

You CAN Feel My Pain

for Lipoedema Sufferers

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I have Stage 2 Lipoedema with multiple connected issues. The other day I was in pain. I said to my husband I needed to sit down because my legs were killing me, I had stood up for over two hours, and not being unconcerned he acknowledged my request but kept on doing what he was doing for another half hour. I thought to myself if he could only feel my pain he would know when I say I need to sit down I need to sit down right now!

That got me thinking. How can someone feel someone else’s pain?

I went on a search looking for answers and all I could up with was Numeric rating scales, simply asking someone on a rating scale of 1-10 what is your pain score? This is not the most accurate way to assess someone’s pain. We all have different pain thresholds and pain can be niggly, sharp, pulsating, dull, and achy, to name a few. I was asked to rate my pain level when I was having my son, they asked me to compare it to giving birth but I hadn’t given birth before and I had a “C” section when I did give birth, so I still haven’t technically, “Given Birth” instead my pain on that day was due to gallstones.

Even in modern medicine today there’s still no real way of feeling someone’s pain. A scan might show a broken bone and yes that would cause pain but I do know of people who have had broken bones and didn’t know it.

When seeing new patients in my clinic with Stage 1 or going onto early Stage 2 Lipoedema they may have bruises on their legs and arms and have no idea how they got there, so no real pain at the early stages. If someone sharply poked their limbs it would cause pain but not the pain experienced in later stages of the disease. I too didn’t have any pain in the early stages and didn’t really understand when later-stage patients complained of pain but since going through menopause I now understand the pain. It is a constant dull ache that considerably increases over the day and can take many hours of elevation and massage to only subside slightly but never really going altogether, even when I go to bed it is still there. It always feels like “Groundhog Day”.

So how can people feel and understand our pain?

After massaging my legs I noticed on either side of my shin bones there are many lumps, around the size of currents-sultanas, then under and around the backs of my knees, in lines, often described as “Strings of Pearls”, similar to large, lumpy varicose veins but not noticeable like varicose veins, more lumps the size of sultanas. As I progress into my thigh area and rake up with my fingertips there are more lumps, all over this time, not in lines. I can feel these lumps in my abdomen and in my arms. This isn’t congested Lymph Nodes as once you massage them they will start to reduce in size. These lumps are thick and fibrous.

When patients have had weight loss surgery they often comment their Lipoedema has become worse but in fact when they have had the surgery they may lose some of the regular fat which then exposes the lippy fat underneath, similar to a stone aggregate driveway.

We can see on ultrasound imaging these “lumps”, we have seen the pictures taken when the fat has been excised during surgery but seeing is not feeling, so what did I do?

I got my husband to feel my legs, I guided his hand from the shin bones to the back of my knees, up the back of my legs to the fronts of my thighs, my abdomen, and lastly my arms. He was very surprised at all the lumps and asked “What are those” and my reply was “This is my Lipoedema!”

He now has a grasp of what is sitting in my body which presses on nerves and creates pain. What I now intend to do and I will ask everyone who reads this article to do is to get their partners and mostly Doctors to feel their “Pain Nodules” and to try to truly understand that our “Fat” is different from just plain old obesity fat.

The key is to catch this disease early and teach about how to keep these “nodules” soft and to a minimum, because once they get fibrous and solid there is no way of breaking them down or removing them in total and the progression of these nodules causes the immobility I constantly see in later stage patients.

Go forth and get them to actually feel.

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