**My search for the Importance of Aftercare in the Treatment of Lymphedema**

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I would first like to say that I am always grateful to be given any opportunity to talk about

lymphedema and its care. I acquired lymphedema in 2005, having had a severe parasitic

infection (schistosomiasis), which went undiagnosed for three years. The infection caused the

enlargement of my inguinal lymph nodes on the right side of my body, with subsequent scarring

of those nodes. Prior, I had worked as an Occupational Therapist for nearly 10 years in a

hospital based setting. I tell you this because even though I worked in a hospital, closely with

many Doctors, I could not find one single clinician who knew anything about lymphedema. I was

astounded to say the least. I even had one Physician that I worked with tell me I must have

sprained my ankle.

So, me being the tenacious person I am, I set out on a journey to learn as much as I could about

lymphedema and its treatment. I can tell you that in the beginning, I received some very poor

care. I went through the traditional complete decongestive physiotherapy (CDP) protocol for

lymphedema, and came out with my leg more swollen than when I began. When I questioned the

therapist about this, she gave me the name and number of a massage therapist who sees

‘difficult’ patients. I made my appointment with this therapist for an evaluation, and I have never

looked back. This person, for lack of a better term, became my lymphedema guardian angel!

Having Lymphedema (LE) I have come to find, requires an enormous amount of time, energy and

attention. When following all guidelines, patients can spend hours a day completing self

lymphatic drainage, exercises, meticulous skin care, and washing and caring for their

compression garments and compression bandages. It is at first an almost insurmountable task.

Even for me, with my therapy background, I felt completely overwhelmed. The only thing which

has carried me through all of this is knowing that I have a support system via Liz Olivas (the LMT

guardian angel mentioned above).

The most important part of caring for LE is what comes after your course of CDP. The need for

aftercare is tremendous. The daily ins and outs of handling all the problems which seem to pop

up can make any sane person crazy. Realizing this prompted me to once again further my

knowledge. I decided that I wanted to become certified to treat LE, and then set out to pick

coursework which I felt most closely matched my belief systems and my ideals as an

Occupational Therapist. After much research, I decided to begin the certification process with

Dr Bruno Chikly’s Lymph Drainage Therapy coursework. I chose to study Dr Chikly’s work over

all others for one very specific reason: manual lymphatic mapping (MLM). In my estimation, this

was what had been lacking in the initial treatment given for my LE. If the pathway the lymph was

taking in my leg could be palpated, then I knew I wouldn’t be pushing it in a direction it did not

want to go. Needless to say, I was extremely excited about the prospects for this new

educational journey.

I completed LDT I, II, and III over a period of two years, and then took and passed the LDT

Lymphedema/CDP Certification Level 1 class and test. Along the way I met some amazing

therapists, some of which are now great friends. To say that I am satisfied with my decision to

study this coursework would be a great understatement. I have learned an enormous amount not

only about treating patients who have lymphedema, but also about myself and my LE. I am proud

to say, the manual lymphatic mapping skills helped me to recognize the alternate pathway my

body was using to drain my right leg. With this knowledge, I have reduced the edema in my leg to

the lowest level it has ever been. I am no longer pushing the lymph into a non-functional

direction, and it changed my health immeasurably! The MLM was the key to making the drainage

of my leg much more functional.

Now getting back to aftercare. When I took the LDT classes, and during my time as a teaching

assistant for the courses, I noticed a somewhat reoccurring topic. Quite a few massage

therapists were debating whether or not to continue through the coursework and complete their

LLCC certification. Because Medicare does not reimburse for lymph drainage therapy (LDT)

given by a massage therapist, they did not see the point in pursuing this avenue. I must tell you

that I was very distraught in hearing this. It is vitally important that we have as many therapists

as possible educated in the treatment of lymphedema. I have explained to these therapists over

the years that even though Medicare may not pay you for LDT treatment, there are lymphedema

patients out there who need your skills and will pay you out of pocket for them. I am a prime

example of this. The person who has helped me the most in taking good care of my LE is a

massage therapist. While she is not trained in the Chiky LDT method, she is a Vodder trained

therapist with 25+ years of experience treating LE. She has taken some of the Chikly coursework

in addition to Vodder, and uses the manual lymphatic mapping skills in her practice. Her

clientele at one point were exclusively people with lymphedema. I want to assure you that you

will have the caseload you need, and that these people will seek you out for your specialized

skills. Medicare only allows a limited number of treatments for LE, and once that’s used up,

patients are left hanging. I cannot emphasize enough how important it is for us to have highly

trained and knowledgeable professionals who can help us take care of our lymphedema for the

rest of our lives.

While this path has not been an easy one, I have learned an enormous amount about myself, and

have met some incredible therapists along the way. I realize it is critical for me to continue being

diligent with my self care, and treatments for my LE. This is the only way I can insure my long

term health. My hope is that those who are considering continuing on and completing their LLCC

certification will do so, for all of us out there with lymphedema who need you!