

Lymphoma Today

Supporting people *living* with lymphoma

Five tips to
support your
wellbeing

p.3

'We had a bit
of a *battle*
on our hands'

p.4

More than
alive –
kicking!

p.6

Navigating
your *journey*

p.7

plus

Resources and
support corner

p.8



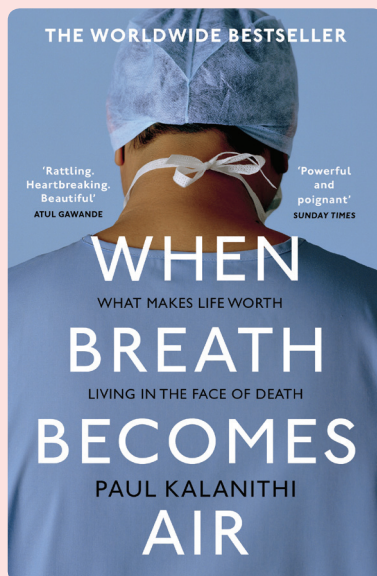
Inspiration corner

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

Fatumata Bah

“When *Breath Becomes Air* by Paul Kalanithi is a memoir about a 37-year-old neurosurgeon who loses his battle with lung cancer and leaves behind his 8-month-old daughter, and his wife.

While it may seem morbid to recommend a book about dying – it is really about the meaning of life. I found the book to be quite profound and a timely reminder of how precious life is.



Dr Paul Kalanithi's story spoke to me and ironically helped me through a tough and dark time with my sickle cell disease. I loved this quote from the book...”

“Even if I'm dying, until I actually die, I am still living.”

Ask the Chief Executive

Q. What is LBC doing to support patients, especially through the COVID-19 pandemic?

A. Behind the scenes, LBC has been working hard to advocate on behalf of patients. With everything going on in the world right now – vulnerable people could get left behind but we're doing what we can to make sure this doesn't happen for blood cancer patients.

LBC is constantly pushing for those who are making key decisions around COVID-19 in New Zealand to keep patients and their families top of mind. LBC has been looking at access to Rapid Antigen Tests,



Peter Fergusson,
LBC Chief Executive

pushing for Blood Cancer patients to be included when it comes to treatments and working with different agencies that have an influence on outcomes.

Please rest assured – the safety, wellbeing and survivorship of patients continues to be LBC's top priority. While we support organisations and groups involved in decision-making, we also hold them accountable. We're working

hard to help them explore and implement robust, long-term solutions. Our goal is to get better outcomes for our patients now, and further in the future, with our vision to cure.



Get inspired! Borrow a book from the LBC library at your local support centre

Five tips to support your wellbeing

Hi! Tracey Hancock here. I'm a blood cancer survivor and a life coach, and I wanted to share with you some of my own tips on supporting your wellbeing.

The past two years have been filled with uncertainty and worry for many of us. But as a cancer patient, COVID-19 isn't all you've had to deal with. Perhaps you've just been diagnosed, or maybe you're well into treatment or further along in your journey.

Wherever you are, if you haven't already, take a moment, pause, and acknowledge how much you've been navigating.

While you've hopefully had a lot of support and resources to help, there isn't a map or guidebook for your own situation. Have you had time to reflect? You might not realise how much you're carrying mentally and emotionally.

It can be hard work to consistently show up for appointments, treatments, and simply live and work as best as you can – let alone processing the thoughts, worries and fears you're experiencing.

But, we can work on this.

1. Begin with the basics

Stay hydrated, eat well, rest, move if you can, and connect with loved ones. These things all make a difference, and they can easily fall by the wayside when we feel stressed and anxious. Choose 1 or 2 to focus on.

2. Write it down

Having trouble with working through your thoughts and feelings, or identifying what your next steps are? Journaling can be a great way to manage this. If it isn't your thing, talk with someone you trust instead.

3. Prioritise your self-care

What do you enjoy doing (and can do given your current situation)? Make that a priority. It might be phoning a friend, reading, pottering in your garden, having a bath, or listening to music. Do something, whether small or big, that brings you joy each day.

4. Breathe in, breathe out

Use breathing techniques when you need to calm down and find peace, or strength. Sit comfortably and gently inhale, then exhale. Focus on the sensation and how your body feels. When your mind wanders, or you get distracted, come back to your breath.

5. Ask for help

You're smart and capable – but at times, we all need help! What is stopping you from asking? Remember, if someone you cared about was in your shoes, you'd want to help them, right? It's your turn to ask.

In times of uncertainty, fear and worry can take more of a toll on our wellbeing than we realise. By using these practical tips, and checking in with yourself each day, you can work through any thoughts or feelings you're sitting with, take action and better navigate life's challenges.

About Tracey

Tracey Hancock was diagnosed with Hodgkin Lymphoma in 2015. To help her through the diagnosis, treatment, and recovery stages, she drew on her extensive experience as a life coach. She's since spoken at many LBC events, sharing powerful, practical, and well-tested tools and strategies to help others better navigate the challenges cancer brings. traceyhancock.com.



