

## Patient Review of The Spring 2017 Conference – with thanks to Donna Adams



"I just love to dance.

Would you believe I once had body issues and felt ashamed of my body?" "I have always had chunky lumpy bumpy legs and a big bum whilst having a much smaller upper body. At one point, I was a size 10 top and size 24 trousers. I went to every diet club possible, dieticians, and GP appointments for 20 years but never got any answers. People just kept telling me to diet and exercise more but I was already doing that! I felt like nobody believed me. And my body had started to cause me immense pain. I feared for the future. The biggest blow was being refused fertility help and not being allowed to apply to adopt because of my high BMI. I ended up signed off work with depression and anxiety. It was during that time that I first heard about Lipoedema.



Claire Tickle (famous Lipoedema sufferer) was being interviewed on a TV programme and as I watched it, I had this overwhelming feeling of 'this is it, this is me.... this is what is wrong with me!!!!'...A light bulb moment....

After years of wondering what was wrong with my body and getting nowhere, I finally saw a woman on TV with legs exactly like mine.

I researched the condition on the Internet, contacted Talk Lipoedema, and asked my GP to refer me to my local Lymphoedema clinic for diagnosis

That was exactly one year ago. What a year it has been since then!

I have always been active. 12 years ago I discovered belly dance and it has been my passion ever since. However, I would never perform. I would do everything else in the background. I would make teas, sweep floors, help with costuming, transport, taking photographs etc.

I would do literally anything but dance in front of people. This was because I felt ashamed of how my body looked and the judgments that people might make. It has deeply hurt me over the years that I dance, swim and exercise but sadly people assume otherwise. I felt like how could I possibly reveal my body and dance in front of people so I hid myself away.



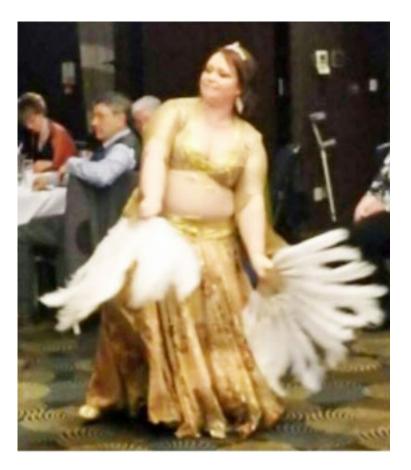
With my Lipoedema diagnosis last year, came freedom - freedom and acceptance of my body. I no longer feel self-guilt or loathing. I understand why my body has developed into the shape that it is and I also now accept that I can do very little to change my lower body. I came to a realisation that I had been putting life on hold until that perfect moment came when I had lost 7 stone and

with my diagnosis of Lipoedema, I finally decided that there was no point in putting life on hold anymore.

That perfect moment where I would be slim and all my troubles would supposedly disappear was never going to be a reality. It no longer became important to me. What became important was trying to be as healthy as I possibly can within the limitations that my body has given me. Wearing compression to support my legs and lymphatic system etc. And also psychologically, I want to be able to really live my life NOW!!!!

After years of stopping myself due to how I felt about my body and being scared of what people might think or say. So, I made a conscious decision that I was going to wear bikinis on holiday, buy clothes that weren't black, not feel embarrassed about wearing leggings outside of the house and to dance as much as I possibly could. I began dancing in public with my belly dance class and friends.

Something still held me back from performing solo, despite people pushing me to do so.



"It was a huge privilege to be asked by the charity TALK LIPOEDEMA to perform and to also teach a few belly dance moves at their Spring Conference 2017"

I had been chatting on the Talk Lipoedema Facebook chat group when I started to mention my hobby of belly dance and post photos of me in costume. The response was incredible in that it seemed to really inspire women. It's such a shame that women with Lipoedema often feel unable to join a dance class or go swimming, because they so often feel ashamed of how their bodies look, or what other people will think.

I have found the belly dance community to be very body positive. It's a place where different body shapes are celebrated and having curves and a bit of wobble is actually an asset and admired. It has helped me feel comfortable and accepting of my body. In fact, it has even helped me find pleasure in my wobbly bits. In the Western World, we are mostly taught as women to try to eliminate any wobble, hide it, disguise it, wear shape control underwear etc. Middle Eastern Dance is incredibly liberating in that it doesn't suffer those same body hang-ups. In fact, the more wobble, the more of a cheer you are likely to get from your audience!

It was a huge privilege to be asked by the charity TALK LIPOEDEMA to perform and to also teach a few belly dance moves at their Spring conference 2017. Of course, I was nervous but how could I say No?! Talk Lipoedema has helped me immensely with learning about my condition and coming to terms with it. I have made so many new friends via Talk Lipoedema and the support that they offer is incredible.

I also knew that this was my moment to show other women with Lipoedema, that they too could glam up and shake their thing! We have been given the bodies that we have and all we can do is make the most of it, look after them to the best of our ability but not let our condition ruin our lives and prevent us from really living life to its fullest. I was right... it was an incredible audience to perform to! So many smiles..... Not only did I thoroughly enjoy myself but it has also boosted my confidence too.

For me, the most special moment, was actually teaching some moves from the stage. I had made sure that a lot of the movements were arms or upper body because some of the attendees at the Talk Lipoedema conference had limited mobility. As I taught some arm movements, I looked out into the audience and I saw so many people joining in, they all had big smiles on their faces. It meant the world to me. It really was a privilege to be able to share the happiness that dance gives me and see it on the faces of those participating or even just watching....

In the evening, I performed a feather fan dance to Diamonds are Forever. A kind of burlesque belly dance fusion to 'I Put a Spell on You' with feather boa and then a more traditional veil dance and drum solo. Then I got everyone up dancing and jiggling about with some coin hip belts.

The theme of the conference was 'Living To Your Full Potential'. I hope I lead by example, inspiring others to accept their bodies and not hold back. And if you fancy joining a dance class, go on..... Give it a try!"

More exciting news from Donna arrived the day after she provided PhysioPod with this review.. "Mary, an incredible thing happened yesterday, I had written a complain/feedback letter to my GP to tell her that I was really upset that she refused to refer me for diagnosis and treatment one year ago. My GP initially sent me away and told me to diet and exercise more. Hubby came back to the surgery with me and we saw another GP who eventually agreed to refer me to the lymphoedema clinic. I wrote and told her how I had now been diagnosed with Lipoedema and Lymphoedema and that I need to wear daily compression hosiery. The clinic has also written to her to explain this and that I can't reduce my legs and BMI with diet and exercise. Anyway, I got an apology letter from the GP yesterday and she has done Lipoedema training, is going to roll it out to the rest of the GP practice and asked if I wanted to put some Talk Lipoedema leaflets in the waiting room. I am gob smacked!"