My Cancer Story

Wait…not so simple…

Disclaimer: I am not an expert or a medical doctor, I am a cancer patient. In telling my story I am trying to describe the process I went through and the information I used to make my treatment decisions. Throughout the entire process I sought advice and guidance from my medical team before making treatment decisions. Every cancer is different. My decisions reflect my specific diagnosis, my values, and my life circumstances. They are not recommendations, and they may not be appropriate for your situation. The point of sharing the detail is to make my decision-making process visible, not to suggest that anyone else should make the same choices.

At the age of 41, I was diagnosed with ductal carcinoma in-situ (Stage 0) breast cancer. Small calcifications were found in my right breast as part of my routine yearly mammogram. Shortly after the unexpected mammogram finding, I had a stereotactic breast biopsy. I still remember getting the call from the radiologist while I was at work, explaining the results of my biopsy and suggesting the next steps. I also remember being anxious and trying to write down all the information my radiologist was telling me on a sticky note. At that moment, my mind was trying to process the diagnosis and figure out how to proceed all at the same time. The first thing my radiologist recommended was to see a breast surgeon and schedule a bilateral MRI to find out if there were any other areas of concern in either breast. Since she understood how shocking this news can be, she gave me the name of a specific surgeon to get me started. Without realizing it at the time, that single recommendation probably shaped the rest of my breast cancer journey.

Immediately, I went into action, scheduling the appointment with the breast surgeon and trying to get the script for the MRI. My engineering training kicked in, and I started to read a lot of information about ductal carcinoma in-situ (DCIS) and treatment options. At that time, the information I was reading was all new to me. It was very important to be prepared for the appointment with the breast surgeon and to ask as many questions as possible about my case. While I waited for the appointment, I got to talk to my surgeon's nurse and she explained what the different surgical options were (lumpectomy versus mastectomy), the recovery time, and what to expect from the surgical procedures. Having that initial information really helped. I prepared a list of questions, including some about radiation even though this part of the treatment process typically comes later. The

first meeting with my surgeon was very informative. He spent a great deal of time talking to my husband and me about the surgical options and providing a comprehensive view of my full treatment. His demeanor and way of explaining the process put us at ease. Since I had detailed questions about the radiation treatment, he recommended I talk to a radiation oncologist he knew to get some answers and get a better feel for the treatment options. He also recommended PubMed, as a reputable online resource for medical articles. Having access to trustworthy information was and continues to be critical in my decision-making. In my case, it brought peace in the midst of an uncertain future.

In the meantime, I wasted no time and set up an appointment with the radiation oncologist. He was super helpful and described the treatment in detail. His calm and knowledgeable demeanor also made my husband and me feel like radiation was a sound option. He said: We can fix you! His whole way of interacting put us at ease and made a challenging situation feel manageable. Interestingly enough, he was willing to communicate with me via email. I have to admit, I thought that was the coolest; another amazing resource with which I did not have to wait days or weeks to be able to communicate. I found it very useful to be able to discuss with him not only radiation but also other parts of my treatment. He always replied to my questions and provided insights regarding my treatment. Having doctors that take the time to listen to all your questions and explain your treatment options and their possible side effects is very important. Good doctors can certainly steer you in the right direction, especially if you want to research possible treatment options.

Shortly after the visit with my radiation oncologist, I had my bilateral MRI done. The MRI highlighted another area in the opposite breast that needed to be biopsied. The finding was surprising and very concerning at the time. Again, I had to anxiously wait for the biopsy results. I always found waiting for the biopsy results to be very difficult. After a short wait this time, big relief, the spot in the left breast was not cancerous, just a benign fibroadenoma.

I forged ahead and after reading many more scientific articles about my specific type of cancer and with only one small, non-invasive breast tumor, the decision

seemed fairly straightforward; lumpectomy followed by whole breast radiation. I was relieved to not have to go through a mastectomy and still have similar odds for long-term survival. Surgery went well, no complications. Actually, the surgical pathology results showed no additional cancer; all the cancer had been removed during the initial biopsy. I continued to communicate with my doctors through my treatment via email, which I found to be very helpful when I needed guidance. I healed quickly and was back at work within a couple of days. Since my surgical specimen had no cancer remaining, I talked to my surgeon about sending my biopsy samples for genomic testing since the core biopsy revealed my cancer was ER and PR positive. I had read several articles about Oncotype testing for DCIS. The Oncotype results could provide recurrence information based on the tumor biology for my specific cancer. My breast surgeon also recommended I talk to an oncologist about the possibility of taking tamoxifen as part of the systemic treatment. That part of the treatment, given its potential side effects, did not seem straightforward. I felt like I had to wait and do more research on it.

