

LIFE BLOOD

Lessons from one woman who survived
serious illness against the odds

CATHY KONING

FOREWORD

As a doctor, one of the hardest things you have to do is tell someone they have cancer. The effect of the word is instant and profound: it strikes terror deep into the heart. If you – or someone you love – have been given this diagnosis, you know exactly what I mean. The shock is profound. It's an assault to the senses. It's almost impossible to take in; to get your head around this frightening new reality, and the dreadful uncertainty that goes with it. Your mind spins in circles: What does this mean? What do you need to do? Where do you turn to? What happens next? I trust this book will be of great comfort to anyone facing such difficulties.

I've known Cathy Koning for many years; her husband, Fred, was the first friend I made when I emigrated to Australia 30 years ago. In these pages, she has written an honest, moving, and real account of her 'close encounter' with leukaemia – which I remember all too vividly. It was such a shock to me, to see Cathy lose all her hair, waste away to almost nothing, struggle to even move in her bed... and such a great delight when she eventually pulled through.

And although Cathy's story is about leukaemia, her experiences are deeply relatable for any type of cancer: her fears, her struggles, her desperation, her obstacles, her courage, and her commitment. This book will give you a good idea of what you (or a loved one) may go through when facing cancer. It's a heart-warming account of a heroic journey. And it offers a message of courage and hope for all. I trust you will find it both a source of valuable information and a comfort amidst times of great suffering.

— Dr Russ Harris, Melbourne, 2021

INTRODUCTION

Five years after my leukaemia diagnosis Professor Curtis asks how I am feeling. I reply, 'I have never been so unhappy.' I tell him about my illness de jour. I see his face fall.

Not for the first time I contemplate how he copes with patients like me when we are feeling scared and sorry for ourselves. Medical staff aim to give us their best care and advice, nevertheless this cancer racket can make a person so self-obsessed and oh-so self-indulgent. Doctors (and nurses) are trained to deal with the science first. They are in the healthcare business and choose to be surrounded by us sooky sickies. If I was a doctor I would become sick and tired of downcast patients who keep on asking what their chances of survival are and probably expect the worst, and let's face it, leukaemia doesn't offer the best survival rates for older people. Still, it must be hard to break bad news... No, the treatment isn't working. Yes, you have reached the end of the line kiddo. Your karma is not great. Maybe you will have better luck in your next life... The satisfaction must be in seeing us cancer survivors, us valiant warriors, sticking around, even if it is to pester the hell out of our doctors and nurses by occasionally feeling sorry for ourselves.

Medical professionals do receive training in breaking bad news, in grief counselling and how to cope with emotionally charged situations. And they do need to find their own particular way of dealing compassionately with those of us who are facing a bleak prognosis.

When Dr Michael Dickinson, a clinical haematologist, was interviewed about this topic by Hannie Rayson for *The Age* he said, 'It's not something I shy away from, but there have been a few situations this year where I've had to stand up and leave because I was about to burst into tears. I didn't want to do that. In front of people. Particularly young people, with their parents in the room. My way of coping is this: Yes, the patient

is scared. They want to talk and be heard. But mostly they want to survive. They want an expert. They want you to get it right. The right treatment. The best advice. I hope I don't sound like a robot telling you this,' he says, 'but my coping mechanism is just to be good at what I do.'*

Welcome to the roller coaster world of Acute Myeloid Leukaemia (AML)

I want to share my experience for all of you who want to know more about cancer from a patient's point of view. I hope it will inform others who are facing a similar path and want to know what may lie ahead, help caregivers support their friend or family member and encourage medical professionals to look beyond the disease to the person. I believe understanding the patient will help inform the management of their disease. The type of treatment and level of support required is very individualised so it makes sense to take time to investigate the person. This is particularly the case with cancer as the relationship between patient and doctor is often maintained over many years. My Professor has been managing my case for nine years and counting.

