

# Leukaemia Today

Supporting people *living* with leukaemia

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books

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“How a  
puppy got  
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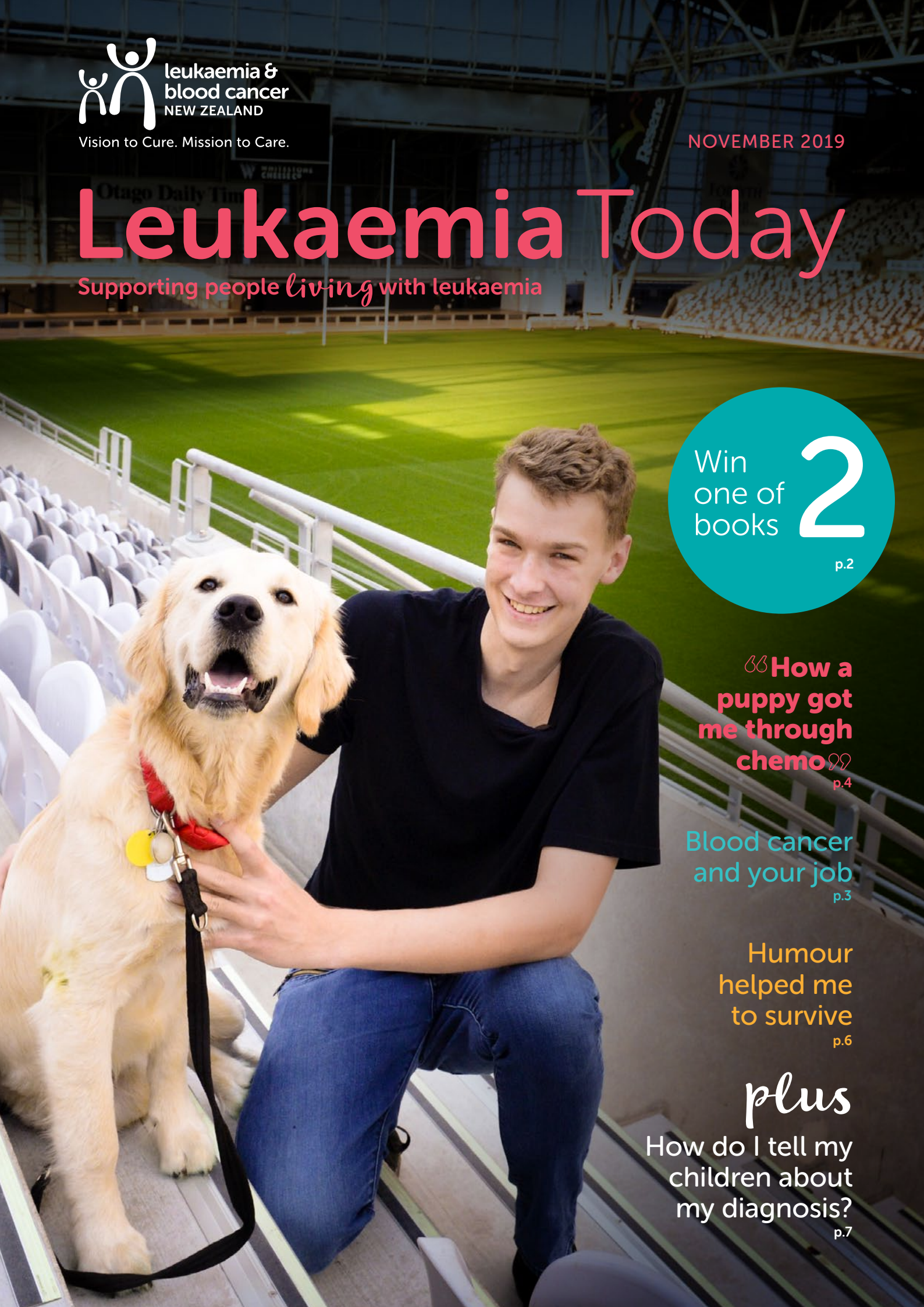
Humour  
helped me  
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# Inspiration corner

Recommended reading from patients and carers on the LBC Consumer Advisory Board.

