



leukaemia &  
blood cancer  
NEW ZEALAND

Vision to Cure. Mission to Care.

AUTUMN 2022

# Myeloma Today

Supporting people *living* with myeloma

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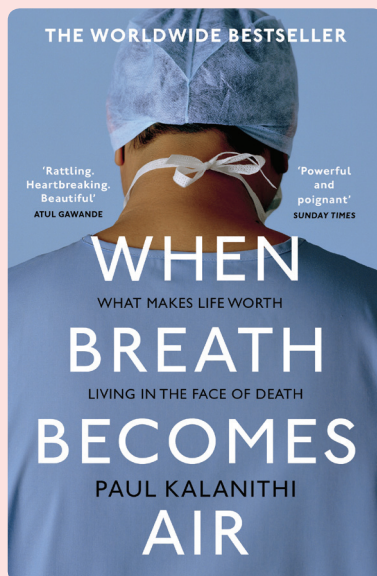
# Inspiration corner

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://traceyhancock.com).



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



# Every journey is different

**“I’ve got ‘myeloma’ and I’ve never even heard of it before!” That was Corley Steunenberg’s initial reaction when she was diagnosed with myeloma.**

The warning signs started appearing in December 2019. “It started with a very sore back. It got so bad that on Christmas Eve, I said to my husband – I can’t get through Christmas without getting some sort of treatment.”

After visiting multiple doctors and getting nowhere, she was finally diagnosed with lambda light-chain myeloma in January 2020. She was shocked. “I was thinking, ‘How long have I got to live?’ It was incredibly stressful.”

*“Thankfully it wasn’t the type that has a shortened life expectancy.”*

Then, before she could even catch her breath, she began treatment in February and she was placed in a clinical trial programme. Because of the fractures in her back, she had to stay in hospital longer than usual, which also meant that her recovery would take longer.

*“I still had trouble doing anything, and that’s why they kept me in hospital for so long. I couldn’t sit up or get out of bed. I couldn’t shower or toilet by myself.”*

When Corley was finally sent home, she could barely walk. She had to learn again, one step at a time. “I had a hospital bed, a walker, and a wheelchair.” She also had a very supportive husband who helped care for her.

Time passed slowly during her recovery, and her mind would often drift toward dark places. *“I sometimes wondered if I could have avoided the fractures.”* What could she have done differently? What if her doctor had caught it sooner? *“But, those types of questions are unhelpful to ask yourself after you’ve already been diagnosed.”*



Corley Steunenberg receiving treatment in hospital

Gradually, her condition improved and she was able to get more of her independence back. *“I can walk without aids now, but if I do a long walk, I use my husband’s walking pole for stability. It makes you feel a bit more athletic having a walking pole instead of crutches!”*

Today, she still gets back pain now and then, but she knows it’s not from the fractures. She also knows that she can contact LBC Support Services Coordinator Natasha for support, if she needs it.



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





“Everyone’s myeloma seems to be different.”

Corley met Natasha early in her treatment at Middlemore, after talking to a man who had myeloma for six and a half years, and his wife – who passed on Natasha’s details. *“Natasha’s awesome. She does a fantastic job. She tries to connect people with ‘like’ issues.”*

*“Everyone’s myeloma seems to be different.” Some people experience fractures almost immediately. Other people are diagnosed well before the obvious signs of myeloma even show themselves.*

*“There are a lot of stories out there, and there are a lot of people who have had a much harder time than I have.”* And, while there are many stories of people with

myeloma and different experiences to learn from – one thing she knows for certain, is that positivity is important.

*“The stories I wanted to read were of people who went through the journey and things started to look better. There is a lot of negativity among people living with cancer, and that is not supportive. It makes you feel worse.”*

What made Corley feel optimistic, was the LBC Support Group she attended regularly. “You have the people who belong to these groups, who are positive and want to help people and talk about their journeys.”

She was moved by the kindness and support of the couple who introduced her to Natasha. *“I thought it was awesome that even after six years, the couple were still going to LBC support groups to encourage other people.”*

For many people, living with a cancer like myeloma can be a lonely and isolating experience, and Corley is aware of how different it could have been, had she not had her husband. *“I can’t imagine going through what I went through on my own. It’s important to have a supportive network around you.”*

Corley’s support network meant that she had the strength to get through Christmas with severe back pain, learn how to walk again, and embrace positivity during a time of uncertainty.

*“Don’t let negative people pull you down. Focus on the stories of hope, and remember everyone’s journey is different.”*

### Fast Facts: Light-chain myeloma (LCMM)

- A less frequent type of multiple myeloma (MM)
- It can be more aggressive than other forms of myeloma
- It is characterized by the inability of the malignant plasma cells to produce heavy chains, resulting in the exclusive production of light chains.

**Register for Ladies Zoom  
Group phone chat on 0800 15 10 15**



# From hōhā to kaha

***"I'm learning gratitude; a gratefulness for life itself. That's been a hard one for me."***

Hine Wikiriwhi is a 69-year-old, proud Māori wahine from Auckland, with myeloma. Her iwi is Tuhourangi on her father's side, and Tainui on her mother's.

She loves to sing, she is passionate about te ao Māori, and she adores her 'fur babies'. Talking to her feels like having a kōrero with your kuia, your grandma.

But, while she is chatty, warm and friendly – vulnerability can be difficult for her.

***"I have a Tainui cousin, Mere. One day, she looked at me and she said, 'you'd be pretty good at hiding things'. I think I cover up a bit, that's the trouble."***

Hine covers up so much, in fact, that she kept her myeloma diagnosis from her workplace and her family for over a year.

***"See, I learnt to put on a mask early in life. The outside looked OK, but the inside wasn't good."***

Hine grew up with a dad who suffered from PTSD. He served in WWII as part of the 28th Māori Battalion. It was through her father that Hine learned, as a child, that you deal with hard stuff in life by **'getting on with it'**.

This is how she approached her blood cancer as an adult. ***"I had been leaving work early on Fridays because I needed to report to North Shore Hospital. But, I was hōhā; I was annoyed. I complained to my doctor; 'I have to keep working to pay the bills.'"***

While it was tough, there were parts of her journey that she appreciated. ***"I'm grateful for the public health system, so that I could have my stem cell transplant. It gave me at least five good years."***

She had help from her partner Kennedy, and she attended LBC support groups too. ***"We did a Christmas Zoom for patients recently. It was nice. I draw inspiration and courage from them – the older ladies there."***



Hine at her home in Auckland

Hine was also grateful for her doctor, who helped her stay level-headed, focussed and optimistic, even though she is hesitant to know too much about her blood cancer. ***"I just have to trust it. I don't usually want to know about my lightchains, or how high-up they are."***

***"But, I know I have this condition."*** Hine says this with clarity.

***"I knew that I'd have to go to hospital on the Friday before Christmas. And, I knew that it would make it difficult to eat food on Christmas Day, because I wouldn't have my taste...and I don't know how long the treatment is going for, exactly. But I think my blood test results are OK."***

Looking back, Hine knows that she could have approached her diagnosis differently. But she is happy with her life, and she is grateful for it. While her myeloma doesn't define who she is, it has taught her a lot about resilience and kaha; strength.

***"I read this quote once about how all organisms are made of four essential things – carbon, oxygen, hydrogen and nitrogen. Dust to dust – you know, that's what we're made of and where we come from. For us Māori, that breath of life – it's God-given."***

***"For me, each breath is precious."***

## Fast Facts: Myeloma

- Affects around 400 New Zealanders each year and is slightly more common in men
- Majority of people diagnosed are aged over 50 years, with around 2% under 40 years
- It is a cancer of the plasma cells.

# 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