

Amy's Butterfly Journey

Living My Life with Lymphedema and Obesity



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Amy Williams, (front left) her therapist Celeste, (front right) and the MTV crew (rear, left to right) Sarah, Rachel, and Stephanie.



By Amy Williams

Amy recently appeared on MTV's *True Life*, "I'm Obese"

I have been overweight for the majority of my life. I have always had a larger bottom than top and when I graduated high school I wore a size 18 top and size 28 pants. I married Kenneth in my senior year of high school, and we have been married now for over nine years. He has been very supportive in my weight loss journey and with my leg condition, which finally has a name: lymphedema. I call my story "Amy's Butterfly Journey" because I feel like a butterfly emerging from a cocoon, in which I have been trapped for so many years.

In 2001, I weighed 350 pounds. Although I was still considered obese, I was still able to be mobile. Then one day I took a bad fall down some concrete steps. My therapist, Celeste Ray, and I now believe that it was this fall that triggered my lymphedema. A couple of days after the fall I tried to put on pants that had fit me the day before—they now were tight in the calf area of my leg. I honestly thought I was just gaining weight.

In March of 2002, I discovered that my socks would no longer fit over my calves. I had to wear short socks, because my ankles were too large for the cuff of longer socks to fit. I thought, "I have to get control of my weight!" I began to research the LAP-BAND® weight loss surgery. Because I didn't have insurance at the time—and I had read about how it had not been done on many larger patients—I just dismissed the idea of surgery and moved on. Months passed and things got harder and harder. I knew something was wrong and I blamed myself, yet I knew that my eating habits had not changed. I didn't know what was happening to me. I prayed for an answer to my problem. Walking was becoming more difficult. I was very short of breath. Kenneth applied for a new job that November. We needed a job that would offer benefits. Finally, a letter came in April of 2003. It was a request for a job interview. I just knew when it came that it was the answer. God provided the help I wanted and needed. Kenneth would get the job.

By this time, things had become much worse. I did not go out of the house and was unable to walk long distances. I did not want to see people. I did not even want to see family for fear of rejection or ridicule about my legs and weight. I started the Atkins diet, because my parents and family were getting very concerned about my health. I was concerned too. I was now 599 pounds. I would not go anywhere except to the bathroom, to bed and to my computer to surf the Internet. I was totally dedicated to the diet. I lost a total of 50 pounds, and I was so happy. Suddenly, I was no longer losing weight, but instead was gaining it all back. I didn't know what was wrong. I was so upset. Our insurance was activated, so I went to our primary doctor and she ordered a blood test. The results came back that I had hypothyroidism. She said that was why my weight was not consistent, and that not until I get my thyroid under control would I be able to lose weight and keep it off. It was like my body was working

against me. I felt relieved because I had started to realize that maybe I had not done all this to myself. I had blamed myself for my weight gain all these months. Something was clearly wrong with my legs, as I now needed a wheelchair to get around. I decided to look into gastric bypass surgery again. I felt it was my only hope to live.

It was August 2003 when I returned to my PCP and told her there was something wrong with my legs. She said, "Oh, it's edema, let me prescribe some Lasix." I was happy, because the first few times I took the pills my legs felt better. As months went by, something was still not right. I questioned her again about it, and she upped my diuretics more.

In November I went to a support meeting for weight loss surgery. We drove all the way to Atlanta. A lady that had been one of the speakers came up to me afterwards and said, "You must have lymphedema. I do too." I said, "lympa what?" I told her I had no idea what that was, so she started explaining how she had gastric bypass surgery and suddenly started gaining weight. They found out that she had lymphedema. She said she got into therapy and it did wonders for her. I went home. She had given me some websites, but I just brushed them aside. A couple of weeks passed, and I thought, "Well, I guess I'll look into this." So, I did a web search. I found several pictures, but none looked like my legs. Finally, one day I found a site with a lady that weighed 400-plus pounds. Her legs looked a lot like mine. I was in shock. So, I did more and more studying. I finally came to my own conclusion: I had lymphedema. I also purchased a wonderful book about lymphedema called *Coping with Lymphedema*. It was very helpful in convincing me that I was suffering from this disease.

