

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?

REALITY BITES

If you asked me to name a significant date in history, February 23rd, 2011, would be it. Not a date that marks a natural disaster, the declaration of war, the discovery of penicillin, or walking on the moon. In fact, not a date that has any tremendous historical importance to the general populace. But for my own personal history, it is by far the most significant.

On the morning of February 23rd 2011, I drove myself to the breast surgeon's office to receive my test results. I was consumed with the thought that my life may never be the same. I remember waiting to turn at the crossroads of Corduroy Road and Warburton Highway on the outskirts of Yarra Junction when a wave of reality crashed upon me and halted my journey. I suddenly couldn't breathe. Anxiety had taken hold and was clinging on, determined to mess with my mind. Fending it off, I sternly reprimanded myself that catastrophising the situation was pointless and detrimental. Wait until the words were spoken...if they were to be spoken.

Concentrating on driving was crucial, a priority, but spaces of time disappeared when my mind drifted back to appointments leading up to this moment. The concerned glance from the mammogram technician, the uncertain reassurance from the ultrasound specialist and the grave and clinical reaction from the biopsy doctor. The seemingly harmless words '*good luck*' from all of the above had taken a sinister turn. My suspicious and irrational mind added to the fear by questioning why good luck was needed.

I arrived at the breast clinic, parked and then paused to calm my thoughts. I would have given anything to stay seated in the car, protected from the future. Ignorance is bliss. Unfortunately, time didn't wait for stoic preparations, and the minutes ticking past the hour pressured me to leave my vehicular sanctuary.

The waiting room was yet another test. I picked up a magazine and blindly flicked through it without any intention of consuming its content. The waiting was long and painful, and distractions were few...



Educational campaigns on breast awareness have been advertised extensively over the past twenty years to promote the genuine need to check your breasts. As a female, it is absolutely essential, and yes, blokes can have breast cancer too, so if you are not checking, then you really should start - right now. The fact is, I didn't have a lump, or a dimple, or resemblance of orange peel, but any change in your breasts is a sign that you need to follow up with your doctor. Upon finding anything unusual, it is quite likely that you will magnify the situation, and without waiting to know the medical results, you will have a breakdown and start planning your own funeral. '*Love You 'Till the End*' by The Pogues and '*Hymn to Her*' by the Pretenders were the music for mine. Waiting on results is agonising.

It was late January 2011, a Saturday, when I woke to discover that my right nipple appeared to be bleeding. I felt totally confused as to why or how this could happen, and no matter how hard the rational portion of my brain tried to justify this bleeding, a massive alarm was loudly and persistently ringing. Shutting out this noise was almost impossible. The combination of panic, apprehension, distress and the availability to search the internet created a tsunami that unleashed and attacked my reasoning, logic, and senses. My advice is never to refer medical issues to the internet. It will offer you various scenarios that will inevitably lead you straight back into a panic, where you will convince yourself that you have the direst of diseases and death is imminent.

The weekend of assumptions finally ended, and I managed to see my GP Monday morning. No doubt she could sense my tentative approach to knowing, but avoiding a diagnosis was not an option.

There was simply no escaping. She explained that bleeding from the nipple is not a particularly common situation but didn't appear overly concerned. The fact that the referral she wrote to the breast surgeon was marked URGENT was evidence to the contrary.

The initial breast clinic appointment with the breast surgeon was pragmatic and clinical and offered no accurate indication of any outcome, good or bad. And trust me, I was looking. Looking for anything to indicate there was a way out of this nightmare. I could have been told that bleeding from the nipple might be caused by heartburn, and I would have believed him. However, of course, the answers were never going to be determined without a multitude of tests. A mammogram, an ultrasound and then finally, a biopsy of my nipple – which by the way, was not a particularly pleasant experience. The biopsy involved being hoisted into the rafters, lying upon a table with my right breast dangling through a hole, a hole in the table designed explicitly for body parts to dangle through. The doctor then stood under the table and proceeded to insert the appropriate medical instrument into my nipple. As I said, it wasn't pleasant. Mentally speaking, well dignity was left to cower in the corner and was forcibly replaced by detached indifference. Ultimately my awkward horror at having to dangle my breast through a hole in a table was simply unimportant.

It then became a waiting game. The rules of this game were minimal and straightforward. I became totally possessed with unrelenting emotion and unable to focus on anything other than a foreboding outcome. The longer it takes for results to be known, the longer you are left in limbo. It is the place where your imagination takes hold, and you cannot move forward until the dice is rolled again.

Finally, I was called to follow the breast surgeon into his room and then sat in a fog of disbelief as he explained my situation.

It was indeed breast cancer. A somewhat rare type, less than four per cent and called Paget's disease of the breast. The surgeon then drew some primitive diagrams and explained the urgent need to remove my right breast. The details of forthcoming medical procedures were unable to penetrate my brain. I was aware that this information was essential, and I should try and concentrate on his words. Instead, I simply sat there. I was hovering in a place that was somewhere between reality and delusion. My mind appeared to have wandered into another realm. A place that was separated from my body, floating somewhere nearby but not attached. For a moment, my entire existence was not present. It was replaced by an enveloping protective numbness that allowed me to retard the emotion - for now.

