

Lifeblood

The difference *you* make

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From Peter

Changing times

These days I'm often reminded of the John Lennon quote "Life is what happens to you while you're busy making other plans".

I know many of you will have experienced the uncertainty and stress that unexpected life events can bring, perhaps through your own, or a loved one's cancer journey - or because of other life challenges.

It was obvious when the first reports started to come in of a novel Coronavirus taking hold across the globe that life would be changing radically for many of us and that blood cancer patients would be particularly vulnerable to the infection.

We knew that we would need to change our plans, increase the help we give to patients, and adjust the way we deliver support to ensure patients, families, and staff are kept safe.

In addition, the fundraising events we rely on for income to run essential support services would be postponed indefinitely – leaving a substantial hole in our budget.

As a designated Essential Service, the team here at LBC has been working round-the-clock through all levels of lockdown to change the way we do things and maximise the care, support, and practical help we give - especially to those who are most isolated and alone. Just a few examples of this work are:

- ✓ Increasing the help we give to the most vulnerable patients by keeping in close contact by phone, text, and online.
- ✓ Providing emergency financial support to people who are struggling with the basics like nutritious food, help with transport to treatments, and parking costs at hospital.
- ✓ Stepping in and organising deliveries of groceries and essentials to the most vulnerable patients.
- ✓ Providing online support groups and live Q & A sessions for patients and families with haematologists, pharmacists, and other health specialists.

Maintaining this support comes at a financial cost, and we are doing all we can to ensure it can continue – because as we all know, virus or no virus, cancer will not rest.

With this in mind, if you are in a position to donate, and would like to do so, I would ask that you please complete and return the enclosed form or donate via our website at www.leukaemia.org.nz/donate.

Any donation of any size is especially appreciated in these difficult times, every dollar makes a difference and will be put to immediate work ensuring our patient services and blood cancer research continues.

Thank you for your consideration and generosity. Stay well,

Peter Fergusson
Chief Executive
Leukaemia & Blood Cancer New Zealand

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



0800 15 10 15



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

Parents find strength

There are few things more devastating than your child being diagnosed with cancer.

Often children have to spend long periods in hospital and undergo distressing treatment with mum or dad by their side. It's a stressful time for the whole family and parents, in particular, feel the strain.

Registered nurse Tim Maifeleni, LBC's Northern Regional Manager of Support Services, identified a gap in support for parents. Many were feeling isolated and overwhelmed and needed an opportunity to meet and share stories.

Tim enlisted the help of Dr Deb Perrott, Psychologist and Director of Lifespan Counselling and together they created a



Having a child in hospital is more difficult than ever under COVID-19 conditions

monthly group for parents. As Deb explains:

"Most of the parents refer to Tim as "The Legend"! The shared learning within the group is powerful, it's a safe place for parents to talk about having a child with cancer. Some folks start out uncertain and end up being the biggest advocates. Every shared experience offers something for someone in the group."

Update: To ensure safety during COVID-19, support for parents has moved online.

A problem shared...

Q I've been diagnosed with chronic lymphocytic leukaemia (CLL) but my GP says the best thing is to just monitor me rather than start chemo, I am really worried and confused and my daughter says I'm being fobbed off – what should I do?

A It can be difficult to be told you have cancer but don't need treatment straight away and it's not unusual to feel worried. Family and friends might also find it difficult to accept this situation.

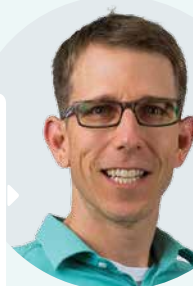
Watching and waiting before starting treatment (often referred to as 'active monitoring') can be very stressful and you may have a lot of questions.

Talking to your GP or one of LBC's support services team like myself can really help and we can answer any questions you may have or refer you to a support group or counsellor.

CLL does not usually need treatment when it is first diagnosed and for many people, it may never need to be treated. However regular blood tests are recommended and you should see your doctor if you experience any changes or an increase in your symptoms.

For more information and support, or to receive the "Monitoring CLL" factsheet, call 0800 15 10 15 or visit www.leukaemia.org.nz

Matthew Eby, Southern Regional Manager of Support Services, has supported thousands of patients and families affected by blood cancer. He strives to provide support that meets their emotional, practical, and financial needs.



