Blood Cancer NZ

MyelomaToday

WINTER 2026



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Kia ora, welcome to your latest edition of Myeloma Today

Blood cancer can change life very quickly. For many people, diagnosis comes with little warning. Suddenly, there are tests and appointments to navigate, treatment decisions to make, and worries about family, work and the future.

At Blood Cancer NZ, we want every person affected by blood cancer to know they don't have to face these challenges alone. Supporting and connecting our community is at the heart of what we do, and this newsletter is one of the many ways we help people stay connected and informed.

Our work is guided by three commitments: supporting patients, advocating for better access to treatments, and changing outcomes through research. These priorities are closely connected. Support helps people through the realities of diagnosis and treatment. Advocacy works to improve care and influence access to medicines. Research creates opportunities for clinical trials, better treatments and, over time, more people living longer and better lives.

Over the past year, Blood Cancer NZ has reached more than 3,500 patients, whānau and support people across New Zealand. Some were newly diagnosed and looking for trusted information and advice. Others needed practical or financial support during treatment, or were seeking counselling or connections with people who could truly understand what they were going through. Each person's situation is different, and our role is to respond to what matters most to them.

We know that many of you also value the role we play in advocating on your behalf for better access to modern treatments that remain unavailable through New Zealand's public health system. The recent launch of our *State of Blood Cancer in New Zealand* report has helped bring the realities of blood cancer into sharper focus for decision-makers and strengthened the case for coordinated national planning. You can read more about this in Rosie's advocacy update on the next page.

We're looking forward to opportunities for our community to come together in the months ahead. On 11 and 12 September, our Patient Forum in Wellington will bring together patients, whānau, clinicians and advocates to share knowledge and evidence to improve care. And on 19 September, during Blood Cancer Awareness Month, Shine for a Cure will bring people together across the country to remember loved ones, show support, and help fund research that can change the future for people affected by blood cancer. We'd love to see you there if you're able to join us.

Inside this edition, you'll find stories and updates from across the blood cancer community. I hope they leave you with a sense of both the strength that comes from connection and of the progress we can make together.

Ngā mihi nui,



Tim Edmonds
Chief Executive
Blood Cancer NZ



Advocacy update

Rosie Shaw,
Head of Advocacy

Things are heating up ahead of the General Election in November, and Blood Cancer NZ is working hard to ensure our future Government understands the needs of the blood cancer community and is committed to meaningful change.

In April, we launched our *State of Blood Cancer in New Zealand* report in Parliament. The report is the first comprehensive look at blood cancer in New Zealand, combining national data with the experiences of 744 patients and carers. It highlights the realities of living with blood cancer, and the challenges patients face accessing timely diagnosis, specialist care, and modern treatments.

The findings confirm what many patients and families already know: blood cancer is a significant and growing health challenge. Around 3,000 New Zealanders are diagnosed with blood cancer each year, approximately 27,000 people are currently living with the disease, and it is now the third leading cause of cancer death in New Zealand. Yet despite its impact, blood cancer has historically received less attention than many other cancers.

At the heart of the report are patient voices. Every story shared helps to turn blood cancer from something people know little about into something they can connect with and understand. Those stories were central to the report launch, where patients stood alongside clinicians, advocates, and policymakers to highlight both the progress being made and the challenges that remain.

It was great to see health leaders from across the political spectrum attend the launch. And we were encouraged to see the Minister of Health, Hon Simeon Brown, announce the establishment of a dedicated blood cancer oversight group in response to the report's key recommendation.

This group will bring together experts from across the health system to help improve planning, coordination and decision-making for blood cancer care. For patients, this is an opportunity to ensure blood cancer receives the focused attention it needs, and an important step towards building a future where no lives are needlessly lost to blood cancer.

To further support the goal of improving access to modern therapies in New Zealand, Blood Cancer NZ is also leading a coordinated campaign involving 17 patient organisations. Taking place in Auckland on 24-25 July, the campaign will feature a public installation highlighting medicines that New Zealand patients still cannot access. It aims to spark public, media and political discussion about what it will take to ensure that all New Zealanders can access the medicines they need.

The months ahead will be critical in shaping the future of blood cancer care in New Zealand, and Blood Cancer NZ will continue to champion the voices of patients and whānau every step of the way.



Blood Cancer NZ staff present the *State of Blood Cancer* report in Parliament

On the horizon

As we look ahead to the rest of 2026, there are still plenty of opportunities to learn, connect with others, and feel supported on your blood cancer journey. Here are two events we'd love you to be part of.

