

Myeloma Today

Supporting people *living* with myeloma

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Changing times with Covid-19

It was obvious when the first reports started to come in of a novel coronavirus taking hold across the globe that life would change radically for many of us, and that blood cancer patients would be particularly vulnerable to the infection. We knew that we would need to change our plans, increase the help we give to patients, and adjust the way we deliver support to ensure patients are kept safe.

As a designated Essential Service, the team here at LBC has been working round-the-clock through all levels of lockdown to change the way we do things and maximise the care, support and practical help we offer. We have increased the help we give to the most vulnerable patients during this tough time by keeping in close contact by phone,

text, and online. We have also provided online support groups and live Q & A sessions with haematologists, pharmacists, and other health specialists for patients and families. Some of these sessions were recorded so, please contact your Support Services Co-ordinator if you would like to view. We've also updated our website with information on Covid-19 and blood cancer, so please take a look www.leukaemia.org.nz.

Take care and look after each other,

Peter Fergusson
Chief Executive
Leukaemia & Blood Cancer New Zealand

Inspiration corner

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

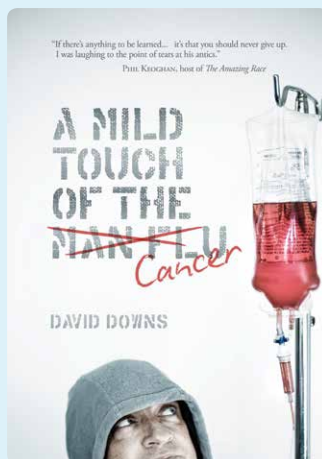
A Mild Touch of the Cancer by David Downs

An amazing account of David's journey with blood cancer.

He documents the highs and lows of his diagnosis and treatment journey, including travelling to Boston to get revolutionary CAR-T cell therapy. Written with joy, curiosity and humour, this isn't just a story about cancer, it's about living with optimism. Highly recommended.

LBC supported David and his family through blood cancer treatment. He has generously donated the profits of his book to LBC.

Order a copy from www.mildtouch.nz (audio and kindle versions available).



Thanks to David we have two copies of this book to give away. Just answer this simple question:

What is the 0800 number for Leukaemia & Blood Cancer NZ? (Hint: it's on the back page).

Email the answer and your contact details to info@leukaemia.org.nz (please insert the words 'Myeloma Today Competition' in the email subject line).



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

Blood cancer and your job

LBC has a series of handy online resources to help people understand and negotiate their rights for medical leave at work.

People living with cancer who are employed may need additional time off for specialist appointments, treatment and recovery. The good news is help is at hand. New Zealand legislation gives patients flexibility and options for requesting time off due to an illness like cancer.

Get tips on how to communicate this sensitive topic at work. Find out about your leave entitlements, government support, flexible working arrangements, whether you have to disclose your medical history, medical retirement and much more. There is even a guide for employers.

These courageous conversations with your employer should be positive and collaborative. In most cases, your employer will be supportive. However, if you feel you have been treated unfairly and need extra help to navigate this issue, call LBC for support.

A big thank you to Naomi McRae from PwC who helped to create these resources. LBC supported Naomi on her cancer journey, and we're happy to share she's been in remission for over eight years.



Blood cancer and your job: www.blood-cancer.online/job

Topics include:

- Employment rights fact sheet
- Flexible working entitlements
- Government support
- Medical retirement
- Returning to work
- Conversations with your employer
- A guide for employers



"When I got diagnosed with blood cancer, I thought, what does it mean for my career? My employers were understanding, and together we came up with a plan to manage my illness at work -I realise not everyone is as fortunate. I worked alongside the HR team and in-house legal team at PwC. I also used my knowledge as an HR specialist to develop a set of resources to help LBC patients with cancer-related employment issues."

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



Kerry wakes up to smell the coffee

When Kerry Bisley struggled to make his morning walk to the letterbox, just 40 meters up the driveway, he knew something wasn't quite right. It was normally an easy stroll, but today it felt like he was carrying the weight of the world on his shoulders.

"For the next 18 months, I was tired and sweating profusely. There was intense pain in my spine and I was bedridden for days with simple ailments. I knew that my body was out of sorts. Then the hospital x-rayed me looking for kidney stones."

