

Lifeblood

The difference *you* make

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From Peter

Looking on the Bright Side

While most people were happy to ‘see the back of 2020’ and look forward (with some trepidation) to 2021 – there have been learnings that we would be remiss to overlook.

Kiwis have, generally, embraced change - although we can forget this quickly too. Some of that change has been subtle but heart-warming like our sense of community, recognition of essential workers, family and friends’ importance, and changing work habits. However, other adjustments have tested us, such as dire health risks, lock-downs, travel restrictions, and family members being far away- to name just a few.

One ‘silver lining’ has been our awakening to what technology can do to keep us connected. While technology has always existed but used in a constrained manner, we have recently been forced to use it more than ever. We know that even though it will never replace the human need for being face-to-face – it has provided a few surprisingly positive outcomes for our communities and us as an organisation.

One example was Leukaemia & Blood Cancer New Zealand taking important information online for our Winter-Spring Webinar Series. These weekly webinars, which covered a range of topics, were delivered by various leading experts within our health and well-being world. Each webinar was a bite-size, understandable and interactive session. If people could not join them live, they could view them online, at a time that worked for them. It has created a fantastic set of resources that can provide information and insights to those who want, or need them in the future.

We are indebted to the sponsors and guest speakers that gave and continue to give, their resources and time to allow us to support patients with this level of information and interaction. It has been a great example of still reaching people when access is reduced to a virtual connection.

Peter Fergusson
Chief Executive
Leukaemia & Blood Cancer New Zealand

Information at your fingertips from LBC’s Winter/Spring Webinar Series



10,238
views online



21
different topics



18
expert speakers

If you, or someone you know with blood cancer, needs support please get in touch - we are here to help.

0800 15 10 15

info@leukaemia.org.nz

@LBCNZ

www.leukaemia.org.nz



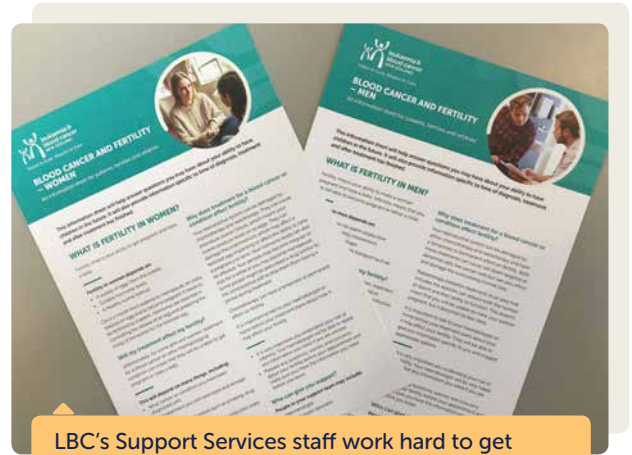
Your support provides ongoing care for people living with blood cancers.

Knowledge is Power

Information in the medical world is always changing and evolving. Here at Leukaemia & Blood Cancer New Zealand (LBC); we strive to keep up with the latest developments and information.

Living with a blood cancer or serious blood condition comes with many question marks. A cancer diagnosis can impact all aspects of life, including how you think and what you may have taken for granted.

That is why the Support Services team has been working diligently to update our information fact sheets and disease specific booklets. Our YouTube channel also contains a vast library of webinars for further learning opportunities. These educational materials are a valuable resource to patients, and their families to refer back to if a question comes up.



LBC's Support Services staff work hard to get patients the information that they may need while living with a blood cancer or blood condition

The new factsheets cover a wide range of topics that include: haemochromatosis, blood cancer and fertility (in men and women), chemo brain, eating well and more.

You can find all of these fact sheets on our website, at <https://www.leukaemia.org.nz/information/information-booklets/>.

A Problem Shared...

Q I am undergoing chemotherapy for my lymphoma, and now nothing tastes the way it used to. Is there anything I can do to help this?

A Taste change is a common side effect of cancer treatment – fortunately, this tends to improve with time once you have completed it.

