

LYMPHOEDEMA IS PART OF WHO I AM

Lindsey Summerhill

In 1999, when I was 19 years old and in my second year of university, I remember standing in the living room saying to my housemates, 'Do my legs look swollen to you?' They agreed they did look a little swollen but we did not know why, so left it there. A few months later I moved to Reading to carry out my placement year for my third year of university. This meant for the first time I had a 'proper' office job. I very much enjoyed my job and was learning lots of new exciting things, however, there was something which appeared to be bothering me during the day at work and that was my legs.

I was concerned about my legs, how they were feeling during my first office job — the heaviness and pain — and so asked the women in my office for their advice as to why they thought I was getting swollen legs. They said it could be due to sitting down all day or water retention. As a perk of the job, the company hired a reflexologist to come in for the day so we could all have some treatment. As I had never had this before I signed up for a session. The lady worked her magic on my feet and at the end asked if I had trouble with the circulation in my legs. I said, 'no, not that I was aware of', as I did not put two and two together about suffering from swollen legs. The lady said that I should keep an eye on it as she had struggled to get my feet to warm up and could feel something was not quite right. I just thought, 'oh yeah, I bet this reflexology lark is all a myth!' I couldn't have been more wrong.

Lindsey Summerhill is 28 years old and suffers from primary lymphoedema

For the rest of my placement year I struggled with my legs at work. They were fine when I woke up but as the day went on and I sat at my desk they became heavier, more swollen and painful. By the time I got home, my legs were really hard. In the evening I used to sit on the floor and elevate my legs on the sofa, as this relieved the pressure for me and it felt as if all the fluid was flowing back down my leg to where it was supposed to be.

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When I returned home for a visit, my mum and I agreed this was not normal. So, off to the doctors we went. I was fortunate in that my GP diagnosed my condition straight away, and it did not take years for someone to realise that I had lymphoedema. However, surprisingly, they did not offer me any support or treatment and when we asked why I had this condition and what could be done we were told that I was either born with it, had a tumour, or had an infection which caused it. The GP said there was no cure for the condition and that was that. When we got home, confused and upset, we started researching on the internet — all that stuck in my head was the reference to the tumour... did that mean I had one?

We decided to get a second opinion from another GP. The second GP was very sympathetic and agreed with what the first had diagnosed, but could not refer me anywhere as I was not her patient. I wrote a letter to the first GP explaining my concern over the tumour and how I did not know what to do. We went back to see her and I wanted to know if there were any tests I could have and how I was supposed to live with this condition — the images we had found on the internet were the worst case scenarios and did that mean that was what my future held? She said she would refer me to our local lymphoedema clinic but did not see the point in having any tests as she was convinced as to what my condition was. However, the waiting list for my local clinic was nine months. How could I wait that long with all these questions and worries in my head? My parents paid for a private appointment and I saw a lymphoedema consultant. He allowed me to have the tests as an NHS patient and I was put on the waiting list.

In the meantime, my friend's boyfriend was studying to be a doctor at university and he had just written a report about lymphoedema, which she gave me so I could learn more about the condition. After I had had all the necessary tests to diagnose the condition, I went to see the consultant for the results. He said all the results had come back normal which confused me even more. He said that sometimes if they came back normal that also meant you had lymphoedema, which made no sense to me whatsoever. Then he had the cheek to say, 'Well I don't know what else to say, your tests are normal and

sometimes people just have chubby ankles.' I was shocked that the one man who I thought was on my side and knew what my condition was dismissed me in one sentence and made me feel like a fake.

Luckily for me, my appointment with the lymphoedema clinic came up and I went for my first appointment. What a saviour St Oswald's Hospice is. The nurses there were supportive, sympathetic and took the time to explain things to me. I was fitted with my first set of stockings. They were knee-length stockings and an horrendous beige colour. I started wearing them and they were incredibly itchy. My knees started to swell, so I was then fitted with full-length stockings, these were even itchier. Needless to say, they made me feel unattractive and totally different to everyone else. By this time I had returned to my fourth year at university. It was a stressful time with a great deal of work, and I was coming to terms with my condition.

I was now 21 years old and had to wear these horrendous stockings for the rest of my life. I felt so alone as no one knew how I felt, and it sounded vain when I tried to talk about it. I would never be able to wear skirts again, I felt frumpy and unattractive, what boy would ever want to go out with me? What happens if the condition gets worse? Would I be able to have children? Although people tried to understand, I did hear a few times, 'Well it could be worse, at least you don't have cancer.' Which is true and, of course, I was grateful for that, but being a young female, body image seemed to outweigh how worse off others were... this was my life and my problem seemed the biggest thing to me.

I kept up my appointments at St Oswald's and the nurses were still great but there never seemed to be any time to talk about how this was affecting me emotionally. I went to our local support group but I was disheartened by this as all the members were a lot older than me, which made me feel even more alone,

as if I was the only young person in the world who had this condition.

I rebelled against wearing my stockings and only wore them for work, taking them off as soon as I got home and not wearing them at weekends. I was only hurting myself and causing myself pain, but I just wanted to be like everyone else my age.

The years went by and I started to come to terms with it a bit more. Then, out of the blue, I met my boyfriend. We went on a few dates and I did not wear my stockings as these made me feel unattractive, but then I thought if this is going to work, I need to tell him. I plucked up the courage and told him about my condition and that I needed to wear stockings every day. He looked at me and said, 'So what, it doesn't bother me. I like you for who you are, and that is all of you.' I could not believe what I was hearing. Well, if he was not bothered, why was I? He made me realise that it was just a part of who I am and that I should just accept it, instead of fighting it. He also told me I had to wear my stockings all the time as he did not want me to be in pain, especially if I was not wearing them just around him. I started to wear my stockings all the time as I was meant to and, my goodness, what a relief. My legs did not hurt as much and felt really supported.

I then started getting complementary therapy from St Oswald's and this was such a blessing. Not only did it help with my condition, but the therapist listened to all my thoughts and emotions, so I was able to get my concerns off my chest without being judged or being told 'it could be worse.' I then also paid for reflexology and, again, the therapist was amazing and she helped balance out all of my body.

I have now been with Richie for four years and we are getting married in November 2009. He has a daughter, who, when I first met her, asked a lot of questions about my stockings and why I had to wear them. She even



Figure 1. Lindsey and Richie at their engagement party in January 2009.

commented on how she had never seen me in a skirt. But now, she too just accepts that I have the condition and putting my stockings on in the morning is just part of my daily routine and it is just part of who I am.

About 18 months ago I was reading *Lymphline* magazine and there was a letter from a 26-year-old girl who also had primary lymphoedema and wanted to speak to someone her own age. This took me back to how alone I used to feel and wished there was someone my age I could talk to. This inspired me to set up a group on the social networking site Facebook to bring together all young people who suffer from the condition to talk about their experiences, concerns or just to meet people in a similar situation. Any age are welcome to join. All you need to do is visit Facebook and search for my group which is called 'Lymphoedema is part of who I am' or a direct URL to the site is: www.facebook.com/group.php?gid=15969030292&ref=ts.

I am so pleased to say that 18 months on my group now has nearly 300 members who suffer from lymphoedema from all over the world and of all ages. We all share our experiences and chat about our condition. I set up the group to encourage people to join, so we can unite and all say loud and proud: 'Lymphoedema is part of who I am.'

It has taken me a few years, but now at the age of 28 and thanks to my family, Richie and St Oswald's Hospice, I have learnt to live with my condition instead of fighting against it. JL