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THE PINK UNICORNS OF MALE BREAST CANCER

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**The Pink Unicorns
of
Male Breast Cancer**



**Written by
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Forward

The Pink Unicorns of Male Breast Cancer is the story of my journey through breast cancer. Yes, with breast cancer. No, not bone cancer or prostate cancer. Breast cancer, you know, all that pink ribbon stuff.

This little preamble is to underline the normal reaction I get when I tell someone I had breast cancer. First, they think they misheard me. Add to that, the looks of suspicion, suspicion of a very bad joke, pure disbelief, and finally complete mental confusion. This is the reaction of many when taking in the mortality rate for men from the disease. With the acute lack of interest in the general media, one British cancer organisation stated: “There were too few men, therefore, women have priority.” In simple terms, men are less important. When all is added together, you will begin to understand why this story needs to be told.

The treatment of cancer is truly holistic. It is very individual in how it affects each person and their world. I don’t intend this story to be about the various cancer treatments; just my story and how I experienced it.

My wide-ranging life experience and medical knowledge did not prepare me for the shock of late February 2012, although I was prepared in that I was reasonably fit at the time of my

diagnosis. I was losing some excess weight and getting back into training for a marathon.

I had a knowledge of cancer treatments and the associated surgery. This was backed up with the black humour of nursing combined with that of the Royal Navy Submarine Service.

All of this came together and was much needed to get me through male breast cancer.

There is little information to look up about male breast cancer. It is easier to join Monty Python in looking for the Holy Grail. My medical encyclopedia doesn't even use the word "male" anywhere in its information on the diagnosis, treatment, and statistics about breast cancer. It only has information about women with the disease. Another cancer organisation's total input is "men can also get breast cancer." Just six words to cover the shock of becoming a Pink Unicorn.

Why a unicorn? The unicorn is a mythical beast. We male breast cancer survivors are truly mythical; the majority of people don't know or believe we exist. We are so rare that some doctors don't even consider breast cancer as a male diagnosis. Misdiagnosis may be as high as 40%. This sad fact often has fatal consequences when it combines with ignorance of the general public.

Everything to do with breast cancer is covered in a pretty pink fog, although truly there is nothing pink or pretty about breast cancer. We unicorns just had to be pink as that is the

media colour of breast cancer.

If you want some figures, I am one of one in 100,000 men and form just 0.02% of all male cancers, and 0.9% of breast cancer cases are diagnosed in males. This all means about 2,000 Americans, 400 British, 100 Dutch, and 40 Swedish men per year will be told “you have breast cancer.” The majority will be in the late stage 3 or too late stage 4 of the disease having already spread into the body when diagnosed. A quarter of those diagnosed will die from the disease. I don’t know if I should belong to the 400 British or the 100 Dutch; it doesn’t really matter.

Relatively speaking, more men die from breast cancer than women--25% as opposed to 19%. While the disease is easier to detect by men and easier to treat, cancer travels through the body much quicker in men. Therefore, early detection is vital, but how can there be early detection if men don’t even know they can get the disease?

After nearly forty years in nursing, I only vaguely knew that men could get it. I had no details, simply that men could get it, but it was very rare. So come, travel my road, it might save someone’s grandad.

What's This Lump?

Somewhere around February 24th, 2012, I was laying half awake in my bed. My left nipple was itching. Sleepily, I gently scratched it and felt a small hard lump just above the nipple. The lump was quite firm but painless. Although very curious, I went back to sleep. I didn't know then that itching and dry flaky skin around the areola are some of the early signs of breast cancer in men.

In the morning, I checked again. I found a smooth rubbery lump about the same texture as a pencil rubber. It only affected one small area (not the whole nipple), and it wasn't tender so I knew it wasn't mastitis. As a long-distance runner and former Judoka, nipple rub and mastitis are things I knew. This wasn't either although I had recently stepped up my running training for the Berenloop Marathon on Terschelling in the coming November.

I waited for a couple of days to see what it did--it didn't do anything. It wasn't hot, it wasn't sore, it didn't get worse, but it didn't get better. My medical knowledge exhausted, I went to see the doctor. I was thinking it was possibly a cyst caused by chronic nipple rub from my running.

My doctor examined me, washed her hands, and turned to me.

"I don't think it is cancer, but I'm sending you for a mammogram just to be sure."

Cancer? That thought hadn't even crossed my mind. She added that if she thought it was cancer, she would have sent me directly to the surgeon but that the lump was smooth.

So a couple of days later, I am sat outside the mammogram unit at the Antonius Hospital in Sneek along with several anxious-faced women and their husbands with equally drawn faces. I was getting a few sideways curious glances as I was a man, and I was there alone.

