

## WHEN CANCER CAME TO VISIT - a carer's life

In 2012 cancer came to visit and shook-up life as I knew it. Mum had been hiding a rather large, strange, coloured bruise on her chest, and persisted in telling me that her beloved cat had scratched her, even for Mum's art of understatement this was indeed a rather far-fetched explanation.

Mum was not a fan of doctors or any form of making a fuss so trying to get her to see a doctor to investigate the bruise was tricky. With great persuasion and a touch of trickery, I managed to get her to see her doctor for a general check-up, I also happened to just casually mention the "cat bruise". I watched intently as the doctor ran her hand over the bruise, not giving anything away with her facial expressions she noted that we best get things checked out just to be sure. At this point, she mentioned she was not too concerned with things so Mum left the doctor's surgery all cheery and I ticked the chore off our to-do list.

It would be Mum's birthday June 1st, 2011, when we were called back to the doctors to get the results. It seemed that breast cancer had been detected, and it was quite advanced, her Dr began to discuss management options to which Mum promptly squared her shoulders and with her stiff British upper lip firmly intact declared she was going to just get rid of "it "and do whatever was required.

If Mum was shocked, she hid it well, I must say I hid my surprise and fear even better. As we made our way back to the car my anxiety began to build as I realised we would have to share the news with my siblings some of whom we both knew would be very fragile.

I sent a group text to confirm our organised catch-up for Mum's birthday tea and made mention that everyone must attend as we had something to discuss. Walking into my sister's home you could feel the heavy weight of knowing. Knowing something was to come, knowing things were going to change and then the greatest fear - **the unknown**.

Mum broke the news in her wonderfully pragmatic Belvin way. I have cancer, it's in my breast, everything is OK, I am going to get rid of it, now let's eat dessert. My siblings followed her cues of bravado, but their eyes told another story as they pierced into mine to give them reassurance or some answers. It is amazing the conversations we can have with our eyes, and they understood that our other conversations would be held later, without Mum around. Mum never wanted a fuss about anything and an inconvenience like cancer was not going to change that.

What followed next were the beginnings of the ride which is the medical merry-go-round. It begins with a series of tests, then MRI's, hospital visits and trips to the local cancer centre to get a medical perspective of where we were at. Mum never really bothered with all this nonsense as the words made no sense to her, so I became an instant medical expert on all things treatment and cancer. I made notes, lots of notes, I asked questions, lots of questions.

We hit an early hurdle with another undiagnosed medical condition, so surgery and treatment had to be delayed due to an immediate need for throat surgery. The doctor whom mum had had for many years kept saying it was asthma each time I raised concerns about her breathing and changes to her voice. It was fortunate that a young locum doctor at the hospital followed up his concerns about her breathing, mum was then immediately booked in for a huge operation before we could even begin to work on the cancer. It would be the first of many times I lost the plot at her doctor and her laissez faire attitude till I eventually dismissed her as a doctor to improve Mums treatment options and found a doctor who would **listen** to what we were **actually saying**.

Mum finally was able to begin chemo and radiotherapy as the initial course of treatment, a double mastectomy would follow when she had regained some strength back and her body was ready. It was agreed that I would become her carer during this time. It seemed I had been unofficially elected to this role as I was "by myself", all my other siblings had partners / family living at home, and I also suspect they felt I was probably the most pragmatic and organised out of all of us siblings to deal with things.

I am so very glad I had the privilege of spending this time with Mum. The first year we were all on track to beat the bloody thing. Mum did everything she was told, surprisingly with no arguments and her stoic English stiff upper lip actually served her well. I nursed her through her double mastectomy and managed to do things I never thought possible. I nursed her wounds, checked all her meds, bathed her, watched as her hair fell out and we laughed as she tried on different head wear until she decided to just embrace the bald.

It is strange to think of happiest memories in this time but there were so very many. We would laugh and laugh at stupid stuff, especially when mum was on her pain meds. It was also not all laughter and positivity, there were days that were just plain confronting. When you see someone, you love in pain you just marvel at how much the human psyche can endure. The bandage wrappings would stick to her oh so fragile skin and I would fret about hurting her. There were times Mum would accuse me of poisoning her, stealing her food and money, times when the medications had addled her brain, and she had no idea what was happening. Mum became very intense about what she could control as she saw everything else spiral out of her control. For all the challenges, long days and even longer nights after eighteen months Mum finally had the all clear from breast cancer and as a family we had a quiet celebration, however something inside me didn't quite settle. I saw my sibling's relief and joy believing it was all over and for them I played the game. But you see cancer is an insidious horrible disease, its tentacles look for weakness and room to grow. Mum had put up an amazing fight the first time around and was just keen to get on with her life, back to bingo, back to shopping, morning teas and family get togethers. For a short time, I returned home to my "normal" life.