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



Lockdown brings back memories

Kath initially thought her symptoms of fever and lower back pain were due to stress and the travelling she had to do for her job. She explains:

"I was living in Australia and decided to change my job and move back to NZ, but within a few months, I was feeling worse. I could hardly walk and had a constant cough and back pain plus my ankles were really swollen."

Kath was back and forth to the GP but it took over a month before she was sent for blood tests, the results weren't good. Kath had acute myeloid leukaemia (AML) and was immediately referred to Christchurch hospital to begin chemotherapy:

"It was a shock. Initially, I responded well to chemo and went into remission. Things were looking good and we decided to move to Geraldine and get back on with life."



Kath at Christchurch Hospital during treatment



Back to health and all dressed up for the races

Sadly Kath's remission didn't last, within 12 months she was back in hospital:

"Facing relapse was daunting - it was hard to get my head around. Going through chemo again and having to decide about a stem cell transplant felt like "do or die" - it was tough."

Travelling from Geraldine to Christchurch was adding a financial burden to the already difficult challenges of treatment:

"The second time around things were getting overwhelming on the financial side - I was feeling the pressure but didn't want to bother the nurses. My LBC Support Coordinator came in, asked a few questions, and it opened the flood gates. She let me know about travel allowances, psychological and other support available, and helped with petrol vouchers."



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Kath will soon be returning to her "no hair" look - this time for Shave for a Cure!



Having someone from LBC who wasn't part of the medical team, wasn't family, wasn't a friend so was one step removed was really helpful.

Thankfully Kath's treatment went well and her brother was a perfect match for stem cell transplant. However, it wasn't all plain sailing, especially after leaving hospital:

"When I was in hospital I was running on adrenaline - as long as I was getting day to day instructions I was OK. When I got home it got harder. I was grateful for having my health back but readjusting to life was hard, I think that's when LBC's support is so important - when you cut the cord with the medical side they really come into their own."

A trip to the supermarket during lockdown triggered a flood of memories:

"I remember being just out of hospital and how nervous I felt being in public places - I'd gone to the chemist and flipped out because I didn't want to be hanging about with sick people - it was similar to how it feels under lockdown."

Kath is passionate about helping other people with blood cancer and the current COVID-19 pandemic has prompted her to take part in Shave for a Cure:

"Going into lockdown everybody was asking "What does this mean?"; "How am I going to do this?" "Will I be OK?". It's the same with blood cancer - there are so many questions. I appreciated the support LBC gave me and want to fundraise for them because they really need it."

Kath shared her story on TV3's The Project and plans to shave in June. You can donate to her fundraising page at www.blood-cancer.online/20.



Fast Facts: Acute Myeloid Leukaemia

- Causes overproduction of immature white blood cells which prevents bone marrow from making normal cells
- People with AML can bruise or bleed easily and be more susceptible to anaemia or recurrent infections
- Following treatment, many patients achieve complete remission. However, sometimes the disease can reoccur and additional treatment is required

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



Your support made the difference

When you spend time talking with Justin Waipouri you are struck by his soft-spoken determination and the values he holds dear – family, hard work and making the most of life - it's difficult to imagine how much this young husband and father has already been through.

Justin's story began when he was living in Melbourne and suddenly began to feel unwell. He explains:

"I had a lump on my leg and one day I started to feel feverish and had body shakes, the doctor thought I had an infection and prescribed antibiotics."

The antibiotics didn't help and Justin felt worse so went back to his doctor who sent him straight to hospital, as Justin says "it all started from there."

What was to follow was a five-year fight for survival for the then 21-year-old.

The hospital team initially focused on Justin's leg, he underwent four surgeries and became so unwell that he spent five weeks in an induced coma.

Justin was dangerously ill and doctors were stumped, eventually, he was referred to the hospital's haematology team who undertook more tests which finally led to the correct diagnosis.



Tim was there to support Justin and his family

When Justin awoke from his coma wife Skye gave him the devastating news - Justin had Non-Hodgkin Lymphoma.