2026 Blood Cancer Patient Forum

Whether you're newly diagnosed, on active monitoring, or well into your post-treatment journey, the Blood Cancer Patient Forum is a wonderful opportunity to connect with others, hear from leading experts, and leave feeling informed and supported. The Forum is a special event open exclusively to patients living with a blood cancer and their whānau, and this year's Forum will take place in Wellington on 11-12 September. It brings together an inspiring line-up of speakers covering everything from the latest treatment developments to living well with and beyond blood cancer.

Registrations are now open. Visit **bloodcancerpatientforum.org.nz** to find out more.

WELCOME EVENT
5pm - 7pm, Friday 11 September

FORUM
8.30am to 4.30pm, Saturday 12 September

VENUE
James Cook Hotel Grand Chancellor
147 The Terrace, Wellington Central

Myeloma Patient Education Workshop

DATE Friday, 11 September 2026
TIME 1:00pm-3:00pm
VENUE James Cook Chancellor Hotel
RSVP georginas@bloodcancer.org.nz





Shine for a Cure

On Saturday, 19 September, join people in Auckland, Christchurch and across the country as we come together to honour loved ones, reflect on our own journeys, and shine a light on everyone affected by blood cancer – all while raising money for life-saving 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.

Can't make it to Auckland or Christchurch? You can still take part by hosting your own lantern event wherever you are in the country and joining the live stream online.

Head to **shineforacure.org.nz** to register!

Understanding your full blood count

People living with blood cancer often have regular blood tests, especially around diagnosis, treatment, and follow-up. One of the most common blood tests is a full blood count (FBC), also called a complete blood count (CBC). It measures the levels of different blood cell types and provides information about how your bone marrow is working.

Your results may include abbreviations, numbers, and "normal ranges". These ranges can vary between laboratories and may also be influenced by your age, sex, treatment, and other health conditions. Your treatment team are the best people to explain what your results mean for you.

Red blood cells and haemoglobin

Red blood cells carry oxygen around your body using haemoglobin (Hb). Low haemoglobin is called anaemia and can cause tiredness, weakness, dizziness, shortness of breath, or looking paler than usual.

Your report may also include haematocrit (HCT), which measures the proportion of your blood made up of red blood cells, and MCV, which describes the average size of your red blood cells.

White blood cells

White blood cells help protect your body from infection. The total white cell count (WBC) includes several different cell types that all play different roles, and some blood cancers affect particular types of white blood cells.

A white cell count can be high or low for many reasons, including infection, treatment, and blood cancer. Your healthcare team will look at patterns and trends rather than at a single result.

Neutrophils

Neutrophils are white blood cells that help fight bacterial infections. Low neutrophils are called neutropenia and can increase your risk of serious infection, particularly during or after treatment.

If you have been told your neutrophils are low, or you have recently had chemotherapy or intensive treatment, contact your treatment team immediately if you:

- develop a temperature
- have chills or shivering
- feel suddenly unwell
- notice signs of infection.

If you are very unwell or cannot reach your team, call 111 or go to your nearest emergency department.

Platelets

Platelets help your blood clot. A low platelet count can cause easy bruising, nosebleeds, bleeding gums, tiny red or purple spots on the skin, heavier periods, or bleeding that is difficult to stop. Tell your healthcare team if these occur.

During treatment, some people need platelet transfusions as a temporary "top-up" while the bone marrow recovers.

Reading your results

It can be worrying when a result falls outside the normal range, but for people with blood cancer, changes are often expected during treatment. Trends over time are usually more important than a single number.

If you would like help understanding your results, speak with your haematology team, specialist nurse, GP, or pharmacist.

Test	What it does	Typical adult range*
Haemoglobin (Hb)	Carries oxygen around the body	Men: 130–175 g/L; Women: 115–155 g/L
Neutrophils	Help fight bacterial infections	2.0–7.5 × 10^9/L
Platelets	Help blood clot and prevent bleeding	150–400 × 10^9/L

*Your results should always be interpreted alongside the ranges on your laboratory report and your clinical situation.

Kate's journey of healing and hope

When primary school teacher Kate began feeling breathless in April last year, she didn't panic at first.

"I just thought, 'I'm a teacher at the end of term – I'm tired!'"

But when it became more painful and difficult to breathe, the Christchurch mother of two visited her GP, who ordered blood tests. That same evening, she got a phone call that changed everything.

"All my blood cell levels were low," Kate recalls. "I needed to go to the hospital for a blood transfusion."