While there is no immediate fix, there are some things you can do to reduce taste changes. Adding intense flavours to your food such as mustard, chutneys, herbs, and spices can help if your sense of taste has become dulled. A squeeze of lemon juice can also enhance the flavour of your food. Also, swapping metal cutlery and utensils for plastic or wooden ones can reduce a metallic

Melody is a registered dietitian with experience working in haematology wards, clinics, and transplant units both in New Zealand and the UK. Currently on maternity leave, Melody is usually based in Auckland. She enjoys being able to use her skills to support patients and families through all stages of their blood cancer journeys.



taste in your mouth. Maintaining good oral hygiene by regularly cleaning your teeth can also make a big difference. If your taste changes are impacting your ability to eat, you are losing weight, or you have other side effects affecting your eating and drinking, it may be worth speaking to your medical team about a referral to a dietician.

More tips can be found in our new 'Eating Well' factsheet. To receive this, or for more information and support call 0800 15 10 15 or visit www.leukaemia.org.nz/information

Your support funds research to help find a cure for blood cancers.



cure

Leading by Example

From the time that Wellington resident Raewyn Moss's routine blood test came back abnormal to getting in to see her GP - she knew that her doctor was going to diagnose her with polycythaemia vera.

After Raewyn went in for her second round of testing in May of 2014, she began to have an idea of what was going on in her body.

"You get to the blood test place, and they go; oh goodness, this has to go on the urgent courier! At that point, you wonder, what kind of tests am I having?! Of course, then you get back to work and start to google the tests."

Polycythaemia vera is a form of myeloproliferative neoplasm (MPN). There are two other types of MPNs, essential thrombocythaemia and primary myelofibrosis.

While Raewyn had experienced general symptoms such as fatigue, headaches, and even itchiness before her diagnosis - she classically just put them down to having a busy year. Additionally, as a very active individual, she found her passion for tramping became increasingly difficult. To begin her journey, she underwent venesection treatments (which follow a similar process to drawing blood) to address her high haemoglobin levels. It was only after she started to feel normal again, did it click that something had been wrong.

"I got my perkiness back, and I'm like oh crikey that was clearly what it was."

Initially, Raewyn was able to be treated with a combination of aspirin and venesections. After about a year, though, her condition changed, and that was when her doctor recommended she try a mild chemotherapy drug known as hydroxyurea.



Raewyn adventuring through the Great Himalayan Trail in Eastern Nepal

"Up until then, I kind of just thought that I had a blood condition; that it was nothing to worry about. Hadn't done a lot of research into it, to be honest, but when someone tells you that you have to go on a chemotherapy medication, you start to take things seriously all of a sudden."

To find more information on her condition and treatment options, Raewyn began to investigate international advocacy channels, specifically in the United States, the UK and Australia. Since then, working with her haematologist, Raewyn has been instrumental in getting MPNs listed on the New Zealand Blood Cancer Registry. Additionally, she has applied to Pharmac to fund alternative drug options for those living with an MPN.



Your support provides ongoing care for people living with blood cancers.



While trekking along Pico Austria in the Cordillera Real Bolivia, Raewyn is experiencing life to the fullest

“Up until then, I kind of just thought that I had a blood condition; that it was nothing to worry about.”

Raewyn first reached out to LBC in 2018, when she was organising a seminar for Kiwis living with an MPN. From there, she joined LBC's Consumer Advisory Board in 2019.

“People think of blood cancer, and they probably think of leukaemia. It is really easy to think of it quite narrowly. When you start to explore it, you realise that it is a bit more than leukaemia, lymphoma, myeloma etc. MPNs were still quite underrepresented.”

Since becoming involved with LBC, Raewyn says she has seen the number of services the organisation offers patients grow and expand. She highlighted the webinar series held during the lockdown in particular, as they provide access to information on various topics that can be re-visited at any time.

