

LymphomaToday

Supporting people *living* with lymphoma

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Inspiration corner

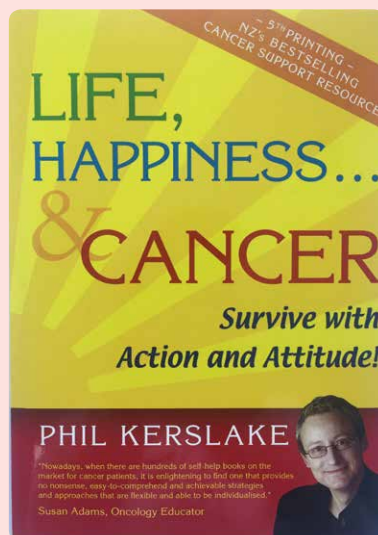
Recommended reading from patients and carers on the LBC Consumer Advisory Board.

Life, happiness & cancer by Phil Kerslake

"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



WIN!

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 (please insert the words 'Lymphoma 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

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."



Resilience is the key

Kirsty's blood cancer journey, like so many others, began with a seemingly unrelated health issue - she had a nasty throat infection called Quinsy, Kirsty explains:

"I ended up in hospital but when I got home my neck kept swelling so I kept pushing for an investigation."

Kirsty had an appointment with a consultant at Christchurch Hospital, who gave her the bad news – she had Double-Hit lymphoma which is a type of Non-Hodgkin lymphoma. Kirsty would need to start chemotherapy straight away.

She was put in touch with Matt from LBC who gave Kirsty a call:

"I was in the supermarket carpark when he phoned and it was the first really practical, knowledgeable help I got. I remember getting off the phone and feeling relieved because there was someone who was there to help me."

Matt was able to walk Kirsty step by step through what lay ahead:

"When you start chemo, you feel like you're stepping into the unknown and for me knowledge is power, so the information Matt was able to provide helped a lot. Chemo is really complicated, you have one appointment with your consultant for 30 minutes and there is so much you miss. My consultant was insanely busy so having Matt to explain and clarify made a big difference."

Matt was also able to help provide support to Kirsty's ten year old son Sam who was dealing with a lot of grief and anger. Matt helped Kirsty find a counsellor for Sam and also organised for them to go a Breakers basketball game as a treat:

"There was no way we could have afforded to do something like that and it was so great for Sam and me to have a break from all the hard stuff and just have some fun."



Kirsty and Sam



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



Kirsty and her family

Kirsty finished her chemo in February and initially all seemed to be going well:

"I'd just started to feel better again, not so fatigued and my fingernails and hair were starting to grow back, but then I started to have fever and night sweats and that was a catalyst for some more tests."

Kirsty had to face an incredibly difficult meeting with her consultant who confirmed she had relapsed:

“I’m looking on the bright side, enjoying the moments and being grateful for what I have - it’s how you face challenges that counts.”

"I walked around in a daze for a day or so and then rang Matt and had a good talk to him - he was incredibly supportive again. I wanted to get my head around things and get my game face on so I didn't frighten my friends and family."

Matt was able to talk through the new treatment plan including stem cell transplant (SCT). He was also able to offer help with grocery vouchers when Kirsty really needed them:

"Vouchers were so helpful - one of the worst parts of cancer is the overwhelming financial stress if a small thing goes wrong, like needing a new tyre, it is a huge problem. I had to call on him a few times and he was able to give me a grocery voucher – I could feed everyone that week."

Kirsty attended a couple of LBC's support group meetings which she found inspiring, she is also working on strengthening her resilience:

"When I was first diagnosed I tapped into Lucy Hone's information on resilience. I'm looking on the bright side, enjoying the moments and being grateful for what I have - it's how you face challenges that counts."

**Connect with patients like you
on Facebook @LBC lymphoma**



Getting on with living

Julian's positive attitude and optimistic outlook on life has helped him get through his lymphoma despite some set-backs along the way.

Two years ago Julian found himself in Middlemore Hospital undergoing surgery for a blocked bowel. Nine hours later his surgeon delivered some unexpected news, Julian explains:

"When I woke up from the anaesthetic the surgeon said 'we've unblocked you but we've found something else' - I had Non-Hodgkin lymphoma. The following morning the consultant stuck around to help tell my wife and son – that was the hardest part, it really threw them."

The haematologist recommended Julian have radiotherapy and start chemotherapy as soon as possible:

"I had a good hit of chemo first time around and after that I had a PET scan to see how things were going. They said that it had reduced but another scan a bit later showed it had come back again - that threw me into a bit of a tailspin but I believe you have to play the cards you are dealt in life so I didn't let it get me down too much."

Julian's haematologist recommended more chemo followed by an autologous stem cell transplant (SCT) which he had in Auckland Hospital:

"That seemed to work but just lately they did a scan and saw the lymphoma may have come back again in my chest. They put a camera down my throat and took samples



Support of whānau made a big difference

– at this stage they haven't found any cancerous cells in the lymph nodes around my windpipe but they want to keep an eye on it."

Julian is having monthly follow-ups and is thankful for the support he has from his family and from his employer Nilfisk Kerrick, who has been there for Julian and his family right from his first diagnosis:

"Everyone is keeping an eye on me - before I could get away with murder but now I can't! I try to keep things as normal as possible, carry on working and spending time with family, plus I am an official with Athletics New Zealand and my wife encouraged me to keep that going."

Julian also appreciates the support he has received from Natasha at LBC who has been able to give him relevant, helpful information, as he explains:

*"It's an interesting journey, there are challenges along the way but I've met a lot of great people going down this path. Being diagnosed was a kick in the pants but I believe in the old saying 'Sh*t happens!'. You're only here once so you've got to get out there and enjoy life and do what you can."*

“You're only here once so you've got to get out there and enjoy life and do what you can.”



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

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

Biology of Lymphoma

Consultant Haematologist and Clinical Head of the Lymphoma Service at Middlemore Hospital, Dr Samar Issa, presented the first in LBC's Lymphoma Series.

In her webinar, Dr Issa gave a clear and informative outline of the biology of our blood and lymph system.

Dr Issa explained the aetiology of lymphoma and gave an introduction to the many different types of lymphoma, which is the most common form of blood cancer.

This is a must-see for all lymphoma patients in order to gain a deeper understanding of this complex blood cancer.



Dr Samar Issa



Dr Clinton Lewis

Coming Up:

Friday 13 November,
New Emerging Targeted Therapies in Lymphoma,
Dr Samar Issa

Friday 20 November,
Indolent B Cell Lymphoma, Dr Allanah Kilfoyle

Friday 27 November,
Stem Cell Transplant: When, Why, and How,
Dr Clinton Lewis

To view the full line up of topics for the Winter-Spring webinars visit 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

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. To find out more go to:
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

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.

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 @LBCCChronicLeukaemia
- f @LBCAcuteLeukaemia
- f @LBCYoungAdults
- f @LBCBloodDisorders
- f @LBCParentsGroup
- f @LBCMPN
- f @LBCBereavement



Vision to Cure. Mission to Care.

Call us on: 0800 15 10 15

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