I was called in by a slightly bemused radiographer and watched by even more bemused patients.

Well, we had fun. The poor radiographers were trying so hard to be professional. That doesn't work with me. A male mammogram is a cross between twister and catch the wet soap, but eventually, they were successful. I was asked to wait in the changing cubicle as they wanted to do an echo as well.

Gentlemen, I will assure you my heart goes out to all the ladies. A mammogram is decidedly not pleasant.

I was called back in and noted an immediate change in the atmosphere. It had gone back to the strict professionals. The fun was over. Another technician came in to do the echo, but first they had to shave the area. I got the impression it was probably another first for them, shaving a breast prior to an echo. This was obvious from their dexterity with a razor. Then it was followed up with a biopsy. No one had said anything about a biopsy!

I have suffered a few “nipple twisters” in my time, but a biopsy is really something else. It’s like someone striking a match inside your breast. That was followed by taking some lymphatic fluid which ached like nothing I have ever known before. In short, it hurt. I asked the technician, strictly off the record being an ex-nurse, what the score was. He said 50/50. He lied.

That evening after I got home and showered, I stood in front of the mirror and took a really good look and there were the faint signs of breast cancer I knew. The slight difference was in the nipples. The left areola was a bit sunken and the nipple misshapen, but it was very slight. When I showered, I couldn’t feel the lump with the flat hand even though I knew it was there. It had to be a fingertip search.

The immortal phrase of Apollo 13 went through my mind. “Houston, we have a problem”--cool, clear, matter of fact. There was a problem that needed fixing. In Naval terminology, I was in deep.

I had been given an appointment to see the surgeon on March 5th for the results. When I put it all together, the mood changed. The sudden unannounced biopsy, the technician’s reply, and my own observations. In my heart, I already knew the results. I had to talk to my kids.

How do you say “Hi kids, it looks like I have cancer,” when you have just come back into their lives after being away for ten years in a different country?

I simply told them what had been going on--all about the lump that shouldn’t be there, and that I didn’t think things were good. I was a medic. I find no point in bull. No rose tints. Just straight facts. It gives people time to get ready in their own minds and also to make any plans they need to. You can only work with the truth.

In the meantime, I started my search for information about male breast cancer beginning with my own medical books. In a word, zilch, the square root of zero. After that, I started searching the internet. You find a snippet here and a snippet there. It seemed to me that cancer organisations have either nothing or some small amount that requires another oncologist to understand it. The internet is worldwide. The most information I have about male breast cancer came from an American site, but that was found after my surgery and during my chemotherapy. From that site, I learnt how to do a fingertip check just like the ladies do. I learnt that the normal age of onset is fifty-five to seventy. Signs include itching and dry flaky skin. I had the dry skin a few weeks previous. Later comes the misshapen, sunken, and discharging nipples which you can read about in the female signs and symptoms which are published on all the other sites concerning breast

cancer. Although when you start showing those later signs as a man, let's just say you are in very deep trouble. The lump is usually located below the nipple, mine was above.

You also begin to ask yourself. How? When? What? Where? Why?

I remembered one evening about three years earlier, my fiancée and I were having a rare little intimate moment, and she found a lump in my breast. It was a little sore when pressed. I was also busy with running training at the time. I put it down to irritation from running; it wasn't painful unless pressed and didn't get worse. I thought it was a little mastitis. It was simply forgotten about. My fiancée was terminally ill with a lung disease and disabled with severe rheumatoid arthritis so a little mastitis is really rather insignificant. Was this the same lump as then? I don't know. I will guess it probably was.

The how? Initially, I put it down to constant irritation from running. Although if this was so, breast cancer would be more prevalent with long-distance runners and it isn't. Later, I read that there are three recognised causes: genetics, hormonal, and radiation. Genetically, there is no known history of any form of cancer in either side of the family. I have since had a full study by the University Medical Centre Groningen, and they can find absolutely no genetic cause for breast cancer or, in fact, any cancer in my genes. My hormones are normal. I do not have Klinefelter's syndrome. Radiation? Yes, I had worked with radiation for five years in the Royal Navy. I had never exceeded any dose; in fact, my life dose hadn't reached my annual limit, and I had never been exposed to anything high level. Or had I?

I remembered being ordered to make an emergency reactor compartment entry for exercise purposes aboard HMS/M Renown. I was ordered to make an actual entry and complete a radiation survey down to the lower level. Exposing anyone unnecessarily like this to ionising radiation is, in fact, against international radiation law. You can try telling that to a lieutenant commander who wants to make exercises as realistic as possible.