Justin's treatment began in Melbourne and after six months in hospital, he was well enough to fly home to New Zealand to continue treatment. He explains:

"I had three years of different chemotherapy but it wasn't working until my specialist put a special dose together for me – I had hard core chemo to wipe out my immune system and then a stem cell transplant from my mum."

Justin was too unwell to work, and with a young family to support, finances were tight.

“LBC helped me to get to my treatments and to my appointments - it helped me out big time.”

Thanks to the generosity of LBC's donors, Tim, one of LBC's support team was able to help with petrol vouchers to enable Justin to get to his treatments. Tim kept in close contact with Justin visiting him in hospital and making sure he and the

family were well supported throughout his long treatment. As Justin says:

"LBC helped me to get to my treatments and to my appointments - it helped me out big time."

Justin continues to do well and is giving back to young people facing cancer by Co-Chairing the Adolescent and Young Adult Cancer Advisory Group who are helping shape policy of the newly established Cancer Agency.



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GP education

LBC's Deborah (Deb) Tomlin is a registered nurse and just the kind of person you want in your corner if you're going through blood cancer. Deb is tenacious in her approach and dedicated to working with other health providers to ensure patients can get the best possible outcomes.

"My colleague Julie Smith, a Clinical Nurse Specialist, and I identified that there was a need for more education and support for GPs serving rural communities and those parts of NZ without permanent haematology services."

In the absence of specialist services, GPs in these communities were managing more and more aspects of blood cancer patient care. But without specialist training, they were becoming concerned about a lack of equity for their patients.

In most instances, patients in urban areas are able to access regular appointments with specialist haematology services whereas outside of these areas, many patients are left having to rely upon GP services.

Deb set about organising education evenings in Southland, delivered by a consultant haematologist who gave up her time to help ensure GPs had access to the latest clinical information and were more able to support blood cancer patients in their care.

The evenings were accredited under The Royal New Zealand College of General Practitioners continuing professional development scheme and were very well received by all those who attended.



GPS and nurse practitioners attend LBC's Southland session

So far 80 GPs and nurse practitioners have been through the programme and Deb plans to extend it to other parts of the South Island with LBC colleagues also implementing the scheme in other parts of the country once lockdown is over. As she says:

"The feedback we've had has been really positive with GPs saying how it has helped them provide better care and information to patients and also a better understanding of the set-up of the haematology service so they know how to go about asking for help on behalf of patients."

“... there was a need for more education and support for GPs serving rural communities and those parts of NZ without permanent haematology services.”

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KISS - a Vision to cure



Dr Peter Browett in
his research lab

Thanks to the support of thousands of people who choose to chip in and donate, LBC is working towards a Vision to Cure that strives to ensure that one day all Kiwis with blood cancer will have access to treatments that will help them defeat their cancer.

One project currently funded through donations is a Phase II clinical trial known as KISS (Kinase Inhibition with Sprycel Start-up). KISS is recruiting newly diagnosed CML patients from hospital haematology clinics across the country.

As part of the trial, patients will undergo a treatment plan using two drugs called tyrosine kinase inhibitors (TKIs). TKIs are already known to be effective in helping many CML patients, but this innovative trial is doing things a bit differently.

The KISS trial aims to determine whether there is an advantage for patients to start on the newer, more potent inhibitor Dasatanib (known as Sprycel) in order to achieve a faster remission, and then switch to the current, older drug Imatinib (commonly known as Glivec) to maintain their cancer in long-term, ideally life-long remission.

Whilst blood cancer research is carried out all over the world, our history of settlement and migration makes New Zealand's population unique, so for New Zealanders to gain the most benefit from research, it's critically important trials like this are carried out here.

Consultant Haematologist and Professor of Pathology, Dr Peter Browett, is the lead investigator for the KISS trial. As he explains:

"I frequently see patients in my clinic who have very few options left for recovery from their blood cancer – too many lives are being cut short by this disease. That's why research is so vital."

Ultimately, the discovery of improved treatments, and ensuring New Zealanders have timely access to them, will revolutionise outcomes for all types of blood cancer.

Thank you for helping make the Vision to Cure a reality through your donations and support.



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@LBCLymphoma

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@LBCYoungAdults

@LBCRareBloodCancers

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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, Christchurch, Dunedin, Hamilton and Wellington