As recommended, I scheduled an appointment with the oncologist. She discussed taking tamoxifen to reduce my chances of recurrence and talked to me about potentially participating in an existing Herceptin clinical trial for DCIS patients if I were to be HER2 positive (still to be tested at that time). From everything I had read, the short and long-term side effects of taking tamoxifen were significant and not something I felt was worth the risk for Stage 0 breast cancer, but I continued to think about it. I struggled with the possibility of increasing my chances of uterine cancer (one of the potential long-term side effects of tamoxifen), especially given my family history. My mom, in her late 50s, was diagnosed with uterine cancer. She went through extensive radiation treatment and struggled years later with the side effects of radiation on her intestines. I understood that the location of the cancer changes how radiation can be aimed. The breast protrudes from the body, so the beams can be angled to spare the underlying organs, but with uterine cancer, the target site sits among organs, like the intestines, that are much harder to avoid. Still, I was concerned about the downsides of radiation. Reflecting back, that was another piece of information that influenced my treatment decision and highlighted

my strong desire to make decisions not only to keep me alive but also to preserve my quality of life. I not only hoped to live long, but to live well!!!

Radiation treatment started about six weeks after surgery. The radiation treatments went well although I have to admit I never liked lying on the table while I was getting irradiated. I did not feel anything but just the thought of having to go through radiation made me feel uneasy. Again, I remembered my mom's experience with her radiation treatment side effects. I completed all thirty three radiation treatments without a problem, just experienced significant redness (almost like a strong sunburn) on my skin. I was very happy to be done with the treatments for good, or so I thought.

As I was going through radiation, I got my Oncotype results. I had the Oncotype DCIS test done because I wanted to understand the nature of my cancer — how likely it was to recur, what its biology actually was. That mattered to me on its own terms, separate from any treatment decision. Radiation had been recommended as the standard approach, in part because of my age, and I went ahead with it. The Oncotype results gave me something different: a clearer picture of the disease I was dealing with.

I was relieved that the recurrence score was below 25, indicating a relatively low chance for recurrence. Now, with all the information I could ever know about my cancer, I decided to not take tamoxifen, or participate in any trials, and continue to be diligent about my yearly mammograms. At the time, I hoped the odds were in my favor in the long run…but the story does not end there…

Here we go again, another primary tumor on the opposite breast

Two years later, on another routine mammogram, a new spot was observed in the opposite breast. I remember feeling deflated when the technician called me back to take additional mammogram images of my left breast. Immediately, I thought… here we go again. Part of me had really hoped I was done with cancer.

The whole process started all over again, with the exception that I knew who to talk to, what to do, and had a better feel for what to expect. Even with that knowledge, I still felt very anxious.

This time I emailed my breast surgeon right away after signs of microcalcifications were found during my mammogram. Once again, I immediately scheduled a stereotactic biopsy and deep down hoped the results did not reveal cancer. A couple of days later, as I anxiously waited for my biopsy results, I got a call from the radiologist while I was pulling into the parking lot at work and she told me… unfortunately you have Grade 2, invasive ductal carcinoma. It was more serious this time since the cancer had spread beyond the breast duct. This new cancer was ER, PR positive, and HER2 negative, which meant I had to start thinking hard about taking tamoxifen.

Just like the previous time, I got my breast surgeon to write the script for my bilateral MRI. Luckily, no other spots were found. Huge relief! Once again, both my husband and I met with our surgeon, and just like the first time, he carefully explained my options. Since this was my second time around, he recommended I get the BRCA genetic testing done to see if I had a genetic mutation that put me at a higher risk for cancer. If I was positive for BRCA1 and BRCA2 gene mutations, then the recommended path was mastectomy. I had the test done as soon as possible. Even though I had no family history, I was really worried about the results. After another anxious wait, the results came out negative. I was relieved! Since the tumor was small and the known gene testing indicated no higher risk than normal for my case, I decided to proceed with lumpectomy followed by radiation just like I had the first time around. Because this new tumor was invasive, I had the sentinel nodes removed and checked to see if cancer had spread beyond the breast area. An additional incision under my armpit would be required. As usual, I sent my breast surgeon an email with a lot of questions about the procedure. He replied right away and explained how sentinel nodes are removed during surgery and how they are checked for cancer. We also had several exchanges about genomic testing and its prognostic value for invasive breast cancer. I would have to wait after surgery to submit the sample for genomic testing. If the predicted recurrence value from the Oncotype test was high it would

