with her GP and asked to be referred to a haematologist.

"I had the bone marrow biopsy and the MRI – all the scans and tests that they do – and then at the end of March I went up to Hamilton and saw the haematologist, and she said it was multiple myeloma."

Barbara during her stem cell harvest

Careful preparation for Barbara's stem cell transplant

Barbara says she didn't feel shocked when her diagnosis was confirmed. *"I guess I'm quite a stoic kind of person,"* she says. *"I was just like, 'Oh, that's a pain.' But I was quite lucky that there were no long wait times. From the time of the blood donation rejection, it was only really about a month before I was diagnosed."*

She was started on weekly VELCADE injections. *"After only a fairly short time, in April, I got this phone call saying to get up to Waikato Hospital straight away. My kidneys were starting to fail. I think they called it tumour lysis syndrome, where there was an overload of the dead cells and my kidneys couldn't cope."*

Up at the hospital, she spent 40 hours on an IV drip to flush out her kidneys.

Barbara enjoys going to her local LBC support group in Taupō

"That first year was the hardest. That was when I had all the neuropathic pain, which could be absolutely excruciating, as well as nausea, vomiting, diarrhoea, rashes, and just feeling absolutely exhausted."

As well as these challenging side effects, Barbara missed being able to do her usual activities. *"I had to give up golf croquet and going to fitness classes and all that sort of thing."*

At the end of 2019, Barbara had an autologous stem cell transplant. *"That was pretty interesting,"* she says. *"I was given this whole lecture about the fact that, at my age, things could be quite difficult. With the stem cell harvest, they said I would probably have to do it over three days – well, after one day, they had more than enough. So I was really happy about that."*

She was told that after the transplant, she would likely need to stay in hospital for four or five weeks. *"And I was actually home in about 12 days!"*

Following her transplant, she was started on thalidomide, switching to lenalidomide in April 2020 when it became funded.

Barbara glances at her diary to remind herself of how everything played out after that first year.

"You know what? From 2020 onwards I have very little written in my diary, because you just know that some days are good, and some days are not so good, and that's it, really."

On the not-so-good days, Barbara has good support. She says her husband, Gary, has been fantastic. *"You know, just things like cooking – he's definitely expanded from baked beans on toast, put it that way!"*

As well as leaning on Gary, Barbara knows she can turn to LBC for support. She's in touch with her local LBC Support Services Coordinator, Sean, and goes along to the Taupō support groups.

"I go to our local meetings with Sean every couple of months, and I really enjoy that. Apart from catching up with the others, Sean usually has info to pass on or discuss."

Last year, almost five years after first being diagnosed, Barbara was given some great news – she was in complete remission, although she was told that this was supplemented by the lenalidomide she was still taking.

"Then, in April last year, I went off all drugs, and I haven't been on any medications since."

The best part? *"I was just told I'm still in complete remission."*

Fast Facts: **Multiple myeloma**

- Multiple myeloma is a blood cancer affecting plasma cells in bone marrow, with around 470 Kiwis diagnosed each year.
- Common symptoms include bone pain, fatigue, frequent infections, and kidney problems.
- Treatment typically includes combinations of chemotherapy, immunotherapy, targeted therapy, and stem cell transplantation.

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.

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.

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.

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.

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.

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
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LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin