

MyelomaToday



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Kia ora, welcome to your latest edition of Myeloma Today

This year marks a significant moment in our organisation's journey. After many years as Leukaemia & Blood Cancer New Zealand, we are becoming Blood Cancer NZ.

This new name reflects our commitment to serving the interests of every person affected by blood cancer across Aotearoa. Our new logo features eight blood drops, each representing an individual life and experience, symbolising how, together, we move forward as one.

As we make this transition, the need for our services is higher than ever before. Six months into our financial year, we have already supported more than 1,000 newly referred patients and whānau, a 10% increase on the same period last year. To meet this growing need, we've expanded our Support Services team so we can be there for people when they need us most. Whether it's practical support, financial help, guidance during treatment, or simply a caring voice in a difficult moment, our Support Services team is here to make sure no one faces blood cancer alone.

While we focus on supporting people diagnosed today, we are equally committed to improving

outcomes for tomorrow. Our advocacy work continues to build momentum, from setting out a bold 10-year vision for blood cancer care in New Zealand through our State of the Nation report, to championing improved access to modern treatments.

These efforts are grounded in the voices and experiences of patients, clinicians and experts who share our vision of a system that delivers the best possible care. Our research funding programme continues to accelerate efforts to discover new treatments and cures across a wide range of blood cancers.

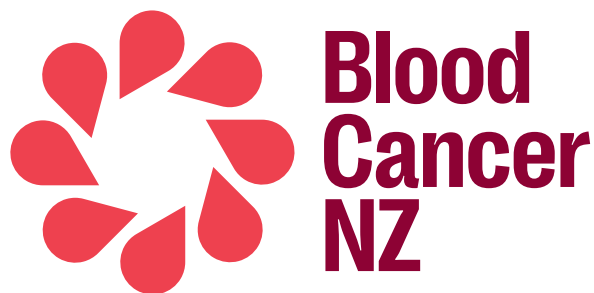
In recent months, I have joined the Pharmac Consumer & Patient Working Group, ensuring that the perspectives of blood cancer patients are well represented as Pharmac begins a period of reform.

Inside this edition, as well as updates on our advocacy work, you'll find stories and insights from across the myeloma community. Whether you are newly diagnosed, in treatment, or supporting someone close to you, we hope these pages offer information, encouragement and connection.

Ngā mihi nui,

A handwritten signature in blue ink, appearing to read 'Tim Edmonds'.

Tim Edmonds
Blood Cancer NZ Chief Executive



Our new logo



State of the Nation: Progress Update

Blood Cancer NZ is continuing work on the State of the Nation report, the first in-depth look at how blood cancer care is provided across New Zealand.

The report will explore care across the full patient journey, from diagnosis and treatment through to recovery and palliative care. It will show where the system is working, where there are gaps, and what needs to change so that every New Zealander can access the best global standard of care.

The core research and engagement phases are now complete. We've heard from people right across the blood cancer community, including patients and whānau who shared their stories living with blood cancer, as well as clinicians, healthcare professionals and international experts. Their insights have helped build a clear picture of current performance and the key areas where system change is most needed. The findings confirm challenges patients have faced for years and reveal some new issues that need attention.

Over the coming months, we'll continue working with clinical leaders and government agencies to finalise the report's recommendations. Our goal is to make sure the suggested actions are evidence-based, practical in the New Zealand context, and focused on what really matters to people living with blood cancer.

The report will be published early next year. Alongside its release, Blood Cancer NZ will lead a coordinated advocacy effort to push for meaningful improvements in care. We look forward to sharing the findings and working to create lasting change for patients.



Valuing Life Summit: Building Momentum for Change

The Valuing Life Summit was held at Parliament on 14-15 October. It brought together patient organisations, clinicians, government officials and industry representatives to discuss New Zealand's access to modern medicines. The summit highlighted how delays in medicine access affect survival and quality of life, and the vital role that medicines play in an effective health system.

Blood cancer patients were strongly represented at the summit. Blood Cancer NZ Chief Executive Tim Edmonds contributed to a panel discussion, and Blood Cancer NZ Board Member Associate Professor Rodger Tiedemann shared a powerful example of how treatment options and outcomes differ between patients in Canada and New Zealand.

CANGO Campaign Update

CANGO, the alliance of New Zealand's cancer charities, is continuing its campaign to make medicine access a top priority in the lead-up to the next election. The group has chosen two partners who will help make this a success – a specialist creative agency will lead the public awareness campaign to highlight New Zealand's current medicine access gap, while a government relations agency will support with engaging political parties to push for change.

By raising public awareness and engaging with decision-makers, CANGO is helping build a future where all New Zealanders can get the treatments they need, when they need them.

Moving forward with myeloma



At the start of 2023, a cancer diagnosis was the last thing on Mark's mind. The 48-year-old was a busy dad to two teenagers, living in Lower Hutt and working for a bank.

Then he started to feel unwell. He was constantly nauseous and struggling to eat. Thinking it might be a stomach issue, Mark went to see his GP, who prescribed an antacid and arranged some blood tests. When the results showed that his kidney function had dropped, he was referred to a specialist at Wellington Hospital for more tests.

"That's when they found the myeloma," he says. "I can vividly remember. It was the afternoon, and I was lying on my bed with my wife next to me. I got a call from the GP, who said, 'You've been diagnosed with cancer, get yourself down to the hospital.'"

Mark describes that initial period after his diagnosis as a whirlwind. "You're just reacting to what's coming, and you're not really processing it."

Wanting to know more about his diagnosis, he turned to the internet for answers. "You start reading about it online, and then you freak out, because it's sort of saying you've got five years to live and it's not curable. That's a bit scary."

Mark began treatment with CyBorD, with doctors hopeful that as the cancer responded to treatment, his kidneys would start to recover. But things didn't go as expected.

"Mine actually went the other way, and they got worse," he says. "So then I ended up on dialysis. I was in there two or three times a week for five hours."

Facing the possibility of long-term dialysis was overwhelming. "I was really scared," he admits, "because they had said to me that once you're on dialysis, you probably won't come off it."



“You start reading about it online, and then you freak out, because it's sort of saying you've got five years to live.”

During this time, Nicki from Blood Cancer NZ stayed in close contact. She regularly called to check in on him throughout his treatment – something Mark says meant a lot.

After six months, there was finally some good news. Mark's kidneys had recovered to the point where he didn't need dialysis anymore.

But even as his physical health improved, the side effects of treatment were taking their toll.

“One of the chemo drugs made me really nauseous and spaced out a bit, so I couldn’t concentrate at work,” he says. “And the steroids were horrible because you just can’t sleep, so I’d be up for like 48 hours. That was pretty hard to deal with.”

When his CyBorD treatment ended, Mark was glad to have it behind him and felt ready for the next big step – a stem cell transplant. “I’d kind of geared myself up a bit for that,” he says, “because everyone says it’s really challenging. So I went in prepared, but it all went to plan – I think I was lucky.”

He took several months off to recover, returning to work in February. “Even though I was excited, that was really hard. I’d battled the physical stuff in 2023, but 2024 was more of a mental battle.”

Shifting from survival mode back into everyday life brought unexpected emotions. “I was angry that I’d got cancer and wondered why it had happened to me. That was actually surprisingly difficult,” he says.

One work meeting became a turning point. “I got really angry, to the point where I was almost shaking, and I thought, ‘Wow. This is extreme.’”

Recognising that he needed help, Mark reached back out to Nicki at Blood Cancer NZ. “She was really great. She just sat with me, and we had a nice chat, and then she put me on to a psychologist.”

Blood Cancer NZ funded three counselling sessions, and Mark decided to continue with a few more on his own. The support helped him find his footing again. “I’d slipped into depression, and that just helped me rebalance.”

“I’m really thankful for Nicki,” says Mark. “I would recommend that anyone who has myeloma reach out to the team and seek support. Even if you don’t need it now, you may need it in the future.”

Today, Mark is in remission and is focused on moving forward. “Having myeloma has given me an appreciation of life. I’m more social now – it’s definitely influenced me to get out in the community and be more active with my friends and family.”

He’s also thrown himself into something he always wanted to do – studying for an MBA. “I think the cancer kind of made me go, ‘Right, time to get this done.’”

The possibility of relapse is always at the back of his mind, but Mark doesn’t let it dominate his life. “There’s an inkling that the cancer will return at some stage, and what’s that gonna look like? But it’s not something that I think about every day.”

For now, he’s focused on what really matters – his family, his health, and making the most of life.

“Overall, things are really positive. Life is great.”



Fast facts: Kidney failure in myeloma

- Kidney failure is a common complication. About 20-40% of multiple myeloma patients have kidney problems at diagnosis, and up to 50% develop kidney issues during their disease.
- Myeloma cells produce excess light chain proteins (called Bence Jones proteins) that damage kidney filters and tubules, leading to kidney failure.
- With prompt treatment of the myeloma (chemotherapy, hydration, dialysis if needed), kidney function can often improve or recover, making early detection crucial.

Welcome to our growing team

We're excited to share some staffing updates as we continue to expand our support for patients and their whānau.



Rachel joins our Auckland team

We're delighted to welcome Rachel Donegan to a new part-time role supporting people in West Auckland, Waitākere Hospital and Auckland City Hospital.

Rachel has many years of experience as a Clinical Nurse Specialist in haematology at Middlemore Hospital, where she also worked as a Transfusion Nurse Specialist. She has a deep understanding of patient care and working with Māori and Pasifika communities – values that align with our commitment to equitable healthcare access.

Rachel is particularly excited about moving into the NGO sector, where she can use her clinical expertise to support our community.



Rochelle returns from maternity leave

We're equally excited to welcome back Rochelle Mills to our Hamilton-based team following her maternity leave. Rochelle will focus on supporting our online activities and helping develop new resources for patients and families.

Healthcare Compass: Haematology Updates

In September, we hosted a 4-part webinar series to help patients, whānau and caregivers learn more about blood cancer care in Aotearoa.

Experts shared updates on new treatments, the future of care in New Zealand, and practical advice to help you navigate your journey.

The series at a glance:

The Future of Blood Cancer Care in Aotearoa

Rosie Shaw, Blood Cancer NZ Head of Advocacy, explored the pathway to delivering world-class care in New Zealand. She discussed current challenges and opportunities in blood cancer treatment and support.

Self-empowerment from Hospital to Home/Community Care

Wendy Jar, Clinical Nurse Specialist in Haematology, shared tips for managing the often-daunting transition from hospital to home and feeling empowered in this process.

And Now What...? Navigating the Practical and Emotional Challenges of Cancer

Lauren Bradley is a social worker and Regional Lead of the Cancer Psychological and Social Support Service. In her talk, she addressed the practical and emotional complexities that come with a cancer diagnosis and ongoing treatment.

CAR T-cell Therapy in New Zealand

Dr Philip George, Consultant Haematologist, and Petra Minehan, Clinical Trials Research Nurse, discussed this groundbreaking treatment innovation and its current use in New Zealand.

Watch Now

All four webinars are now available to view on our YouTube channel. You can catch up on any missed sessions or revisit key information at bloodcancernz.link/webinars.

Educating our health professionals



The team behind the Winter Workshops

Winter Workshops: A Transformational Journey of Healing

Over winter, we ran a workshop series in six cities around New Zealand. Around 300 healthcare professionals who work with blood cancer patients attended.

The workshops featured Vonda Nepia, an AML patient and passionate advocate. She shared her powerful personal story, “A Transformational Journey of Healing: Restoration of Mana & Tapu”.

She spoke about weaving Te Whare Tapa Whā cultural principles into healthcare, and how this supported her wellbeing. Healthcare professionals learned how honouring mana and tapu in clinical settings can improve the experience and outcomes for patients and their whānau.



Dr David Scott presents at the Summit

Lymphoma Summit NZ 2025

On 3-4 October, Blood Cancer NZ supported and hosted the first Lymphoma Summit NZ at the Napier Conference and Events Centre, in partnership with the Lymphoma Network of New Zealand (LNNZ).

Around 90 healthcare professionals gathered to learn about the latest research and treatments for lymphoproliferative disorders, including CLL and lymphomas.

The summit featured international experts Dr David Scott and Dr Kerry Savage from Canada, alongside leading Australian and New Zealand specialists. The programme included scientific presentations, clinical discussions, case-based learning, and networking opportunities.

These initiatives show our commitment to supporting the healthcare professionals who care for our community. Together, we are working to ensure that blood cancer patients across New Zealand receive compassionate, evidence-based and culturally responsive care.

Living with cancer, not dying from it



Debbie lives in Upper Hutt with her husband, Greg. She's a mum to two adult children and a proud Nan to three grandkids. She's had a busy career – spending more than 30 years working at TVNZ before taking up a job at a GP clinic closer to home.

For many years, Debbie always began her day with a swim or a gym session. So when she noticed some pain in her ribs in 2019, she assumed it was nothing major. When the pain worsened, her doctor suggested she might have sprained her intercostal muscles.

But months later, the pain still hadn't gone away. In fact, it was getting worse, and it seemed to shift from one side to the other. With an overseas holiday coming up, Debbie realised she was in too much pain to travel. She went to see a GP at work, hoping for some clarity.

When the first test results came back, the GP told her to go straight home. "She said she didn't even know how I'd made it in!"

The next day, Debbie was sent to the emergency department. Her kidneys were failing – and that was only the start of it. "It turned out I had eight broken ribs, a fracture in my spine and lesions in my pelvis," she recalls.

A haematologist explained to Debbie that she had lambda light chain myeloma. Shocked, she asked him whether it was going to kill her. "He said, 'Well, it's quite serious – I think I could maybe get you a year from the start of treatment.'"

Debbie couldn't believe what she was hearing. She told the doctor he must have her confused with someone else. But he didn't. "He said, 'Your myeloma is going to be difficult to treat.' On diagnosis, my light chains were over 148,000 – unreadable."



It turned out I had eight broken ribs, a fracture in my spine and lesions in my pelvis.



While still trying to take it all in, Debbie began high-dose chemotherapy and treatment to support her kidneys. Thankfully, her kidney function improved, and the chemo showed promising results.

Next came a stem cell transplant. "They actually had to bring that forward," she says, "because my light chains had started to move again." In March 2020, just days before the first Covid lockdown, Debbie was admitted to hospital.



I'm very grateful, because so many people could have quality of life with daratumumab, but it's not funded. I know how lucky I am.



"I spent nearly a month in hospital," she says. "I got really sick from the melphalan they gave me. I was supposed to have a tandem transplant, but my haematologist said I was just too sick from the first one, and we wouldn't do it again."

Throughout this period, Debbie had support from Melody at Blood Cancer NZ, who checked in regularly and organised a TV for her hospital room. It was a small gesture that made a big difference during long, lonely days in lockdown.

After her transplant, Debbie completed another eight months of chemotherapy before moving on to lenalidomide once it became funded.

Unfortunately, in late 2022, Debbie relapsed. "Luckily they picked it up early – and lucky for me, there was a clinical trial going, the MagnetisMM-5 trial being run by Pfizer out of Singapore."

After extensive testing, Debbie was accepted into the trial and began treatment in January 2023.

"The arm I got randomised to was daratumumab, pomalidomide and dexamethasone," she explains. "I'd only been on the treatment maybe two months, and I had a stringent complete response – so, in effect, a remission. And I'm still on it now – in January it will be three years on this regime."

Debbie is aware of how fortunate she is. "I'm very grateful, because so many people could have quality of life with daratumumab, but it's not funded. I know how lucky I am... It's hundreds of thousands of dollars."

Although she's in remission, Debbie still lives with lingering symptoms. "I've always got sore bones, and I've broken my ribs again several times – it doesn't take a lot to do it. Some days I feel really crappy, but then other times I'm like my old self – although I will say I don't have the same energy that I used to."

Despite these challenges, Debbie and Greg are determined to keep living fully. They continue to travel when they can, and Debbie stays active in ways that feel manageable. She also attends her local Blood Cancer NZ support group, run by Nicki, which she finds invaluable – both for connection and for practical guidance.

"Nicki's a really lovely person. She pops into the hospital on chemo days, just to have a chat. I can also ring her if I want to – at different times I've contacted her for resources and information. That's been really great."

It has now been six years since Debbie was told she might only have one year left to live. The significance of this isn't lost on her.

"It's amazing," she says. "For me, I had to get in the mindset of, 'I'm living with cancer, I'm not dying from cancer.' The mental battle is a huge part of it."

"And I don't want to be dying yet," she says with a smile. "I've got lots of things I want to do!"

Fast facts: Myeloma



- Multiple myeloma is a blood cancer affecting plasma cells (white blood cells that produce antibodies) in the bone marrow. Approximately 470 New Zealanders are diagnosed each year.
- Common myeloma symptoms include bone pain, fatigue, frequent infections, and elevated calcium levels. It often damages bones and kidneys.
- While not curable, treatments like chemotherapy, immunotherapy, and stem cell transplants can control the disease and extend survival significantly.

Steroids and blood cancer



What are steroids?

Steroids play an essential role in managing some blood cancers and blood conditions.

These medications are man-made versions of substances our bodies naturally produce. They help control essential functions like blood pressure, inflammation, metabolism, and immune responses.

The steroids used in cancer care are usually corticosteroids, which mimic the steroids made by our adrenal glands. Examples include dexamethasone, prednisone, methylprednisolone, and hydrocortisone. They may be prescribed alongside other cancer treatments or on their own.

How steroids can help

Steroids have several benefits in cancer treatment:

- Directly kill cancer cells and make other treatments more effective
- Reduce inflammation and help prevent allergic reactions to certain chemotherapy drugs
- Help to prevent complications after a stem cell transplant by reducing the body's immune response
- Improve appetite and help ease nausea and vomiting caused by treatment

Side effects

While steroids are an important part of treatment, they can cause temporary side effects that usually improve once treatment ends. Everyone's experience is different, and side effects can vary depending on other treatments being received.

Common side effects:

- Stomach discomfort such as indigestion or heartburn (can often be eased by taking steroids with food or milk)

- Raised blood sugar levels (regular monitoring is important, especially for those with diabetes)
- High doses or long-term use can suppress the immune system, increasing infection risk (try to avoid people who are unwell and practise good hand hygiene)

Other side effects may include:

- Increased appetite and weight gain
- Swelling in the feet, legs, or abdomen
- Difficulty sleeping
- Feeling anxious, restless, or having difficulty concentrating
- Changes to skin, hair, or face (more body hair, thinning scalp hair, rashes, or facial puffiness)
- Muscle weakness, fatigue, and vision changes

If you're worried about any side effects, speak to your medical team. They may be able to adjust the dose or timing of your steroids.

Important safety considerations

Always follow your medical team's instructions carefully.

- Taking high doses of steroids stops your body from making its own supply, so it's dangerous to stop suddenly
- If you've been taking steroids for more than three weeks, your dose must be reduced gradually under medical supervision to avoid serious complications
- Steroids can interact with other medications, supplements, and certain foods and drinks
- Always tell your medical team about anything else you're taking, whether prescribed or over-the-counter, along with any allergies or existing health conditions

For more information, see the Steroids and Cancer Treatment factsheet on the Blood Cancer NZ website.



Shine for a Cure 2025

In September, Shine for a Cure lit up the night in Auckland and Christchurch – a celebration of hope, remembrance and togetherness for the blood cancer community.

Now in its second year, this special event brought together patients, families and supporters from across Aotearoa to walk side by side and shine a light on blood cancer. Everyone who raised over \$100 received a lantern, and together participants raised an incredible \$135,000 for blood cancer research.

With more than 2,000 people joining us at Auckland Domain, and another 500 people in Christchurch's Hagley Park, the energy on the night was powerful. Lanterns in gold, teal and white created colourful ribbons of light through the parks. Some walked in memory of a loved one, others to honour their own journey, and many to simply show support for those living with blood cancer.

Adding to the magic of the night, walkers were treated to a surprise 'hidden choir' along the route in each location.

Shining across the country

Those who couldn't join us in Auckland or Christchurch were invited to host their own local community event, and we were blown away by the effort and creativity shown by supporters across the country.

In Balclutha, locals came together for a special walk in honour of seven-year-old Aaliyah, who

was diagnosed with leukaemia earlier this year. The event was a great success – with face painting, a Mr Whippy van, a head-shaving fundraiser, and even an auction. Together, the community raised more than \$3,300 to help fund life-saving blood cancer research.

Be part of it!

We'd love you to join us for Shine for a Cure 2026. Keep an eye out from June for details on how to register.



A 'hidden choir' surprised participants in each location



More than 2,500 people came together to shine a light on blood cancer

We're here for you



Talk to our team

Our dedicated Support Services team is here to help you, your family and your support people.

We can answer questions, listen to your concerns, connect you with practical or financial help, and provide clear information.

If you ever need support, please reach out to your local Support Services Coordinator and they will be happy to help.

Education and support programmes

We offer support groups for patients and their whānau across the country – both in person and online. These groups are a safe space to share experiences, learn from others, and build connections with people who understand what you're going through.

Our programmes are designed to help you make informed choices about your condition, treatment and lifestyle.

Find a support group near you at bloodcancernz.link/groups

Information

Reliable information can make a big difference when you're navigating a blood cancer diagnosis. We offer a wide range of free booklets, factsheets and online webinars covering a variety of topics.

Our latest factsheets cover:

- Steroids and Cancer Treatment
- Immunotherapy and Cancer (in collaboration with the Malaghan Institute)
- Acute Promyelocytic Leukaemia (APL)

Explore our full library at bloodcancernz.link/info, or contact your local Support Services Coordinator to request printed copies.

Kids' Zone

We also provide dedicated programmes and resources for young people affected by blood cancer.

Our Super Kids' Club supports children living with cancer, while our Kids' Club helps those with a parent or family member diagnosed with blood cancer. Both are facilitated by play therapists and psychologists, giving children a safe space to talk, learn, and connect with others in similar situations.

We also offer picture books for kids, as well as a range of other initiatives. Head to bloodcancernz.link/kidszone to find out more.

Stay connected

Follow [@BCNZ](https://www.facebook.com/BCNZ) on Facebook for updates on our research, advocacy and awareness work, as well as support opportunities.

You can also join one of our closed Facebook groups to connect directly with other patients and support people who understand the challenges of blood cancer.

Support for specific cancers and conditions:

[@BCNZLymphoma](https://www.facebook.com/BCNZLymphoma)
[@BCNZMyeloma](https://www.facebook.com/BCNZMyeloma)
[@BCNZChronicLeukaemia](https://www.facebook.com/BCNZChronicLeukaemia)
[@BCNZAcuteLeukaemia](https://www.facebook.com/BCNZAcuteLeukaemia)
[@BCNZBloodDisorders](https://www.facebook.com/BCNZBloodDisorders)
[@BCNZHaemochromatosis](https://www.facebook.com/BCNZHaemochromatosis)
[@BCNZMPN](https://www.facebook.com/BCNZMPN)

Support for young adults and parents:

[@BCNZYoungAdults](https://www.facebook.com/BCNZYoungAdults)
[@BCNZParentsGroup](https://www.facebook.com/BCNZParentsGroup)

Further support pages:

[@BCNZSupportPersonConnect](https://www.facebook.com/BCNZSupportPersonConnect)
[@BCNZBereavement](https://www.facebook.com/BCNZBereavement)
[@BCNZCARTTherapy](https://www.facebook.com/BCNZCARTTherapy)
[@BCNZConnect \(Blood Cancer NZ & Health Professionals Connect\)](https://www.facebook.com/BCNZConnect)