Looking to the future, Raewyn hopes to see the access to haematological care spread throughout rural New Zealand. Since most haematologists are based in the larger cities, it leaves those living in other areas of the country in the dark regarding education on their diagnosis. Access to up to date medical information is vital - especially for those living with conditions that may not get the exposure that others do. That is why she says initiatives such as LBC's that provide essential information to GPs and public health nurses are so important.

“As long as we are supported through agencies such as LBC, we can lead a relatively normal life. We can still continue to give back and contribute to society - possibly even in ways that other conditions can't.”



Fast Facts: Myeloproliferative Neoplasms (MPNs)

- An overproduction of red blood cells as well as platelets and white blood cells
- In most cases MPNs develop slowly over many years
- Treatment may include the use of oral chemotherapy or other agents

**Your support funds research to help
find a cure for blood cancers.**



A Time to Reflect

Laura Bonney was eight weeks into her nursing career when she was diagnosed with blood cancer.

Laura's path to a diagnosis started in August of 2017 when she couldn't shake a particular symptom:

"I had just had itchy skin for months and months. I had been treated for skin infections; he treated me for scabies. He was like I don't know what is going on, but you know your body."

Her GP ran tests, but nothing caused the alarm bells to sound for her doctors until she went back in December with lumps in the front of her neck.

After running various tests, with nothing coming back abnormal – Laura's doctor referred her to a surgeon in January for further biopsies.

"By the time I actually got an appointment with the surgeon, it was the end of February. It was two weeks from the time I saw him to when he diagnosed me with Hodgkin's Lymphoma."

When asked about her diagnosis, Laura admits it was scary but chose to look at her cancer journey as a positive force in her life. She used the time to reflect and ask herself some difficult questions. The one that sticks out for her was the simple, yet challenging question;

"If this was my time, would I be happy?"

That is a sobering thought for most people - but it is the reality that cancer patients face every day.

Fortunately, Laura responded well to chemotherapy, is in remission, and completed treatment in September 2019.

When asked about Leukaemia and Blood Cancer New Zealand (LBC), Laura describes it as a "family".



Laura and her parents celebrate her final chemotherapy treatment at Canopy Cancer Care in Tauranga

"The youth and young adults group has really brought together a group of people that I can chat to who have dealt with something similar. They might have a different diagnosis or might still be going through treatment but we've all been there. I still go to the youth events, and I think that really became my cancer community."

Laura says that when her Support Services Coordinator, Rochelle Mills, mentioned the educational sessions that LBC offer, she jumped at the opportunity. She highlights one in particular that addressed the process of getting in contact with Work and Income

New Zealand (WINZ) to apply for a disability benefit.

"I was only working part-time, and I found it so difficult to navigate. LBC had this education session where they told me to speak to this person who is their liaison with WINZ, and that they would talk to me about what I was eligible for and what LBC could help me with. I was like, oh, amazing!"

It is support like this that is at the heart of what LBC do.

"You don't know what's around the corner. I think contributing to LBC is so important to me now because by doing that, you are helping build a community for people like me who felt so lost and so alone."

☝ I still go to the youth events, and I think that really became my cancer community. ☝



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The Personal Touch

While the world spent 2020 battling COVID-19, Dean Cole had another challenge thrown into the mix - being diagnosed with blood cancer.

Dean says that his body first tipped him off that something was wrong when he woke up with chest pains on a Sunday morning.

"I thought I had just slept quite awkwardly and I didn't really think too much of it. But over the period of about five days, it became really, really intense. I was at work, and I couldn't do anything. I couldn't breathe."

From there, Dean went to visit his GP who saw him right away. She ran a whole bunch of tests, which included a chest x-ray and some bloodwork. His results showed that he was slightly anaemic, along with a few other 'abnormalities'. It was then that his GP referred Dean to a haematologist who ordered a bone marrow biopsy.

"He got me back in a couple of days later and said that it was myeloma and that we needed to get me started on some treatment, quickly!"

This news came in January 2020, but his symptoms started in the middle of December 2019.



