



An **empowered** Pink Hope woman uses her talents to express herself, while encouraging other women to take control of their health.

Meet Pascale.



Pascale: EMPOWERED

My name is Pascale and I am 40 years old. I immigrated to Melbourne from England in 2005 and I became an Australian citizen in 2007. I have lived in the artistic and leafy north-eastern suburb of Eltham with my young family since 2009. In 1994 my mother, Christine, died of secondary breast cancer in the Pilgrim's Hospice, Canterbury, Kent, when she was 42 and I was 16. I have now been without her for 24 years and over time this has become very normal to me. I miss Mum more than ever now that I am a mother myself to two young daughters, Florence and Isla, aged 7 and 4, and feel that I understand more of her own experiences. We are from a family of women affected by hereditary breast cancer, with a total of 8 relatives diagnosed and not surviving their cancers (5 women and 3 men all under the age of 50), and currently no known genetic mutation.

Mum was French, very French. She loved clothes, jewellery, perfume, good food, fun company, fine wine, an occasional cigarette and the sun, the sun and more sun. She was an only child who had lost her own mother to breast cancer. I never knew my French grandmother, Marinette, who died aged 46. I remember the first time I saw my maternal family tree on paper. I read it in my small flat in Hawthorn in 2007 as I began to collate the medical history on Mum's side with help from my family abroad. The information was for the high risk Familial Cancer Clinic at the Peter MacCallum Cancer Centre

in Melbourne. I didn't know all those second cousins who died early from cancer but when I saw the numbers I cried for them right there and then. The youngest was just 33 when she died. I remembered woeful talks of remembrance around the kitchen table when we occasionally visited during our summer holidays in France but I could not understand how I had not known the full facts until that moment.

When Mum was diagnosed with breast cancer in 1991 she said to Dad, "I have been waiting my whole life to get this". She was 40 years and 1 month old. She had a lumpectomy, radiotherapy and took Tamoxifen to treat the breast cancer. People thought she was strong and that her strength would be all she would need to beat it. Everything was looking positive but about a year later she had a feeling that the cancer had returned in her hip. She had chemotherapy and we shaved off her hair in the bathroom. She wore hats and a hot and itchy wig, and continued working until the end of 1993 when one day she collapsed at the school where

she worked as a teacher and was taken to hospital in an ambulance. Her hip was massively weakened by secondary breast cancer. She used a crutch to get around, then a wheelchair and Dad had to rapidly learn to drive. Then came paralysis on the right side of her body and soon afterwards she was moved from her bed downstairs at home by ambulance to the Pilgrim's Hospice. I knew she wouldn't be coming back and it was absolutely heartbreaking to see the crew lift her into the back of the vehicle and drive away. I am sure she also knew it.

The cancer quickly spread to her liver, through her body and finally it became a brain tumour. Hallucinating on morphine she saw "G O L D I N F I N I T Y" spelled out on the wall of her hospice room and beautiful ghostly girls dressed in roses and gypsophila came towards her. She wrote farewell letters with the free left hand and listed out her jewellery on green paper hand towels from the dispenser. Three years on from diagnosis she died just short of her 43rd birthday, early in the morning



on 7 June 1994. It was the second day of my G.C.S.E. final school exams. We went to see her lying peacefully in the hospice in the morning and I remember touching her skin which was stone cold. Light from a small window fell on her face. She was pale and had lost all her hair. The steroids had made her body swell to twice the size. Mum would have hated looking like that at the end, stripped of her looks and mobility, but she never really said it out loud. In the afternoon I went in to school and sat Maths and History on a teary, blurry day I will never forget.

Mum had a face like beautiful warm sunshine. She was popular and well-loved and friends, family, students and colleagues came to the crematorium. Dad gave the eulogy and expertly held it together. I don't know how he did it because I seem to cry at just about everything. I couldn't look up at him or at anyone else because my eyes were so full of tears. Nothing had ever hurt or could ever hurt me as much again. Her coffin was brought in to Handel's The Arrival of The Queen of Sheba, traditionally a wedding march. Dad said that he had chosen the music because it sounded just as she was: bright, lively, triumphant. I always like to think that there was a little bit of Princess Diana in Mum. We said goodbye to our queen of hearts and life was never the same again.

Not long after moving to Australia I was asked by my G.P. about my family history of breast cancer and she suggested she refer me to a surveillance program at Peter Mac where I would be risk assessed and then monitored in a familial cancer clinic at 6 monthly intervals with annual mammograms. This was 2007 (I was 29) and

my risk was considered moderate but I would be monitored as high risk, based on the fact that Mum was an only child and had no other immediate family members. To be considered high risk you needed to have a third affected person. I only had two: my mother and my grandmother. At this time I still felt young and had my head buried in the sand about my situation. In 2009 I became eligible for annual MRI screening through new funding and this came as a big relief as I knew mammograms are not as effective in young, dense breast tissue.

