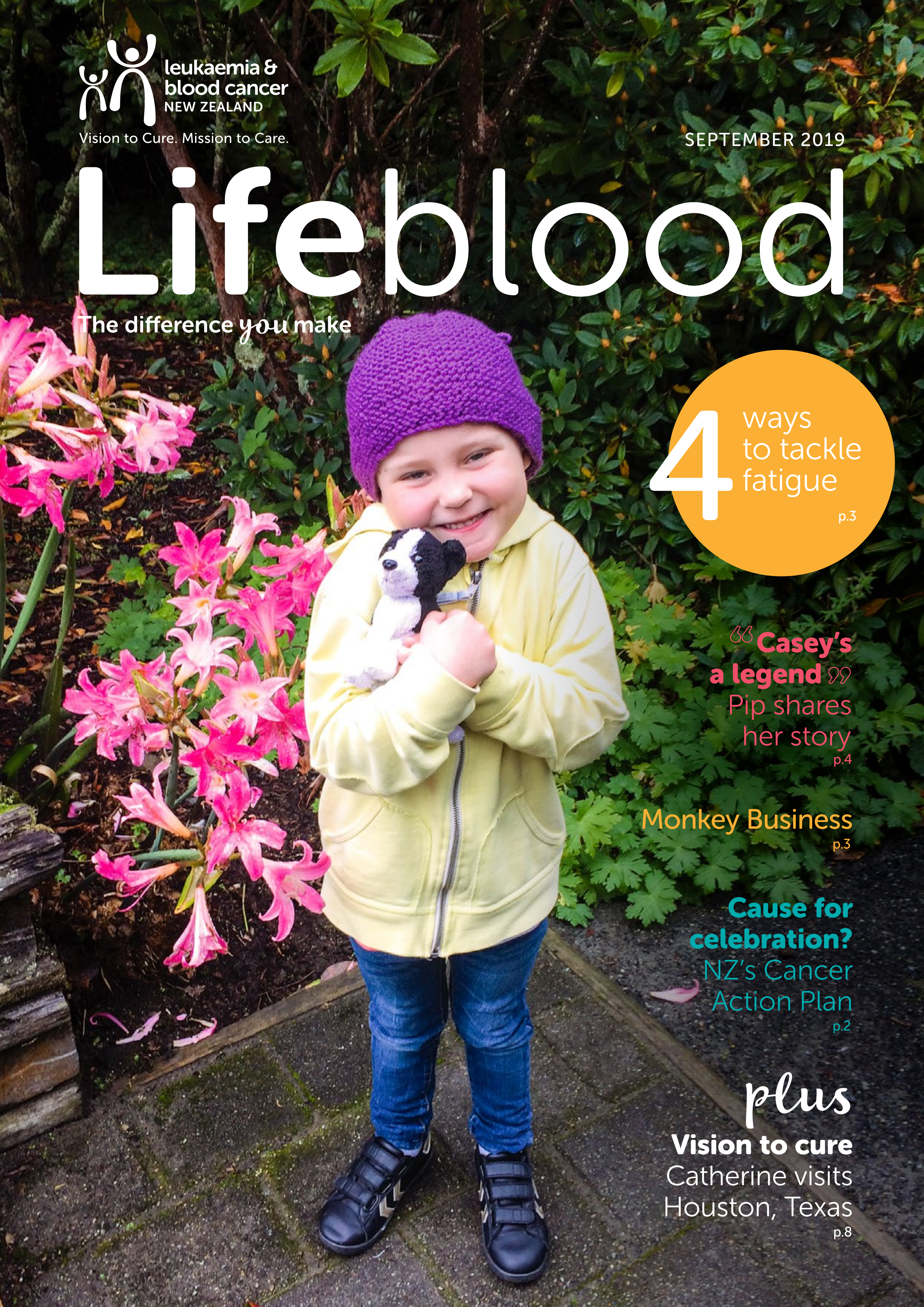
leukaemia & blood cancer
NEW ZEALAND
Vision to Cure. Mission to Care.

