

# Leukaemia Today

Supporting people *living* with leukaemia

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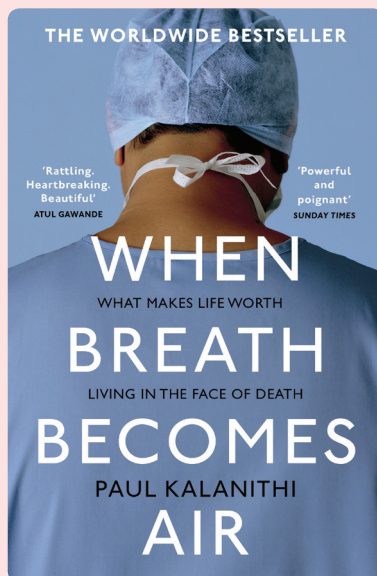
# Inspiration corner

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](https://www.traceyhancock.com).



**Go to [lbcnz.link/resources](https://lbcnz.link/resources) to view all of our blood cancer resources**



# You are enough for your child

***“The doctor called me while I was on my bike ride. She said that Ayla’s white blood cells were low, and I just knew. I had a breakdown on the side of the road and I said to her – ‘It’s cancer, isn’t it?’”***

*“She said, ‘well, we don’t know, and I can’t confirm that but it sounds likely based on her symptoms and her blood results’”*

Yvonne was talking to her doctor about her 6-year-old daughter, Ayla. The school holidays had just ended, and Ayla had been dealing with fatigue and a persistent cough. It seemed like a mild cold and nothing to worry about.

*“But we started thinking, when she didn’t seem well enough to go to school, and even that day, tossing up whether to send her or not...”*  
Yvonne takes a deep breath, holding back tears.  
*“We thought – OK, she’s not well enough to go to school. Maybe the fatigue isn’t linked to the cold.”*

Yvonne and her partner Nathan took Ayla to their GP, who noticed small bruises on her body. She checked her lymph nodes, then her liver, and immediately got on the phone with the hospital to discuss the symptoms. Blood samples were sent off urgently.

This is when their whole lives changed. Ayla was diagnosed with acute lymphoblastic leukaemia (ALL). Then, ten days later, Yvonne’s father lost his battle with pancreatic cancer.

*“I’m really upset that he had to find out about Ayla’s diagnosis before he died. And he didn’t get to see the good outcome on the other end, which we are well on our way towards now.”*

*“I’ve accepted it – mostly – day to day, but there are still moments where I think, is this real? Sometimes I think: I can’t believe I have a child with cancer...I can’t believe Ayla has cancer.”*



👂 **Sometimes I think: I can’t believe I have a child with cancer...I can’t believe Ayla has cancer.** 🗨️

Whereas for Ayla, she processed the diagnosis differently. “She deals with things quietly, but then goes away to think. And she comes back with the most amazing things that make you say – yup, you get it.”

For example, Ayla immediately bonds with people who have nasogastric tubes (feeding tubes), even if they don’t have cancer. She knows some sign language, which was useful at one point when her body shut down, and she almost stopped talking completely. Her signing was a useful tool to communicate with her parents.



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



Ayla and mum Yvonne Bohn in the Butterfly House at Otago Museum

Communication was important, and Yvonne is grateful of LBC's Super Kids' Club for facilitating connections for Ayla. "It's so helpful for Ayla to have contact with other children with leukaemia."

*"In the first Super Kids' Club session, she opened up much more than usual. She asked the other kids whether they also had hair loss, and whether they had nasogastric tubes too...things that took her a long time to come to terms with for herself."*

LBC gave the family a picture book called *Joe Has Leukaemia*, which was immediately helpful for Ayla's brother Mikah. Whilst it took some time for Ayla to engage with it, it helped her do something incredible when she finally did.

*"She wrote her own book called Ayla Has Leukaemia. And when she went back to school, she read it to her class to explain to them what was going on."*

Yvonne could also write a book of everything she has learnt. But her advice for other parents is simple. "Trust that you will learn how to navigate all these things. Know that you're enough for your child. You might not be perfect, but all they need is for you to be there. All the other stuff? You'll learn."

