

FINDING MY 'NEW NORMAL' BY SELF-EMPOWERMENT AND SELF-CARE

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My personal journey with lymphoedema has been a rocky road, filled with misinformation from various healthcare professionals. I hope that no other patients have to go through the distress I went through in getting a diagnosis and finding an appropriately qualified lymphoedema therapist and treatment.

Removal of lymph nodes and disruption to the lymphatic system during breast cancer surgery means that breast cancer survivors who have had this treatment are at risk of lymphoedema for the rest of their lives. Recent research has shown that patient education can make a huge difference to quality of life in living well with lymphoedema — or the threat of lymphoedema (Fu et al, 2008).

Hopefully, surgeons will become better aware of research and give breast cancer patients full information on lymphoedema, its symptoms and risk reductions, both before and after breast cancer surgery and will stop giving patients misinformation.

While it is up to the patient to take control and practise appropriate risk reduction behaviour and self-care after initial diagnosis and intensive treatment, we need help to get that initial diagnosis and intensive treatment. In my experience working on the website www.stepup-speakout.org, an online support group for breast cancer survivors with lymphoedema, many of us, before our surgeries — and in many cases after having sentinel node biopsies — had never heard the word 'lymphoedema', much less understood what it was all

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about. We knew what lymph nodes were, and that they would often swell when we were ill, but beyond that knew little else about the lymphatic system.

For women who are at risk of developing lymphoedema after breast cancer surgery to practise appropriate risk reduction and self-care, they need appropriate diagnosis, referral for treatment, education and support from healthcare providers. We need our breast surgeons and oncologists to give us full information about lymphoedema, our risks, risk reductions, what the symptoms of early (sub-clinical) lymphoedema are, what to watch out for and when to report these symptoms to healthcare providers.

Receiving the diagnosis of lymphoedema is like receiving the call to say the biopsy was positive all over again. Some of us are in denial, are not in pain, and think it will go away on its own. We need help from our healthcare team to come to terms with the diagnosis. We need their support to let us know that a lymphoedema diagnosis is not the end of the world, and that lymphoedema can be treated and brought under control. The sooner it is diagnosed the better, so that we can begin to care for ourselves and keep our lymphoedema at bay and have a great quality of life, with a 'new normal' which we will adjust to, given time, education and practice.

I recently met a physician at a Lymphoedema Framework Conference who said that she did not believe in speaking to her breast cancer patients about lymphoedema, symptoms or risk reduction behaviour before surgery, as the patient would either get it or not, so why worry them. Needless to say, I got my message across to her that if I had been given information on lymphoedema,

I would have practised risk reduction behaviours, known what to watch for, and would have been diagnosed well before my lymphoedema was stage 2 in my breast, arm and thigh.

In August 2007, having received breast cancer diagnosis in July, I had a unilateral left mastectomy, with two sentinel nodes removed, and transverse rectus abdominus myocutaneous (TRAM) flap reconstruction. I started chemotherapy in September. On 20 November 2007, I flew to Paris from New York using no compression garments of any kind as I did not even know what they were at that time. My breast surgeon was aware of my trip but did not suggest using compression garments.

Upon arrival in Europe, my trunk, the reconstructed breast and my left arm were swollen and sore. I put it down to being post-surgical and in the process of chemotherapy.

After that flight, I had a soft, painful, warm red lump in the cleavage of my new breast which was not there after surgery or before the trip. I went to see my breast surgeon and she told me it was fat necrosis. I told her how different it was from the fat necrosis on the axilla side of the reconstruction, which was hard and never got warm or red. She said it was fat necrosis, and told me to come back and see her in six months.

In February 2008, I flew to Hawaii from New York via various stops. My breast surgeon was well aware of this trip but again failed to suggest using compression garments, about which I still knew nothing. There were many take-offs and landings, causing breast/trunkal and arm discomfort. I still thought that this was just post-surgical, post-chemotherapy

problems that I needed to deal with. I cannot believe I was so naive and uninformed, and had taken each word from my breast surgeon as gospel.

When I finished chemotherapy in March 2008, I had a positron emission tomography/computed tomography (PET/CT) scan that showed all was clear. My sister and I went to celebrate at the Canyon Ranch Spa in the Berkshires. We looked through the 'menu' of massages and treatments and chose a lymphatic drainage massage, which was listed as boosting the immune system.