Kerry's scan revealed something more sinister. When his GP broke the news he had lesions on his spine from multiple myeloma, it was a day he will always remember.

"Afterwards, I sat in the car for two hours, wondering how I would pay the mortgage and how I would put food on the table. And most importantly, how I would tell my wife and daughter."

As it turns out, Kerry didn't need to worry about explaining myeloma to his loved ones. A phone call to Leukaemia & Blood Cancer New Zealand (LBC) meant help was at hand.

"It was a relief to see Amanda from LBC arrive at my door that night. She explained in simple terms the treatment pathway and different types of support offered. She answered our questions and handed over a myeloma DVD and booklet for reference."

Kerry's cancer journey was a roller coaster for the next few years. He had many cycles of chemotherapy and two stem cell transplants which clocked up an intense 52 weeks of treatment.



Kerry's daughter Ellen stood by his side through his journey with myeloma.

“ I created a coffee cart business which gave me flexible hours to manage fatigue ”

"My humour gets me through tough times. I remember the haematologist explaining the process for a transplant operation. When asked if I had any questions. I replied 'can I take my coffee machine into hospital?' He asked my wife if I was taking my cancer seriously enough."

Kerry didn't realise it at the time, but coffee would become a reoccurring theme in his life.



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

Kerry spent 14 weeks in hospital during his first stem cell transplant.



After the move, Kerry and his family have never looked back. A big personality in a small town, he generated a loyal following for his spectacular coffee brew at Stand Easy with a dash of witty banter.



Kerry's coffee cart called Stand Easy in Otorohanga.

"I quit my high-flying, 36-year career as a chef. Sold the house in Hamilton and moved to Otorohanga. It was a lifestyle change so I could focus on my health without mortgage and career stress. I created a coffee cart business which gave me flexible hours to manage fatigue."

Kerry's coffee cart transformed into a popular rendezvous for locals. His charming personality and wise counsel means he provides more than just coffee as a community service.

"People gravitate to me for advice, and the roadside cart feels more like a makeshift consultancy. I'm the local barista, marriage counsellor, farm consultant, employment agent and confessional. Someone suggested I write a book with anonymous characters called 'Confessions at my Coffee Cart'. But I'd never do that!"

Kerry and his family maintained a connection with LBC attending support groups and the LBC Blood Cancer Patient Forum conference. It was an opportunity to connect with others in the same boat, learn about managing myeloma and understand the latest research and developments in the fast-moving field of blood cancer.

"I've been in remission for two and a half years. Humour is my secret weapon for battling illness. I take the mickey out of myself first. If you don't laugh about things, they will consume you. People take life too seriously and sweat the small stuff. I remember when the doctor diagnosed me with myeloma– I replied with a knowing smile 'you can't kill gorse with weed killer'.....and I was right!"

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



Tattoos represent peace with diagnosis

Kerr Stubbing from Hamilton knew something wasn't quite right. The normally fit and energetic 23-year-old lost weight and suddenly felt exhausted all the time. Even simple everyday tasks became an uphill battle.

"I could see Kerr was worn out and not coping. I became even more concerned when his skin took on a pale white glow, so I booked a doctor's appointment," says Sam his mother.

Little did Sam know, this appointment would change the course of her son's life.

"Within 24 hours of receiving blood test results, Kerr was in Waikato hospital having a blood transfusion and on a drip to stop his kidneys from shutting down."

He stayed at the hospital for a week of rigorous testing. Eventually, doctors broke the news that Kerr had myeloma. Sam still remembers that moment like it was yesterday.

"It was surreal, like a slow-motion movie and I kept thinking this can't be real. I felt overwhelmed and in shock."

Kerr's diagnosis was unusual because myeloma is normally diagnosed in people over 50. He is the youngest person in New Zealand living with this form of blood cancer. Chemotherapy started immediately, then Kerr explains how he received another surprise.

"A new tumour appeared on my spine impacting the nerves in my foot, causing drop-foot. I had to get used to using crutches during outings and sometimes around the house," explains Kerr.



Kerr's diagnosis aged 23 was unusual because myeloma is normally found in people over 50.



Kerr and his mum got matching tattoos of a turtle wearing a burgundy myeloma ribbon.

