

MyelomaToday

Supporting people *living* with myeloma



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2023 in focus

Peter Fergusson, LBC Chief Executive

Kia ora! Welcome to Leukaemia Today.

I'm so proud of the hard work that our Support Services team has put into supporting and caring for patients and families - you will read more about that in some of the stories shared in this edition.

However, patient support is only one side of the mahi we do at LBC to make our mission to care and vision to cure, become a reality. A key part of that future vision to cure, comes from our advocacy work.

LBC is a key member of the Haematology Leadership Group that assists Te Aho o Te Kahu (Cancer Control Agency) with providing the knowledge, feedback and direction to advise the Minister of Health.

A small number of these advisory Leadership Groups exist (8 in total) however across all these, LBC is the only patient body

represented – which elevates our input, responsibility and intent to ensure that your 'voice' is heard at the highest level.

In addition, I currently chair CANGO (Cancer Alliance of Non-Government Organisations), a group of 9 collaborative cancer-focussed NGOs in New Zealand. This year, CANGO is focussed on the 2023 General Election, ensuring the concerns and needs of cancer patients are documented, heard and considered by all political parties.

We also work closely with a range of key organisations that advocate regularly - including:

- Australasian Leukaemia & Lymphoma Group (ALLG), which deals with submissions, research and clinical trials
- Haematology Society of Australia and New Zealand (HSANZ), an influential clinician led ally
- Adolescent/Young Adult Cancer Services (AYA)
- National Child Cancer Network (NCCN).

However, LBC also has a voice of its own. Already this year we have formally submitted on a number of key issues:

- Daratumumab - reviving the discussion on funding this important myeloma treatment and pleased to be working alongside Multiple Myeloma NZ to further this important cause
- Therapeutic & Natural Health Products Bill - raising our critical concerns
- Paediatric Cancer Treatment – the proposed changes to children's cancer treatment access
- A co-signatory to the CAR-T National Service Framework application.



What's next for Te Aho o Te Kahu

We sat down with Cushla Lucas, Regional Manager at Te Aho o Te Kahu (Cancer Control Agency) to talk about what the changes to Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority) mean for blood cancer patients.

Q: How have the recent health reforms affected Te Aho o Te Kahu?

Our role, as a standalone government agency, is to provide high quality advice to the Government on what the needs and priorities are for New Zealanders with cancer. We also play an important role in shaping the environment for cancer care by listening to people and whānau who experience cancer and by supporting decision makers and providers to deliver care. This role hasn't changed as part of the health reform.

In everything we do, our core values to be person-and-whānau-centred, equity-led, knowledge-driven and outcomes-focused are at the forefront. It's early days for the

reforms, but we are optimistic about the changes and recognise that the previous structure of having multiple independent providers made it complicated to address variation in healthcare across the motu, or to provide seamless care for people who have to travel for cancer treatment.

One of the significant changes has been the establishment Te Aka Whai Ora – Māori Health Authority bringing the issue of inequity in Māori cancer outcomes into the spotlight. This is a really positive step.

There is a lot more to do but we believe it's important to be focused on moving forward.

Q: What is the Te Aho o Te Kahu vision for cancer care in Aotearoa?

Te Aho o Te Kahu has a three-prong vision for New Zealand's cancer care:

1. Fewer cancers - which starts with better community health, but also includes some cancer screening activities.
2. Better survival - which is about national screening and early detection of cancers, access to more timely diagnostics and high-quality treatments.
3. Equity for all - we know that inequity exists at all stages of the cancer continuum, especially for whānau Māori.

And we know that New Zealand's health system could do more for those with cancer, and we acknowledge the advocacy of LBC and other NGOs in this space.

Q: What about blood cancer specifically? What can blood cancer patients expect?

We'd like to see people and whānau with blood cancer have better access to services and information, experience greater consistency across the system and experience better outcomes.