In 2011 and 2014 I had a couple of scares while breastfeeding my daughters. The first was a benign cyst that was drained and the second was a painful infection. Both times sent me into a panic, going from A to Z in a heartbeat thinking this was finally the Big C coming for me. I was scared and by age 37 I was starting to feel like a ticking time bomb. I realised that I had never really projected life beyond my mid-forties. I thought about Angelina Jolie and I thought about Kylie Minogue and the importance, power and influence of their public stories. I read everything I could about them on the net and I knew then that surveillance and mammograms were no longer enough for me. The rite of passage into motherhood had made me see clearly. After a mammogram and an MRI at the end of 2014, lots of thinking about the future of my little girls and nights spent staring at their sweet sleeping faces, I knew it was time to square up to my risk. I didn't want to get breast cancer but, more than anything, I didn't want them to be motherless.

Gene testing had suddenly become more "affordable" for



unaffected women through newly available government funding and I decided it was time to do it. The option had been raised at the time of Mum's diagnosis in 1991 but because of the newness of the testing there were concerns relating to discrimination with insurance and personal privacy and, as I was only a teenager, it was decided not to do it. In 2014 we discovered that Mum's tumour had been preserved according to a 30-year protocol at the William Harvey hospital in Ashford, Kent, and was therefore viable for another ten years. I spent 6 months at the end of 2014 trying to establish whether it could be tested in the U.K. with the same science newly available in Australia. Unfortunately this wasn't possible and so her tumour was flown to Melbourne for testing on a pilot scheme by Peter Mac but when it came to it the DNA had deteriorated too much. I then waited for all the genetic test results from living tissue to be completed which told me that I was negative for the faulty breast cancer genes BRCA1 and BRCA2. This genetic investigation had taken up

another whole year of waiting - all of 2015.

Of the women diagnosed with breast cancer only 5% have a family history. Of that 5% of women only 10% have a known faulty gene. By 2016 I had established that I was genetically grey and couldn't prove otherwise. Despite my efforts and all the risk assessments by Peter Mac, there didn't seem to be any numbers I could truly believe in when it came to my own risk and so I made the next decision mostly because of my emotional experience with breast cancer. **My overriding feeling was that if I was diagnosed with the disease I wouldn't survive it, because no-one else in my family had so far. I discussed my rationale at great length with my genetic counsellor who made sure I had taken everything into full consideration. By then I was dead set certain.**

In early 2016 I went on the public waiting list for nipple sparing prophylactic bilateral mastectomies with air expander to implant reconstruction.

I waited about 6 months for a date for surgery and then I had a nipple sparing procedure on 10 August in the brand new hospital I called Vanilla Sky, after the movie. I was lucky enough to have a team of female breast and plastic surgeons who, for me, represent amazeboobs girl power. These women fall into a 7% minority of surgeons who are women in Australia! I am so glad I got them for nineties feminism alone. The mastectomies followed on Friday 26 August 2016. The operation removed all of the breast tissue and the nerves in front of my chest wall and created a cavity behind the pectoral muscle in which to place the expanders. The untrained eye should not mistake mastectomies for a boob job!

The recovery wasn't easy for me. I get nauseous with most things: cars, boats, pregnancy... too much wine: you know the story! It was inevitable that I would find myself in a long period of nausea and pain. I managed to lose 10kg of baby weight in a few short weeks. I vomited for three days straight after the operation, from Friday to Monday, and I couldn't really distinguish between pain and nausea. When I went home I quickly found myself in 36 hours of constipation. This episode was so horrible and one I wouldn't wish on my worst enemy! I also had a general intolerance of pain relief because it made me nauseous so it was a difficult juggling act – pain/appetite/eat/drink/sleep/rest/move. This doesn't happen to everyone, of course, but typically it happens to tall, skinny types like me. (You see, the grass is not always greener!) I kept an illustrated diary to distract me from the reality of it and to record all the details of my journey. I posted my drawings, thoughts and progress to the socials to stay connected. The diary

quickly became a coping mechanism and a way of life.

A few weeks later I began self-expansion of the air expanders by remote control. Within the expander a canister containing CO² released small increments of gas designed to inflate and stretch the cavity, up to a maximum of three times a day. In my usual impatience for now, now, now, I did this far too quickly and got myself into trouble. One day I felt so much pressure I thought I might explode all over Eltham and my good friend took me to Emergency. I didn't explode, of course, but the expanders were like rocks and wore me down physically, mentally and emotionally. It felt like concrete had been poured into my chest. I found that I got tired really easily. As a tummy sleeper (note: freefall position) I suffered from anxiety and insomnia from lying on my back trying to sleep and it took about three months for my mojo to return after surgery. My husband, Rob, looked after me in the first few weeks and when he had to return to work Dad flew over from England to help out with the girls, who were aged 2 and 5 at the time. A 'new normal' began.