When she turned up at the hospital, she expected to have the transfusion as an outpatient and head home later that day. But she was in for a shock.

"They admitted me onto a ward where people were walking around with scarves on their heads," Kate says. "I remember thinking, 'Holy s**t, I'm on a cancer ward.' That's when I realised what was actually going on."

Kate was told that she likely had a blood cancer, but it wasn't clear which one.

"It turned out I'm non-secretory," she says, "so they can't pick it up with blood tests – only with a bone marrow biopsy or a PET scan."

In mid-May, Kate was officially diagnosed with myeloma.

A biopsy showed her bone marrow was 90% cancerous cells. She also had holes throughout her bones, which explained the back and hip pain she had been seeing a chiropractor about.

Shortly after her diagnosis, Kate reached out to her local Blood Cancer NZ Support Services Coordinator, Kate McHardy. Having that one-on-one support and meeting other patients she could relate to helped her feel less alone as she began treatment.



Kate was isolated in a plastic "bubble" for much of her treatment



Kate was started on a regimen of lenalidomide, dexamethasone and bortezomib. "I was on that for about three or four months, and then in August, we looked into paying for daratumumab," she says. "We found out you could get a deal if you switched from lenalidomide to thalidomide, where they would pay half."

The treatment came at a significant financial cost.

"I ended up having 11 Dara shots," Kate says. "I paid $5,000 11 times, plus administration fees – only to find out that Dara didn't work for me."

At the beginning of November, Kate's doctor sat her down for a frank conversation.

> It wasn’t possible for me to have a stem cell transplant. My haematologist basically said, ‘New Zealand can’t do anything more for you. You need to look at CAR T-cell therapy.’

“By this stage, I’d had five bone marrow biopsies, and the treatment had really done nothing,” Kate says. “It wasn’t possible for me to have a stem cell transplant. My haematologist basically said, ‘New Zealand can’t do anything more for you. You need to look at CAR T-cell therapy.’”

Suddenly faced with limited options, Kate began searching for other Kiwi myeloma patients who’d had the treatment overseas.

She says, “I remembered reading an article about a woman in Christchurch who’d had CAR T, and I managed to contact her through Facebook. And then Kate from Blood Cancer NZ put me on to another lovely man who’d had it.”

The next day, Kate and her husband, Mike, met with both patients to learn more about their experiences. They’d both been successfully treated in Shanghai, but at different hospitals, and with very different price tags.

After carefully considering their options, Kate and Mike chose a more affordable programme run by Professor Hou, who was trialling a form of CAR T-cell therapy targeting two distinct myeloma markers. Having been given less than a year to live, Kate used her life insurance payout to fund the treatment and travel costs.

On the 10th of December, Kate and Mike set off for China.

“I arrived in Shanghai and had a week in hospital, having all these tests – 25 vials of blood taken,” she says. “It was just bang, bang, bang, bang. Every day, something else. They were so efficient.”

Then, on Boxing Day last year, Kate received her infusion of CAR T-cells.

She and Mike had been told to expect a stay in Shanghai of up to seven weeks. But complications extended their time away from home to ten and a half weeks.

It was an incredibly difficult journey, but one that ultimately gave Kate something she had desperately hoped for: another chance at life.

“I’m in remission,” Kate says, “which in China means there were no myeloma cells in a million cells.”

Returning home was a relief, but it also marked the beginning of a different kind of recovery.

“It all hit me when we came back,” Kate says. “We were both thinking, ‘What the hell did we just do!?’. We were drained, exhausted, emotionally vulnerable. It took about six weeks to decompress.”

Since returning home, Kate has had monthly blood tests. “I don’t get nervous for those,” she says, “because I know my myeloma doesn’t show up in my blood.”

Awaiting her first PET scan is a different story, as it will be the first real look at whether she’s still cancer-free.

For now, at least, Kate is still focused on her recovery and taking each day as it comes.

“Obviously, I’m still really tired, still in recovery mode,” she says. “And I’ve got little to no immunity, so I can’t work.”

But it’s not lost on her how far she has come. Her pain has eased, her quality of life has improved, and she can once again look ahead with hope.

“I’m feeling so, so much better than I felt before I left,” she says. “I’m down to a third of the pain meds that I was on. And I have a stack of library books I’m ploughing through, which is lovely!”



An update on your Support Services team

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



A new face in the Wellington office

In March, we were pleased to welcome Stephanie Waterbury to our Wellington Support Services team. Stephanie is an experienced registered nurse who enjoys building meaningful connections with people and making sure their needs are heard and addressed.

