

Lymphoma Today

Supporting people *living* with lymphoma



Win
one of
books

2

p.2

Blood cancer
and your job
p.3

☺☺ **Ronnie's
making a
run for it** ☺☺
p.4

Why men need
to talk about
their feelings
p.6

plus

How do I tell my
children about
my diagnosis?
p.7

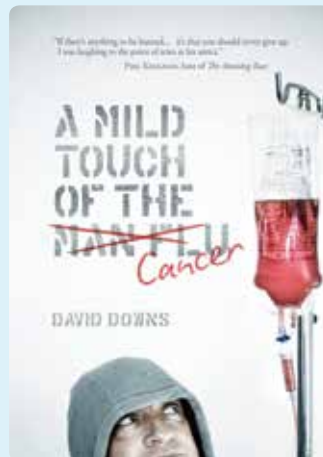
Inspiration corner

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 (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 (please insert the words 'Lymphoma Today Competition' in the email subject line).

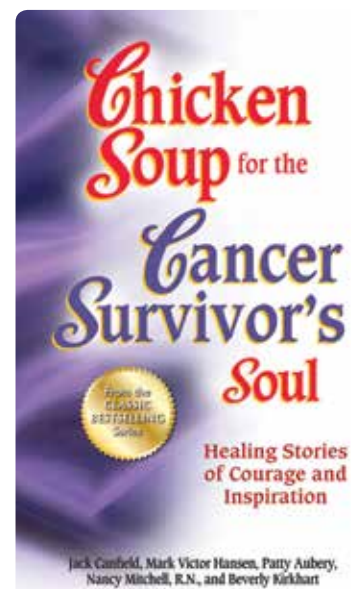
Chicken Soup for the Cancer Survivor's Soul

"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

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



Front cover photo credit: Alistair Guthrie, NZ Life & Leisure



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.



Naomi McRae

"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."



Blood cancer and your job: 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

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



Ronnie makes a run for it

Originally from Lesotho in Africa, Ronnie Reid has called New Zealand home for over 40 years. The 70-year-old has always been fit and healthy, so wasn't too worried when she found a small lump behind her ear. However, when it became really painful she went straight to hospital, and that's when life took an unexpected turn.

"They did a biopsy on the lump and couldn't find anything, so I went into surgery. After the operation, the doctor told me I had lymphoma. I didn't even know what that was!"

The doctor explained it was a cancer of the lymphatic system and Ronnie would need to start her first round of R-Chop chemotherapy as soon as possible. As Ronnie explains:

"During chemo, I was exhausted, I felt terrible! It was awful because I couldn't get out and do the things I loved."

Ronnie's Kiwi husband passed away many years ago but thankfully she has the support of her neighbours just a few steps away.

"I love doing my gardens, but I just couldn't get out of the house to do them when I was having chemo. My wonderful neighbours wanted to help so much that they were fighting over who was going to pull out my weeds!"

Ronnie's neighbours are like family in sickness and in health. Her bond with them continues to grow, and she still has weekly dinners with them today. Ronnie is also touched and forever grateful for the support of her stepsons and their wives.

"They were so good at looking after me. They would take me to my appointments, so I never missed a single one."



Ronnie loves spending time with her granddaughter

"I always told myself to be kind, happy and positive, and I will be ok. It really worked!"

One of the hardest parts of her treatment was not being able to do the running and walking she loves so much.

Women in Lesotho were discouraged from running because it was their job to cook, clean and look after children so Ronnie's passion for running began in 1979 when she arrived in



Share your story ideas.
Email info@leukaemia.org.nz



Ronnie has competed in over 600 walking and running races since moving to New Zealand

New Zealand. Since then she has competed in more than 600 walking and running events.

"I came to this new country, and I saw people running a lot, and they all looked so happy. I thought maybe I should try it too and loved it straight away. It was really hard not being well enough to do my running!"

After she finished her final round of chemotherapy, Ronnie's clinician ordered a CT scan.

"When the doctor told me I was in remission – I was overjoyed!"

Despite constantly battling fatigue, the doctor encouraged her to get back into walking, starting with small distances. Ronnie first attempted to walk around the block, but headed home after just two minutes because she was totally exhausted.

"The first walk was so hard, but I wanted to keep trying. I set myself small goals such as walking for 10 minutes then when I could do that, it was 15 minutes, and I kept going until I was ready for small races again. It was good to be back on the competing circuit. I've known the same runners and walkers for many years, and everyone was so happy to see me racing again."

