

Chasing Normal

Balancing the ups and downs
of life and cancer



A Memoir by Jo Rothwell 

Our lives are better left to chance,
I could have missed the pain,
but I'da have to miss the dance.

Tony Arata
Sung by Garth Brooks

THE PREAMBLE BIT...

I will scream from the mountaintop that cancer will not define me, yet here I am writing about it. Forgive the irony...or not.

There are not many words in the English language that appear to conjure up such trepidation and fear as the word '*cancer*'. Until the age of forty-eight, I was smugly unaffected by the power of this word. Of course, I knew what it meant and had observed its rage from afar, but I was not prepared for the impact of its fury and its command for attention that was about to be unleashed.

This book is simply an account of my experiences, thoughts, hopes and emotions that have been connected to my life with cancer over the past eleven years. You may notice contradictions in thoughts and feelings or perhaps simply a growth in understanding and acceptance, leading us to where we are today.

I have no doubt that overall it will be deemed that my story is my cancer story. However, I hope it is considered more than that. I have included an account from '*Wednesdays with Harry*' at the end of each chapter. A few years ago, I started a diary-type narrative of times spent with my son Harry. It was important to me to create enduring memories. And, in the future, if I am not here, hopefully, he will overlook remembering me as the one nagging him to tidy his room, but rather the one who provided laughter, enjoyment and meaningful moments. It seemed essential to compile these memories into written form, perhaps as a keepsake for Harry or perhaps as an outlet for my own need to build words into sentences. Either way, they are intentionally light-hearted and showcase indulgent exaggerations and my personal sense of humour.

I fully realise that some readers may question why I have alternated the seriousness of cancer with the whimsical Wednesdays chapters and perhaps become frustrated with this structure. If this is

the case, then you have truly come along for the rollercoaster ride that is my dealings with cancer. It is, in fact, the whole point of this book. One day I am laughing with Harry, and the next, I am confronted with concerns. The insight is intentional.

Of course, I hope my cancer ramblings create thought-provoking awareness, but honestly, I hope the Wednesdays chapters shine brighter and are valued more. They are the essence of my life and are what gives me strength, laughter and purpose. They are the hero chapters because they put cancer in its place by denying its very existence. Their presence stomps on cancer's power and represents life without intrusion.

To quote Viktor E. Frankl, 'When we are no longer able to change a situation, we are challenged to change ourselves.'



THE BIT YOU NEED TO READ FIRST

We are currently living with the very real threat of Covid-19. It has spun the world on its head, and we are forced to proceed with caution. For many, the pandemic has been an introduction to physical and mental health issues, perhaps for the first time. My own initiation into a medically provoked upheaval began many years ago...

I live a very modest life in the incredibly picturesque Yarra Valley in Victoria, Australia. I dearly love my two golden retrievers and twenty-two-year-old son Harry, most likely not in that order. I am old enough to have spent my twenties exploring the world without fear and young enough to still remember most of it.

I am quite determined not to define myself by circumstance or situation; however, I wish to tell you what is currently sitting close by. I have breast cancer. Not the type that is grieved, treated, survived and hope restored. I have the kind that wants to play a nefarious game. Mortality challenged to stamp its reality when I learnt the cancer had spread. It has wandered off from its original source and constantly attempts to lure me into its power and to fall into a chasm of fear. Prognosis is stage four and incurable.

Eleven years ago, when those around me suddenly began to tread lightly, words were lost, and the manual for behaviour was incomplete. Since then, I have become a student in the cancer classroom. I acknowledge its rebellious nature but understand that it is a part of me. Lessons learnt include; resilience, acceptance, purpose, distraction, adaptability, perspective and a master class in humour.

Clearly, I don't have it all sorted, as I absolutely feel the grips of mortality as a scary and lonely place. It is owned entirely by yourself, and no one can buy into it. Needless to say, everyone travels their own path. But my life is not about cancer or about fear. My life is about hope and purpose, adventure and laughter, curiosity and insights, learning and understanding...and love.

To counteract cancer's chaos...I chase normal.



Shall we dance?

HAIR TODAY, GONE TOMORROW

I have never felt particularly confident. Growing up with rampantly thick auburn hair, a sprinkling of freckles, and a slight gap between my front teeth most likely didn't help. Sure, my Nana loved my hair and called me Stargirl, but I was the 'carrot top' or 'ranga' in the family growing up. Don't get me wrong, I didn't feel marginalised or tormented at all; in fact, I probably quite enjoyed the idea that I was a bit different and unique, and I suspect it would not surprise you to know that Pippi Longstocking was one of my favourite reads.

According to the internet, redheads make up less than two per cent of the world population, with Scotland claiming the majority. In the Middle Ages, redheaded women were thought to be witches and burnt at the stake, and the ancient Greeks believed that redheads turned into vampires after they died. Gingernut, Mark Twain once said, *'While the rest of the species is descended from apes, redheads are descended from cats.'* It is thought that redheads have a higher pain threshold than average, and research has shown that redheaded women have more sex than blondes or brunettes...finally, a benefit. Sorry ranga fellas, you not so much. Gingerphobia is apparently an actual fear; fortunately, in more recent years, it seems the phobia has dissipated somewhat, and the appeal of having red hair has grown globally. Acceptance has flourished, and various celebrations, including National Redhead day, Ginger Pride and the Night of the Walking Red, are a long way from stake burning days. Non rangas now choose to become a redhead, and I cannot tell you how many times over the years I have been asked what colour hair dye I use.