I went back to my PCP in the beginning of December and asked her about lymphedema. She didn't know much about it, so she dismissed the idea. I then spoke with the main PCP in the office and he seemed to think I had the disease. Again,



615 pounds before surgery

550 pounds after 20 days of therapy



Stage 3 Lymphedema
(right picture) shows the progress of 27 days of treatment.

nothing was mentioned about treatment. It was like they were saying, “You are fat—so deal with it.” I went home upset and crying. I didn’t know what else to do. So, I thought about it for a couple of days and said, “No, I am going back—they are going to get me help.” Finally, my PCP explained the problem. She could not refer me because the therapist I needed to see was not at a hospital in their network, so she suggested that I talk to my cardiologist. That day I came home and we called his office. My call was not returned because it was during the Christmas holiday. I received a referral in the mail in 2004. By this time I had reached my all time highest weight of 615 pounds. The weight gain was from the lymph fluid that had built up. I was so happy that finally someone was finally going to help me.

A couple of days later, I got a call for an appointment to see therapist Celeste Ray. She told me I had was Primary Stage 3 lymphedema. It’s been a long, hard struggle to get this treatment. There is not a lot of data about lymphedema in the US. I’ve found myself amazed by the correlation between it and super morbid obesity. Lymphedema is widely overlooked as something else. When it comes to lymphedema, no one else will be your advocate except you! The results thus far have blown me away. I can now walk farther and better. I can wear socks and shoes for the first time in three years. I’ve lost a total of 65 pounds in 20 days of therapy. This treatment was a battle to get, but, in the end, I am so thankful I was able to get it. If I had not pushed for this, I would still be suffering. No one that has lymphedema should suffer. I hope that more doctors will take notice of this debilitating disease.

In early May 2004, ObesityHelp™ approached me with the idea of appearing on MTV’s *True Life*, “I’m Obese.” I decided to do the show as a way to educate people about lymphedema and obesity. As luck would have it, after waiting what seemed like a lifetime, I underwent weight loss surgery on May 27, 2004. That same week, I was being filmed on the show. The show was a great experience, and I could not be happier with my decision to have the surgery. To date, I have lost 111 pounds, and my lymphedema has improved due to the weight loss. The MTV show was hard for me to do, because it exposed a lot of things about myself that did not make me proud. However, thinking of the people that would be helped kept me motivated during filming.

Lymphedema and Obesity

by Celeste Ray

There are many health risks associated with obesity, including heart disease, diabetes, sleep apnea, high blood pressure, gallbladder disease, joint pain and depression. Another common but often overlooked health problem associated with obesity is lymphedema, the accumulation of protein-rich fluid in the body’s tissues. Although lymphedema has many causes and can affect people who are not overweight or obese, obesity increases a person’s risk for developing this serious disorder.

More than 3 million people in the United States are diagnosed with lymphedema each year. One of the first symptoms of lymphedema is swelling, usually of an arm or a leg, but the trunk can be involved as well. Lymphedema sufferers report feelings of “heaviness” and “tightness” in the affected areas, and often find that clothing that once fit is now too snug. When both legs or both arms are involved, the swelling is usually worse on one side. Once lymphedema symptoms begin, the disease gets progressively worse. Untreated lymphedema can lead to disfigurement, skin hardening, life-threatening infections, psychological distress, and certain forms of cancer. The rate at which the disease progresses depends on many factors, including a person’s medical history and how often the swollen part becomes infected.

THE LYMPHATIC SYSTEM

The lymphatic system transports excess fluid from the tissues back to the bloodstream and helps the body fight infection. As blood circulates through the body, it feeds the tissues by dropping off oxygen, water, and proteins. Any extra fluid left behind in the tissues is then returned to the circulation by the lymphatic system. If the lymphatic system fails, fluid accumulates in the tissues, leading to swelling (lymphedema) in the affected areas.

The lymphatic system is composed of superficial (in the skin) and deep (below the skin) vessels and lymph nodes. When the excess tissue fluid enters small vessels called lymph capillaries, it becomes “lymph.” After entering the lymphatic system, lymph then travels through a series of progressively larger lymphatic vessels and lymph nodes before finally re-joining the bloodstream at the veins of the neck. Muscle, joint, and tissue movement during normal, everyday activity are major forces that propel fluid into and through the lymphatic vessels. Rings of muscle surround the larger lymph vessels, and their contractions (five-ten per minute) also help move fluid through the system.

Lymph nodes are bean-shaped structures that occur periodically along the lengths of the lymphatic vessels. They are filters that function much like airport security checkpoints. As lymph fluid passes through them, waste products and potentially harmful substances such as bacteria, viruses and cancer cells are removed. Those substances that

are “detained” are destroyed by immune cells that reside in the nodes.