A key piece of work for us has been looking at cancer journeys that describe, end-to-end, an optimal pathway for people with blood cancers – covering aspects such as what does advanced care look like? Or, survival aspects? Prevention or earlier diagnosis? As well as what treatments / medications are appropriate and how to support and coordinate care across all the steps.

Better and more timely access to services is critical for people with blood cancer. For many people, this treatment may not be close to home and that's where access to the best possible support and partnerships with

groups like LBC is really important.

One key project this year has been to work closely with hospitals that provide stem cell transplants – who are facing growing demands and need to grow capacity for the future. We have supported processes for people and whānau to travel between centres, where needed, and to build business cases and models of care for the future so we can be better prepared.

Of course as part of that future, we are also aware of the CAR T-cell trials that are currently happening in Wellington. CAR T-cell therapy may be more of a standard of care overseas, but it is new for New Zealand and it's going to be an exciting time to see what next for this treatment.

So a lot is happening in the blood cancer space.

Life without expectancy

"They said, 'your bones look funny, they've got holes, like they're moth-eaten.' And I thought, 'that's weird.' But I didn't care, I was full of fentanyl by then!" Annie laughs.

It was September 2021 and Annie was in hospital after falling onto her bed. Despite the soft surface, she had broken her pelvis. ED doctors were working hard to understand what had happened.

"A couple of weeks later, still in Masterton Hospital, practicing walking, and after many tests including a trip to Lower Hutt for an MRI, doctors asked for a meeting with myself and my two sons. We were told, gently, that I have multiple myeloma."

"There's nothing like that heart-stopping moment. Nothing in life ever prepared me for that."

After the confirmed diagnosis Annie and her sons FaceTimed her daughter in Australia. **"We tried to break the news to her as gently as possible - she only knew I had a broken pelvis. It broke my heart to tell her this when she was so far away."**

There's nothing like that heart-stopping moment. Nothing in life ever prepared me for that.

Annie was then transferred by ambulance to Wellington Hospital where her chemotherapy journey would be mapped out and multiple myeloma explained in depth. She would, after being released from hospital, end up travelling from Featherston to Wellington Hospital for weekly chemo, then eventually weekly to Masterton Hospital.

Once in Wellington Hospital Annie and her children had a family conference video call with one of the haematologists and Kelly (the wonderful myeloma Nurse Specialist) to help them wrap their heads around Annie's sudden diagnosis.



"The first thing this doctor said was, 'As far as life expectancy goes, you've got around 10-13 years.' I never asked that, didn't want to know that, and my children didn't want to know. My plea to doctors is, please make sure that your patients want to know this before you tell them."

Unintentionally, that short sentence caused a lot of pain for Annie's daughter. **"Your life expectancy could be 1 hour, 1 day... it could be 50 years, whether you have cancer or not. What that doctor said really got to her,"** Annie says sadly, **"and she got stuck on that."**

Nervously, the family pushed on with Annie's treatment. She had 20 weeks of non-stop chemo, ending mid-February 2022. **"I was meant to have a stem cell transplant in March 2022 but Covid changed that. So I went back for another 8 weeks of chemo and finally had the transplant on June 1st 2022."**

Annie was so terrified by all she read and heard about stem cell transplants that she seriously considered not going through with it. **"I was dreading it, I was certain I would die."**

"I sailed through the whole thing. Since the transplant I've been OK - which is astounding, apparently. I got to come home after 10 days - instead of the predicted 3-4 weeks in hospital."



There's no specific amount of life that you can expect, that you know you've got.

Despite the good news Annie's daughter was still anxious.

"After the transplant her first question was, 'What's your life expectancy now Mum?' And I said, 'Same as yours Lucy. Exactly the same as yours.' 'What do you mean?', she said.

"Well... there's no specific amount of life you can expect, that you know you've got. But I'm here right now."

It was a difficult conversation - just one of many hard conversations that Annie needed to have - and she found a safe space for those discussions with Nicki, and later Sally, from LBC.