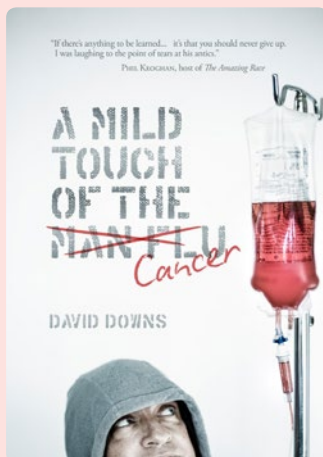
## A Mild Touch of the Cancer by David Downs

An amazing account of David's journey with blood cancer.

He documents the highs and lows of his diagnosis and treatment journey, including travelling to Boston to get revolutionary CAR-T cell therapy. Written with joy, curiosity and humour, this isn't just a story about cancer, it's about living with optimism. Highly recommended.

LBC supported David and his family through blood cancer treatment. He has generously donated the profits of his book to LBC.

Order a copy from [www.mildtouch.nz](http://www.mildtouch.nz) (audio and kindle versions available).



Thanks to David we have two copies of this book to give away. Just answer this simple question:

What is the 0800 number for Leukaemia & Blood Cancer NZ? (Hint: it's on the back page).

Email the answer and your contact details to [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz) (please insert the words 'Magazine Competition' in the email subject line).

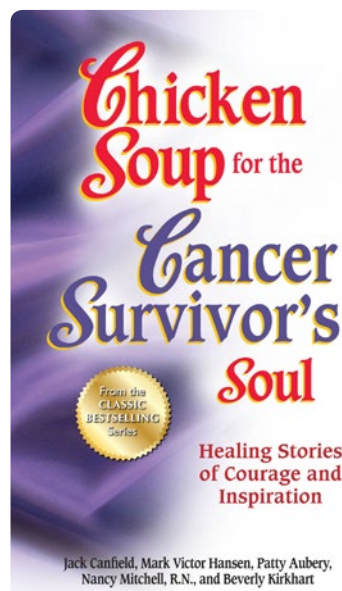
## Chicken Soup for the Cancer Survivor's Soul

"This is the book that someone gave me when I was in a very difficult place managing my illness. Not specific to blood cancer, but a collection of stories from patients and their families that are uplifting and inspiring."

This is a handy book for when you go through treatment and heal. You and your loved ones will benefit from the wisdom, calm strength and advice – it's a reminder you are not alone.

Order this book, with free world-wide delivery from [www.bookdepository.com](http://www.bookdepository.com)

*The LBC Consumer Advisory Board represents the patient and carer voice. They give LBC feedback on support services and resources.*



Front cover photo credit: Otago Daily Times



Get inspired, borrow a self-help book from the LBC library at your local support office

# Blood cancer and your job

**LBC has a series of handy online resources to help people understand and negotiate their rights for medical leave at work.**

People living with cancer who are employed may need additional time off for specialist appointments, treatment and recovery. The good news is help is at hand. New Zealand legislation gives patients flexibility and options for requesting time off due to an illness like cancer.

Get tips on how to communicate this sensitive topic at work. Find out about your leave entitlements, government support, flexible working arrangements, whether you have to disclose your medical history, medical retirement and much more. There is even a guide for employers.

These courageous conversations with your employer should be positive and collaborative. In most cases, your employer will be supportive. However, if you feel you have been treated unfairly and need extra help to navigate this issue, call LBC for support.

A big thank you to Naomi McRae from PwC who helped to create these resources. LBC supported Naomi on her cancer journey, and we're happy to share she's been in remission for over eight years.