Stephanie began her nursing career in Washington State, USA, as a medical oncology and haematology infusion nurse. In 2021, she moved to Wellington, where she has since gained further experience in hospice and clinical oncology nursing.

Stephanie has taken over from Nicki Roy, who was a valued member of the Blood Cancer NZ Support Services team for five years before recently moving away from Wellington with her family.



Extra support in Christchurch

We are delighted to share that Nish Mohun has recently joined our Upper Southern Support Services team in a newly created role.

Nish is a certified health coach and health and disability advocate, bringing a wealth of experience to the team. Most recently, she spent five years at the Nationwide Health and Disability Advocacy Service. She will be working alongside Helen and Kate to support patients and whānau across the region.



Developing our online services

After almost 10 years working in the Blood Cancer NZ Support Services team, Rochelle Mills has recently moved into a new role as our Online Support Services Specialist.

In this role, Rochelle will be working to strengthen and expand our online services, helping us reach more patients and whānau throughout New Zealand. She will be running a quarterly post-treatment workshop series (see details below), hosting regular webinars, and overseeing our disease-specific online groups and closed Facebook groups.

New post-treatment workshop series

As part of our growing online support services, we're pleased to launch a new post-treatment workshop series for people with blood cancer who have completed treatment within the past year – often referred to as the 'survivorship' phase.

The six-week online programme will run four times a year. It includes a one-hour Zoom session each week and is designed to help you navigate life after treatment, build practical knowledge, and connect with others who understand your experience.

Topics include:

- Nutrition to support recovery
- Fatigue reduction and exercise
- Psychological wellbeing
- Self-empowerment and ongoing care
- Redefining "normal"
- Exploring the question "what now?"

To register your interest, please email **rochellem@bloodcancer.org.nz**



Protecting your immunity this winter

As we roll into the cooler months, many of us are more aware of the coughs, colds and flu bugs going around. People with blood cancers or blood conditions are often classified as immunocompromised. While this does mean you're more vulnerable to infection than other people, it does not mean you're destined for illness.

Taking a proactive approach can empower you to feel safer this winter. Here are some practical steps you can take to help prevent getting sick this season:

- **Eat plenty of fruits and vegetables.** This will help keep your immune system in tip-top shape. Eat a variety of colours so that your body can use nutrients, minerals, and antioxidants to give your infection-fighters the fuel they need.
- **Prioritise rest and sleep.** While this is not something people commonly think about when boosting their immunity, 7-9 hours of regular sleep can help your body heal and recover from the stress of the day.
- **Stay active.** Exercise (within moderation) can promote the circulation of immune cells and reduce stress hormones. As a bonus, moving your body also helps lessen fatigue. Consider gentle yoga or walking to start out.
- **Talk to your haematologist or GP about vaccines** that can keep you safer this season. These recommendations may change depending on your age, medical conditions and what treatments you're on.
- **Always use hand hygiene.** Remember to wash or sanitise your hands before eating or touching your face, and after using the toilet. Keep a travel-size sanitiser gel in your bag or purse for easy access.
- **Consider wearing a mask** in crowded situations like on public transport or at large events. Remember, a well-fit N95 will give you more protection than a surgical mask.
- **Tell your sick loved ones to please stay home** to prevent illness from spreading to you and the wider public.

Remember that everyone is different. People have different bodies, treatments, conditions and risk factors. There may be points when you are more or less vulnerable to infection. If you feel unwell, please seek advice from your medical team. Keep in mind that it's impossible to never get sick – but by making proactive decisions, you can reduce your risk, stay connected to your loved ones and continue to take part in your community.

If you decide to take any supplements, let your treatment team know. They can make sure that what you're taking won't interact with any treatment you're receiving.

Living well with myeloma

At 78 years old, Jane Jackson has no intention of slowing down.

Qualifying as a physiotherapist in 1969, Jane worked in the field for nearly 50 years. She spent her youth travelling as much as she could, and in her mid-30s, she decided to get fit. “It ended up taking me to places I never expected,” Jane says. “I’ve done several marathons, I did an Ironman and the Coast to Coast. I was New Zealand’s top race walker. So I did a huge amount.”

Even into her late 60s, Jane stayed active, entering the World Masters Triathlon in 2017. “I wasn’t as fit as I had been, putting it all down to age, of course,” she says. “But I was still competing, still teaching pilates, and still travelling around New Zealand and overseas.”