Backpacking around Turkey in the '80s, I became aware that my hair seemed to attract quite a lot of interest. I may have been a tad paranoid from the lingering remnants 'Midnight Express' left polluting the air; however, I did become aware that attention gained was in direct proportion to whether or not I wore a hat. I also know that red hair dye was used extensively by women in Moscow in late 1987. At the time, I was working for Contiki Tours and had an eye-opening experience witnessing life behind the Iron Curtain. The deprivation and scarcity of essential goods was confronting. I was in charge of food rations, and so armed with plenty of Rubles and humble curiosity, I spent many hours searching through nameless basement shops hoping I would stumble across cheese and eggs. Locals would queue for hours for whatever so-called luxury item had been recently unloaded; from toilet paper to sardines to stockings and hair dye. Actually, come to think of it, this is not a great example of women preferring to become a redhead as I suspect their hair would be tinted blue if the latest shipment dictated.

Anyway, the crux of all this is that from early adulthood, I actually *liked* the colour of my hair. Its wiry thickness and tendency to form a curly mess was clearly not great; however, I had learned to train and tame it and had come to rely on its frizz ability to predict the forecast of rain. It had finally become one of the physical features that I felt actually looked okay.

The list of side effects from chemotherapy is long, and you must be informed thoroughly. I was told that the type of chemo I was on would most certainly cause me to lose my hair, which would happen fairly soon after treatment started.

After the second round, falling strands began to weave a carpet that blanketed the bathroom floor. I remember it was actually painful to put my head on my pillow. It was like sleeping on needles. At that point, I had little choice but to face the fact that my hair wouldn't last much longer. A hairdresser friend helped out by

giving me a shorter style, but it was only a week later that I had to remove the remaining locks.

I stood in the bathroom, staring at my reflection, towel wrapped tightly around my shoulders and the Remington Power Clippers charged and ready to assault. I knew that procrastinating wouldn't change the outcome, yet I did pause for a moment. The significance of that moment suddenly became overwhelming, and I needed to take a minute for it to sink in. I was very aware that vanity was creeping into this emotion. I realise that many women embrace being bald and wear it like a badge of honour and let's face it, compared to a cancer diagnosis, it is a pretty minor outcome. However, I wanted to cling to what I felt identified as me with every fibre of my being. Baldness is one of the many faces of cancer, and I simply didn't want to be branded with a look that represented it. Being treated for cancer and being ill from that treatment was onerous enough, but actually *looking* like cancer was incredibly confronting. I tried my hardest to remind myself that being bald was temporary and if being bald was what it took to combat cancer, then grieving was pointless. Had I known then that this wouldn't be the only time I had to shave my head and that today I live with hair toppers and bald patches, then I may have allowed myself to be a tad more dramatic.

Ultimately, when there is nothing you can do about a situation, the sooner you accept it, the quicker you can find peace. I finally took hold of the clippers and silently surrendered to reality. It didn't take long. I stood there with clumps of auburn locks scattered at my feet and a stranger staring back at me.

Breastless, instantly menopausal and now hairless. The challenge to feel feminine was growing. The only bonus of losing hair that I could deduce was that it meant I would be incapable of growing a beard anytime soon!

Prior to the great shave, I organised to be fitted with a wig as I figured any type of hair was better than none. I discovered that it is not until you lose your hair that you uncover the shape and size of your head. Unfortunately, no offence Dad, but it appears that I take after my father in this department. Now don't get me wrong with all this bald talk; many women adapt to a hairless noggin and look fantastic. I would argue, however, that they are blessed to have perfectly small round heads. My noodle does not fit into this category, as I soon discovered in trying to find solutions to head coverings. The wig that I had so carefully selected didn't seem to stay on without copious amounts of glue, specific for wig adhering situations. The warm and steamy weather ensured that the glue struggled to cope with the furnace-like conditions cooking on my head. The final straw was when a low lying tree branch snagged it right off my head, catapulting it skyward until it gracefully floated down and landed in a tangled mess. I took this as a sign and, at this point, put my vanity aside and began to look for alternatives. Pretty soon, the troops rallied. Beanies were knitted, scarves were gifted, and reassurances were offered with unfaltering enthusiasm.

A few months into treatment, I was invited to a morning of pampering from a wonderful organisation that understands the challenges females face when undergoing cancer treatment. Various companies donated cosmetics, and a group of female cancer patients gratefully accepted being groomed. One by one, those without hair removed their wigs, hats and scarves along with cautious inhibitions. No words were needed to understand the quiet bond that was so very relevant at that moment. It was a safe place to experiment with using makeup and styling headwear with help from professionals. However, I am not sure the organisers were prepared for my peculiar shaped noggin and most likely quickly regretted using me as their model to showcase and instruct others on headwear. Whilst there were many wigs and hats in their arsenal, nothing seemed to fit, so it

soon became apparent that the lesson then shifted to what NOT to wear. The parameter of a scarf is without definitive size, and so with a quiet prayer to the milliner gods, they gave that a whirl and proceeded to wrap, tuck and fold, a hundred and one ways to apply a scarf. Unfortunately, no matter what style they attempted, it simply exaggerated the irregular shape of my head. Before I knew it, I looked like a babushka doll or a mourning widow of Latin descent. Credit due, they tried hard, but no one was convinced that my head was suited to anything other than the particular hat that I had arrived in. I had already discovered that brimmed hats with a concertinaed type arrangement created the illusion of shape and a style that suited. So whilst I didn't gain in the apparel department, I really appreciated the event and lapped up the generous gesture.

In retrospect, I probably should have persisted with various wigs as when I went through chemo the second time, I did manage to find a great line of wigs that depicted my colour and length, and they fitted and stayed in place just fine.

What I think now about wearing head coverings has changed from those early days. Looking '*normal*' is one of my key defences against the power of cancer.



Bad hair day