## **Blood cancer and your job: [www.blood-cancer.online/job](http://www.blood-cancer.online/job)**

Topics include:

- Employment rights fact sheet
- Flexible working entitlements
- Government support
- Medical retirement
- Returning to work
- Conversations with your employer
- A guide for employers



*"When I got diagnosed with blood cancer, I thought, what does it mean for my career? My employers were understanding, and together we came up with a plan to manage my illness at work -I realise not everyone is as fortunate. I worked alongside the HR team and in-house legal team at PwC. I also used my knowledge as an HR specialist to develop a set of resources to help LBC patients with cancer-related employment issues."*

**Phone 0800 15 10 15 for a catalogue  
of blood cancer resources**



# How a puppy helped me through chemo

**Shortly after his 21st birthday Alex Yarnell was feeling unwell and thought he had the flu. When he couldn't shake it off, he decided it was time to visit the GP.**

Alex explains: *"I knew something was wrong when the doctor put me in a side room to chat about my blood results. Before I could take a breath, I was bundled into an ambulance with the sirens going and the lights flashing, speeding to the hospital."*

In a strange twist of fate, Alex ended up in Dunedin hospital where he worked part-time as an orderly while completing his engineering degree. Ironically his mother, Tamsin worked there too as an orthopaedic nurse along with Alex's father, who is a doctor.

*"I remember the look of disbelief on my colleague's face when the ambulance door opened and they wheeled me into 'my work' on a stretcher,"* says Alex.

Further hospital tests confirmed that Alex had acute myeloid leukaemia. The doctor rang Alex's father, Nicholas first. Nicholas felt overwhelmed, and his heart dropped thinking about how he would break the news to his wife, Tamsin.

Tamsin remembers that moment clearly:

*"Nicholas was choking back tears and said, 'I've got some terrible news... Alex has leukaemia'. I was completely devastated; Alex is a 6'7" basketball player and just beginning his life. We both dropped everything and rushed to his bedside."*

Alex went on to receive multiple rounds of chemo, blood transfusions, and his brother donated stem cells for a bone marrow transplant. His basketball team also rallied around.



*"...I don't know what I'd do without him."*

*"They wore orange patches – the leukaemia support colour – on their uniforms. My blood transfusion was a lifeline, so the whole team decided to lend a helping hand by giving blood together."*

Meanwhile, Tamsin was receiving support of a different kind from Deb at Leukaemia & Blood Cancer New Zealand (LBC).



**Share your story ideas.  
Email [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz)**



Alex with Chemo as a puppy

“...He gave me something to focus on apart from my health.”

*“We met for coffee and Deb gave me advice and literature and suggested I attend a support group. I’m glad I went, it was helpful to rationalise what I was going through with others on a similar journey.”*

Alex’s chemotherapy and transplant started to take its toll, he was losing the stamina he once had. Then his mother had a bright idea that would change his life.

*“I promised Alex the family would give him a puppy as a special gift for getting through his transplant and chemotherapy. It was the light at the end of the tunnel and something he dearly wanted,”* says Tamsin.

Alex named his furry companion, Chemo.

*“Chemo helped me to heal, especially when I got home from the hospital. He was great company while the family were at work. Chemo got me out and about each day as I would take him for a walk. I felt physically stronger with every walk we did. He gave me something to focus on apart from my health,”* says Alex.

Alex is feeling well now and has some words of wisdom for those living with cancer and considering a new pet.

*“Make sure someone in the house will care for your pet when you’re unwell or in hospital. It’s a big responsibility, but worthwhile. Chemo is very special to me, and I don’t know what I’d do without him.”*



Alex, Chemo and his younger brother (left) who donated his stem cells



## Share My Pet

Share My Pet is a service where pet owners temporarily share their pet with someone in the community who doesn’t own one. An ideal service for patients with pets, living by themselves and undergoing treatment. Membership is free for LBC patients. Simply create your online profile, make it live and contact Share My Pet who will make it free for you. Go to [www.sharemypet.co.nz](http://www.sharemypet.co.nz)

**Register for Blokes with Blood Cancer group phone chat on 0800 15 10 15**



# Humour helped me to survive

**Sonia's evening started just like any other, as a caregiver in Christchurch. That is until she collapsed in the middle of her rounds, and her life took an unexpected turn.**



Sonia and her family

*"I was dizzy and staggered to find a chair but collapsed. It was scary because it was 2am and I was working alone," says Sonia.*

Sonia visited the doctor the next morning to get blood tests with her mother.