LYMPHEDEMA

For lymphedema to develop, there has to be both damage to the lymphatic system and a trigger that stresses the system past its limited ability to carry fluid. There are two types of lymphedema—primary and secondary. Primary lymphedema is present from birth and is caused by defective development of the lymph vessels and/or nodes. It affects women more than men, and, although commonly seen in one or both legs, it can also involve the arms. Symptoms of primary lymphedema may be seen at birth or may not appear until later in life. Events that may trigger the onset of symptoms include puberty, pregnancy, insect bites, minor injuries, tight clothing, airplane trips, long car rides or obesity.

Secondary lymphedema results from damage to lymph vessels and/or nodes that occurs anytime after birth. Surgery, trauma, radiation therapy, cancer, paralysis, and obesity are a few of the many ways that the lymphatic system can be damaged. A woman who has had a mastectomy with one or more lymph nodes removed, for example, is at risk for developing secondary lymphedema in the affected arm. Once the lymphatic system has been damaged, many of the same events that trigger symptoms in primary lymphedema can also bring about the onset of secondary lymphedema symptoms. These symptoms can occur immediately after the initial injury, years or months later, or not at all. Secondary lymphedema can be distinguished from primary lymphedema based on physical examination and a patient’s medical and family history.

In Stage I lymphedema, the skin is soft and indentations can be made in the swollen tissue by pressing it with a finger (“pitting”). The swelling usually goes down if the affected extremity is elevated, and can get worse with heat, activity, and high humidity. In Stage II lymphedema, swelling becomes more severe, resists “pitting,” and does not decrease when the limb is elevated. The skin also begins to develop fibrosis, a

hardening and thickening of the tissue. Chronic inflammations and repeated fungus and/or bacterial infections are common in Stage II lymphedema. In Stage III lymphedema, also called lymphostatic elephantiasis, the edema (excess fluid in the tissues) is severe and non-pitting. The skin hangs in large folds and feels very hard and thick. Other common skin changes include wart-like lumps and small holes that leak fluid from the skin.

LYMPHEDEMA AND OBESITY

Obesity is a risk factor for lymphedema and can also trigger primary or secondary lymphedema. Obesity affects the lymphatic system in several ways. The weight of the tissue, especially in the abdomen, blocks the flow of lymph and blood coming from the legs, causing swelling. Also, the walls of blood and lymph capillaries are weak in obese patients. This causes more fluid to leak into the tissues and makes it harder for the lymph vessels to transport lymph out of the extremities. Obese people often have problems walking. Because movement helps push fluid along in the lymph vessels, the more sedentary a person is, the more likely they will have swelling in their legs.

LYMPHEDEMA TREATMENTS

Lymphedema cannot be cured but can be effectively managed. Treatments for lymphedema have included lymphedema pumps, compression stockings, surgery, and diuretics (“water pills”). These techniques have had limited success and also have many undesirable side effects. The use of pumps, for example, is inconvenient and can cause genital edema, and many of the lymphedema surgeries cause even more swelling in the affected extremity.

Currently, the most effective and least invasive approach in managing lymphedema is Combined Decongestive Therapy (CDT). There are four essential components of CDT. First is hygiene and skin care, which are important to minimize the risk of bacterial and fungal infections. Second is Manual Lymphatic Drainage (MLD), a light massage technique that stimulates lymph flow

Resources for Lymphedema

<http://www.lymphedemacircleofhope.org>

<http://lymphedema.omno.org>

National Lymphedema Network

<http://www.lymphnet.org>

<http://www.lymphnotes.com>

Coping with Lymphedema

by Joan Swirsky, RN

and Diane Sackett Nannery

and directs the fluid around congested areas. Third is compression bandaging, which prevents lymph from re-entering the affected arm or leg and assists the fluid in moving through the lymphatic system. Exercise is the fourth component of CDT. Exercises are done with the bandages on and are designed to increase muscle activity and stimulate lymph flow. Exercise programs are individualized and address any muscle or joint problems a person may be having.

During the intensive phase of therapy, patients attend five two-hour therapy sessions per week. The number of weeks necessary for treatment depends on the severity of the lymphedema and the condition of the skin. As part of therapy, patients and their families are taught how to do all four CDT components for themselves, so that they can manage their lymphedema at home. Once the intensive phase of therapy is completed, patients begin their home management program, which consists of wearing a custom-fitted compression garment during the day, wearing self-applied bandages at night, practicing good skin and nail hygiene, performing daily exercises and performing MLD as needed.

