

Hi I am Jo,

As June is Lipoedema awareness month I thought I would share my story.

Lipoedema is a chronic condition that causes fat to accumulate below the waist, often giving hips, buttocks and legs that are out of proportion with the upper body. It is related to a major hormone event like puberty, pregnancy and the menopause. It runs in families and I recognise that I have the same body shape as my Aunt and Grandma on my Dad's side. I also have Lymphoedema swelling in my legs (fluid retention).

When I first received my diagnosis I was very relieved. It wasn't my fault, I have a body that is programmed wrongly and stores fat in a very strange way. The reverse side of this was that lipoedema was here to stay! Although intellectually I already knew that no amount of dieting or exercise makes any difference – there was always something at the back of my mind that said – you will sort this, you will just need to be more focused on getting 'it' right, or 'it's my own fault because I wasn't doing 'it' properly (even though I didn't really know what 'it' was). Emotionally that is very difficult as I am a doer, a problem solver, a fixer, and I can't fix myself.

I now know that my huge legs and the oedema (swelling) and the reduced mobility isn't going away and that I'm going to need a lot of determination to prevent it getting worse.

My day to day challenges are quite varied but here's a few things

- **People think I am fat** (of course I am I have a genetic fat disorder!).
  - Body image is a big deal today. Some people and some health professionals in particular make an immediate assumption that I am obese and that I am incapable of eating healthily, that I cannot / do not / choose not to follow instructions regarding healthy eating and exercise. Even when provided with a full explanation of what lipoedema is (and trust me I am very happy to explain!) there is almost always an inappropriate comment that slips out, like lose some more weight or exercise more, or just eat less and the weight will come off!
  
- **The world is not designed for me**
  - Seats are too small (especially if they have arms) and usually very uncomfortable. This is a big deal, restaurants, toilets, airplanes, cinemas, buses, trains, most places really.
  - Buying size 8 eee wide shoes that have a decent arch support that I want to wear is challenging to say the least.
  - Buying clothes that fit rather than I want to wear
    - Wide leg trousers that are not wide enough
    - Plus size AND tall – hello clothing manufacturers I am not the only one who needs this.
  - Pants – that's another story all together.

- **Tired**
  - I can't remember the last time I didn't feel tired, I just exist with varying degrees of tiredness which varies from ok and functioning to I am sooo tired that I can't think any more and I need a nap ( bit like a mobile phone that needs its battery recharged).
  
- **Getting on and off the floor**
  - I can, but it hurts my knees going down and it's easier to have something to hold on to, to get up. This was something I have always taken for granted, and is one of a number of things that I no longer find easy to do.
  
- **Some days my mental body image doesn't match with the image of me in the mirror.**
  - I try not to look in the mirror anymore as most days I don't like what I see. That is a tough statement to write but true.

So this is a glimpse into me and my world. I know I am not alone in having challenges in my life. Many of you reading this will be dealing with issues that aren't general knowledge, or immediately apparent, that has the potential to impact on your mental health.

If you think you might have Lipoedema, there is a support group that meets at Shuttlewood Clarke Foundation, Ulverscroft Manor, Priory Lane, Ulverscroft, Leicestershire, LE67 9PH, on the third Thursday of each month. For more information please contact Kathleen Wass [kathleen@shuttlewood-clarke.org](mailto:kathleen@shuttlewood-clarke.org) 07860 639693.

We would love to meet you.

If you want to find out more about Lipoedema click the links below



[www.lipoedema.co.uk](http://www.lipoedema.co.uk)