Go to lbcnz.link/resources to view all of our blood cancer resources



'We had a bit of a battle on our

Imagine – you're in the bathroom, staring at your toothbrush, trying to figure out how to get it wet. Thirty minutes go by and you just stand there, blankly. It's a simple task – why can't you do it? Ross Baker says, "Because you're that fried with the chemo."

'Fried' was putting it lightly. Ross went through a staggering amount of chemotherapy in just his first session - over 100 hours.

This kind of disorientation was unfamiliar for a guy like Ross – a self-described typical Kiwi bloke into muscle cars, competitive golf and spending time with his family.

It all began one day when Ross was struggling at a golf tournament; something felt off. He went to the doctor and had blood tests done at 3pm in the afternoon. By 7pm, he was told to report to the hospital immediately.

"Within a few hours, they found all the tumours through MRIs and scans, and they basically told me to get my lawyer in to set up my will."

Ross was diagnosed with a very rare and aggressive form of double-hit lymphoma. He was told that he had only 5-7 days left in his life.

"I didn't really understand it, because I had still been walking around. I thought... 'you can't be well enough to walk around, and then just die?'"

Ross refused to accept this. His doctor said, *"Well, what's your reasoning?"*, to which Ross replied, *"Look mate, I've got too many people I want to p*** off, before I die!"* His doctor just looked at him, and burst out laughing.

Ross must have been doing something right – as he survived well beyond day number 7.

It was a good thing that he had a sense of humour, because it was only going to get harder from there. *"It was like bang, bang, bang. I basically spent from October until New Year's Eve in hospital, in and out with treatments."*



Ross Baker with Georgia, his daughter and partner Michele

Bang.

One month after his diagnosis, it was his daughter's 14th birthday. He was determined to be well enough to buy her a present, because suddenly, every single day, moment and gift could be their last one together.

Ross bought her a jewellery box for keepsakes. It contained mementos, like the identification band she was given in hospital when she was born.

"The day of her birthday was tough. I broke down that night. I was quite upset."



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

hands'



Fast Facts: Double-hit lymphoma

- An aggressive form of non-Hodgkin lymphoma
- Affects the white blood cells called B-lymphocytes or B-cells
- Relatively rare and makes up approximately 14% of aggressive B-cell lymphomas.

"We got some helium balloons, and my family wrote their own thoughts and messages on them, and let them go. It helped everyone. That's when we realised we had a bit of a battle on our hands."

Bang.

One of the hardest parts about coping with his blood cancer, was managing the feelings of the people around him. *"I had to ask some friends and family to give me space, as I felt all they wanted to do was memorialise me, by crying and taking photos for their memory books"*

"You get people visiting and they're like, 'oh, what have you got?' and they're not doctors. Well...if you're not a doctor, then just say you can't help. And other people say, 'how long have you got to live?' and it's like, 'what, do you want to book your day off work now?"

"Come on, guys. I'm fighting for my life here, and you're asking me when I'm gonna die?"

Bang.

Ross was introduced to LBC Support Groups, through LBC Support Services Coordinator Natasha. While he found the groups useful, he needed his partner Michele with him for support. *"Because when you're in there, it's like white noise. Michele would takes notes and then we would talk about them a couple of days later"*

"I was in insane pain. I wasn't moving around like I was used to, I was vomiting. I wasn't focussed on listening. I was focussed on breathing, trying to get food in, sleeping. Trying to get through the pain."

Ross took a deep breath, he rested, and he got through the pain. Eventually, the initial battle was won, and he came out the other side of his lymphoma. He is doing better today, but he knows that there's a chance his condition could worsen.

"My energy levels are down, so I use a golf cart on the course now. I can't walk around. I'm forcing myself to do some building on the house, but that takes forever. But, I can do stuff. I can walk the dog, I can vacuum the house. I can do the dishes."

Being able to do the little things makes a big difference for Ross, like brushing his teeth or cooking for his partner. And, the meaningful stuff too. Like celebrating his daughter's birthdays.

He's also back on the golf course, bringing his cancer journey full-circle. *"I really pushed myself to do that. I won the club champs, four months after I finished treatment. I won by ten shots, with 65, 65"*

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



More than alive – kicking!

“Why are these pesky mortals doing another medical procedure on me!?” This was running through Wendy Harrex’s mind while in intensive care.

“I got really close to dying. I felt so awful, I was ready to die.” It’s a humbling thought.

Wendy had spent an entire year feeling ill, with her doctor unable to figure out what was wrong. Endless infections, fatigue, and finally symptoms of what seemed to be acute onset rheumatoid arthritis. “I was referred to a rheumatologist.”

On Christmas Day in 2017, before her test results came back, her condition suddenly worsened. She was rushed to hospital, where she was diagnosed with a lung infection – and follicular lymphoma.

She wasn’t shocked or overwhelmed, but grateful that she finally had an explanation. *“Christmas and January are a special time for my family and me, because I almost didn’t survive.”*

Her story includes alternating big scares and rounds of chemotherapy. “Now I’m on a low dosage regime of tablets. It’s chemotherapy that I take three days a week. That has transformed my life and I feel better than I have in four years.”