☺ One of Kerr's biggest lessons was to listen to his body and be mindful of any changes ☹

Chemotherapy, radiation, and a stem cell transplant occurred during the next two years. So did the roller coaster of emotions experienced by Kerr and his family. Sam reached out to Leukaemia & Blood Cancer New Zealand (LBC) for help.

"We read the LBC myeloma medical booklet, which helped us to understand Kerr's illness. It was written in simple language, so it was easy to read. It was a relief to know I did nothing wrong as a parent. Myeloma is made in the bone marrow and it doesn't discriminate who it targets. We attended support groups and Kerr's brother was lucky enough to go to the LBC Kids Club which he loved."

Continued



Connect with patients like you
@LBCmyeloma

Sam had some words of wisdom for Kerr that will ring true for so many other patients living with myeloma.

"One of the biggest lessons was for Kerr to listen to his body. This means being mindful of any changes. It also means understanding his coping levels, he can't do the long hours like he used to."

Thankfully Kerr has defied the odds and gone into remission. Sam admits it has taken two

years for them both to come to terms with his diagnosis. They marked the occasion with something extra special that would last a lifetime and signify new hope.

"We got matching tattoos of a turtle wearing a burgundy myeloma ribbon. They were symbolic of our journey and represented healing and being at peace with the diagnosis. We have finally accepted our new normal and are feeling positive about the future."



Say it share it

with Tim Maifeleni, Northern Region Manager, LBC Support Services

Q I have recently been diagnosed with a blood cancer. How do I tell my children and help them to adjust?

A A conversation like this is never easy. We have resources to help you talk with your children. For example, picture books will help them to understand cancer and the treatment journey. It is also a good idea to explain changes in your life and how it will affect them.

Use the LBC sticker diary to record your treatments and ask children to write and share journal entries with you.

Check out the guide for parents, 'Supporting a child through a loved one's cancer diagnosis'.

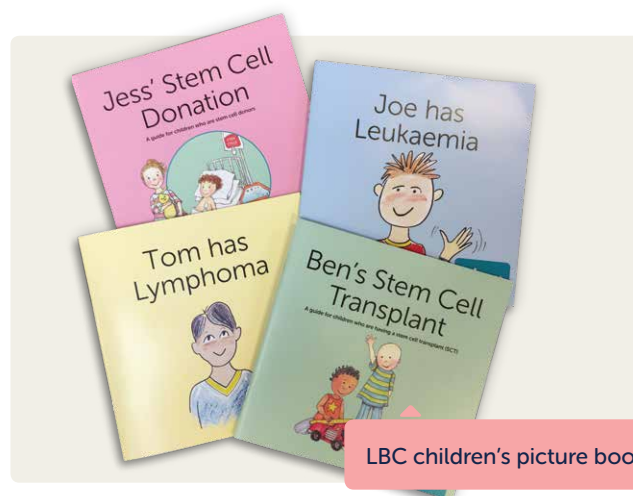
Have an open dialogue with your child's school, making them aware of your diagnosis including how it affects family routines and relationships. If you are concerned with how your child is coping, please tell us so we can make a counselling referral.

We run a Kids Club for 5–12 year olds, to help them cope with a loved one's diagnosis of blood cancer. It is hosted by psychologists and play therapists and is available in Auckland, Hamilton and Christchurch (coming to Wellington soon).



Resources

Resources are available at www.leukaemia.org.nz or phone us on **0800 15 10 15** if you would like them posted.



LBC children's picture books

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 hosts a group phone call every six 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.

LBC Blood Cancer Patient Forum is a conference for patients and carers to educate on well-being plus the latest in research and developments with blood cancer. Due to the situation with COVID-19, the forum in 2020 has been cancelled and moved to a virtual alternative – the LBC's Winter-Spring webinar series. Please contact your local Support Service Coordinator for further details.

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 booklet
- ✓ cancer and fertility fact sheet
- ✓ blood cancer and your job
- ✓ MPN fact sheets

You'll find these and many other resources online at leukaemia.org.nz. Phone LBC for more information or if you would like them posted.

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. It's supportive and informative – there are groups for carers and young adults too.

- f** @LBC Chronic Leukaemia
- f** @LBC Acute Leukaemia
- f** @LBC Lymphoma
- f** @LBC Myeloma
- f** @LBC Carers
- f** @LBC Young Adults
- f** @LBC Rare Blood Cancers
- f** @LBC Parents Group