

# Myeloma Today

Supporting people *living* with myeloma

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to **win**

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# Inspiration corner

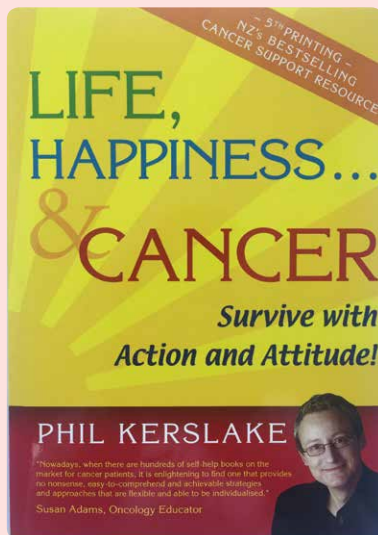
Recommended reading from patients and carers on the LBC Consumer Advisory Board.

## 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 'Myeloma 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



# Still going strong after 14 years

**When Nick began experiencing back pain that progressively got worse he went to the osteopath and chiropractor in an attempt to get some relief. As he explains:**

*"I was only 48 at the time and was otherwise fit and healthy but it got to the point where the pain was so bad I couldn't walk."*

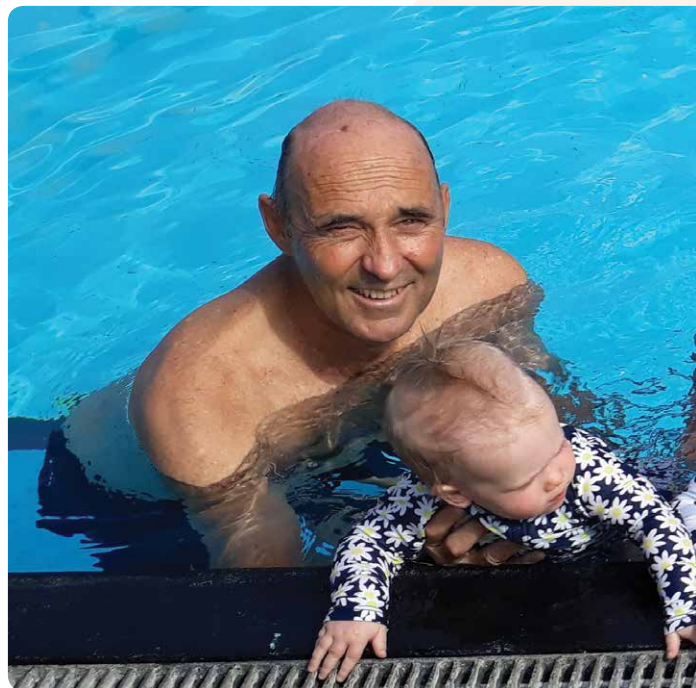
Nick's osteopath recommended he see a doctor. He was referred by his GP to an orthopaedic surgeon and an MRI showed Nick had a growth on his sacrum.

Nick was sent to Wellington Hospital from his home in Whanganui where further tests revealed the growth was a plasmacytoma – his doctors told him it was likely to progress to multiple myeloma.

That was back in April 2006 and by May, Nick had begun radiation treatment in Palmerston North Hospital. Nick's pain improved but his cancer was progressing – in 2007 he had an autologous Stem Cell Transplant (SCT), he explains:

*"They told me the SCT was likely to last about five years – they were spot on! For most of the next five and a half years I was in remission and, once the pain had resolved, I was leading a pretty normal life and got back to tramping and playing tennis and golf."*

In 2012, after a move to Rotorua, Nick's cancer started to reappear and his haematologist recommended a second SCT – at the time he was told it would likely last a further two years. By 2015 blood tests revealed Nick's cancer had started to progress again so he began Lenalidomide (which at the time, had just been funded by Pharmac). That worked for nearly a year but as Nick explains:



Nick with his daughter on Father's Day this year

*"In 2016 the cancer came back and they didn't know what they could do next so they looked at an allogeneic SCT. However the doctors explained it had only a 10% chance of cure and 60% chance of ongoing problems."*



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



Rose & Nick visited the Grand Canyon in 2019

“Physically I am doing Ok - I can still walk around the golf course and get down on the floor and play with the grandkids!”