Ronnie is slowly working her way back to half marathons and says the support she received from her family, church, neighbours, Dove Hospital and Leukaemia & Blood Cancer New Zealand (LBC) has helped her through it all.

"Sharon from LBC would always phone to check on me. She also sent petrol vouchers, which were really helpful. Just hearing her voice always cheers me up and lifts my spirits," says Ronnie.

Ronnie is amazed at how far she has come since her diagnosis – she believes her positive attitude played a huge part in her recovery.

"I always told myself to be kind, happy and positive, and I will be ok. It really worked!"

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



"It's ok for men to talk about their feelings."

At 27 years of age, Kent was looking forward to the next chapter of his life, he was enrolled at university to follow his dream of becoming a secondary school teacher.

Normally an enthusiastic and motivated student, six months into his diploma Kent found he was really struggling. He was facing the prospect of having to abandon uni and his life-long career passion.

"I was always exhausted and dragging myself around campus. When I woke up in the morning, my bed was drenched with sweat. I lost heaps of weight, and my stomach was sore. It was difficult to get out of bed, let alone do my assignments," says Kent.

Kent's doctor put him on a special diet to settle his stomach pain. The diet didn't help, so he got a second medical opinion that changed his life forever.

"After a biopsy and scan, the doctor told me I had stage four lymphoma. Hearing the news was like watching a film of someone else's life playing in front of me. My spleen and lymph node in my stomach was swollen, which explained the stomach pain. I was tired because my body was running overtime making white blood cells."

Kent banked his sperm at the advice of his haematologist before starting six cycles of ABVD chemotherapy. Infertility can be a risk with chemo, and Kent knew he wanted to be able to have children in the future.

Over the next two years Kent went through chemotherapy, a lymphoma relapse and a stem cell transplant. Teaching was put on the back-burner while he focused on his recovery.



Kent has learned some life-long lessons in his journey back to health

“I’m a stronger and more open person now – and that’s a good thing!”

"When I was out of the doctor's hands and back at home, I was struggling to get back on track emotionally and physically. I lost confidence. With every small ailment I would get paranoid it was another relapse."

Kent's mother was worried and contacted Tim at Leukaemia & Blood Cancer New Zealand (LBC) to find a support group for him.

"The support group was therapeutic. It was a relief to meet other patients with a deep understanding and compassion. I didn't feel like I was alone anymore. It's ok for men to talk about their feelings. If you don't, then pent-up emotions will surface in all sorts of unhealthy ways."

Continued



Connect with patients like you on Facebook @LBC lymphoma

Kent attended the LBC Blood Cancer Patient's Forum, where he connected with a network of other patients and made some great friendships. Kent's life turned a corner at the forum when he was introduced to Ian from Randstad, who is part of LBC's Return to Work programme.

"Ian connected me with a mentor to get me back into the classroom again – it was a big milestone."

Kent is now teaching full-time and has been in remission for several years. He has learned some important life-long lessons in his journey back to health.

"As a male, I felt it was my role to provide, and I couldn't be vulnerable. Meeting other patients encouraged me to open up emotionally. It was a new experience to talk about my feelings. I'm a stronger and more open person now – and that's a good thing!"



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'.

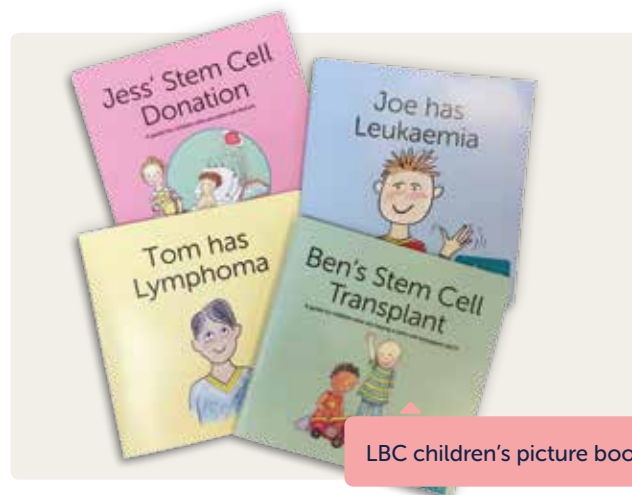
Have an open dialogue with your child's school, making them aware of your diagnosis including how it affects family routines and relationships. If you are concerned with how your child is coping, please tell us so we can make a counselling referral.

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).



Resources

Resources are available at www.leukaemia.org.nz or phone us on **0800 15 10 15** if you would like them posted.



LBC children's picture books

Find a support group near you
www.blood-cancer.online/support



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

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. 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