mean chemotherapy would be recommended as it could have a better chance of reducing the odds of my cancer from coming back. I have to admit, the thought of undergoing chemo was very scary but having as much information about my cancer as possible was always essential for my decision-making process.

Once again, I scheduled an appointment with my radiation oncologist. This time he talked to me about hypofractionated treatment, which involves whole-breast irradiation using a slightly higher dose for fewer days. There was a significant amount of literature on the efficacy of this treatment even though it was not considered the standard of care in the US at the time. He gave me a couple of articles to read about the treatment and explained how it worked. This treatment works as well as the longer-duration series and may reduce the risk of some of the side effects. After reading about it in detail, I was sold. I think patients should consider asking for other possible treatment options. In a good number of instances, the standard of care option is not the only choice. There may be other reasonable options that might not result in the best statistical outcome but may be the best choice for a specific patient.

Surgery went well. The surgical pathology showed no evidence of cancer left. Also, the lymph nodes showed no evidence of cancer. That was great news!!!

Now, I had to get the original biopsy sample sent for Oncotype testing to guide my decision on systemic treatment. To my surprise and relief, I got a low score in my Oncotype test. It predicted a 4% chance of distant recurrence at 10 years with tamoxifen alone, no real added benefit from chemo. I certainly hope this continues to hold true for the future.

My next stop in the process was to meet with the medical oncologist to discuss the pros and cons of tamoxifen. Both she and my breast surgeon strongly recommended I take tamoxifen given the nature of my cancer and the fact that it was my second time around. I remember her telling me having hot flashes was not such a big deal, especially considering the potential for staying cancer free. Her view of how this pill could affect my life did not resonate with me, especially as I thought of potentially increasing my chances of developing uterine cancer. After a lot of thought, I decided not to take tamoxifen: my 10-year recurrence risk was low,

and the additional benefit it offered felt small relative to its side effects. With cancer, you can never be 100% sure your decision is right. All you can do is try to understand all the different options, assess how those options can impact your life, and ultimately decide what is best for you. I was ok with my decision then and continue to be to this day.

My radiation protocol was monitored by another radiation oncologist since I had my treatments done near the area where I live. He talked to me about his thoughts on the hypofractionated treatment. This type of treatment is not something he personally would recommend since it was not considered the standard of care in the US. He was willing to proceed with it given that the attending oncologist had brought it up as a good and equivalent option. I explained that I had researched it carefully and felt confident to proceed. As expected, I completed my radiation treatments without a problem. My skin was less burnt this time since the treatment was completed in fewer sessions.

With all the treatments completed, I went back to my "normal life". I continued to be monitored carefully, checking for any signs of recurrence. I also stayed in contact with my breast surgeon through the years that followed even as he moved to other medical systems. It became a tradition to send him an email after each yearly mammogram. Once again, I hoped to be done with cancer, especially since in both instances I had treated my cancer early and it had not spread beyond the breast. For nearly 10 years, that thought seemed to be true…

And the story continues, regional recurrence…

Fast forward ten (uneventful!) years since my initial cancer diagnosis, another surprise. During my yearly mammogram, the radiologist found another area of concern in my right breast. Throughout the years getting my mammograms, I learned to interpret the radiologist's understanding of the findings in the mammogram. He seemed concerned. I was worried!!! This time the spot that was identified in the mammogram was also detectable in the ultrasound image, so he performed a biopsy immediately. I waited four days to hear the news…you have invasive breast cancer. I asked him to tell me more of what the biopsy results said,

just hearing the words invasive cancer was not enough. He proceeded to tell me that it was a Grade 3 tumor with a Nottingham score of 8 out of 9 (considered more aggressive), and a Ki-67 of 30%. He said I should try to deal with it sooner rather than later since it appeared to be a more aggressive type of cancer.