*"The doctor said: 'I'm sorry for delivering bad news, you have leukaemia and you've got less than an hour to get to hospital'. I felt numb and couldn't talk. Then Mum gasped: 'Don't let my daughter die!'"*

Sonia's husband of 12 years, Alex dropped everything to take her to the hospital.

*"They told me chemo was starting soon. It was a blur and I remember thinking, but my socks are mismatched and I'm still in pyjamas."*

Sonia's family are proud of her strength and resilience. These qualities carried her through a rollercoaster of health complications over the next year. Her trump card for overcoming adversity above all is her quirky sense of humour.

*"I lost circulation to my feet after an infection. My toes were different colours and looked like mixed vegetables, so I named them all. The big toe was pumpkin, the little toe was potato and the ones in between were kumara, carrot and peas. I lost potato in March and then all the others.*

**☝ I'm a survivor, I can laugh at myself. Even without toes, I've got lots to be thankful for. ☝**

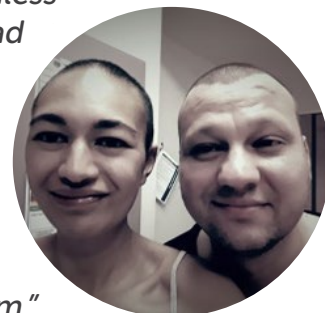
*I'm a survivor, I can laugh at myself. Even without toes, I've got lots to be thankful for."*

Ady, the LBC Support Services Coordinator, visited Sonia in hospital. She gave her a leukaemia booklet, information on the LBC Kids Club, and an invitation to join a local support group and patient beading workshop.

*"I learned to make jewellery at the beading workshops, it was part of my healing. I felt a kinship with the other women living with blood cancer and lasting friendships were formed. Kids Club is run by a psychologist, and she was like my guardian angel – for the first time, my daughter was opening up and expressing her emotions."*

Sonia is in remission now and credits her recovery to her husband, who was like a rock in tough times.

*"He stuck by me for endless weeks in hospital. He had no sleep, was living on coffee, and never left my bedside. He even shaved his hair off to match my bald head during chemo. I dedicate this story to him."*



**Connect with patients like you on Facebook @LBC chronic leukaemia**



# Say it share it

with Tim Maifeleni, Northern Region Manager, LBC Support Services

**Q** I have recently been diagnosed with a blood cancer. How do I tell my children and help them to adjust?

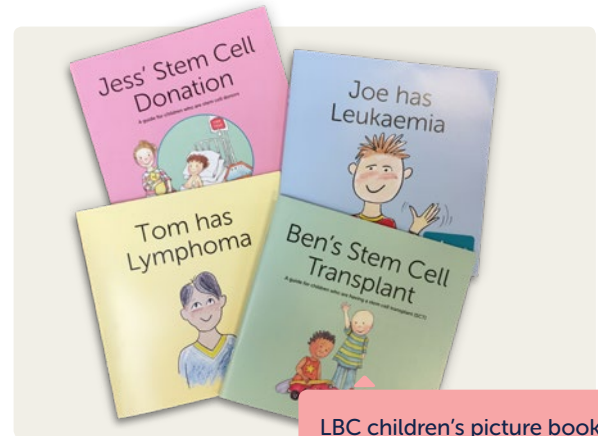
**A** A conversation like this is never easy. We have resources to help you talk with your children. For example, picture books will help them to understand cancer and the treatment journey. It is also a good idea to explain changes in your life and how it will affect them.

Use the LBC sticker diary to record your treatments and ask children to write and share journal entries with you.

