



**M3 MAGNIFIED
SERIES**

MEET SUSAN



Susan is 48 and lives in Rochester, New York in the US. When she was 43, she was diagnosed with invasive ductal carcinoma.

Susan's wasn't the typical diagnosis, as she'd had a mammogram nine months before and was given the 'all clear'. Then in the autumn of 2013, she started feeling some back pain and generally wasn't feeling well. She went to see her general practitioner (GP) and she treated Susan for a kidney infection. When test results revealed that she didn't have a kidney infection, the doctor sent her for a CT scan to see if she had kidney stones. While the scan didn't find kidney stones, it did reveal that she had a cancerous lesion on her rib. The doctor sent Susan for an MRI of her complete spine and that revealed that she had quite a large tumour on her thoracic spine. A few days after that, the doctor told her it was cancer. But, the doctor didn't know if it was bone cancer or if it was coming from someplace else and she had to consult an oncologist and there would probably be more testing.

After that, Susan had a PET scan that revealed she

had breast cancer. The assumption was made that the breast cancer had already metastasised to her spine and the rib. Next, they did a biopsy of the breast and a biopsy of her rib to make sure the pathology matched up, which it did. Her cancer was stage four.

Susan had no real family history and after conducting research, she knew she wasn't genetically predisposed to breast cancer. She spent time researching through the government website cancer.gov and the American Cancer Society and learned what all the related terms meant and learned about the different types of cancers. She discovered which breast cancers were aggressive and which were not. She especially found this research important when it came time to understand the pathology report, once the biopsy was done, because that was going to tell her how aggressive her breast cancer was and what kind of treatment she was going to need. She wanted to be prepared for that.

Susan feels that this research helped her because having this knowledge made her feel more like she



MEET SUSAN

was in control, that she had a sense of having some type of you know power over the disease. She felt that not knowing is the worst part about it. The most unnerving part of her experience was going into a doctor's appointment, especially when it came to scans, and she didn't know what they were going to tell her. So, the more knowledge she could gain, the better she felt; it took the fright out of things when she knew more and could be better prepared.

It was shocking for Susan to be told she had stage four breast cancer. When her GP called with her PET scan results, she didn't understand what it meant. She didn't know what metastasized breast cancer meant. Because it was a GP and not an oncologist, Susan suspects she was hesitant to say too much. As soon as she got off the phone with the doctor, she immediately went to the computer and started googling everything and that's how she found out what it all meant.

Susan doesn't recommend people do that just after getting a diagnosis. But, as far as the technical parts and as far as medications and what pathology reports and scan reports mean, she does think the internet is very helpful.

It's been five years since Susan's diagnosis. The breast cancer in her case was oestrogen and progesterone positive and was HER-2 negative, which is usually the most common type of pathology for breast cancer.

For treatment, she was put on an aromatase inhibitor, which at the time was Femara. Susan assumed she was going to get chemo right off the bat because she thought "that's what everybody does." She was surprised that she was instead put on a pill that she took daily along with a monthly injection to help strengthen her bones. Additionally, because she still had her ovaries, she was given a monthly shot called Lupron which was supposed to suppress the production of estrogen in her body.

Susan couldn't tolerate the Femara, as she encountered too many side effects. After a month on that the doctors switched her to a different drug Exemestane that she stayed on for about 18 months. During that time, she had her ovaries removed so that she didn't have to continue with the Lupron shots.

She came off the Exemestane in order to have breast surgery to have the tumour and the breast



MEET SUSAN

taken out. Because her cancer was metastatic, she found that doctors don't want to do a mastectomy like they would normally do with breast cancer patients because they figure there's no point. But, Susan really wanted the tumour out, so she found a surgeon that would at least agree to do a lumpectomy. She stopped the medication to have the surgery and after the surgery, she went on lbrance. In combination with that she got an injection called Faslodex and has been on that combination for two and a half years now.

Susan has a very good relationship with her local oncologist in Rochester. She visits her every month because she visits the cancer centre for her injections, so, she sees her oncologist while she's there. She feels she can talk to her oncologist about anything and discuss any issues that come up. She also visits an oncologist at Sloan Kettering every six months—when she goes for her PET scans—who she thinks is amazing.

Because Susan had no family history and didn't know anybody she was close with who had been through breast cancer, it was difficult at first for her to find people and connect with people who could understand what she was dealing with. She found a local group, but it took her a while to connect with them because her monthly trips to New York

City for her Sloan Kettering appointments limited the time she had to physically go and meet people.

Due to this, she turned to social media and started connecting with people first on Twitter, to her surprise. This led her to a weekly chat specifically for breast cancer each Monday at 9:00pm. From there, she discovered some specific groups on Facebook for all different types of breast cancer and even different branch off groups for people that have different views about breast cancer. She found there are metastatic groups, there are groups based on pathology, groups for certain types like triple negative, where people can discuss topics specific to their disease.

Susan has stayed with some of those groups—more as a lurker than a participant—so that she can learn about other people's experiences with different medications and such things as the side effects they encounter.

Initially, Susan's breast cancer diagnosis affected many of her relationships. She lost a number of friends that either didn't want to talk about it or just didn't know how to talk about it. She feels that she found out who her real friends were based on who stuck by her through it and who didn't.



MEET SUSAN

Before breast cancer, Susan worked as a corporate technical recruiter. Cancer affected her ability to work and she no longer works a regular job like she did before because she no longer has the stamina for it and has too many doctor appointments.

In the beginning, it took a lot for Susan's body to adjust to the medication. She was exhausted, her muscles and bones were very sore, and it hurt her to walk. The side effects were debilitating at times. It affected what she can do and can't do with her family. In the beginning, it kept her from going on vacations, which was difficult for her. Because she was constantly tired, she couldn't participate everywhere she wanted.

But on the flipside, it has allowed Susan to make connections with some people that she probably never would have met before and it's enabled her to make a difference in how people see breast cancer.

She's tried to help people realise that they can make donations to research instead of buying all the pink products they see in the supermarket that may not go toward funding anything substantial. She's tried to elevate the conversation around metastatic breast cancer so that people understand

that there are people out there that still die from it and it's not just a disease that elderly women get—that there are young women out there with children that get this.

Susan feels that the war on breast cancer awareness has basically been won and that the focus should really be shifted to getting more investment into research. She feels strongly that it needs to be the right kind of research that is funded. People may know they are contributing to breast cancer research, but don't know exactly what type of research their donation is funding.

Susan believes that this research shouldn't just be focused on breast cancer prevention but that there needs to be more focus on treatment research because those who are already living with metastatic breast cancer can't prevent it. Whereas, treatment research can help people like her.

Susan hopes that those individuals that have had early stage breast cancer don't end up having their cancer come back and metastasise. She hopes that there will be campaigns that are going to get research money into the right hands to make a real dent in this disease and get to the right kinds of medicines that are going to continue to keep



MEET SUSAN

people like her stay alive and help people that have early stage not progress.

Susan believes the studies she has participated in for M3 Global Research are important because participating gives the patients a voice. She says, “It helps whoever is behind the study—whether it’s a pharmaceutical company or an agency behind the survey—get the right information from the patients, which is who they’re trying to help.”

The studies Susan has participated in have been varied. They’re not all necessarily about medications she’s been on. But, she thinks they are all very valuable and she thinks all patients should have a voice in research like this. Whether you are talking about side effects or the types of medication that patients have been on, they’re hearing directly from the patients like her who are living with it.

The best advice Susan could offer to someone who has been newly diagnosed with breast cancer is to get as much information as he or she possibly can and to understand that this is a serious illness and they need to do whatever they can to learn about the illness and to advocate for themselves.