Just like I had done years ago, I had already emailed my breast surgeon as soon as I had the mammogram and told him I may need his help again. I actually ended up talking to him on the phone that afternoon, the same day I heard the news. We discussed the evidence-based treatment for a recurrence which is mastectomy. This was just the beginning of my third breast cancer diagnosis, one filled with many decisions to consider.

When I got home, I studied the biopsy results more carefully. The cancer was once again ER and PR positive, and HER2 negative and was located near the same spot I had DCIS ten years ago; a local recurrence. I emailed the results of my biopsy to my breast surgeon right away. In the meantime, I had my local PCP order the bilateral MRI to see if there were any other spots of concern in either breast. They were very helpful at the office. They understood I was trying to deal with the situation quickly since the radiologist mentioned my cancer appeared to be more aggressive. With their help I was able to get my MRI done the same day I called them. That was impressive! Unfortunately, my MRI revealed a second spot in the same breast that needed to be biopsied as well. I moved quickly to schedule the MRI-guided biopsy at a nearby hospital. Getting on the schedule quickly was tricky since there are limited appointments for this procedure. I got in within a week and a half; not bad.

While I waited to have the MRI-guided biopsy, I sent an email to the radiation oncologist I had consulted before. I explained the results of my biopsy in detail, along with a complete description of my previous diagnoses to remind him about my case since it had been 8 years since the last time I was in his office.

To my surprise and relief, he replied within one hour! He said that in some cases, mastectomy is not needed even in local recurrence in a previously irradiated breast. He also told me he would be willing to review everything and discuss my case. This approach represented a second possible option. Definitely worth

considering and discussing further! Just a week later, my husband and I met with the radiation oncologist at his office. He went over my case and explained that there is a significant amount of evidence to show that lumpectomy followed by focal irradiation in patients with a cancer recurrence that is detected early is an effective treatment. However, my case was not straightforward since there was a chance I had a second spot that could be cancerous and I was still relatively young. He explained that depending on the biopsy results of the second spot there may be a chance I could also have focal irradiation on that spot. Two-site focal irradiation, although uncommon, was still a possible option if the cancer was not aggressive. He wanted me to discuss this option with my surgeon to make sure he felt a two-site lumpectomy was an acceptable and safe choice from a surgical perspective.

Just a couple of days after my appointment with my radiation oncologist, my husband and I met with my breast surgeon at his office. He went over my entire case in detail. We talked about the evidence-based, preferred treatment option, which in this case was mastectomy. We also discussed alternative options like lumpectomy followed by focal irradiation. From our conversation, it was clear that lumpectomy followed by focal irradiation was a reasonable option, especially since the radiation oncologist was on board. Now, I had to wait for the results from the MRI-guided biopsy. As part of the visit, we also talked about the entire treatment, not just local treatment but also the systemic treatment. The end goal was to reduce the chances of another local/regional recurrence and more importantly to reduce the chance of metastasis. These conversations are scary but real and important. It is good to take the time to think through them carefully. The decisions you make can have a significant impact on your life.

Shortly after our discussions with the breast surgeon and the radiation oncologist, I had the MRI-guided biopsy. The procedure went well and after anxiously waiting for the results I got more bad news. The biopsy revealed I had a very small papillary carcinoma tumor. This type of cancer only accounts for a small percentage of invasive breast cancers. It was likely to be invasive but I would have to wait until it was removed to confirm it. With this information in hand, I certainly would need two lumpectomies or a mastectomy. I made the decision to

deviate from the evidence-based path and go ahead with the two lumpectomies. This was the first of three big decisions I had to make.

Evidence-based recommendation: mastectomy for recurrence in a previously irradiated breast. My choice: lumpectomy followed by focal irradiation, supported by evidence of similar survival outcomes for early-detected recurrence and discussions with my medical team.

