

REDUCING THE RISK OF LE AFTER BREAST CANCER SURGERY

Deborah Hannah

After being diagnosed with breast cancer, Deborah Hannah underwent a bilateral mastectomy. Some weeks later she experienced a tight and uncomfortable feeling in her arm and immediately feared the onset of lymphoedema, the condition that had caused her beloved grandmother so much discomfort and pain.

Nearly 20 years ago, my 80-year-old grandmother was diagnosed with breast cancer. She underwent a mastectomy on her right breast and the removal of several underarm lymph nodes. Shortly after the surgery her right arm blew up like a balloon and grew considerably larger in size than her left arm. It looked deformed and painful. I often asked her 'Grandma why does your arm look like that?' But, she never knew herself. Years later, I learned that her swollen arm was a condition called lymphoedema, a complication from her surgery that caused her great discomfort. However, Grandma had a special way of turning challenges into positive situations. She called her inflated arm a 'stuffed sausage'. Her optimistic outlook enabled her to continue her passions for gardening and cooking. She survived 16 healthy years, passing away at 96 not from breast cancer but from old age. She will always be my hero.

The same month my grandmother passed away, a suspicious area was discovered on my own routine mammogram. Due to the location of

Deborah Hannah is a flight attendant and suffers from axillary web syndrome. She works hard to minimise the risk of developing lymphoedema

these 'microcalcifications' I was unable to have a stereotactic biopsy (needle aspiration) and required an excisional biopsy (lumpectomy) of my right breast. The biopsy results showed early stage breast cancer. I immediately decided to schedule surgery for bilateral mastectomy with the left breast being removed for prophylactic and symmetrical reasons.

Although I had minimal pain after my mastectomy, a few weeks later my upper right arm felt uncomfortable, almost as if there was a tight rubber band around it. The tightness was due to a condition called axillary web syndrome (AWS).

When my surgeon mentioned that she would perform a sentinel lymph node biopsy at the time of my mastectomy I panicked. I worried about my career as a flight attendant and kept having thoughts of my grandmother's swollen arm. Rationally, it seemed that if my grandmother had developed lymphoedema I was at higher risk due to genetic factors, but I could find no medical literature that supported my theory. I became somewhat defensive and did not wish to have any of my lymph nodes removed. My surgeon made it clear to me that there are currently few side-effects resulting from this type of biopsy. She explained that updated procedures consist of a blue dye, injected in the body near the tumour, clearly marking the sentinel node so that it can be easily removed without disrupting other lymph nodes. I agreed to the sentinel lymph node

biopsy under the false assumption that since only one lymph node would be removed, I would not be at risk of developing lymphoedema.

Before my mastectomy I inquired about getting a prescription for physical therapy so that I could begin sessions as soon as possible. I read numerous complaints on the internet written by women whose inability to achieve full range of motion resulted in a 'frozen shoulder'. My doctors did not think that I would require physical therapy but I adamantly pressed for it as I wanted to regain full range of motion quickly. My main concern was not being able to lift heavy items above my head into the overhead compartments, or manoeuvre heavy metal drink trolleys at unstable altitudes — a few of the many flight attendant responsibilities. I believe that physical therapy should always be recommended for patients who have to return to physically demanding professions.

Although I had minimal pain after my mastectomy, a few weeks later my upper right arm felt uncomfortable, almost as if there was a tight rubber band around it. The tightness was due to a condition called axillary web syndrome (AWS). Often referred to as 'cording', this is a condition in which rope-like structures attach themselves most commonly to the underarm area but sometimes extending down the arm. Studies indicate that these 'cords' are most likely lymphatic in nature. This condition is extremely uncomfortable, as I felt like I was wearing an inflated blood pressure cuff on my arm. I was certain that these symptoms were indicative of lymphoedema so I became curious as to just how many lymph nodes were dissected. I discovered that my surgeon

was unable to remove only the sentinel node on the right side because five lymph nodes were attached to each other in a group. Medically speaking, I am sure there is no clear-cut answer as to why my nodes were clumped together making it impossible to remove only one. Perhaps the removal of more lymph nodes than I had anticipated caused me to develop axillary web syndrome (AWS) and put me at a higher risk for developing lymphedema.

Physical therapy

Since I had pressed my surgeon for the physical therapy prescription before surgery, the process of scheduling the sessions was already in place. My physical therapist was a trained lymphoedema specialist who knew a great deal about axillary web syndrome. She constantly reassured me that the discomfort I was experiencing from the 'cording' was not lymphoedema. The therapist provided incredible relief from the 'rubber-band' feeling by applying myofascial massage, a form of soft tissue therapy achieved by applying gentle sustained pressure into the myofascial connective tissue restrictions, which increases circulation and lymphatic drainage.