Four months later after a routine check it was noted that the bastard disease had made its way to her lungs, a few little sneaky cells had begun their silent journey and had made themselves comfortable.

Now we knew the real fight had begun.

This time around Mum was not so buoyant and ready to fight the world, this time there was a strange quiet acceptance about her, and that in itself was the scariest part. Once again, I had to tell the siblings, but it was breaking it to all Mums grandkids and great grandkids that was the hardest part. They all adored her and the first-time round we had sort of shielded them all and kept everything super upbeat for them.

Mum seemed to get sick quickly, there was no treatments that could help her now and she went in and out of hospital with simple infections. I returned to live at her house this time it was full-time. Again, I became her nurse maid, confidant, cook, cleaner and everything in-between. Again, despite the circumstance we laughed and laughed about life and silly things that would happen. Mum had spent all her life being on a variety of diets to lose weight but now she decided that it didn't matter as the weight began to fall off her. Mum would have chocolate for breakfast lunch and tea, KFC Krushers with double chocolate topping were her favourite and I was forever doing KFC runs for her or ordering pizzas with double anchovies and cheese. Mum loved this new freedom to eat what she liked. We would watch mindless TV, and my happiest memories of this time is watching Eurovision and Mum choking with laughter at the performances. I got her hooked on Big Brother reality TV and she became so invested in it all, it was a great distraction. Mum would have her music on most of the day and I would sing all her old songs to her, which she was amazed I knew the lyrics to, forgetting I had spent the best part of my life having those songs playing in the background of our life.



Mum decided to get rid of all her clothes as she was now just living in her nightie most days, she would never know that many months later I would be so glad she had done this whilst she was living. Mum also invited all the grandkids around to select a treasure from her special ornament cabinets, all those treasures that they had known never to touch. That again was a lesson in what we value, they bypassed all the crystal and valuable items and selected the blue haired troll

dolls and animals and people made from shells that Mum had collected on her various trips. Again, I am so happy she turned this into a fun event whilst she was alive as months later it would all of been too hard when she was gone.

Mum was determined to hang on to see her beloved Hawthorn football team win one more premiership before she died and one of the happiest most joyful memories my family and I have is of us celebrating a premiership together. Mum was so weak yet so feisty and deliriously happy. Mum paid for her following years football membership even thou she knew she would not be there to see her Hawk boys.



Mum also organised and planned her funeral just in case, whilst my siblings just closed down and would not discuss it, this was a masterstroke by Mum as all her wishes were put on paper. I remember gathering with the family to talk about her wishes and they struggled immensely to have the conversation, so it was left to my sister Bev and I to organise.

As the months went by ever so slowly Mum got weaker and sicker. Her mind began to go as she fought against the medication and her loss of control. Mum was convinced I was poisoning her and even thou I knew this not to be true, to be in that space is just awful. My greatest fear at this time came each morning when I would go to her room to see if she was still breathing and alive. The feeling of cold fear running up and down my arms as I opened the door to then be matched with the wave of relief as I heard her soft English accent wish me good morning is something that still affects me. They don't tell you this part about being a carer. I was petrified of finding her passed and would spend half the night listening for noises or for her calling for me.

Mum always said she wanted to die at home but despite all good and noble intentions sometimes this is not the way things go. It was becoming exceptionally difficult to manage the pain meds, her breathing and making her comfortable. Despite the nurses coming daily to assist me with Mums care I knew Mum was struggling. It was also extremely difficult to manage well-meaning visitors and family, as well as manage their distress and expectations. I

know Mum was finding this hard also and in a rare moment of lucidity asked to go into hospital for palliative care, so finally an ambulance was called.

It is a strange pain to see someone you love begin their journey from the home they have lived and loved in, to then be placed in the back of an ambulance on their final trip.