"I got in touch with Nicki first. My son Shaun went to the LBC website and read up on myeloma. He then sent a video of a myeloma survivor that he found on the website to myself and my other son James. It gave us hope."

"I'm a great believer in support groups, and I've enjoyed Sally's groups. It's nice to be able to say things that I can't say to my children, because I want to protect them."

Annie's big heart isn't only limited to her children. While recovering in hospital, instead of worrying about herself, she came up with an amazing plan to help others.

"I've always loved sewing dresses for little girls. One day, I was wondering where I would send the dresses to my daughter-in-law Jane Keig. Jane had the Defence Force contacts to put us in touch with the Timorese ambassador Her Excellency Ms Felicidade Guterres. We visited the embassy and got approval from Her Excellency to make dresses for the little girls of Timor-Leste. Stitch 4 Kids NZ was born!"

With a lot of talking to people, newspaper articles and goodwill they were donated tons of fabric from around Wairarapa. Several women locally and around Aotearoa joined in, making dresses for girls from 1-14 years old. Annie had created something special during one of the hardest times in her own personal life. But, this isn't unusual; Annie really is this tenacious.

"My doctor says the cancer will come back - it's not curable but treatable - but I'm saying not for at least 15 years. I've got a friend in Auckland who has myeloma and she's 8 years out from her transplant, and she's perfectly ok."

"Get on with life and enjoy it, that's what I say. Looking back from the great old age of 66, it goes fast. I've had a wonderful life, and this experience, whilst it's been horrible and heart-breaking, it's not the be-all and end-all of who I am."

"I've been stubborn and determined since I was a little girl: and I don't plan on changing. I'm glad I've got that stubborn streak. There's always going to be good and bad, but it's what you do with your life that matters, eh?"

Fast Facts: Myeloma

- Approximately 430 New Zealanders are diagnosed each year
- The majority are over 40 years of age and it is more common in males
- Myeloma affects the plasma cells, which grow uncontrollably, causing damage in the body, most commonly in the bone marrow and different bones.

Warrant of fitness

"At 35 I started having a yearly 'warrant of fitness' - getting my body checked out. I was pretty rough on it!" Craig laughs.

"At 38, my doctor did the usual thing, had my blood test done. A few days later, he said that we need to have a chat."

"At first he said, 'Unfortunately, you might have leukaemia (not myeloma). He was a good doctor, but he had a funny way of approaching things. He just blurted it out.'"

"I sat there, thinking. Oh f***. Excuse my French, but what is this all about?"

Craig was referred to a haematologist. "I didn't even know what a haematologist was! But I went to the hospital and had an excruciating bone marrow biopsy."

"The doctor said, 'This might hurt, yell if you wish', and my wife Janet said my language was very colourful!"

A week later, the doctor told Craig that he had Monoclonal gammopathy of undetermined significance (MGUS) - which he explained looked like the beginning stages of myeloma.

"It was like a pimple. It could either grow or it could go away - unfortunately mine became myeloma."

At 49, Craig needed a bone marrow transplant. He searched amongst all of the people in his life, and unfortunately no one was a match, so he used his own bone marrow.

"Even though I was numb, the doctor used this sharp bore needle through the muscle to extract blood. I jumped when I saw it, and then she jumped too, because I scared her as well!" Craig cracks up, "And then I was on some intense chemo."

"Everything tasted metallic. I was a bit overweight, so when I lost 10kgs - I thought that was great!" Craig says, grinning. "I went completely bald and I'd stand in front of the mirror, and think - it's not so bad, being bald, actually."

Having picked up a bug, Craig spent Christmas day in hospital. "I ate hospital food, while Janet sat there next to me, enjoying crayfish! So I was like, oh what a great Christmas this is." He says, laughing.

Craig on holiday in Vancouver, Canada



Craig's happy-go-lucky attitude played a part in his recovery - as well as the support from LBC. "We went to the support groups in Tauranga, Auckland and Sean's online Zoom meetings. It's fantastic what LBC do for patients like us."

