

# Leukaemia Today

Supporting people *living* with leukaemia

Your chance  
to **win**

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# Inspiration corner

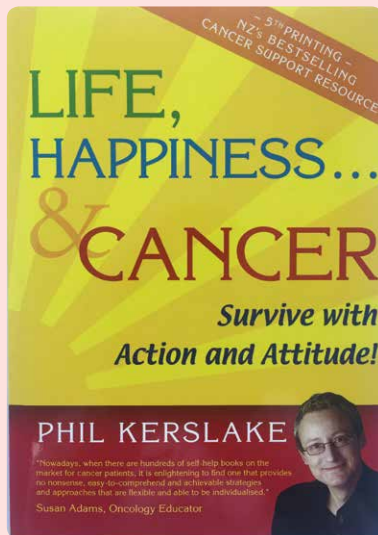
Recommended reading from patients and carers on the LBC Consumer Advisory Board.

## Life, happiness & cancer by Phil Kerlake

"This book is an easy read, user friendly, knowledgeable and I found it inspirational during my treatment and recovery.

I have recommended it to many cancer patients and support people - I even carry a spare copy in my car so I can give it to anyone interested when taking them to their hospital appointment".

Steve



**We have a copy of this book to give away. Just answer this simple question:**

What is Leukaemia & Blood Cancer New Zealand's website? (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 'Leukaemia Today Competition' in the email subject line).

## The subtle art of not giving a ##### by Mark Manson

"I found this book good reading and it helped give me a different perspective on what it means to be happy.

Manson says that instead of trying to turn lemons into lemonade, we should learn to stomach lemons better! It's a counterintuitive approach to living a better life, but Manson argues it's time to recalibrate our values. The book applies to life in general and so is not so much about illness but about making the most of what life deals us."

Maree

**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. Members give LBC feedback on support services and resources.*

## COVID-19 and Support during lockdown

**LBC's priority during the COVID-19 pandemic was to ensure patients and families were well supported and in a safe way.**

Our focus was to continue to deliver emergency financial support and maintain all our services online during Level 2 and above. Our team developed new online forums and Facebook groups. We provided a range of interactive seminars on health and psychological well-being to help patients through these difficult times.

Regardless of alert levels, our services will continue. Please see our Support Directory on page 8 and head to our website for all our updates.



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

# Managing stress

Living with blood cancer can be challenging and stressful. COVID-19 has added an additional level of anxiety for many patients and their families. While core lifestyle elements such as gentle exercise and eating and sleeping well are important, there are other simple things you can do to help improve your mental wellbeing. Try one or two of these quick tips each day:

## Breathe

Stress can lead to chronic shallow breathing which can cause increased agitation as well as muscle aches, light headedness and tingling. Follow these steps to regulate stress hormones and feel a sense of calm:

- Loosen your shoulders by raising them up and down
- Breathe in slowly through your nose for a count of 3 – pull your breath deep into your tummy.
- Hold your breath gently for a count of 3
- Breathe out slowly for a count of 3
- Repeat a few times. Do this several times a day and choose your own pace.

## Notice the little things

You can inject mini moments of mindfulness into your life - try this quick exercise for a few minutes of break from the busy chatter in your mind:

- Find an object – anything will do e.g. a piece of fruit, a cup of coffee
- Go through each of your five senses to describe your object in detail:
  1. What can you see?
  2. What does it feel like to the touch?
  3. What can you smell?
  4. What can you hear?
  5. And, if appropriate, what can you taste?



Noticing nature can help reduce stress

## Notice Nature

You can do this mindfulness exercise by sitting outside somewhere peaceful, or just looking out of the window and repeat the previous steps.

## Release endorphins

The simple act of squeezing and releasing muscles in your body can release endorphins (our feel good hormones). The same can happen if you simply smile! Try clenching various muscles in your body (e.g. your fists, or press your knees together) for a few seconds and releasing. Repeat this several times. Follow this with the breathing exercise described in this article for an extra dose of relaxation.



Emma Barker  
Head of Support Services

*"Fear of the unknown and the uncertainty that can come with a blood cancer diagnosis can have a negative impact on mental health. Looking after yourself and doing simple things to help manage your stress levels is really important."*

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



# Spiritual strength the key

**When David started to experience chest pains, blood cancer was the last thing on his mind.**

David's GP was able to reassure him that his pain wasn't heart-related and did some blood tests which showed that David's neutrophils were low - he recommended a re-test in a month's time.

