Living with lymphoedema: Maria Boyle shares her story

Maria Boyle works in science but is best known as the cartoonist and illustrator Twisteddoodles. She is a regular contributor to New Scientist magazine and lives in Dublin with her husband and twin girls.

How long have you had lymphoedema?

I developed secondary lymphoedema when I was 15, now over 25 years ago. The lymph nodes in my groin had to be removed because malignant melanoma had spread to them. I was informed lymphoedema was a risk of the surgery, so when my leg started to swell, at least I knew why. Although the lymphoedema developed quickly post-surgery, it was then stable for several years. I was given compression at the time but felt it was more trouble than the mild swelling, so I didn't wear it. That changed last year when I visited a lymphoedema therapist for the first time as I felt my swelling was not resolving as it previously had. I thought that she could just give me a massage and fix me, but instead she told me that my condition had progressed and that I had hardening of my tissues (fibrosis) and thickened and scaly skin (hyperkeratosis). She advised that I start wearing compression and all I wanted was for her to be wrong. The last 6 months or so have been trying to fix myself before finding acceptance and adapting to looking after my lymphoedema properly.

How do you manage it on a daily/weekly basis?

I went from not wearing compression at all to wearing compression almost all the time. It was not an easy transition.

For a routine, I put on my compression garment before I get up in the morning. I wear thigh-high compression class 3 (34–46 mmHg). I use gloves which are not unlike gardening gloves to adjust the stocking and make sure it doesn't bunch up at my ankle or behind my knee. I can't lie that in the evening, when I get home from work, I can't wait to take off my compression.

When I remove it, I generally wash my leg using a skin-friendly soap and moisturise my leg before putting on my evening compression garment that is comfortable to wear, and which helps breakdown fibrosis.

Activity

I like to keep active and walk a lot. If I'm sitting for a while I get up and move around, as activating my leg muscles helps to pump the lymph around. I have started using a vibration board, something I had seen mentioned online related to lymphoedema management. I do not know if it improves my condition, but it feels good after a day at work. However, I don't know how much I could recommend it. The other thing I do is use my stockings in a wear one, wash one daily rotation. I was washing them in a washing machine but now I handwash them. All of this sounds like a lot but the more I do it, the faster I get and I know the benefits will last throughout the day.

What do you find the most helpful treatment?

Compression. Always compression. I've tried loads of different things and for me, at the stage that I am at, compression is now the biggest part of it. In particular, compression that helps to reduce my fibrosis as well as swelling.

What do you find hardest about having lymphoedema?

It is expensive, and there is not as much help with it as I would like. It can also be incredibly time consuming.

The hardest part can be the emotional toll as it can be quite frustrating and isolating. People look at my leg and go 'oh there's not that much of a difference' but is that what they would want for themselves? It's easy to say that when it isn't you. Sometimes I have intense body dysmorphia about my condition, sometimes I think my leg looks huge, other times it looks almost normal even though size wise it might be the same.

Earlier this year, when things got worse, I found myself obsessing over my condition, it took up so much head space and I would feel myself spiral a bit with it. Now I repeat the mantra 'I am doing my best' to myself because I am, I am doing all these things and I'm really trying. Someone recently told me that having a body is like owning a house, sometimes you'd like to fix it but mostly you will do a lot of work to just maintain it as it is. If I'm able to stabilise my condition, even if that is a lot of work, it's work well spent.

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