Nick with daughter Maria and grandchildren

Nick went on to cycles of different drugs, some had benefits for just a few months, others for up to 18 months.

In May this year Nick’s online research uncovered a drug called Selinexor that had been recently approved in the USA. His haematologist supported him in making an application to receive a compassionate supply which he began taking in July.

It has been a long road for Nick as he says:

*“The most difficult time for me was at diagnosis – I was 48 with one child still at school and I was told there’s no cure. But my youngest daughter is now 30 and whilst I am certainly not going to have an average life expectancy, I am still here!”*

Nick has now retired from full-time work but still volunteers in his community and leads a full life:

*“I can still walk around the golf course and get down on the floor and play with the grandkids!”*

Nick attends LBC’s local support group:

*“I’m now in my 14th year with myeloma and it can be helpful for people who have just been diagnosed to meet someone like me. When I was first diagnosed it was a nervous wait for each set of results of scans and blood tests but now it’s just part of the fabric of my life.”*

Nick and his wife Rose had a lot to consider. When it came time to meet with the team at Wellington Hospital things took a sudden turn:

*“We had decided to try the allogeneic SCT but the team said “we don’t need to give you one – there is a drug trial you can go on... it might help you!”*

Nick entered an international trial of 300 patients to test if the immunotherapy drug Keytruda, when given in conjunction with Dexamethasone and Pomalidomide, had benefit for patients:

*“I was randomly selected to receive just Dexamethasone and Pomalidomide (so was in the control group), it helped me for three to four months but the trial had a rule that if your counts increase 25% you have to stop and that happened for me.”*

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



# Help available if you reach out

**Frances from Waitara turns 80 in December – it's a birthday she wasn't sure she would see.**

As is the case for many people, Frances' cancer journey began with a seemingly unrelated incident, she explains:

*"I tripped and jarred my back and started to get back pain which didn't get better. I went to the doctor and they gave me painkillers and said they thought it was a combination of the injury and my age."*

Frances' pain went on for six months and got to the point where she was practically bed ridden. Eventually her doctor did some blood tests which showed up some worrying results and in February 2019 she was referred for a bone marrow aspirate in Palmerston North Hospital.

Test results showed that Frances had multiple myeloma:

*"I was quite calm when they told me, in fact I was a bit relieved because at least there was something diagnosed - I had been putting up with things for so long. The worst part was having to ring my daughters and tell them."*

Frances began six months of chemotherapy, as she explains:

*"I didn't lose my hair and I only had a bit of nausea and could sleep alright - by that stage my back pain was a bit better too which helped."*

After six months Frances was changed onto a regime of thalidomide and



Frances having an infusion at Taranaki Base Hospital

dexamethasone and by early December 2019 her bloods were looking so good that her haematologist recommended she come off treatment:

*"I've been off the treatment ever since although I have blood tests every three months and regular infusions."*

Frances was a regular attender of her local LBC support group before lockdown changed things, as she explains:

*"I find the meetings useful and enjoyable. For me it was really eye opening – how did I get to this age without knowing about these things!"*

Frances continues to have regular check-ups and blood tests but tries not to focus

solely on her condition:

*"I know there's no magic remedy so I don't dwell on it. I wanted to share my story to give people a bit of hope – when you are diagnosed it's not necessarily the end of life as you know it. There's lots of help out there if you reach out."*

*“I know there's no magic remedy for this so I don't dwell on it and I don't stress too much.”*



**Connect with patients like you  
@LBCmyeloma**

# 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)

## Managing Side-effects of Treatment

Myeloma Clinical Nurse Consultant Tracy King presented a must-see practical, and helpful webinar for myeloma patients.

Tracy developed a specialist interest in myeloma 20 years ago and is currently based at the Royal Prince Alfred Hospital in New South Wales as well as lecturing and undertaking her own research as a Clinical Research Fellow at Sydney University.

Tracy's webinar gives a clear and comprehensive outline of what to expect from treatment, what the common side effects are, and how these can be managed from both a medical and patient perspective.



Tracy King



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)

Find a support group near you  
[www.blood-cancer.online/support](http://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](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