SEPTEMBER 2019

Lifeblood

The difference *you* make



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From Peter

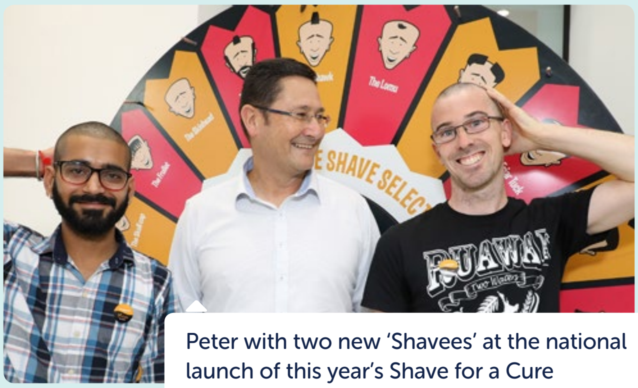
Cause for celebration?

The Government's recently announced Cancer Action Plan is welcomed, as is the announcement by Pharmac that Venetoclax will finally be funded for Chronic Lymphocytic Leukaemia – great news!

There are aspects of the plan that deserve celebration, like the creation of a National Cancer Control Agency and additional funding for Pharmac.

However, beyond those two specific items the remainder feels like a 'plan to have a plan'. My initial exuberance is tempered by the realisation that there are few targets, few timeframes and minimal investment identified.

New Zealand has one of the highest cancer rates in the world with 46% of men and 33% of women developing cancer before age 75. As our population ages, these numbers become even more daunting, with cancer diagnosis expecting to double over the next 15 years.



Peter with two new 'Shavees' at the national launch of this year's Shave for a Cure

The agency will be tasked with ensuring consistency of care; equitable survival outcomes; fewer cancers and better cancer survival overall. An immediate priority will be establishing performance indicators to measure cancer care across DHBs. Whilst the agency will provide centralised leadership, it needs investment at ground level to deliver these improvements.

This investment is not yet evident and remains my key concern. With your support, I'll continue to ensure the voices of blood cancer patients are heard and kept at the forefront of policy changes and cancer investment decisions made by Government.

Best wishes

Peter

Peter Fergusson
Chief Executive
Leukaemia & Blood Cancer New Zealand

What *your* donations achieved in the last 12 months

1,385
new patient and family referrals

4,687
patients and families supported by LBC's Support Services team

3,302
people attended 330 support groups

✉ If you would like a copy of the full report, email **Sarah.Frayne@leukaemia.org.nz**

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

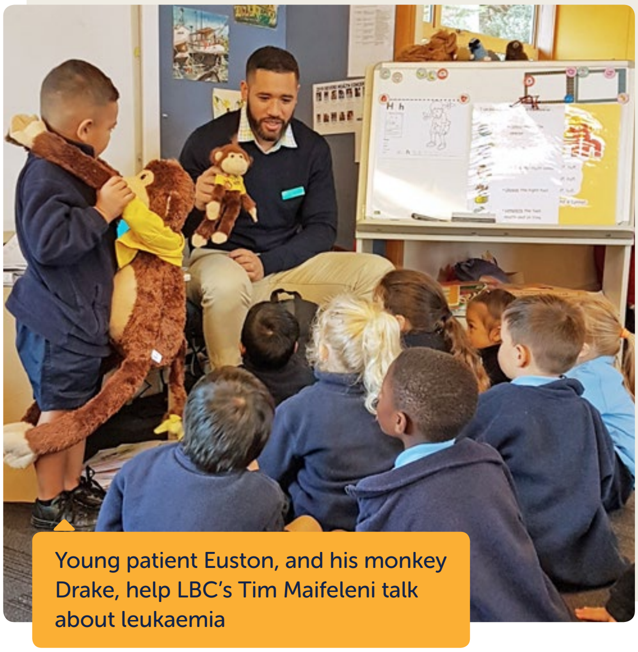
Monkey in Euston's *chair*

Monkey in My Chair is an innovative programme designed to keep young patients connected to their classmates while they undergo treatment.

When a young person is away from school, the bigger of two monkeys sits in their chair, while the smaller monkey keeps them company in hospital or at home.

Each Monkey in My Chair kit comes with a range of educational books, teacher guides and Leukaemia & Blood Cancer New Zealand (LBC) resources.