Dean and his family with their dog Milo at their home in Christchurch

"We were on edge over Christmas. It was quite scary."

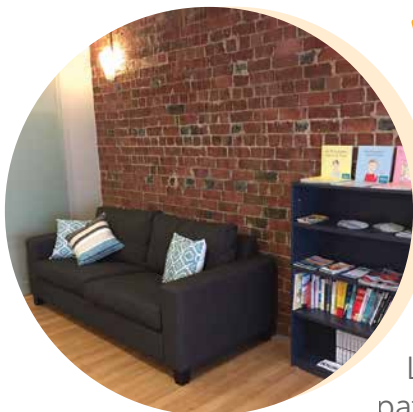
Despite his concerns over a potential diagnosis, Dean and his wife Jasmin decided not to tell their daughters (Anika who was 6, the twins Aaliyah and Jayde at 7, and 9 year old Maea) until they were sure. Their response, when the couple did tell them, was one that we can all take to heart:

💬 We still see you as you. 💬

Dean had a stem cell transplant in July, and throughout his journey has since kept in contact with his Christchurch-based LBC Support Services Coordinator, Matthew Eby, who had made contact with him within days of his diagnosis. The couple's four daughters also attend the LBC Kids' Club, which he says they thoroughly enjoy. Dean summarised these key touch points in one word, "support".

"A random phone call from Matt every now and then to see how I'm doing is quite heart-warming. It's these little things, like showing you they care."

Winds of Change



Heads up Wellingtonians - your local Leukaemia & Blood Cancer New Zealand Support Services office has moved. You can now find us at 11 Riddiford Street (next door to our previous location), and we look forward to seeing you there.

In other Support Services news, LBC is excited to announce Nicki Roy joining the team in Wellington and Sean Reeves in Hamilton. LBC's Support Services team are the instrumental force in helping patients in their respective communities nationwide.

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A Malaghan Institute scientist conducting research

Bringing cutting-edge treatment to Kiwis – a Vision to Cure



There's been a lot of news over the past year regarding a revolutionary new approach to fighting cancer called CAR T-cell therapy on trial at the Malaghan Institute of Medical Research.

This option is cutting edge, and takes a patient's immune cells (the T-cells) and re-directs them in the laboratory to identify and attack cancer cells. They then return the modified T-cells to the patient to start destroying the cancer cells.

A phase 1 safety trial called ENABLE was started at the end of 2019 for people with certain types of relapsed and refractory B cell non-Hodgkin Lymphoma who have exhausted other treatment options. Dr Robert Weinkove leads it as the Institute's Clinical Director. He is also on LBC's Medical and Scientific Committee.

LBC has a close relationship with the Malaghan Institute. Thanks to our donors' support, we have assisted with funding to ensure that this trial is available for patients across New Zealand.

The Institute is based in Wellington, so before the commencement of the trial, LBC provided travel grants for nursing staff from Wellington Hospital to receive intensive training in Australia where some "second generation" CAR T-cell therapies are now licensed for use on certain types of leukaemia and lymphoma.

With the trial underway, your donations enable travel and accommodation support to be available for patients outside the Wellington Region. About 12 patients are anticipated for this early exploratory phase trial. The data collected will be closely analysed with the option to lead to a phase 2 trial with more thorough tests.

In the long term, these T-cells could not only attack cancer cells but provide long-term protection against relapse, similar to a vaccine. Good things take time, and it's early days, but with your help, LBC is delighted to support the Malaghan Institute's ground-breaking research and stride toward our Vision to Cure.



Find us on Facebook @LBCNZ or join one of our Facebook groups

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@LBClymphoma
@LBCMyeloma
@LBCChronicLeukaemia
@LBCAcuteLeukaemia
@LBCYoungAdults
@LBCBloodDisorders
@LBCParentsGroup
@LBCMPN
@LBCBereavement
@LBCHaemochromatosis
@LBCNZConnect (LBC & Health Professionals Connect)



Vision to Cure. Mission to Care.

If you would like to get in touch:

Call: 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