Seven and a half weeks after I had my mammogram, I had the two lumpectomies and the sentinel node dissection. It was important to remove the tumors and understand if the cancer had spread to the lymph nodes. Surgery went well and I recovered quickly. I am always appreciative to have the cancer removed from my body. I had a little more discomfort from the sentinel lymph node dissection than from the actual lumpectomies. Nevertheless, I started to heal quickly. I returned to work right away and just a few days after the surgery in the late afternoon I got the pathology results from the surgery specimen. The results were surprising. Not only did the two lumpectomy sites have cancer (as expected), but two out of the three sentinel nodes removed during surgery had cancer. I still remember reading and re-reading the results to understand the information while I sat in the parking lot at work. I have to admit, I felt really bad. Right away, I texted my surgeon and asked him if we could discuss my pathology results. I wanted to get his perspective on the results. It would have been pretty hard for me to wait until the next day. He was so nice to take time while at home to read the results and discuss them with me. He was surprised about the positive lymph nodes. I realized the results were somewhat unexpected. We started to go over all the possible options I had to deal with the positive lymph nodes. The "by the book" approach would require having another surgery to remove the axillary lymph nodes (axillary lymph node dissection (ALND)) for staging purposes and planning adjuvant treatment. Knowing the stage would determine the recommended evidence-based treatment option. Removing the axillary lymph nodes could result in lymphedema, a permanent condition in which there is swelling of the arm and hand. The percentage of patients that can experience this condition is roughly 30%, although it can occur in various degrees from very mild to more severe. There could also be changes in sensation in the arm, such as pain or numbness (if nerves are

damaged). The potential for these types of permanent side effects made me stop and think! I went into overdrive trying to understand more about the ALND surgery and the potential long-term effects on my quality of life. It was particularly hard because my radiation oncologist, who I also later talked to about my options, emphasized this as a good option. At that particular time, I felt I had no real good choices, not the best place to be. In the midst of the conversation I had with my surgeon regarding the lymph nodes, he also mentioned I should have bone and CT scans for staging purposes. Given all we knew about my cancer, he said it was highly unlikely the cancer had spread beyond the lymph nodes, but even the small possibility of it being true hit me hard…my cancer may have metastasized?!?!. Honestly, this is when reality becomes frightening. Somehow, the scary thoughts have to be put aside while you continue to work the problem. We cannot change reality but we can try to figure out how to best deal with the situation. What is considered the best treatment option is different for everyone but it is important not to lose that perspective in the process.

As I analyzed my options regarding the axillary node dissection, I scheduled the bone and CT scans. I maneuvered my way through the system to get the earliest possible appointments. Waiting to know if the cancer had metastasized was the hardest. While we waited for the appointment, my husband and I talked to my surgeon over the phone once again. I had researched a lot of information about ALND and tried to understand the available data for the different trials. Keep in mind the vast majority of the information out there is for patients with a first time cancer occurrence with one to three positive sentinel nodes, not a recurrence on a previously irradiated breast. In the process of trying to understand my options, I found a very good online presentation by a breast surgeon from UCLA. She explained how the lymph nodes work, mentioned all the studies that have led to current standard of care practices, and described the potential side effects of the lymph node dissection surgery. After reviewing all the information, I had two possible treatment options I wanted to discuss with my surgeon (following the lumpectomies): No further lymph node ALND surgery, two-site focal irradiation followed by adjuvant therapy (chemo and/or endocrine therapy), or ALND plus two-site irradiation followed by adjuvant therapy (chemo and/or endocrine

therapy). My husband and I were interested in understanding how the two options compared in terms of survival rate, side effects (and potential impact on quality of life), and overall effectiveness. I always found it very useful to have my husband involved in these conversations. There is so much new information discussed that it is hard to process it right away. In preparation for our conversation, I had written the options on another sticky note (somehow those really help!) along with several key questions I had because I did not want to miss anything I needed to make a good treatment decision. I remember us asking him if thinking of not having all the axillary lymph nodes removed was foolish or reckless. To our surprise, he said not removing the lymph nodes was not a foolish decision but it deviated from the guideline recommendations. Knowing if there were more nodes with cancer might help with decisions regarding chemotherapy or radiation but the process itself would not cure me. My option did not fit the mold, but it did not lower my long-term survival rate. This conversation was different. We discussed the options more from the perspective of survival rate and the potential implications for quality of life. The natural instinct for most people (me included!) is to take action: you want all the cancer out of your body as soon as possible, you want to treat it aggressively right away to get rid of it and stop it from ever growing again, and you want to continue living like it never happened or feel like it will never happen again. However, we need time to think through the options because each decision can have a significant impact on our lives and whether we want it or not cancer may never fully go away. Lymphedema is a real and potentially permanent consequence of ALND. In a severe case, the chronic pain and limited mobility last a lifetime and can affect both work and quality of life. That risk was not something I was willing to accept without weighing it carefully against the benefit of the surgery. After going back and forth, I made the second biggest decision for my treatment; not to have the additional surgery to remove the axillary lymph nodes and proceed with the focal irradiation followed by systemic treatment (more to come on this one…). This decision meant to take a “wait and see” approach on the lymph nodes. It is possible I will have to deal with cancer in the lymph nodes down the road. Keep in mind with cancer, there are no certainties. Even if I decided to do all possible treatment, the cancer can still come back. It is hard to