It was fortunate that I had art, music and social media because it was a place I could literally illustrate my own experience. A place to put all the cray-cray! I practised this religion throughout the 7 months of reconstruction until the day of my exchange surgery on Friday 7 April 2017. My plastic surgeon kindly swapped the rocks for firm but soft implants which I nicknamed 'The Baps' (British for a soft bread roll) and also grafted fat from my hips to inject over the top of them like a cosy duvet which would help to disguise the dimples and rippling. The female anaesthetist gave me the

perfect cocktail of drugs this time and my stay in hospital felt like a mini-break! I was black and blue with bruises but they didn't really hurt too much and I was genuinely overjoyed, relieved and thankful. I pinged my topless selfies into cyberspace! The aesthetic result was fantastic thanks to the work of the expanders and the surgeons. No pain, no gain! FINALLY I was free!

Or so I thought... ten days later while I was recovering at home I experienced terrible pain in my tummy, like labour pain. I thought it was related to the surgery somehow. The pain would come and go every day in crippling spasms for two more months while my new breasts settled in, the drains came out and the bruising healed. I couldn't eat fat or sugar. After scans, more investigation, lots of expense and seemingly endless appointments with medical people, I found out that the culprit was my gallbladder. I carried on drawing and writing from behind the screen. I mostly ate dust - just about the worst thing for a hangry person with a ferocious appetite. I actually thought I was going insane.

A different surgeon at a different hospital removed my gallbladder in a laparoscopy on 6 June 2017. When I woke up he told me that there were complications - three gallstones had escaped out of my gallbladder and were stuck in my bile duct. They had to come out. On 7 June, the anniversary of Mum's death from breast cancer, he performed a procedure via my throat to remove them but unfortunately he accidentally perforated my bowel after the first part of the two-step procedure, leaving two out of three stones in the duct. It was agony. My bowel was leaking inside me. I spent a week in the hospital with nil by mouth, in a ward full of

old men, hoping and waiting for the hole to close. I can't even describe the horrors of being in there - the sounds, the sights, the smells, the drips, the injections, the extractions, the drugs, the gastric nasal tube. In my head I gave gold medals to all the incredible nurses for being in there day in, day out. I dreamt of all my favourite foods, especially the fatty French ones. I made a long list to look forward to which didn't include dust. I got down to 54kg, pre-2005 emigration weight. My reflection in the bathroom mirror was an emaciated horse with big knockers! I wasn't really there. I didn't even realise the bed was plastic. It was during that week that I profoundly understood that you really do only get one life and I that I had in fact hardly painted anything yet!

I had to wait another 2 months for my body to settle down before having an MRI to locate the stones missing in action. The head surgeon was threatening me with "tricky zipper scar surgery". His face was grim and serious. I was so terrified. I carried on with my diary. I called on my British sense of humour; I tried to find the funnies. I counted all the numbers conspiring against me. I became superstitious! And for the first time I felt like a victim. Fortunately the MRI revealed that the stones had passed in a big band of pain I had experienced in July and so on 10 August 2017, exactly one year on from the nipple delay procedure, the surgeon finally gave me the all clear. I was alive but I was broken, lonely and incredibly depressed. Looking back, I am certain I had PTSD. The gallbladder loss had completely eclipsed the loss of breasts. I had been robbed of any celebration and I could do nothing about it. **I had previved and then survived. My mind was in overdrive and my body felt hopeless. Everybody told me, "Well, you look**

good!" and I became obsessed with insides and outsides.

Today I feel like I have a thousand paintings in me: I'm every woman! I was extremely lucky to have the support of Pink Hope with me all the way through this experience, from 2014 until now, and I could not feel more grateful, more empowered or more free to be myself. In the early days I shared my story in the belief that it would help others. I never could have known that writing, drawing, painting and listening would continue for as long as it has, or that it would become a part of me which I can't close off. I now know myself really, really well and I accept it. I feel like who I was in the very beginning and I'm not afraid to be that person. There is no line in the sand. You take what you know with you, it helps you to grow and it can also help others if you share it.

I have not had breast cancer and I can't imagine what it must be like. I am just one woman among many who has been impacted by it. I have stopped expecting anyone to fully understand my perspective, my vulnerabilities and my strengths, how grief will never leave you even if you remove the body parts, and how one day you will have to think about the future of little girls with no experience of their own if genetic science has not caught up with them. But in the meantime I have to believe that I can make my own impact if I use my voice, my art and my heart. I definitely would not have found Pink Hope anywhere else but here in Australia, so, I conclude, in the profound words of Pascale Minogue: I should be so unlucky-lucky!