LBC's Support Services staff talk with the patient, parents and school about blood cancer and how classmates can help ensure their friend is kept safe when they are able to return to school.



Young patient Euston, and his monkey Drake, help LBC's Tim Maifeleni talk about leukaemia

Classmates are encouraged to include Big Monkey in lessons and send messages and news to their friend using Big Monkey's bright yellow backpack.

A problem *shared...*

Q I finished chemo six months ago but still feel exhausted no matter how much I sleep, is this normal?

A Feeling worn out after treatment finishes is common and can be a symptom of 'cancer-related fatigue'.

People with fatigue are often incorrectly advised to limit activity, but cancer-related fatigue isn't improved by rest. In fact, inactivity can cause muscle weakness, increased stiffness and pain, and can make fatigue worse.

There are things that can help so it's important to speak with your doctor as soon as possible – together you can make a plan to help manage your fatigue.

Tips for managing fatigue

- ✓ Track symptoms in a diary – this is helpful information to discuss with your doctor
- ✓ Eat well and drink plenty of water
- ✓ Keep a normal sleep routine
- ✓ Take regular, gentle exercise

Your doctor may order additional blood tests, make sure any pain is under control and talk to you about managing feelings of stress, anxiety or depression.

LBC provides information and support, to find out more visit www.leukaemia.org.nz or call 0800 15 10 15

Based in Christchurch, Helen McDermott is part of LBC's Support Services team. She is a registered nurse and provides practical & emotional support to patients & families.

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

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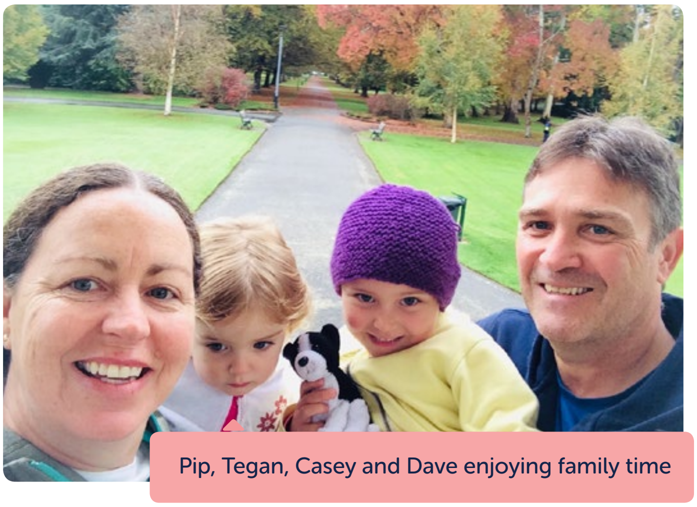
The *long* road

When Pip McIlwrick's four-year-old daughter Casey came home from Kindy feeling run down with a sore neck, Pip didn't have any idea of the long road that lay ahead. She explains:

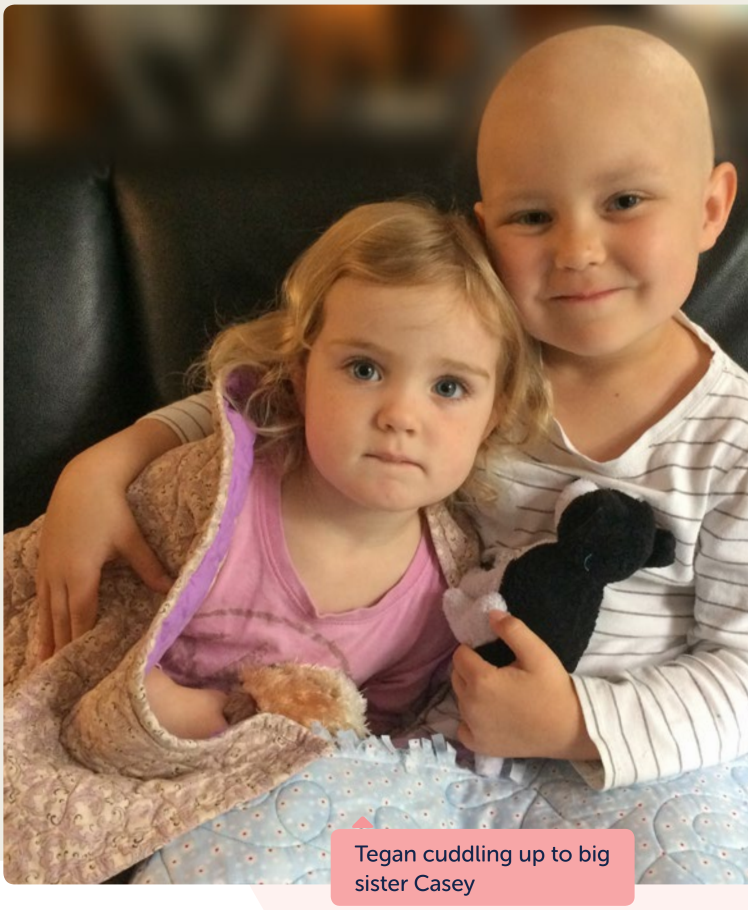
"I took Casey to the doctor just to be sure – he thought it was a virus and said she'd be fine. After a few days she was worse, I was really worried so took her back to a local GP and said, 'Look at her hands and feet, they're yellow, she can't even walk any more. We need help!'"