wrap your head around that reality but it is super important to keep on living, as well as you possibly can.

Evidence-based recommendation: axillary lymph node dissection (ALND) for staging and adjuvant treatment planning. My choice: no further surgery, with a wait-and-see approach on the lymph nodes after considering potential side effects like lymphedema.

While I worked through the decision-making process, I scheduled an appointment with my oncologist to discuss my case. I finally got the scans done. I have to admit I was very nervous about the results of the bone and the CT scans. I remember lying on the table while they performed the bone scan hoping the cancer had not metastasized. The results came back a few days later. Waiting always seemed like an eternity. In general, the results of the bone scan were good. There were a couple of findings that were not conclusive. I would have to wait for the CT scan to make sure everything was ok. The CT scan came out clean. No evidence of metastasis. I have to admit, I was so, so, so relieved!!! Now, I had to get ready for my third big decision: systemic treatment.

I had convinced my surgeon to submit the pathology sample for Oncotype testing. This took some convincing but he actually ended up submitting both tumors (invasive ductal and papillary carcinomas). He cautioned me many times that the results may not be applicable in my case because there was a possibility I had four or more lymph nodes positive and that my cancer was recurrent. Without knowing the exact number of lymph nodes positive, the Oncotype results may or may not be applicable. I still wanted to know the recurrence score for my specific cancer. If the value was high, it would help me consider undergoing chemo more seriously. As I was waiting to see my oncologist, the Oncotype results for the invasive ductal carcinoma came in. My recurrence score was considered low; similar to the recurrence value I had received 10 years earlier. I have to admit I was encouraged that the value was considered to be in the low recurrence category (below 25) even though I understood the results may not be valid since I did not know if I had four or more positive lymph nodes. The results were interesting. The test predicted an 18% chance for distant recurrence risk at 9 years with the use of hormonal treatment as part of the systemic treatment. I discussed the results with my breast

surgeon. He again reiterated this result predicted the best case scenario, assuming I had a maximum of three positive lymph nodes. That percentage would be higher if more positive lymph nodes were involved. In some way, the 18% distant recurrence risk was very revealing to me. The number was not small enough to be disregarded. I knew I had to do more to try to prevent the cancer from coming back. After three breast cancer occurrences, the spread to the lymph nodes, and the possibility of metastasis, it was time to really consider my systemic treatment options more carefully.

With all this information in hand, my husband and I met with the medical oncologist, first on a video call and later at her office. I had actually met with her before surgery just to get a feel for her approach to systemic treatment. This time, with all the information from the surgical biopsies and the genomic testing, she started to formulate a treatment plan. She started the conversation by reviewing the Oncotype result. The test showed the added benefit of chemotherapy for premenopausal women. Right away, she told us chemotherapy was recommended in my situation (assuming I was premenopausal) because it offered a 5% benefit over hormonal treatment alone. I was not fully surprised with the recommendation but thought, in my case, there may be another way to essentially have similar odds. One key piece of information to consider was written as a footnote in the Oncotype test results: 'It is unknown whether the benefit observed with chemotherapy is due to chemotherapy alone, ovarian function suppression or a combination of the two.' As data from an existing study revealed, more than the score itself, the woman's menopausal status plays a key role in determining whether or not chemotherapy can be beneficial. My oncologist mentioned the long-term study to determine the benefit of chemotherapy on postmenopausal women with ER, PR positive, HER2 negative cancers (with and without lymph node involvement) is still ongoing but the initial data showed postmenopausal women with one to three positive lymph nodes saw no benefit from chemotherapy. From what I understood, the theory (not yet fully proven) behind the benefit of chemotherapy for this specific type of cancer comes from ovarian suppression. If your ovaries are already suppressed (or if they are intentionally suppressed), the thought (based on the trial results) is that you are not likely to benefit from chemotherapy; hormonal treatment by itself can

provide the potential benefit of reduced recurrence by lowering the estrogen levels produced by other sources in the body (i.e., adrenal glands and fat tissue).

