

## Thank you, lymphedema

I am 6ft. I am told, that when I walk into a room I command a certain presence. This may be true. However, there was a time when lymphedema changed how I saw and felt about myself. Lymphedema did what two bouts of breast-cancer and two mastectomies didn't. Lymphedema robbed me of the self-esteem that I fought to build over a lifetime.

I have lived with lymphedema for 36 years. It went untreated for 30 of those years. For most of those 30 years, the swelling was minimal and didn't have a big affect on my life, I went on as usual. No one really ever asked me about it, and I never brought it up. It simply was invisible in my mind.



By 2009 my lymphedema was out of control. I didn't want to leave my house, I became a recluse of sorts, and when I did force myself to go out, I dreaded the stares and finger pointing (mostly from children). I would hear "she's so pretty, but what's with that fat arm and hand" or perhaps what I heard was my inner self-consciousness. My hand and arm were so huge, that I could no longer pretend. I became very self-conscious. Whenever it was that I did out in public, I would hide my swollen hand in my oversized purse, or stuff it into the pocket of whatever I was wearing at the time. Working from home made it easy to hide from the peering eyes of the public. I spent a lot of time trying to find a deeper, spiritual meaning for the swelling that had taken away my self-confidence. Metaphysically, swelling means that you are holding on to things. I certainly was holding on to a lifetime of hurt and pain. Ok, so that explained the thought process. But. What about the physical, how would I take care of this big swollen limb.

On October 23, 2009 a bout of cellulitis sent me and my self-esteem spiraling. I awoke that morning unable to get out of bed. My head was pounding, my hand and arm were painful, red and hot, I was unable to walk and I couldn't swallow, so could not eat. I was terrified. I called my niece and asked that she come over and help me. I wondered if I had cancer again and that I was dying. I was in bed for a week. I remembered that a friend had given me a business card for the Lymphatic Center of Las Vegas a few weeks earlier. I held onto the card but never called, because I had no insurance. I searched for and found the card. I called and asked if they accepted patients without insurance and was told YES. I would simply have to pay for my bandages and wraps upfront and they would work with me on paying for my treatments. Oh happy day!



November 1, 2009, was my 1st appointment with Dr. Richard Hodnett, who explained in detail what was going on with my lymphedema and how MLD (Manual Lymphatic Drainage) along with bandaging would help me. I was filled with so much emotion that I began to cry.

I was in treatment for 3 months 3 times a week. I was compliant and did everything that I was instructed to do. I wore my bandaged arm like a suit of armor. Funny thing about the wrapped arm, it made me feel safe. I got out of my house and went about life like a boss. I even had my fingernails painted red. I learned much about the lymphatic system and how crucial it is to our overall health. I was surprised to learn that many physicians are uneducated when it comes to treating lymphedema. This explained why no doctor mentioned my swollen limb in the past.



As a result of treatment my arm was reduced by 15 cm (almost 6 inches) and it was time for my compression garments. What an emotional and exciting time. I decided at that moment that I would take my life back. I would become an advocate for lymphedema awareness. I chose black garments. They would become my trademark. I would use my 6ft frame as a walking billboard for lymphedema awareness.

In September of 2011 I was asked by Dr Hodnett to appear in a commercial for the Lymphatic Center of Las Vegas. It was at the shooting of the commercial that I met Christine Wunderlin, who filmed a commercial as well. A few weeks after the shooting, Christine called and asked if I would be interested in co-hosting a podcast devoted to lymphedema awareness. My answer was YES! Another life changing event. We decided to call ourselves [The Lymphedema Mavens](#). I found my passion! I love co-hosting our podcast.



I continued searching the internet for lymphedema resources. The 1st organization that I became involved with was the Lymphedema Advocacy Group. I learned about the [Lymphedema Treatment Act](#). It struck home with me, as my garments were paid for by a grant. It was through this group that I learned how to use my **voice** as an advocate. I became deeply involved and in November 2011 I took my 1st trip to Capitol Hill to advocate The [Lymphedema Treatment Act](#). I joined the Board as Secretary in 2012.

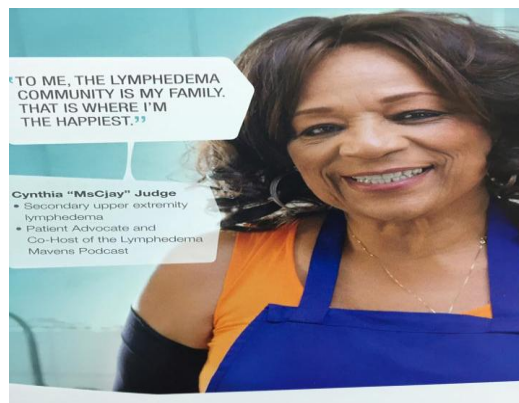


Upon returning from Capitol Hill, it was suggested that I apply for the [National Lymphedema Networks Lymph Science Advocacy Program](#) (LSAP). My application was accepted and I attended and graduated with the class of 2014. Another big step in gaining my voice and self-esteem. Attending the conferences and being exposed to so much knowledge gave me life. I AM my happiest when I attend them.



July 2015, I was diagnosed with endometrial cancer. I opted to have the da Vinci Robotic surgery; I knew that lymph nodes would be removed and it was a valid concern. At the time of my pre-surgery appointment I expressed those concerns to Dr. Kowalski, my surgeon. She informed me of the “[sentinel lymph node](#) detection” clinical trial that she was involved with. I was so thankful that I knew the value of the research from attending the [NLN](#) conferences. I told her that I would be happy to participate in the groundbreaking research. And, thanks to the clinical trial she only removed 10 lymph nodes. They were negative. No chemo. No radiation. Thank you, lymphedema.

I have found that it takes strength and courage live with what the world calls a “flaw” or deformity. For me, having lymphedema was far worse than losing my breasts 14 years apart. I can camouflage my missing breasts, not so with my swollen limb. Every day when I look in the mirror and see my body, my swollen limb stares back at me. It’s when I decided to step outside of myself and to own my lymphedema my entire life changed. I’ve never advocated anything. Lymphedema changed that. I found my passion. I found my voice. I regained my self-esteem. I have learned to love myself in the deepest way. Thank you, lymphedema.



[LymphCareUSA](#) [Lymphatic Education and Research Network](#) [Lymphedema Lifeline Foundation](#)