Check out the guide for parents, 'Supporting a child through a loved one's cancer diagnosis'.

Have an open dialogue with your child's school, making them aware of your diagnosis including how it affects family routines and relationships. If you are concerned with how your child is coping, please tell us so we can make a counselling referral.

We run a Kids Club for 5–12 year olds, to help them cope with a loved one's diagnosis of blood cancer. It is hosted by psychologists and play therapists and is available in Auckland, Hamilton and Christchurch (coming to Wellington soon).



LBC children's picture books

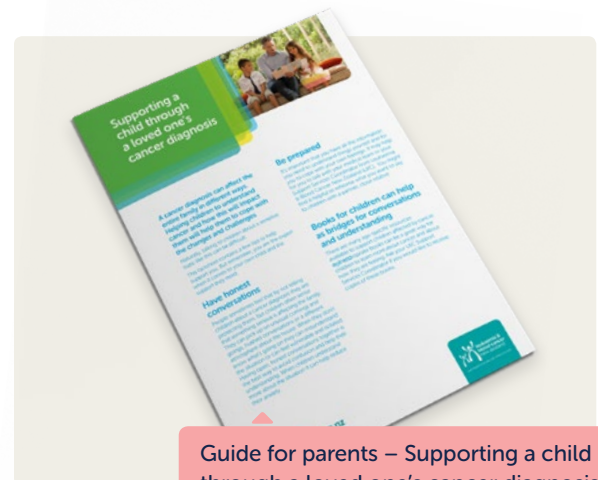


LBC sticker diary



## Resources

Resources are available at [www.leukaemia.org.nz](http://www.leukaemia.org.nz) or phone us on **0800 15 10 15** if you would like them posted.



Guide for parents – Supporting a child through a loved one's cancer diagnosis

Connect with patients like you  
on Facebook @LBC acute leukaemia



# Support Directory



**Support Groups** are hosted nationwide in a casual coffee and chat environment. Share experiences, exchange advice, get well-being tips and meet others in a similar situation. To find a group near you go to:  
[www.blood-cancer.online/support](http://www.blood-cancer.online/support)

**Education Groups** are nationwide with health professional speakers covering a variety of well-being and survivorship topics.

**Blokes with Blood Cancer** hosts a group phone call every six weeks. Create some banter with the lads who 'get' what you're going through. Phone Matt to register on 0800 15 10 15.

**Kids Club Support Groups for Children** 5–12 years, to help them cope with a parent or sibling living with blood cancer. Hosted by play therapists and psychologists in Auckland, Hamilton and Christchurch (coming soon to Wellington). Call LBC on 0800 15 10 15 for more details.

**LBC Blood Cancer Patient Forum** is a conference in 2020 for patients and carers to educate on well-being plus the latest in research and developments with blood cancer. All LBC patients will be notified closer to the time.

**Clinical Trials** information is available on a downloadable app called ClinTrial Refer NZ. Find out which hospitals are hosting suitable trials and your eligibility to join.

**LBC General Facebook Page @LBCNZ** is for everyone, including your friends, family and acquaintances. Win free stuff, listen to blood cancer podcasts, watch LBC on the news, learn about developments in the blood cancer space and much more.

## New Resources available:

- ✓ Revised AML booklet
- ✓ Blood cancer and fertility fact sheets
- ✓ Blood cancer and your job

You'll find these and many other resources online at [leukaemia.org.nz](http://leukaemia.org.nz). Phone LBC for more information or if you would like them posted.

**The LBC Library** located in every support office has many fiction and non-fiction books you can borrow. They are designed to educate, uplift and inspire those living with cancer.



**Closed Facebook Groups** allow you to connect online with others who understand the challenges of blood cancer. It's supportive and informative – there are groups for carers and young adults too.

- @LBC Chronic Leukaemia
- @LBC Acute Leukaemia
- @LBC Lymphoma
- @LBC Myeloma
- @LBC Carers
- @LBC Young Adults