Throughout 2020, Jane had noticed she was getting more infections than usual. “In early 2021, my doctor did some blood tests, probably for that reason. While I was away in Stewart Island doing a tramp, he rang me. He said he wasn’t happy with one of the results, and that I had an appointment with a haematologist when I got back.”

On the same trip, Jane broke a rib while rolling over in bed. She was also feeling more tired than usual and had been short of breath. “It all came on quite suddenly,” she says. “I hadn’t really cottoned on that I was getting less fit, or that I’d had all these infections. But then it was quite clear something was wrong.”

At this stage, it was February 2021, and Jane’s appointment with the haematologist was scheduled for just days after she got home. But the life-changing news came sooner than expected.

“My eye specialist actually rang me the night before my appointment,” Jane says. “He said he thought I had myeloma because the MRI for an eye problem showed I had lots of holes in my skull. He shouldn’t have told me, really. I wasn’t even sitting down.”







Her diagnosis was quickly confirmed with a bone marrow biopsy, and she was started on CyBorD treatment almost immediately. “I got the huge stomach and the fat face and the weak legs, things like that,” she recalls. “But it did put me in remission.”

The next step in her treatment plan was a stem cell transplant. “Even though I was older, they decided I was fit enough for it and had a good attitude,” she says.

But unfortunately, it wasn’t to be. “Sadly, I couldn’t produce enough stem cells, so that was off the table,” she says. “That was gutting to start with, because it seems that people who’ve had stem cell transplants have a longer remission.”

> Over the last year, I've had a good quality of life. I still exercise almost every day.

But over time, she came to terms with it. "I thought that at my age, I probably would have been quite knocked around by it and not have had such a good quality of life for a while. So I came to accept it."

When Jane's myeloma came back a few months later, she was put on a new trio of drugs – lenalidomide, cyclophosphamide and dexamethasone. "They were able to fund it because the stem cell transplant had failed," she says.

This combination didn't give Jane another remission, but it did keep things under control for a while. "I had a couple of visits to the hospital for pneumonia," she says, "but apart from that, I was reasonably fit and well."

When the lenalidomide eventually stopped working, Jane was offered an experimental stage clinical trial. Unfortunately, it didn't go well.

"It was the worst time in my life," she recalls. "The side effects were absolutely horrendous. All my skin peeled repeatedly, my nails fell off, I had a rash from head to toe, and I couldn't eat for six months."

The trial group Jane was allocated to meant she was taking the new drug in combination with an already proven drug. "That's the only reason I stuck it out," she says. "Because I knew it was going to help me. I did get close to remission, but after five months, I felt very, very unwell."

When she came off the trial, she was started on yet another drug – this time, pomalidomide. She's tried it in combination with several different drugs, and now seems to be in a place where her myeloma is well-managed and her side effects are tolerable.

"Quality of life is important to me," Jane says. "And over the last year, I've had a good quality of life. I still enjoy overseas travel, I love watching movies and shows, and I exercise almost every day. Nothing like the level I used to, but I think it helps me with pain tolerance, and it helps my mood. And exercise sometimes entails coffee with friends afterwards – so the social side of it has helped me through, too."

Something else that has helped Jane through is attending her local myeloma support group run by Blood Cancer NZ. "I've found it really, really helpful," she says. "It's not just that I don't want to burden the people around me, it's that they don't always understand. So it's good to go along and tell your story, and hear other people's stories."

Jane doesn't know what the next few years will hold, but she's prepared for whatever is to come.

"I feel accepting of my future," she says. "It's quite reasonable that someone of my age might have something terminal. When this treatment fails, I don't want to spend hundreds of thousands of dollars on a new treatment that will also have side effects. So I'll stop, and we'll just see what happens."

Fast facts: Myeloma

- Multiple myeloma is a blood cancer affecting plasma cells (white blood cells that produce antibodies) in the bone marrow. Approximately 500 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.

How we can help

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 booklets include:

- Blood Cancers in Primary Health Care
- Blood Cancer Awareness for New Zealand's Rural Sector

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 **@bloodcancernz** 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
@BCNZMyeloma
@BCNZChronicLeukaemia
@BCNZAcuteLeukaemia
@BCNZBloodDisorders
@BCNZHaemochromatosis
@BCNZMPN

Support for young adults and parents:

@BCNZYoungAdults
@BCNZParentsGroup

Further support pages:

@BCNZSupportPersonConnect
@BCNZBereavement
@BCNZCARTTherapy
@BCNZConnect (Blood Cancer NZ & Health Professionals Connect)

Call us toll free on 0800 15 10 15
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Blood Cancer NZ