Fortunately, I had a German massage therapist who had been trained in lymphoedema treatment and had worked in hospitals in Germany all her life until retiring to the USA. After about five minutes, she asked me if I knew I had lymphoedema in my reconstructed breast, my arm and thigh, and it was stage 2 with fibrosis. She pointed to and massaged the stage 2 lymphoedema in the breast and arm (showing me the hard, fibrotic spots) and told me I needed to see a certified lymphoedema therapist when I got home for treatment. I told her this could not be possible as my breast surgeon said it was fat necrosis. She assured me that it was definitely not fat necrosis. The left side near the axilla was fat necrosis but the spot in the cleavage was hot and red and she told me that I needed antibiotics to make sure I did not develop cellulitis.

Thus, this chance meeting at a spa began my diagnosis and search for proper treatment of my lymphoedema. It took four weeks to get an appointment with the physiatrist (rehabilitation doctor) for the referral to the lymphoedema therapist, so I called the physical therapist I had seen after my reconstruction and asked her to help. She is not Lymphology Association of North America (LANA) certified, but with instructions/pictures and exercises that the German massage therapist had given me, we did the massage and exercise. When we started she measured my arms, and the left arm was two inches larger than the right. I saw her every day and did the exercises, deep breathing, and manual lymphatic drainage (MLD) as shown to me by the German

lymphoedema therapist, and I also did the exercises daily on my own which helped the arm and breast swelling to go down.

Finally, on 1 May 2008 I had an appointment with a LANA-certified LE therapist. We got off on the wrong foot when she said that she could not believe my left arm had been two inches larger than the right arm and my physical therapist and I had reduced the swelling by that much without wrapping. I did not argue with her; since I had a trip to London scheduled later that month and my goal from our meeting was to get measured for a compression sleeve/glove and compression bra. She did not think that the glove or compression bra were necessary, but (having learnt a lot about lymphoedema by this point) I insisted on both. The LE therapist took my measurements and ordered a sleeve (CC1), a glove (CC0) and a Bellisse bra.

I knew this was not a relationship made in heaven and only wanted the compression garments ordered and received before my trip to England, and I would then continue my quest for a LANA-certified LE therapist who would believe what I said. How can a relationship work out between a patient and a healthcare provider when there is no trust?

The garments came in several days later and I went to try them on. I had no idea how they should fit, so assumed that the sleeve being several inches short of my axilla and the fact that there was a space between the glove and sleeve was appropriate. However, when I tried on the Bellisse bra and saw the 'open spaces' in my cleavage, I asked her if she had some foam bag chips (I had done my research) or something to put in there because I saw that, as a simple matter of physics, there were obvious places where fluids could easily accumulate during the flight. She told me it was not necessary and would only irritate my skin.

Needless to say, upon my return from Europe, my lower arm and torso were fine, but I had developed new spots of hard, painful fibrosis in the cleavage area of my reconstructed breast and the top of my arm.

My physical therapist recommended a different LANA-certified LE therapist and I had an appointment with her within two weeks. She asked me to bring my sleeve and glove to our first meeting. She shook her head and sent me to 'Lucy the fitter' at the nearby surgical supply unit, who was purported to be the best fitter around and would get me set with a properly fitting glove and sleeve.

My new LE therapist and I set up an appointment schedule to start MLD and intensive therapy, since we had lots of work to do to soften the fibrotic tissue. The new therapist gave me a sheet of risk reduction practices, explaining the importance of deep breathing — the strongest pump of the lymphatic system. She also taught me to do my own MLD and wrapping.

I then went to 'Lucy the fitter' with my glove, sleeve and Bellisse bra from the first therapist. I had an informative session. She easily stuck her finger in my glove where it did not quite meet the sleeve and asked me how much compression I thought this glove was giving me and how much room it was leaving for gravity to collect fluids. She explained that the sleeve was much too short for my arm and I definitely needed a size 1 long, not regular, as previously prescribed. She had the appropriate fitting garments in stock and taught me to put them on with donning gloves, smoothing the fabric appropriately from wrist to axilla to prevent any wrinkles that could impede lymph flow. Finally I felt that I was in the right hands, and that I could begin to get this under control.

After finishing my intensive treatment with my second LE therapist, I still wrapped my arm at night and slept with a breast binder and full breast Swell Spot™ (Solaris) and wore my sleeve and gauntlet during the day.

I slowly weaned myself to wrapping my arm every other night (still sleeping with the breast binder and full breast Swell Spot™) and only wearing my sleeve/gauntlet when doing activities such as exercising, housework and grocery shopping.