As Yvonne says this, she pauses and attends to Ayla, who is playing with a toy. It's a profound moment which shows that despite having ALL, Ayla is not just a patient but she is a normal seven-year-old girl, who wants to be a kid. And Yvonne is more than a nurse or a carer for Ayla, but she is a mum doing her best. This is not something that Ayla's cancer could ever take away from their family.

*"It's been such a big lesson in learning to say to myself: What's happening right now? when I get carried away. I think – ok, well she's actually having a really good day. Things are really good at the moment."*

*"So, focus on that and enjoy what we're doing right now."*

### Fast Facts: **Acute lymphoblastic leukaemia**

- Affects around 65 New Zealanders each year
- Majority of cases are under 5-years-old
- More common in boys - around 75% diagnosed are male.

Check out Kids' Zone at [lbcnz.link/kids\\_zone](https://lbcnz.link/kids_zone) for resources and support for children and families



# Raising your empathy

***"It was like a military operation, just trying to break the news!" Ian Scott had just received his chronic myeloid leukaemia (CML) diagnosis, and he was trying to figure out how to tell his mum, who lives in the UK.***

*"I phoned my siblings and said – 'look, I need you to go to mum and dad's house, and I'm gonna phone you there. Be there for when I tell her the news.'" Operation: Reveal the Diagnosis had begun.*

Ian knew the news would hit his mother hardest, considering the extensive toll that cancer has had on her family. In fact, this was one of the first things that ran through his mind when he was told by his haematologist that he had CML.

He had the usual questions – like whether he now had a shortened life expectancy; the answer was no. He wondered how his job would be impacted. *"I said, 'What about work?'; and my haematologist said, 'Look, sorry to break it to you, but you're still going to be working!'"*

It turned out that Ian's CML is manageable, thanks to recent developments in treatment. *"I thought to go on treatment, you go on chemo. You don't know what you don't know, right? The natural thinking, is you get cancer, you have chemo."*

But he didn't need chemo. Instead, he was prescribed a drug called Imatinib. Prior to his diagnosis, he spent an entire year struggling with shortness of breath and trouble with intense exercise. Imatinib helped him get all of that under control.

Maintaining 'control' is a theme that sticks out in Ian's story. Early in his diagnosis, he was given some practical advice that helped him navigate his journey.

*"Straight after the diagnosis, I freaked out. My boss calmed me down and gave me a process to follow. He helped me to put structure around how I wanted the conversation with my mum to go. And we*



Ian Scott participating in Step Up Sky Tower Challenge in 2014

*talked about the value of good information - avoid Google and Facebook!"*

Ian learned the importance of meeting other patients. He attended an LBC conference where he was able to connect with other people living with CML. It put things into perspective. *"Their stories were far more troublesome. They had been to hell and back, some of these people."*

This wasn't the first time that Ian had been involved with LBC. He participated in past fundraising activities like the Step Up Challenge Sky Tower in 2014. *"Somebody organised that at work and I thought, 'yeah, they look like a good group of people to support.'" And, since receiving his CML diagnosis, he has continued to support LBC in an advisor role, joining the LBC Consumer Advisory Board in 2019.*

As a senior manager at a recruitment company, Ian knows just how important it is to make genuine human connections with people, especially when you share a major life challenge. *"It raises your empathy, it raises your understanding, and it raises your care factor."*

## Fast Facts: Chronic myeloid leukaemia

- About 50 people are diagnosed a year
- Most people with CML have a gene mutation (change) called the 'Philadelphia' chromosome
- Tyrosine kinase inhibitors (TKIs) are the initial treatment of choice for most people with CML. Imatinib (also known as 'Gleevec' or 'Glivec'), a TKI, was called a 'magical bullet,' when it revolutionized the treatment of CML in 2001.

# 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](https://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](https://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](https://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](https://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](https://lbcnz.link/contact)



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Visit: [www.leukaemia.org.nz](http://www.leukaemia.org.nz)

Mail: PO Box 99182, Newmarket, Auckland 1149

LBC has Support Services offices in Auckland, Hamilton, Wellington, Christchurch and Dunedin