The doctor put in an urgent call to the paediatric ward at Invercargill Hospital and Pip took Casey there straightaway. The team did blood tests and confirmed she'd need a blood transfusion and IV antibiotics. Pip rang her partner who works in the mining industry in Western Australia:

"Dave's out in the middle of nowhere, it takes him 24 hours to get back to NZ. I rang him and said, 'I don't know what's going on but you need to get home.' He was in shock."



Pip, Tegan, Casey and Dave enjoying family time



Tegan cuddling up to big sister Casey

Casey was transferred by air ambulance to Christchurch Hospital:

"I felt completely numb. They took us to oncology and I remember thinking, 'Why are we here? It's a virus, Casey hasn't got cancer!'"

Sadly, bone marrow tests confirmed Casey did have cancer – she was diagnosed with Acute Lymphoblastic Leukaemia (ALL):

"We spent four months in the hospital – Casey was a legend – she's an incredible little girl and coped really well. I thought to myself, 'If she can be so strong and positive, so can I.'"

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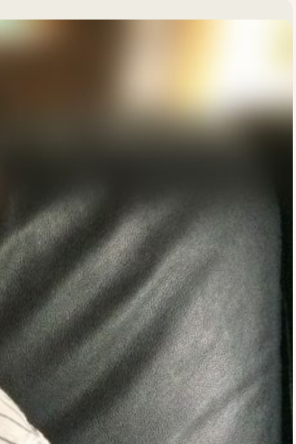
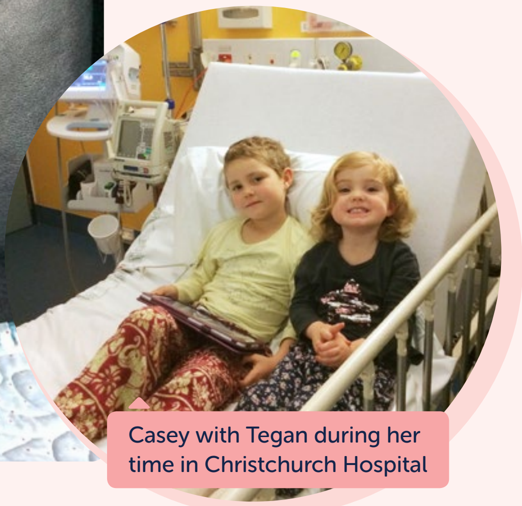
> ...the bond between them is beautiful; they're best friends and very protective of each other.





Casey with Tegan during her time in Christchurch Hospital

Pip would need help though and was put in touch with LBC:

"Deborah from Support Services called me, she's so knowledgeable and approachable, it's easy to retreat into your shell but Deb made it easy for us to reach out and ask for help."

Deb encouraged Pip to attend one of LBC's local support groups:

"I was nervous about going but it was good to connect with others who've walked the same path and are going through the same emotions and hardships."

Casey is currently in her sixth round of chemotherapy and has another 15 months of treatment ahead of her.