I began an exercise programme using the Lebed method DVD every day after my shower and before my MLD. I began to learn exactly what self-care meant — what I needed to do every day, and what I should never do if I did not want my arm to swell. I also accepted that this condition was incurable and would be with me for the rest of my life.

I had some grieving to do at having truly lost something else from this breast cancer beast by developing lymphoedema, but I tried to keep looking at the glass as half full not half empty, and actually managing to be happy to have the glass at all. I realised that as long as I practised self-care things were going to be all right and I would learn to cope.

Whether it is weeding or cooking with heavy pots and pans, I need to wear a sleeve and/or a glove or gauntlet, without exception. This was quite depressing at first (as was learning to wrap), I shed many tears and threw a lot of bandages around in the beginning, but I learnt, and the wrapping became easier and quicker. I adjusted and accepted my 'new normal' and the self-care became habit.

Throughout the day, I take short breaks to do deep abdominal breathing. I also remember to take breaks from the computer and raise my arms above my head, and open and close my hands 10–20 times either with or without a stress ball to 'pump' my lymphatic system and to keep well hydrated at all times.

When I thought I had it all under control and had adjusted to incorporate self-care into my life, I took two flights from New York to Chicago on two consecutive weekends. Of course I wore my chest compression garments, compression stockings and sleeve and glove on my left arm.

Unfortunately, within a week after the second flight, my right arm began feeling heavy and tight and I felt it swelling. A few days later I was bitten by an insect on my right arm which swelled the entire arm. I started ciprofloxacin immediately and went back to my LE therapist. She confirmed it was swollen and she could feel the fluid. It did

not look like cellulitis (thanks to the ciprofloxacin), but she could not begin further treatment until she was sure that nothing else was going on.

I scheduled an appointment with the physiatrist, who saw and felt the swelling on my right arm (which had had no surgery or nodes removed). She said this was rare and not something that she had seen before. There had only been one paper written on lymphatic changes in the contralateral arm (Stanton et al, 2009).

She thought that the oedema might have been caused by something else, and arranged for a magnetic resonance imaging (MRI) scan to rule out any other causes. The MRI showed significant arthritis in the right shoulder, but nothing that would be causing oedema or lymphoedema in the non-surgical right arm. I subsequently sought a second opinion from my rheumatologist. He X-rayed both shoulders and told me my right shoulder had arthritis, probably caused by an old horse riding incident many years ago which had been accelerated by the Arimidex® (Astra Zeneca) I was taking. He saw no reason for this to lead to lymphoedema or any other oedema in the non-surgical arm.

I have continued with my lymphoedema therapist and, indeed, the right arm is improving significantly. Measurements were taken on 29 May 2009 and the size is back to the normal measurements taken when both arms were first measured for the LE of the left arm.

Much research is being done regarding genetic disposition to lymphoedema and changes in the contralateral arm after surgery, and it looks like I am falling into that category. I would be lying if I said the diagnosis of bilateral lymphoedema was not depressing. However, at least with this diagnosis I knew exactly how to care for my arm, how to wrap it and what I must do each and every day regarding self-care. In some ways, it was actually easier than the first lymphoedema diagnosis.

My biggest problem now is ensuring that I have no blood draws or blood

pressure from either of my arms. I am blessed with a healthcare team that totally understands this.

On our website, www.stepup-speakout.org, we are encouraging other bilateral lymphoedema patients to insist on foot draws. They are neither painful nor difficult and only require an appropriately trained nurse to do them.

We are also encouraging all breast cancer survivors who are either at risk of or actually have developed lymphoedema, to make blood draws and blood pressures on the affected or at-risk arm non-negotiable. We must advocate for ourselves and not be intimidated by a physician telling us, 'it may swell, but it is no big deal — it will go away'.

Living with lymphoedema and practising risk reductions and self-care, while not easy and time-consuming, helps patients to retain quality of life and the health of impaired lymphatic systems.

Wearing compression garments is no fun but, fortunately, gloves, gauntlets and sleeves are now made by many manufacturers in a variety of colours, and can coordinate with your wardrobe.

Lymphoedema can make a patient feel isolated, sometimes to the extent that they feel like withdrawing from life. Giving up and not practising risk reductions and self-care can only worsen the condition — and possibly put your life at risk from cellulitis. Joining a support group, either online or in person, and sharing experiences and coping tips that have been learnt over many years of dealing with lymphoedema, can be a great comfort. With appropriate self-care, our 'new normal' can be a great and fulfilling life. JL

References

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