Even though the weekly physical therapy sessions minimised discomfort, increased my range of motion, and provided me with a list of lymphoedema precautions, the mental turmoil that these visits caused was heartbreaking. I no longer have the need for physical therapy yet the inescapable images of the women sitting in the waiting room with lymphoedema haunt me; their arms wrapped in gauze and ace bandages, looking like helpless mummies. I engaged myself in many conversations with these discouraged women who candidly expressed their frustrations.

Lymphoedema seems to be a taboo subject that physicians and surgeons rarely discuss with breast cancer patients until it is too late. I wonder whether these anxious and discouraged women would have found themselves in that desperate situation if they had been educated on how to reduce the risks of lymphoedema before their breast cancer surgeries. Perhaps the medical

community's focus on aggressively treating the cancer prevents it from understanding that the development of lymphoedema can actually be as devastating to patients as the cancer itself. I can attest to this personally. If I had to be wrapped up in ace bandages and gauze, I would not be able to do my job. It would be challenging to cook, write, clean and dress appropriately. Even though I possess an extraordinarily positive attitude, I am quite certain that I would become severely depressed if I developed this debilitating condition.

Study programme

Shortly after my surgery I was shopping in the boutique located in NYU's Clinical Cancer Center. I happened to overhear a breast cancer patient who was discussing the positive effects of certain exercises that were helping the uncomfortable feeling in her arm with a researcher. I introduced myself to the researcher who invited me to participate in her study titled 'Improving Clinical Practice to Empower Breast Cancer Patients: Reducing the Risk of Lymphedema' ('The Optimal You through the Optimal Lymph Flow Program'). This programme is affiliated with NYU School of Medicine and supported by a research grant from the Avon Foundation. One of the study's main objectives is to reduce the risk of lymphoedema through enhanced education, precisely what breast cancer patients desperately need before surgery or treatment. Participants in the study undergo two types of measurement; an imaging machine (perometer) measures their arms and bio-electronic equipment measures their arms and body composition.

Patients in the study are also given an opportunity to participate in pilot biomarker and genetic testing. As I suspected, it is quite probable that I am at a higher risk for developing lymphoedema due to genetic factors. As this is the first study to explore genetic biomarkers in the development of lymphoedema in breast cancer patients, it is not yet certain whether the findings will be clinically relevant. Therefore, participants in the study will not be given their own genetic biomarker results.

In the programme we are taught valuable pumping and breathing exercises to help decrease the build up of fluid in affected arms, hands and chest area. The pumping exercise keeps the lymphatic fluid moving by essentially creating one's own manual 'pump'. This most beneficial exercise is quite simple and can be performed while sitting or standing. I raise my arms straight up in the air, as high as I can without pain or strain, and open and close my hands 10–20 times. I began doing this exercise numerous times (more than instructed) each day as it provided relief. Accompanying the physical part of this exercise is a mental visualisation technique performed by imagining that you are pumping the lymphatic fluid, flowing out of the body. I find that the visualisation techniques complement the pumping exercise in alleviating symptoms. I believe that the mind is a powerful tool; a positive mental attitude can help to reduce inflammation and increase immunity.

Other step-by-step actions that I learned in this study were instructions for physical activity such as brisk walks several times throughout the day. Since I live in New York and use public transport, brisk walking is a normal part of my daily regimen so this directive was easily achieved. The principal investigator of 'The Optimal You Program' also emphasised the benefits of elevating my affected arm above my heart while sleeping. I noticed a significant relief in the heaviness and tightness when doing so. However, many nights I would toss and turn, roll over on my affected arm, and have difficulty keeping it in the elevated position. I then learned about a custom-made, therapeutic nightwear garment created by Solaris, designed to help regulate fluid fluctuations, decrease tissue turgor and assist a weakened lymphatic system. This particular garment, which I now wear nightly, is incredibly comfortable and helps to keep my arm elevated. In the morning my arm feels rested and I no longer experience the irritation I used to upon waking when my arm was not elevated.

Since I did not have breast reconstruction I was wearing fiberfill fabric puffs that came in the package with my post-surgery camisole, instead of proper prosthetic breast forms. I was then presented with a pair of therapeutic breast prosthetics manufactured by American Breast Care. The special prosthetics are handcrafted and designed to provide lymphatic massage on the chest wall while wearing them. When I began wearing these breast forms, accompanied with pumping exercises, it seemed that a considerable amount of the discomfort in my arm dissipated.