David's neutrophils were still low and the GP again recommended a re-check which showed a similar result. Eventually, David was referred to a specialist.

Once David saw the specialist he was given the news that he had acute myeloid leukaemia (AML). As he explains:

*"When I got the initial blood results I had done some research online and thought I had chronic leukaemia - so when the specialist told me it was AML it wasn't a total surprise. My wife Elaine was with me and it hit her harder than me. I asked the doctor how long I would have if I decided not to have treatment and he said "about three months" - that really shocked the family."*

David and Elaine weighed up the pros and cons of treatment and decided it was a better option to proceed, he explains:

*"We looked at the percentage success rate and it was clearly a better option for me to go with treatment. The specialist said that the first two years after treatment were touch and go as lots of things could go wrong but if I got past that the chances of a longer life extended all the time."*

David's treatment began a few days later in Wellington Hospital with his first round of chemotherapy. He spent most of the next three months in hospital with just a few days' break between each round of treatment. As he explains:



David with his brother Richard

*"I'd never been in hospital before so I didn't know what to expect but I tried to keep a normal routine - I got up and dressed so I wasn't in my pyjamas all day and got some exercise by walking up the stairs a few times each day."*

It wasn't all plain sailing as David experienced adverse reactions to drugs, infection and, just after his first round of chemo, his wife Elaine became unwell with a brain lesion that doctors initially thought might be cancer:

*"Elaine was on Level 7 of the hospital and I was on Level 5 - thankfully Elaine is on the road to recovery now - but it was a really difficult time for the family."*



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



David receiving one of his first rounds of treatment

“ I’m very grateful to be in my third year of remission with the possibility of more as my body continues to gradually regain strength.”

David needed a stem cell transplant - thankfully his brother in the UK was a match and travelled over to New Zealand to be his donor. Things progressed well, and David’s transplant was a success - his cancer was put into remission.

David has just started his third year in remission and reflects on his cancer journey:

*“It’s amazing to consider what has happened to my body and how the doctors have carefully navigated my cancer with all its possible pitfalls. I’m very grateful to be in my third year of remission with the possibility of more as my body continues to gradually regain strength.”*

*The things that were key in my journey were having a strong positive spirituality and the joy of having family close. Also the ability to eat good food, especially curries from the local restaurants near the hospital!.....and the thought of another family Christmas, this next one will be my third.”*



David with his wife Elaine

David has a strong, positive spirituality which helped him during his cancer, he explains:

*“My faith is important to me and the idea of my own death wasn’t so frightening because for me, death is not the end of life but more the end of a chapter, and a new chapter begins.”*

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



# Journaling the best medicine

In 2018 Peter was working as the curator at Black's Point Museum in Reefton and looking forward to retirement. He hadn't been to his GP for a while so decided to go for a routine check-up and blood test.

The GP noticed a problem with Peter's blood and referred the results to a haematologist in Christchurch. He got a report back and called Peter in to talk about it, as Peter explains:

*"The GP told me I had chronic lymphocytic leukaemia (CLL) - it was a shock. He explained it might be years before I would need treatment, I remember feeling annoyed at the time because I wanted it to be fixed but put it to the back of my mind and carried on with life."*

Peter had regular blood tests to keep track of the progress of his CLL. At the beginning of last year, just 12 months after his initial diagnosis, his blood markers started to increase:

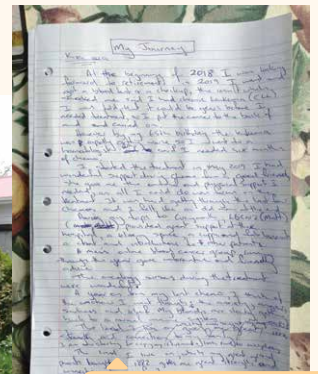
*"The haematologist told me that things were progressing more quickly than expected and I would need to start chemotherapy right away."*

Peter had six months of chemotherapy – traveling to Greymouth regularly from his home on the family farm:

*"I started chemo in May and finished in October – the first few rounds were OK but it got harder as it went along. When I came out of the last chemo I felt like an old man –but I got through it and I'm starting to get my strength back now."*