After I had done the survey, I told the engineers that I hadn't heard the control rods drop. They told me that they hadn't dropped the control rods which absorb the neutrons and stop criticality! They had been ordered to just turn the power right down low so that they could make a fast recovery after the entry was complete. That meant all the time I was in that reactor compartment, the reactor was still critical, and I had certainly too high energy Gamma radiation. Yes, that would cause it... Thank you, lieutenant commander FG. I hope your guitar goes permanently out of tune, all your strings break, and you forget the words of "Greenback Dollar"! He never really understood anything about radiation anyway. All I could do was wait for the results from the

mammogram, echo, and biopsy. Until then, life continued as normal. You can't do anything with what if's. All I had was an almost certainty I had a disease that I could find no information on.

The Day My World Changed Forever

March 5th, 2012. D-day. First thing that morning, I had a meeting with the jobcentre. It seemed they may have finally found a job for me as an industrial first-aid instructor. I had to give up my nursing registration when I became fulltime carer for my late fiancée. I hadn't been able to do the required continuation studies to keep up my registration. The job looked promising. I didn't have the required papers but had plenty of experience. I had been trained to a very high level in the Royal Navy. I had given lectures and trained first-aid parties on board ship. I had also been part of the Dutch Red Cross disaster team for North Nederland. Getting my instructor's certificate would be fairly basic.

So there I was sitting in the surgical waiting room with my daughter waiting to see the surgeon. Once again, I was surrounded by ladies, most with their husbands, all with drawn faces. Their minds tying themselves in knots and wondering if.

I was already certain of the results.

We were called in, and the surgeon was wearing a serious face and being very correct. I told her

I was quite okay with the situation.

The results. In simple terms, the tumour was malignant and the lymph glands had also tested positive. The former I had expected; the latter, shall I say, was rather disappointing. I was then immediately dispatched for liver, lungs, and a bone scan.

Little did I know how much the simple sentence, "You have cancer, and it's malignant," does to your life.

Everywhere I went, all was explained in very simple terms despite my telling them I was an ex-nurse. Knowledge in this case really is power as only the unknown causes fear. I had worked in the operating theatre, seen the operation worked on a breast surgery ward, and run an oncology clinic.

So the information. I have breast cancer. It is malignant, and it has spread. The question now being how far? I had recently had a liver scan, and that had come back clear so I could assume it was probably still okay. This is the "waiting for results." It is pure torment. You know you have cancer so you want to get going and get it sorted, but you must wait patiently. All the time your mind is doing handsprings, and everyone that cares about you is also in a blue funk.

A week later, once more by the surgeon. Again she wore the serious face. My liver and lung scans had come back clear. That was good. The bone scan showed two hot spots on my ribs.

Now was my time to panic. Bone cancer is scary stuff. It is very difficult to treat. Often there are periods of remission only for it to reappear again. I had lost three friends to that in the past. It is not pleasant.

I was sent off for a detailed x-ray. Again, the wait for results. Until everything was cut and dried, they would not give me any information, not even a pencil line plan, no prognosis. All I had was a diagnosis and a hundred unanswered questions doing gymnastics in my brain.

This is, in fact, the worst time to my mind as there is so much uncertainty. All you do know is you have cancer.

Eventually, the results were all in. The detailed scan was clear. The surgeon had a happy face on and showed me the picture of the scan, and I told her exactly what the cause of the hot spots was. On February 16th, I had crashed on my motorcycle. The hot spots were from the straps on my jacket that pulled tight when I hit the ground at 50 mph. That's why you should always wear the correct protective gear. If I hadn't been, I would have spent weeks in the hospital with several open fractures instead of walking away with some bruises and pulled muscles but still passing the job interview the next morning. A possible job that had just become merely academic under the new circumstances.

My smile was back. Yes, I could smile again. I am still smiling. I am a man plus I was “Jack” and a submariner. Let’s be really honest. Breast cancer isn’t the same traumatic disaster for a man as it is for a woman.

My breasts haven’t been a major factor in my life since I was about nine or ten years old. They mean nothing to my manliness. I haven’t been finding the best way to show them off to attract a mate or dominate a rival for most of my adult life. They have absolutely no function for me as a man. They are merely some small masses of redundant tissue. Therefore, those psychological aspects of breast cancer for me are minimal. Yes, I have cancer. It’s stage 3 and has spread into the lymph glands. That is scary, but it can be treated. The plan is finally unveiled. Initially, surgery -a mastectomy and lymph node toilet. This will probably be followed up with chemotherapy and/or radiotherapy depending on the laboratory results following the surgery.

The medical staff have an easy time with me as I am not terrified by it all, and I still have a sense of humour. The mammacare nurses think I am great. Well, I suppose they should, after all, I’m the only man they have on their books.

End of Two Chapters