I did my own research on the trial (RxPONDER) my oncologist mentioned. It is always helpful to take the time to research the trials and understand what the results mean or how they relate to your particular diagnosis. I also read an article written in the ASCO Post [Gini F. Fleming, MD, FASCO, "RxPONDER Trial: Another Step in Defining Which Patients With Breast Cancer May Be Spared Adjuvant Cytotoxic Chemotherapy," February 10, 2022] discussing the findings of the RxPONDER and the questions that remain to be answered regarding the benefit of chemotherapy for postmenopausal women with 4 or more lymph nodes positive. My case certainly fits into the unanswered questions category. Keep in mind my case is a recurrence and since I decided not to have complete axillary lymph node dissection, I also do not know if other lymph nodes are positive. In the midst of uncertainty, it is important to evaluate the information that is available from the existing trials and make informed judgments on how to proceed with the known data and the available treatment options.

Also in my particular case, even though I did not officially qualify as postmenopausal (more than 12 months since the last menstrual period), I considered myself to be very close. My menstrual cycle had been irregular for close to 4 years and I had not had a period for over 8 months at the time I met with my oncologist. She recommended I check my estrogen levels to get a sense for my menopausal status. If the estradiol value was less than 40, I would be considered postmenopausal. If I was not, I could consider suppressing my ovaries to reduce the amount of estrogen in my system. Even though I was hoping my estrogen levels were naturally low, I was willing to consider going through ovarian suppression since it would reduce my estrogen levels which my tumor needs to grow, reducing my chances of recurrence. This option could provide an alternative to chemotherapy. An alternative that was going to be the best choice for me at the time. From everything I had read and my discussions with my doctors, this was a viable option, one that would reduce the possibly significant side effects of chemo.

The results from my estradiol test came in within hours. My level was 11 (significantly lower than 40) which meant I was considered to be within postmenopausal range. That felt like good news, I could then consider forgoing chemo and pursue hormonal treatment after focal breast irradiation. My path to treatment started to look less cloudy, more defined in my mind. Given this piece of information and working with my medical oncologist, I decided to take aromatase inhibitors (AIs) as part of my hormonal treatment. This was the third complex decision I made in my cancer treatment. None of the hormonal treatments come free of side effects. From the discussions with my oncologist, there are three available AI drugs I can use. If one of them has unbearable side effects I can switch to one of the other two. I still felt like after three breast cancer occurrences, I had to do more to slow down, or potentially reduce, the chances of the cancer from coming back. From my perspective, doing nothing was not an option. Only time will reveal what happens next…

The Oncotype results for my second tumor finally came in. My recurrence score for this cancer was low. I understood that using my Oncotype results in my scenario had some question marks but still felt there was some utility. In this case, a recurrence score of 17 or less meant no apparent benefit from chemo. After getting this final piece of the puzzle, I was more at peace with my decision.

Close to two and a half months after my initial diagnosis, I completed the two-site focal radiation treatments. I received a total of 5 treatments, each one given every other day. The treatments went by fast without any major side effects. The day after completing my radiation, I started taking Arimidex.

Evidence-based recommendation: chemotherapy plus hormonal treatment, given my unconfirmed premenopausal status. My choice: hormonal treatment alone (aromatase inhibitor), after estradiol testing placed me in postmenopausal range.

So far, I am tolerating the hormone treatment well. No major side effects. Huge relief for now! I will have to continue to be monitored for any signs of recurrence, metastasis, or potential long-term side effects of the hormone treatment (i.e., bone loss, increase in cholesterol levels,…). It will be a long journey. Hopefully treatment works and I continue to stay healthy.

The past several months since my diagnosis have felt a bit like a rollercoaster ride. With every new test came more information to understand and consider in the process of choosing the best possible treatment for me. The decisions were certainly not straightforward and my case was complex. It was also challenging to navigate through the pro-treatment bias approach in our medical system. Understanding other possible treatment options was a key element for me. I feel like I was super fortunate to have an excellent team of doctors that were willing to discuss not only the evidence-based standard of care but also other effective treatment options when prompted. Their willingness to listen, include me in the discussions, and guide me through the decision-making process was exceptional.