Treatment of lymphedema in obese patients is complicated by the fact that they usually have other illnesses that must be considered. Congestive heart failure, sleep apnea, diabetes, thyroid disease, blood clots and joint disease are just a few of the problems associated with obesity that can make lymphedema treatment ineffective or even dangerous. Make sure your doctors and therapists

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are familiar with the indications and contraindications of treatment before you begin therapy, and that other medical conditions you have are being treated.

In addition to therapy, diet is important in managing lymphedema associated with obesity. A dietitian can be helpful in developing a safe, effective diet plan to assist with weight loss. In addition, low-sodium, high-fiber diets are recommended, since increased salt intake can increase edema. Although lymph fluid is high in protein, the protein is derived from the blood, not directly from the diet. Consuming less protein does not affect lymphedema and can have serious health consequences. At least one study has suggested that weight loss after gastric bypass surgery can help decrease lymphedema in obese patients.

LIPEDEMA

Lipedema is a disorder that is commonly misdiagnosed as either obesity or lymphedema. Sometimes called “cellulite,” lipedema affects women more than men, and can be recognized by the symmetrical accumulation of fatty tissue in both legs from the hips to the ankles. The arms are sometimes involved as well. Symptoms of the disorder usually appear around puberty and include pitting edema that worsens with activity and heat. Lipedema can be distinguished from lymphedema in several ways. Unlike lymphedema, lipedema affects both legs equally and does not involve the feet. Also, people with lipedema bruise easily and are especially sensitive to touch and pressure on their legs. Cellulitis, the infection frequently seen in patients with lymphedema, is not seen in those with lipedema. Lipedema can also be distinguished from obesity. Obesity is related to diet and results in more uniform distribution of weight in the trunk, arms, and legs. In lipedema, fatty tissue is unequally distributed in the body, with most of the accumulation

in the hips and legs. Because hormones are thought to play a role in the development of lipedema, dieting does not help lipedema patients lose the weight in their legs.

CDT can be effective in managing lipedema. Although leg size does not change dramatically with treatment, CDT helps manage debilitating lipedema symptoms such as pain and the swelling that occurs after standing and walking.

Correct diagnosis of lipedema is frequently complicated by the fact that it can be present along with lymphedema, obesity, or other disorders. In fact, untreated lipedema can lead to the development of lymphedema in the legs after many years. It is still important, however, to have a correct diagnosis, especially if you are considering gastric bypass surgery or liposuction. Because pure, uncomplicated lipedema (not lymphedema or obesity) is not affected by diet, it will not be improved after gastric bypass surgery. Liposuction is also not recommended, since it can damage the lymphatic system in the skin and lead to secondary lymphedema.

RESOURCES

If you suspect that you have lymphedema or lipedema, seek the advice of your health care provider. Although more providers are now aware of these disorders, they may not be experienced in diagnosing them or in prescribing proper treatment. You need to be prepared to get a second or even third opinion. Also, beware if you are told to use a compression pump or compression garment alone without any other type of therapy, since improper use of these approaches can lead to complications. In choosing a therapist, ask how many hours of lymphedema training they have had (135 is considered the minimum), how many years they have been practicing, and if they have been certified by the Lymphology Association

of North America (LANA).

Several on-line resources are available to help you understand lymphedema and lipedema and find appropriate treatment. Many sites also have links to other related websites. The National Lymphedema Network (www.lymphnet.org, 1-800-541-3259) publishes a quarterly newsletter, and provides referrals to lymphedema treatment centers, therapists, and support groups. It also has a good selection of books and educational materials available for purchase.

The Lymphology Association of North America (LANA) (www.clt-lana.org) has established guidelines and certification requirements for therapists who provide lymphedema treatment. To be LANA-certified, a therapist must have a minimum of 135 hours of lymphedema training, at least one year experience treating patients, and a passing score on the written LANA certification examination. The LANA website lists certified therapists and provides other information to assist you in locating qualified therapists in your area. ♥



Celeste Ray, PhD, PT, CLT^{LANA}

Senior Physical Therapist

MCG Health System

Department of Physical Therapy

Augusta, Georgia, 30912

e-mail: cray@mail.mcg.edu