It's been hard on the whole family, as Pip explains:

"Casey's little sister Tegan has grown up a lot over the past year as she's watched Casey go through treatment. The bond between them is beautiful; they're best friends and very protective of each other."

The family still has a long road ahead but things are progressing well:

"We've got to keep doing what we're doing. My message to others going through this is to accept help – don't be too proud to say 'yes' as the right help can really take the pressure off."

Fast Facts: Acute Lymphoblastic Leukaemia

- A cancer where bone marrow makes too many immature lymphocytes
- The most common type of cancer in children. Occurs in adults but with less frequency
- Can appear suddenly and progress rapidly
- Improvements in diagnosis & treatment means the majority of children will achieve remission and most will be cured

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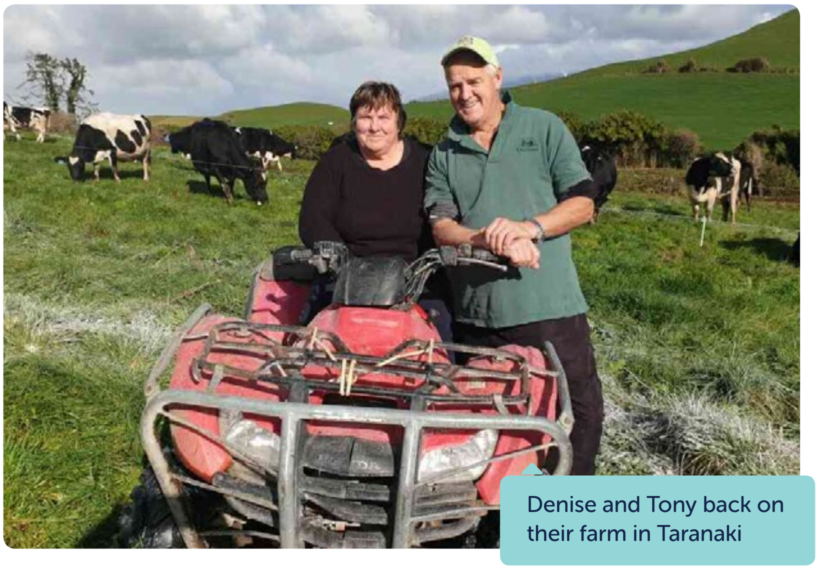
Support makes all the difference

When dairy farmer Tony Dravitzki from Taranaki experienced chest pain, cancer was the last thing on his mind. He explains:


Denise and Tony back on their farm in Taranaki

“The A&E in New Plymouth tried to find out what was wrong, they’d eliminated obvious things, but as a last effort did a bone marrow biopsy … that’s when they found I had Acute Lymphoblastic Leukaemia (ALL). It was a bolt from the blue – I was told it was rare for somebody my age because it’s more common in young people.”

Tony was diagnosed on Sunday, by Thursday he was in Palmerston North hospital having his first round of chemotherapy. It was a huge shock for his family:

“My wife Denise has been alongside me every step of the way – she was managing the farms and looking after me in hospital, and our three daughters kept the home fires burning.”

> **“I feel like I’ve aged! But I’m back to full farm duties and playing around with one or two slow race horses... so life’s good!”**

Tony had three rounds of chemo before travelling down to Wellington for a stem cell transplant from his brother Michael.

As soon as Tony and Denise arrived in Wellington, LBC were in touch to make sure he had all the information and support he needed. Thankfully his transplant went well and three months later Tony was home continuing his chemotherapy and anti-rejection medications.

It wasn’t all plain sailing though, soon after getting home Tony experienced symptoms of depression and anxiety:

“It was a surprise to us and not something that is talked about – but we found out afterwards it’s really common. It was harder to come to terms with the mental health stuff than the cancer. If someone had told me I’d be going to a psychiatrist and psychologist, I’d say they’d be the ones needing their heads read, not me – but it really helped!”

Tony and Denise also joined LBC’s support group in Taranaki:

“The group has people at all different stages – some just diagnosed and some who’ve been through the mill for years. I find it rewarding when somebody asks how we coped – you can see their spirits lift when they realise someone has gone through it and come out the other side.”

Tony is finally finished with his chemotherapy and as he says:

“I feel like I’ve aged! But I’m back to full farm duties and playing around with one or two slow race horses….so life’s good!”