Ultimately, I have had to learn to live with uncertainty and MOVE FORWARD the best way possible. Remember, none of us have all the answers.

What I learned in the process…

The goal of telling my story is to describe the process I went through and the tools I used to help me make treatment decisions in hopes that it can help others going through a similar situation.

Everyone's cancer journey is different but here are some of the things I learned along the way:

I am no expert by any means. Just like many other patients, I am trying to figure out the best way to treat and survive my cancer. The decisions I made were influenced by the guidance from my medical team, my own personal experiences (e.g., mom's cancer history), my analytical skills, and my own view of what is important in life.

Cancer can be very unpredictable. All you can do is try to understand as much as you can about your particular cancer, ask questions, and take some time to think through treatment options before making decisions.

Making treatment decisions can be very complex. It is a unique experience for every cancer patient. Finding the best treatment choices can be hard. At the end of the day, it is about finding a balanced approach to avoid both under and over treatment; not an easy task given all the uncertainties. I tried to find that balance even with all the uncertainties.

Keep in mind the standard of care may not be the only possible and effective treatment option available. As best you can try to research your choices and ask your doctors about other possible options. Consider asking about existing trials and studies. This information can provide some insights on other treatment options.

Cancer makes you look at things in a different way. I personally feel like I have developed a strong drive to focus on the important aspects of life. Time is limited; it is better to use it purposefully.

Lastly, the future is always uncertain. Whether we have cancer or not, we have to try to keep on living, keep on going, and take care of ourselves!

Other thoughts

As I reflect on my latest cancer diagnosis, I am very thankful for:

Life and God!!! I got another chance at trying to figure out how to survive cancer. Even though there are no definite answers it felt good to find a reasonable treatment path.

Good doctors! I definitely benefited from having multiple good doctors to talk to when I had questions regarding my treatment options. The ability to talk to my surgeon regularly was super helpful!!! Our conversations became more important than ever during my most recent diagnosis since the decisions I had to make were complex.

My inquisitive mind! Having the ability to explore treatment options and become my own advocate made the process manageable. I am very thankful to God for giving me the strength and clarity of mind to keep trying to figure out how to move forward.

Having a strong support system! Being able to share my thoughts about my treatment options with my husband was always super helpful. I always felt like I could bounce my ideas and thoughts off him and have a second pair of ears to listen to all the new information coming at me all the time. Also, having my family check on me regularly provided me with much comfort.

Update: Two and a half years in

Two and a half years in, I can say this: it is not always easy — but so far it has been manageable.

Like many others, I have experienced some of the common side effects of aromatase inhibitors: joint stiffness and pain — especially in my hands — dryness, and mild hot flashes. These symptoms come and go — sometimes noticeable, other times barely there. I have been fortunate that none have become severe or debilitating. I have also experienced mild bone loss.

But I also know this is not everyone's experience. For some, the side effects are much more intense. If this is your case, you are not alone. What matters is not to suffer in silence.

I have learned that it is important to discuss the side effects of the medication with the doctor. We have discussed the potential for switching aromatase inhibitors to help reduce or shift symptoms to something more tolerable. It is not a one-size-fits-all journey — and that is why personalized care matters.

In addition to medical support, I have found that regular movement and exercise — even gentle walks or stretching — help with joint stiffness and mood.

It is about trying to achieve balance. Not perfection.

What is next…

None of us really know! Time will tell… I am hopeful my treatment can prevent my cancer from coming back. While I was making decisions on my cancer treatment, I asked my surgeon if there was something else I could do to reduce the odds of my cancer coming back. In my particular case, he mentioned reducing the percentage of body fat may help prevent cancer development and progression. I truly believe changes that can improve my overall health and reduce the odds of

my cancer coming back are worth exploring. For me, my next project is to figure out how to reduce the fat content in my body since estrogen can also be produced in fatty tissues. I continue to prioritize regular exercise to improve my health and mitigate some of the potential adverse effects of the hormonal treatment.

Certainly, not all cancers progress or respond to treatment in the same way. Also, cancer research keeps evolving. As doctors learn more and more, other treatment options will become available over time. It is important to keep searching for alternative treatment options. My life journey continues…