

Living with metastatic breast cancer

I have a very close friend, K, in the UK. We have been friends for a long time. I moved away from the UK and travelled and had Mallorca as my base. K is still close to me even though we do not see so much of each other. Unfortunately, one of K's closest friends, J in the UK was diagnosed with breast cancer and even worse for K two weeks later so was I. We both went through our journeys with surgery, mastectomies and treatments with poor K bouncing from one of us to the other. J and I even became pen pals and discussed how we were coping. I went back to the UK a few years later and K organised a lovely dinner for the three of us. At the dinner J really upset me by keep telling me how I had not really "done" cancer and I didn't understand what it was to really have cancer. For goodness's sake I had gone through so much and had a mastectomy, how dare she. J had been diagnosed with metastatic breast cancer or as often called in the UK secondary cancer. She had a new partner and children and enjoyed life to the fullest. The cancer progressed quickly, and she left this world and her loved ones. A regret in my life now is I would love to be able to tell her that "I get you now". I too have been diagnosed with Metastatic breast cancer to my lung. This means that even though I had a mastectomy and treatment a small part of my breast cancer broke off and lay dormant for 10 years before finding a new home in my lung. It is still breast cancer but in my lung. It is so very different this time round than it was the first time. This time it is not curable, and treatment is forever.

I am in the lucky position that there has been a big breakthrough in the last few years, the first one in 30 years that they have found a way to control the spread for a longer period. There is no cure, but we do have medicine now that can extend our life expectancy from 2 years to 5 and more.

Like me before my experience many people have never heard of metastatic cancer or what it means. This makes it more difficult for people to understand or to talk to people about it.

Metastatic breast cancer, (MBC) is essentially stage 4 breast cancer. It's also referred to as advanced breast cancer or secondary cancer. The word "metastatic" refers to cancer that has spread beyond the part of the body where it started. In comparison, the term "localized" means the cancer is contained to its primary site.

With earlier-stage breast cancer Doctors treat it more aggressively because the goal is to cure it: destroy all the cancer cells and leave none behind, reducing the risk of recurrence as much as possible. With MBC, the goal is control so that patients can live well for as long as possible. And chemotherapy isn't necessarily the mainstay of treatment.....

Metastatic cancer is further described as local, regional or distant, depending on the location of the cancer cells in relation to the original tumour.

- Localized metastatic breast cancer often means the breast cancer has spread to nearby lymph nodes.
- The more distant locations include the bones, lungs, skin, liver and brain, although it's possible for other parts of the body to be affected.

The most common signs that breast cancer has spread:

- Bone pain or bone fractures due to tumour cells spreading to the bones or spinal cord
- Headaches or dizziness when cancer has spread to the brain
- Shortness of breath or chest pain, coughing caused by lung cancer
- Jaundice or stomach swelling

My symptoms were a prolonged cough but there was flu about so did not think so much about it but decided after a couple of weeks to get it looked at. (Pre the days of covid) With X-rays it showed fluid on my lung caused by the cancer.

Treatment for metastatic breast cancer often is based on systemic therapies, which use drugs rather than surgery or radiation. Metastases treatments are designed to shrink tumours and slow their growth, help ease symptoms and improve quality of life. Treatment may change, such as when one therapy stops working, or the side effects become too uncomfortable. Rather than having only one

treatment, most patients undergo several treatments combined to help fight the cancer. I have hormone treatment and an inhibitor drug which have successfully been working for 2 years keeping my cancer from spreading further. They each have side effects that have taken time to live and cope with and change all the time. I will never be off treatment now as there is no cure. I will continue one line of treatment for as long as my body responds and then hopefully they will find another.

Here are some Myths about MBC

Myth 1 MBC is curable.

It cannot be cured but treatments can keep it under control. I am often asked “when will you finish treatments” or “wont it be good when you are finished this”. It only ends when it stops working and they run out of options.

Myth 2 MBC means immediate death.

I have stage 4 incurable cancer not terminal cancer. It will shorten my life drastically but is manageable for years at a time.

Myth 3 MBC makes you look sick.

” You look so well” or “you don’t look sick” are often said to me. I am lucky to live in Mallorca in the sunshine and have olive coloured skin so I do not look the image of what a cancer patient should look like with grey skin, and I also still have my hair. The drugs have made me put lots of weight on, so I am not grey, bald or skinny as expected of a cancer patient!

On a bad day you will not be seeing me out as it will mean that I will have fatigue and joint pains and not be able to move.

Myth 4 MBC means that you did something wrong the first time.

Unfortunately, there is no explanation of why it happens to some and not to others. I have found that I have had to defend myself and my oncologist for my original treatments and what I did and the way I have lived. If only I had run 500 times the other way round the lemon tree singing a different song, then this would never have happened! People try to help with lots of information on how somebody they knew cured and saved themselves by doing certain things. Everyone’s cancer is different and how we react to it also. I wish that our treatments could be as individual especially the dosages given so that the side effects could be minimalised more, but this is a costly exercise. The medical treatment in Mallorca is amazing and I believe in my fully trained team of oncologists and know if there was a cure, they would be the first to offer it to me. It is mentally very hard to deal with MBC anyway without the extra feeling of unjustified guilt of not looking after myself being added to it

Myth 5 MBC mentally and emotionally is the same as early-stage cancer.

Mentally and emotionally, people with MBC have a completely different experience. There is no end to treatment, and you must plan your lives around hospital visits and treatments. Cancer is always in the back of your mind as it is part of living. The first time I had cancer was so very different to this.

The hardest part for me about MBC has been the shock of it and the huge impact on my lifestyle. Everything has changed forever. It is like waking up one day 30 years older than when you went to bed. I grieve the loss of the old me. Yes, I can manage to do things on my good days, and I am grateful for all those times, but I use to be able to do so much more. The knowledge that I will never have that old self back makes me feel selfish as I am lucky that I have this life and ability still. I look well but hate that inside I am out of control of my body and how it reacts to all that it must deal with now. The statement “we are all dying” or “I could be run over by a bus” that people think will help me really doesn’t. I have a bus that is close and heading my way that I cannot move out of the way of. Friends that acknowledge that I fear my future, my ability to live and length of life left help much more.

I am not fighting or brave I am just trying to come to terms with this new life and make the most of every single part of it that I can while I can. It is not the dying that upsets me the most it is losing control of how I live that is hard

I am so lucky to have family and friends that help me to adjust to this new me and try to adjust with me when things change. I want to live life as fully as each day allows. Covid and cancer have not been a good mix and have stopped me like many others from being with loved ones with my clock of time ticking away. Hopefully this can change a bit now. I do not want cancer to define me I want to find a way to live with it as happily as possible. I talk to people about MBC and try to help them understand so that they can be a better person than I was to J years ago when I didn’t understand how she felt for which I am truly sorry and hope that somehow, she knows that.