When Peter was in Greymouth for his treatment he met up with LBC's Matt Eby as he explains:

☺☺ **I'm optimistic and have goals and enjoy the important things in life like friendships and family and working on my land.** ☺☺



Writing a journal helped Peter work through his emotions

Peter back home at the end of his chemo

*"It was great meeting Matt, I could sit comfortably with a cuppa and talk to him about anything – it was a nice little sanctuary to go to!"*

Matt let Peter know about support that was available but one of the best pieces of advice he received was from a friend who suggested he write down some of the things that had happened in his life:

*"I am a typical Kiwi bloke and didn't always deal with my emotions well, but I found if I wrote things down it helped me come to terms with things."*

Peter continues to have three monthly blood tests and so far everything is heading in the right direction, as he explains:

*"I do realise I have leukaemia and it will come back one day but I have accepted it, I could go another 20 years so there is no point worrying about it. I have goals and enjoy the important things in life like friendships and family and working on my land."*



Connect with patients like you on Facebook @LBC chronic leukaemia

# LBC's Winter-Spring Webinars

LBC's Winter-Spring Webinar Series continues until 18th December and features a great line up of speakers providing Friday lunchtime webinars each week on a wide variety of disease specific and survivorship topics.

All webinars are recorded and are available to view anytime on LBC's YouTube channel at [www.blood-cancer.online/wsws](http://www.blood-cancer.online/wsws)

## New data and insight from vitamin C studies: personalised medicine in the treatment of AML

University of Otago Research Professor Margreet Vissers presented a must-see webinar outlining research into the role of Vitamin C in leukaemia treatment.

Margreet has established an international reputation for her research work on Vitamin C in cancer and general health.

Margreet's webinar helps us to understand the important role of vitamin C in the human body and takes us through a detailed outline of the ongoing research into the specific role of Vitamin C in cancer treatment.



Prof Margreet Vissers



Dr Clinton Lewis



Dr Tony Fernando

## Coming Up:

**Friday 6 November,**

Helping you get a better night's sleep,  
Dr Tony Fernando

**Friday 27 November,**

Stem Cell Transplant: When, Why, and How,  
Dr Clinton Lewis

**Friday 18 December,**

Understanding research on cannabis,  
Dr Claire Hemmaway

To view the full line up of topics for the Winter-Spring webinars visit [www.leukaemia.org.nz/winter-spring-webinar-series](http://www.leukaemia.org.nz/winter-spring-webinar-series) or to watch webinars that have already taken place, visit LBC's YouTube channel at [www.blood-cancer.online/wsws](http://www.blood-cancer.online/wsws)

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. To find out more go to:  
[www.blood-cancer.online/support](http://www.blood-cancer.online/support)

**Blokes with Blood Cancer** is a hosted group phone call every eight 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, Wellington and Christchurch. **Kids Club Zoom** now available online for children living in areas outside of the main centres.

**LBC's Winter-Spring Webinar Series** was created as an online alternative to our Blood Cancer Patient Forum during the COVID-19 lockdown. This year we are holding weekly Friday webinars until December on a range of disease specific topics and relevant survivorship themes. These are recorded and available by visiting LBC's YouTube channel at [www.blood-cancer.online/wsws](http://www.blood-cancer.online/wsws)

**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, CLL and CML booklets
- ✓ Revised Blood Cancer booklets in Mandarin, Māori, Samoan & Tongan languages
- ✓ New Chemo-Brain factsheet

You'll find these and other resources online at [www.leukaemia.org.nz](http://www.leukaemia.org.nz).

**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. They are supportive and informative – there are groups for carers and young adults too.

- f @LBCCarers
- f @LBCLymphoma
- f @LBCMyeloma
- f @LBCChronicLeukaemia
- f @LBCAcuteLeukaemia
- f @LBCYoungAdults
- f @LBCBloodDisorders
- f @LBCParentsGroup
- f @LBCMPN
- f @LBCBereavement



leukaemia &  
blood cancer  
NEW ZEALAND

Vision to Cure. Mission to Care.

Call us on: 0800 15 10 15

Email: [info@leukaemia.org.nz](mailto:info@leukaemia.org.nz)

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