Yoga classes

Seven months after surgery I was incredibly fortunate to discover a bi-weekly cancer survivors' yoga class at OM Yoga Center in New York. These special classes embrace the experience of yoga through breathing, stretching and strengthening exercises and restorative postures. Individuals who do not know about the yoga practice often have the misunderstanding that there is only one type, yet there are many. The methodology in the class is a combination of Vinyasa Yoga which incorporates 'breath-synchronised movement,' and Pranayama, a separate yoga practice used to clear and cleanse the body and mind. This special combination is incredibly beneficial for cancer survivors. I am quite certain that the stretches, poses, restorative postures, and breathing exercises are providing lymphatic flow in my body.

Before participating in this yoga class, I had some challenges with the deep breathing exercises and often felt pressured to do them, even though I firmly believe that they help move my lymphatic fluid and relieve symptoms. However, after only a few of the yoga classes I received the gift of 'conscious breathing', i.e. my deep breathing became incorporated into all of my movements outside of the class rather than just during a separate breathing exercise. I find myself inhaling before I lift the rubbish out of the bin and exhaling as I set the bag on the floor. I hear the instructor's gentle voice telling me to breathe in deeply and exhale slowly.

Returning to work

I had a great deal of anxiety about returning to work as a flight attendant, however; eight months after surgery I took the plunge by going back to my turbulent career. I was indecisive as to

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whether or not to wear the compression garment when flying. There seems to be a great deal of medical controversy on this subject — to wear or not to wear. I have come to the understanding that if a person has not yet developed lymphoedema, wearing the compression garment could cause swelling, especially if it is not fitted properly or worn without the hand gauntlet. I decided to go ahead and try to wear the garment so I was measured at a surgical store by a certified person to ensure an accurate fit. For proper use of the garment, patients are instructed to place it on their affected arm one hour before their flight and remove it one hour after. It is impossible for me to follow recommended instructions when I work several flights, back to back without a break. The first day back at work I wore the garment during two consecutive flights. When I arrived at my destination I noticed that there were deep red indentations in my wrist area and there was some slight swelling in my hand, most likely from the constriction. I made the immediate decision to refrain from wearing the compression garment altogether.

Before my first flight of the day I perform the lymphatic draining massage that I learned in physical therapy. Also, I perform the pumping exercises before, during and after my flights. If it is a long flight, I give myself the lymphatic draining massage at some point during the flight as well. As a precautionary measure I wear a lymphoedema medical alert bracelet on my affected arm indicating, no blood pressure, no IVs or needles in my right arm. Over washing my hands can cause dryness, making my hands more susceptible to cuts or

scratches that could become infected and precipitate the development of lymphoedema. To keep my skin moisturised and protect my hands from exposure to bacteria or viruses, I wear disposable nitrile gloves when collecting discarded items from passengers. I carry a small first-aid kit with me which includes bandages and antibiotic ointment so if I get cut, scratched or bitten by an insect, I can treat myself immediately to reduce the risk of infection. I never leave home without my therapeutic nightwear garment and on my stopovers I relentlessly elevate my arm. So far, this regimen appears to be working in reducing my risks and minimising symptoms.

Upon returning to work I have encountered several other day-to-day challenges. I used to pull my luggage with my right hand and carried a heavy bag on my left shoulder. I have now lightened my load by no longer carrying my laptop and other unnecessary items. I now pull my luggage with my left hand (this took some major adjustment) and wear a 'bumbag' around my waist rather than carrying a bag on my shoulder.

I can clearly see that caffeine, alcohol and salty foods affect my arm negatively so I watch my diet closely. I keep myself hydrated by drinking eight to ten bottles (500ml) of water each day. I now only have one cup of coffee in the morning and have cut out alcohol completely. Most of all, I continue to carry my grandmother's positive attitude in my heart and I truly wish that she had had the opportunity to learn ways of reducing the risk of lymphoedema as I have.

Minimising my risks of developing lymphoedema will remain a life-long challenge for me, especially in the environment in which I currently work. However, with the relief I gained from attending physical therapy sessions, the knowledge I acquired by being a participant in 'The Optimal You Program' and embracing deep breathing techniques through yoga practice, I am minimising my risk of a condition that is one of the most frightening and unsettling aspects of many women's journey with breast cancer. JL