You know they are not coming home, and I knew Mum would never again see the home she was so proud of. I followed Mum to the palliative care hospital leaving behind my sobbing siblings and Mums grandchildren on the concrete driveway with its cracked pavement. There had been a slow procession of sad goodbyes, gentle kisses, whispered love language and broken hearts. Mum was thankfully oblivious as she was quite medicated, she would never have coped with such sadness. We settled her into palliative care expecting the end was imminent. At this time, I feel I was quietly holding it together, I don't know how in reality, but I just felt I had to for her. Mum would be seven days in the palliative care room, I stayed there on a fold out bed as my greatest fear was that I just did not want her to die alone. My siblings came in short visits whilst one of my sisters Bev joined me for an overnight stay, they were all living in this frozen moment of waiting for a phone call. At this time Mum was completely out of it, she would call for her Mam in the strongest English accent I had heard for a while, at times she would squeeze my hand, and I do believe she knew I was there. We would place ice over her dry lips and wash her face with a warm face washer just as she had done for us as little children when we were unwell. I told her lots of stories, and I wonder if she heard them. I told her how much I loved her and thanked her for everything she had done for me in my life, I hope she heard that. One of my sisters had been in the ward with me for a few days and I always believed that Mum would not pass if she was there, my sister had experienced the pain of death before and some instinct told me Mum would not do that to her, she would hold on till she had gone. I finally managed to send her home to rest as my younger brother Eddie came in to spend some time with her. My brother went to one side of the bed as I sat at the other and in the quietest of moments Mum took her final gentle breath. It is strange to say it was perfectly gentle and Mum let out almost a sigh of relief as she went towards the light and home to be with Dad.

My brother and I looked at each other and it was such a peaceful experience we both felt the same thing, it is hard to describe in reality. The nurse came to do all the official stuff then left us in moments of silence with Mum before we had to face the reality of a world that would be full of broken hearts.

I think they were all expecting the call and had spent nearly a week expecting it but that does not make it any easier. The sobs echoed through my phone and all I could do was console them with the fact she was now at peace. My siblings all arrived at the hospital to give her one final kiss goodbye then we arranged to meet at Mums house a bit later.

The moments after are a blur, there are official things to do and sign, thank you's to the nurses and hospital staff and then this realisation that you are letting go. No more coming here again, your duties as a carer are over and yet this has been a large part of your life the last few years, you are kind of lost in this time.

We gathered at Mums to talk, cry, reminisce and tell tall stories. In this time, it was just us kids before we had to tell the world it was real. I went back to my

own home for the first time in months and that in itself was a new experience. All these things I had to reacquaint myself with as I had to return to my life, but first there was a funeral to organise and other real-life things to undertake.

No-one ever tells you about this bit and what a horrible experience it is. In the days to follow banks, solicitors, utility companies, Mums house, Mums things, all had to be dealt with at some stage. I operated on a strange, organised auto pilot. The day of Mums funeral came along, we always thought Mum had few friends as most of her time was spent with family, for that reason we booked the small church room that would fit around a hundred people. As we arrived, we were surprised to see the church was packed to the back room, it was standing room only with all the people who Mum had made welcome in her home over the years. It was like looking at a living movie reel of moments, people and times. All those naughty teenagers who had crashed on her lounge room floor were now all grown adults and had come to pay their respects and share their memories, it seemed Mum was loved more than we could know. It's funny what we think of our parents isn't it? Mum had an impact on many with her generosity and kindness, we only ever just saw her as Mum. The funeral was as sad as all funerals are, the sobbing of her grandchildren and great grandchildren was the most heartbreaking sound. There was moments of great laughter as Belvin stories were told and I smiled secretly as her coffin was decked out in her beloved Hawthorn colours, Mums last wish was to have the Hawks theme song to send her on her way, we all knew she wanted to annoy the Geelong supporting bingo ladies who may be there, we all smiled at that, such a Mum thing to do.

After a funeral comes the wake and stories are told, long lost friendships reconnected, and tears are shed. It is such a long emotional day full of people and at the end of it I went home alone to sit in the silence to process the next phase of life. You see it is all not quite over as yet, there is more to do, so grief parks itself aside as life goes on.

It is always the little things that tip you over the edge. I had not really cried or grieved as yet; I was in this strange kind of lost. One day whilst tidying up at Mums I noted there was mail in the letterbox. It was from the electricity company requesting immediate payment as Mum's bill was overdue to the amount of around \$50.

**And there it was** - the thing that broke me. If you knew my Mum, she would never ever be late with any bill, never in debt, it would be an affront to even suggest it. That this account had somehow slipped by amongst all the illness and grief and was now overdue just sent me into an emotional screaming rage. My brother just happened to call at this time and I just couldn't stop crying and screaming, he implored me to calm down, take a breath and he would fix it, but I was done.

It was the one thing that finally pushed me to explode and release the months of pain, grief, loss and uncertainty.

I cried for hours over that stupid bill.

xxxx

for Belvin

"To know and feel grief is to know that the one we lost meant something important to us. The grief we feel is equal to the joy and love that person gave us, the greater the love the deeper the grief."