In fact, just last summer, Wendy dusted off her e-bike, which she had previously been too weak to use, and completed the rail trail in Central Otago.

Wendy had found it hard sitting on the sofa for months during 2018 while facing her diagnosis, and wondering what lay ahead.

Here she gives credit to LBC – although it wasn’t straightforward at first. *“When I first met the person from LBC in the oncology ward, I thought, what’s their job? Soothe the dying brow? I was a bit sceptical.”*

“But subsequently I have attended the patient seminar in Wellington, the Christchurch webinar; my partner has



Wendy Harrex with her e-bike and partner on the Otago Rail Trail, 2021

gone to LBC’s support group for carers (Support Persons Connect) and we’ve seen the development of a really good support group in Dunedin. Contact with other people living with blood cancer has been really important to me.” In short, she has learnt how meaningful LBC’s work can be for patients.

For Wendy, life is for living – *“Try to be positive. Believe that you’re alive and enjoy every day – that’s why I like to say, ‘I’m alive – and kicking!’”*

Fast Facts: Follicular lymphoma

- Represents around 20% of all non-Hodgkin Lymphomas
- Gets its name from the lymphocytes arranged in clusters called follicles within the lymph node
- Affects both men and women, but is slightly more common in women.

Navigating your journey

Check out these useful tips from the LBC Support Services team for maintaining good mental health as you navigate the different stages of your cancer.



RECEIVING THE DIAGNOSIS

Sally Black

"It's normal to feel overwhelmed with all of the medical appointments throughout the first few weeks, especially if you're going to them by yourself. Taking a support person with you is a great idea, because it can allow you to have someone to discuss things with afterwards and to feel less alone."



STARTING TREATMENT

Natasha Donovan

"How's the treatment going?" If answering this kind of question constantly is getting a bit too much, consider assigning someone you trust to be your 'updater'. They can share how you're managing on your behalf. There's also apps you can use. Some people set up a group chat or a Facebook group to communicate what's going on."



RECOVERY

Tim Maifeleni

"It's normal to feel anxious when you have follow up appointments, tests and scans. You have been through a very challenging experience and you might feel wary about good news. Confidence will grow with time. Trust yourself and your doctors that if there is a problem, it will be found. Let yourself relax and enjoy feeling well."



HOME FROM HOSPITAL

Melody Bevan

"Sometimes the adrenaline of being in hospital and going through treatment fades when you are discharged. It's common to feel exhausted when you get home. Allow yourself to slow down and get extra rest when you need it. Don't try to push yourself back to 'normal life' too quickly – that 'normal' will look a little different now, and that's OK."



RELAPSING

Nicki Roy

"Hearing that you have relapsed can be devastating, and if you need us, we want to be here for you. LBC is not connected to the hospital notes, so we may not be aware this has happened. It's important to let us know, so we can do our best to offer you the support that you need to get through this."



LONG TERM SURVIVORSHIP

Deborah Tomlin

"Recognise that surviving cancer can be emotionally challenging. Some people feel guilt and others feel anxiety for the future. This is common, but don't let it overwhelm you. Keep in touch with your loved ones, be kind to yourself and remember how far you have come."

Resources & Support Corner



Connect & Learn

For adults:

Join a personalised support group and share your experiences, advice, and wellbeing tips and meet other people, families and support people living with blood cancer. Available online or in-person.

Learn more at an education group with health professional speakers covering a variety of wellbeing and survivorship topics, either online or in-person.

Get support with finding work at an Employment Workshop, designed for patients who are looking for new work, re-entering the workforce, or planning ahead due to gaps in employment because of treatment. Available either online or in-person.

More information for all of the above can be found at lbcnz.link/groups OR, scan here:



For children and families:

Check out Kids' Zone for all the resources, support and programmes that LBC has to offer for children and their families affected by blood cancer.

More information: lbcnz.link/kids_zone

Get social:

Follow @LBCNZ on Facebook to get the latest news and updates on LBC's research, advocacy and awareness work, as well as support opportunities and developments in the blood cancer space.

Join a closed Facebook group designed to support and inform patients or support people in your situation and connect with others who understand the challenges of blood cancer.

Support for specific cancers and conditions

@LBCLymphoma
@LBCMyeloma
@LBCChronicLeukaemia
@LBCAcuteLeukaemia
@LBCBloodDisorders
@LBCHAemochromatosis
@LBCMPN

Support for young adults and parents

@LBCYoungAdults
@LBCParentsGroup

Further support pages

@LBCSupportPersonConnect
@LBCBereavement
@LBCNZConnect
(LBC & Health Professionals Connect)



Watch

Check out our great selection of talks on YouTube and enjoy a wealth of videos including LBC's 2021 Blood Cancer Patient Forum and recent talks about keeping safe through COVID-19.

Watch here: youtube.com/user/LBFNZ/videos



Read

Read up on our resources about all kinds of topics, issues, challenges and tips for living with blood cancer. More information: lbcnz.link/resources

Browse the LBC libraries and get informed, uplifted, educated and inspired. Each support centre has a collection of books you can borrow. Find your closest support centre here: lbcnz.link/contact



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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