Acute Myeloid Leukaemia seems to be a particularly insidious cancer as a stem cell transplant may remove the cancer from your body but managing the effects of the transplant can bring many unforeseen and unpredictable side effects. Being cured can feel like a victory but it does not mean back to business as usual. For me recovery has not been a single line from diagnosis to medical intervention to feeling better and thanks, see you later. The cancer train stops at many stations. It has been a series of setbacks and recoveries which have gone on much longer than you would expect after being cured. These

* Hannie Rayson 'Life at the Cancer Coalface: My coping device is just to be good at what I do.' *The Age*, 26 January, 2019, p. 20

have included the initial chemotherapy; developing sepsis resulting in over three weeks in an Intensive Care Unit (ICU); the actual stem cell transplant; graft vs host disease (GVHD) which can often occur after the transplant; shingles; type 2 diabetes; pneumonia and the challenging side effects of the drugs you need to take to manage the side effects of treatment.

Cancer is a remarkable teacher, a life-changing learning experience. To a large extent it is all about the numbers. It does take work to achieve the good readings. Years of work in my case. I have been asked if the journey, or expedition as I like to call it, has been worthwhile. Definitely. I am grateful to still be 100% alive. But I haven't always felt this way. Although rewarding in ways I never expected, being a cancer patient can be challenging, taxing and energy sapping too. Sometimes a change of terminology can help. I decide to call my cancer the little c rather than the Big C. I'm not giving it that much power!

Today

There are no guarantees, but for now I am feeling well.

I'm sitting at my writing desk, looking out the window and making a note of what I see. It is all happening in my haven. The view expands out to farmland, all dry, brown and yet gorgeous in the Australian summer heat. A row of blindingly white tee-shirts hang from the makeshift clothesline strung up between two blue gums. A mob of kangaroos stops by, alternatively grazing and staring intently. One has a little joey poking its head out of the pouch and two of the young roos are having a little boxing match. Galahs, whose pink, cream and grey feathers remind me of the colours in a 1950s formica table, drink at the bird bath. Baby magpies squawk nonstop while their parents show them how to find worms. White cockatoos hang upside down off a seeding wattle bush like fat Christmas ornaments. A thrush sings a delicious melody, up and down the

scales, perfectly in tune. Meanwhile our tabby cat, Gus, naps in the sun, enjoys a dust bath and then demands a back scratch from my husband Fred.

I revisit this book's chapter describing the sojourn in ICU. I tell Fred I started crying after rereading the emails he sent during that awful time.

Accepting the changes

I cry easily these days. A while ago I attended a performance of Mahler's *Ninth Symphony* in San Francisco and surprised myself by quietly weeping right through the final movement. It is difficult to put the feelings Mahler's music evokes into words. Whatever regrets or grief Mahler may have had at this time in his life, only a few years from his own death, seem to disappear, giving way to peace and silence. I thought of my mother taking her last breath. I couldn't help but feel quite melancholy. My dear friend Paulette, who we were staying with, happened to be a nurse who worked with blood cancer patients. She offered some wise words to me. 'The past is past. It is like a cancelled cheque and the future is yet to come. If you are dreading and dreaming about the future, you are missing what is here now.'

The future

Will I be around to see further positive change? I certainly hope so. The chances of the AML returning are statistically small thanks to my donor stem cell transplant. That's the good news. I don't worry too much about getting sick again. I'll deal with it at the time. If the worst happens, I will hop right back to Melbourne's Alfred Hospital and see what they can do for me. As to the future, like most of us I hope to live out my days at home, eating well and enjoying life surrounded by lush native foliage and watching cockatoos from my back veranda. This could be unrealistic but fingers crossed.

Cancer *does* change your life, without a doubt. For better, for worse. For richer, for poorer. And I cannot deny, and don't want to deny, the many wonderful (and challenging) experiences I have had since AML came into my life and I want to recount some of them for you. For patients who are confronted with a life-threatening illness I want to share my story to show you there will be bad days but there are also good ones and some of my experiences may help you through. Although I do challenge certain perceptions, I don't have a particular barrow to push. Your thoughts and insights about cancer may be quite different to mine, and just as valid. Everyone has to meet the challenge of illness in their own way.

There are many things family and friends can do to help. I have included what worked for me. I offer show and tell, ideas for you to compare and contrast, along with some practical advice. For medical professionals I hope to give you a glimpse into the world of one patient and the strengths and fears I brought to my treatment.