And, of course there is his wife Janet.

"Janet gets involved when I need help. She thinks I'm the biggest pain in the a** when I'm on Dexamethasone! It's such an intense drug, and it makes me grumpy, and I don't sleep well on it. But, I know this is hard for her as well."

However, Craig is optimistic. After his bone marrow transplant, he was OK for about 16 months. At 52, he retired after working and traveling through his treatments. Now at 62, he's been on a number of funded drug trials which he estimates has given him over 9 'extra' years of life that he may not have had, otherwise.

"Alongside all the other drugs, I've had thalidomide, lenolidimide and pomalide. I've had ALL the 'mides' - I don't think there's anything left! I was a bit of a guinea pig. But that didn't bother me, because it was about the future of the disease and helping patients after me. Remember - keep positive, the brain is a strong tool."

Fast Facts: MGUS

- MGUS is a non-cancerous condition that has a small risk of developing into myeloma (only 1% of those with MGUS develop myeloma every year)
- It does not tend to cause symptoms and is usually not treated, but it is monitored due to the small risk of developing myeloma
- Average age of diagnosis is 70

Support for you, where you are

LBC Support Services cover every corner of Aotearoa – no matter where you are, or your situation, we can be there for you. Check out of some of the ways that our team has supported Kiwis throughout New Zealand.



"It can be wonderfully therapeutic for patients to meet other people that have gone through a similar disease process, at one of our support groups."

Annette Cody and Sharon Verrall, Northern Region



"Some people in our region travel over 4.5 hours to get to their treatment, we often send petrol vouchers to help with these journeys."



Natasha Donovan and Tim Maifeleni, Northern Region



"We facilitate bi-monthly haematology patient groups in six different towns/cities across our region."



Sean Reeves and Rochelle Mills, Midland Region



"We run 58 in-person support groups throughout the Central Region each year."



Sally Black and Nicki Roy, Central Region



"Our area covers 9 hospitals where we do in-service education to the staff."



Helen McDermott, Upper Southern Region



"Families travel from all over the South Island to Christchurch for transplants."

Kate McHardy, Upper Southern Region



"I regularly provide support to patients in 5 hospitals/ treatment centres in the lower South Island and travel approximately 20,000kms per year."

Deborah Tomlin, Lower Southern Region



"We have supported over 6,000 patients and family members all over New Zealand in the last year."



Emma Barker, Head of Support Services

Resources & Support Corner



Connect & Learn

Available online OR in-person

For adults:

Join a personalised support group and share your experiences, advice, and wellbeing tips and meet other people living with blood cancer.

Learn more at an education group with health professional speakers covering a variety of wellbeing and survivorship topics.

Get support with finding work at an Employment Workshop, designed for patients who are looking for new work, re-entering the workforce, or planning ahead due to gaps in employment.

More information for all of the above can be found at lbcnz.link/groups

For children and families:

Check out Kids' Zone for all the resources, support and programmes that LBC has to offer for children and their families affected by blood cancer.

More information: lbcnz.link/kids_zone

Get social:

Follow @LBCNZ on Facebook for updates on LBC's research, advocacy and awareness work, as well as support opportunities.

Join a closed Facebook group 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
@LBCNZConnect
(LBC & Health Professionals Connect)

2023

Blood Cancer Patient Forum

SAVE
THE
DATE

WELCOME EVENT

Friday 15th September
5 to 7pm

FORUM

Saturday 16th September
8.30am to 5pm



The RYDGES, Latimer Square, Christchurch



leukaemia &
blood cancer
NEW ZEALAND

Vision to Cure. Mission to Care.

Call us on: 0800 15 10 15

Email: info@leukaemia.org.nz

Visit: www.leukaemia.org.nz

Mail: PO Box 99182, Newmarket, Auckland 1149

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