Whilst my intuitive voice had tried to warn me, there really was no preparation for this.



Wednesdays with Harry

IN ART WE TRUST

April 14th, 2021

What does it say when your son declares that a trip to the National Gallery of Victoria is where he would like to spend today? Unless alien artistic culture gremlins infiltrated his brain during the night, the only explanation is that we are having a scheduled power cut, which of course, ends all forms of life as he knows it.

Harry had heard that the current exhibition was worth a gander and so, with very little research, realised that it ended on Sunday and was free entry. Perhaps he should have researched a little further to discover that you still needed a ticket, and school holidays meant hordes of desperate parents seeking free holiday entertainment were also on the prowl. So now I found myself questioning whether the pull to experience another mother/son art gallery encounter was greater than the hassle of driving 1.5 hours, traffic, parking, queuing, crowds and all whilst nursing a head cold.

Side note: During a global Covid pandemic, it is not wise to acquire a cold/flu, cough, sneeze, hay fever, allergies or anything that indicates such symptoms. The consequences from the sneeze police are stares, glares, judgement and condemnation that is undoubtedly without sympathy and punishment more aligned to burning at the stake. I did, in fact, have a Covid test on Monday. Yes it was negative. Perhaps they should also issue a tee-shirt announcing such results.

After queuing for a ticket and then queuing to enter, I realised that many of this art-loving population simply sought where next to queue. Was it the queue to the toilet or the queue to look at the

miniature sculptures that persuaded and encouraged this piper approach? From desperate bladder bursting looks, particularly from middle-aged females, I quickly surmised that those looking for the loos were horrified to find themselves herded into any lines that formed and were sadly standing in front of a tiny sculpture instead of sitting down to pee.

This latest NGV exhibition was aimed to be a unique, thought-provoking view of the world from various artists, some known, some up and coming, all displaying different perspectives and genres. It was a diverse collection of art, design, science, and technology seemingly wrapped up in a statement. The overwhelming theme encompassed subjects such as race, gender, environment, climate, social inequality, you know, all the big ones. There appeared to be an emphasis on pushing the traditional boundaries of what actually constitutes art, and that is why I found myself staring (although somewhat briefly) at a chair covered in blue plastic shards and indeed questioning, '*What is Art?*' Harry was standing next to me looking at a stack of PVC pipes, and his judgement was not so philosophical. His assessment of that particular display was, '*what the fuck?*' Actually, that was his assessment for many of these exhibits.

I often find myself people watching when attending such events. It was evident that this particular crowd could be divided and assessed into three groups.

First was the already recognised parents with young children, attempting to occupy another day in the holidays that was free of charge and who were desperately hoping the Wiggles were on display. They walked rapidly through the gallery sniffing out anything bright, colourful and kiddy friendly that would appease little Mason, Harper, Logan or Amari, and they breathed a sigh of relief when discovering the vivid oceanic exhibit. Whilst its theme was regarding toxic waste in marine life, the humungous orange octopus created from hand-felted cigarette butts was a big hit with

the kids. Perhaps the massive polystyrene coffee cup hovering skyward filtered in the message of waste products, or maybe it was simply a fun object gawked at by the kids before they started chanting for Maccas.

The second is the *'We are here, but not sure if enjoying it'* group. This is Harry's people. They have heard it worthwhile and so took the risk. They question why so many people were there with young kids, troubled themselves about the length of queues, open-minded enough to look at all the exhibits yet judgemental enough to think much of it pointless. Find reading the blurbs a little too taxing, so take a random guess at the purpose and mostly declare, *'what the fuck?'* They encounter Pinocchio's Reality, a row of different sized noses and are confused how it relates to power, politics and perception. They walk down the dark hall to trigger the air dancer, but with all due respect to its artistic concept, they find the giant inflatable prop more associated with used car lots. They honestly don't care to watch the video of a sleepless girl in bed, wrapped in her doona, sending texts into cyberspace regarding her love life. They finally feel at home when they enter a room full of sporting trophies, only to learn their inscriptions are focused on racism and classism and clearly scoffing at the obsession of triumph and competition. They ponder over metal tapestries claiming that *'You are Not Tequila'* and they gravitate towards the interactive exhibits such as the Humming Room -- a completely empty room with a security guard out front and simply the instruction, *'To enter the room you must hum a tune. Any tune will do.'* If they wanted to look at fine porcelain plates, they would watch Antiques Roadshow; however, they did enjoy the shoelaces creating the *'Last Words of John Brown'*. And finally, they believe creating their own art by taking a photo of their shadow is essential to complete the visit. All in all, they are glad they went but would rather watch the footy or go to the pub.

The third group are true art lovers. They are easily recognised by their crushed linen uniform and no care hairstyle. They are genuinely there to spend as long as it takes to ascertain every detail and underlying nuance from every piece of work. They have their NGV membership card tattooed on their forehead and walk with a calm yet determined stride. They know exactly where to find the toilets without a queue, and they are experienced to seek out the limited seating. They sit and contemplate the artist's views and intricacies and appear to accept that art is whatever it needs to be. The creative practice of this changing landscape reveals a new paradigm, and they are up to the challenge. They have no desire to eat at Maccas nor the need to photograph their shadow. So there you go...