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Choosing to be happy

When 26-year-old Noelle graduated from Auckland University she was thrilled to receive a job offer in Wellington – but life took an unexpected turn:

"I felt a lump on my collar bone, I thought it was a pulled muscle but went to my GP to be sure."

Noelle's doctor ordered blood tests, a chest X-ray and an ultrasound. Everything seemed normal but to be certain, Noelle was referred for a fine needle aspiration.

The results weren't due for a week, by which time Noelle had moved to Wellington. In the very first week in her new home she received a call from her Auckland GP:

"She said, 'Your results came in, you need to make an appointment with a GP'. I was worried, I thought if she can't tell me over the phone it must be bad."

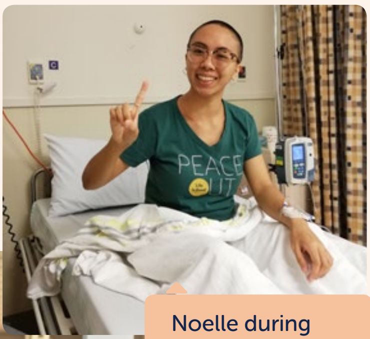
Noelle quickly found a new GP:

"He sat down, looked me straight in the eye and said, 'We think you have lymphoma.' From then on everything was a blur."

Noelle was alone in a new city and facing a diagnosis of cancer.

She decided to move back to Auckland to be with family. Within a week a biopsy confirmed Stage 2 Hodgkin Lymphoma, Noelle then began six rounds of ABVD chemotherapy:

"Towards the end of treatment I felt quite down and isolated, so I got in touch with LBC and spoke with Dónal. He made me realise my feelings were normal and referred me to a psychologist. Dónal kept in touch and had great information about my lymphoma, which really helped."



Noelle during her first round of chemotherapy

A positive outlook helped Noelle get through her treatment

Noelle finished her last treatment in May:

> **"The specialist said I had a 'full metabolic response'. I wasn't sure what he meant, but then he said I was in remission – it was the best news!"**

In July, Noelle moved back to Wellington and started her job. Apart from experiencing fatigue and some late effects of chemo, life is getting back on track:

"I'd say to anyone going through blood cancer to get in touch with LBC, they have great resources and can get you the help you need. I also think having a positive attitude helped me, treatments have improved a lot over the last 20 years and the outlook for many blood cancers is good."

Noelle shared her cancer experience on Instagram, you can follow her @choosingtobe.happy

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Vision to cure

Clinical Nurse Specialist
Catherine Wood

One of the cornerstones of LBC's 'vision to cure' are the research grants your donations provide to enable scientists and clinicians to further their work seeking improved outcomes for patients.

In addition, LBC's travel grants enable New Zealand's brightest and best to attend national and international scientific meetings and conferences, where they can learn developing best practice to apply to their work with blood cancer patients back home.

Catherine Wood is a recent grant recipient – a Clinical Nurse Specialist at Wellington Hospital, Catherine coordinates bone marrow transplants (BMT) for recipients from all over the mid and lower North Island as well the Nelson and Marlborough region.

Catherine works with health professionals to coordinate donor and patient care before and after transplant and is involved in the education of nurses, junior doctors and allied health staff:

> "I was fortunate to attend the Transplantation and Cellular Therapy meetings in Houston in February this year. As a registrant for the conference, I was able to dip in and out of any of the sessions, which were very stimulating and thought provoking."

"One highlight was a session on secondary cancers that sometimes occur post BMT and recommended screening and preventative practices. Another session looked at what can be done to diagnose and treat bone loss and osteoporosis in BMT recipients.

A session on sexuality and fertility was also a timely update on a much overlooked topic. Doctors often don't discuss this important quality of life issue so it was good to have an update and some practical tips for bringing it up with patients."

Thanks to your support, nurses like Catherine will be able to apply their learning to improve outcomes for New Zealand patients.

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

@LBCCarers
@LBCLymphoma
@LBCMyeloma
@LBCChronicLeukaemia
@LBCAcuteLeukaemia
@LBCYoungAdults

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Or visit one of our Support Services offices in Auckland, Christchurch, Dunedin, Hamilton or Wellington