

NON-COMPLIANCE? IT'S EASY FOR YOU TO SAY...

Liz Dart

Recently, I was delighted to receive an invitation to attend the 20th birthday celebration of the Lymphoedema Practitioners Education Group of Victoria (LPEGV), which I gladly accepted, looking forward to catching up with some old friends from my time with the Lymphoedema Association of Victoria (LAV). I was not disappointed. It was a great evening, with the highlight being the address by the guest speaker, Professor Neil Piller:

I have listened to many of Professor Piller's talks over the years and he never fails to inspire me. My first encounter with him was well over 20 years ago, when I was first attempting to get a diagnosis for my 'swollen' legs. As is common to most 'lymphoedemics', I was finding it difficult to get help and had been referred to a plastic surgeon who then referred me on to a vascular surgeon, thankfully before operating on me.

The vascular surgeon sent me for lymphoscintigraphy and my lymphatic function was found to be within normal limits, although it was abundantly clear that this wasn't the case. However, the vascular surgeon said that there was nothing he could do for me. He did, however, have a pamphlet about the newly formed LAV in his waiting room.

This proved to be my salvation. I found out that a certain Professor Piller from Adelaide was lecturing at a local seminar the very next day. I attended the seminar and was surprised to find that I was in the company of about 300 others who had similarly swollen limbs.

Professor Piller's talk was inspirational. It all made sense and was a moment of huge enlightenment — a real 'road to Damascus' experience. Here was somebody who knew the answers to

our questions and made us feel that we weren't freaks after all.

I joined the LAV on the spot. My newly appointed therapist obtained my lymphoscintigraphy films and sent them to Professor Piller who confirmed that I really did have very poor lymphatic function, resulting in lymphoedema. This came as no surprise to me as I had a family history of it, although it was referred to under different names at the time — elephantitis being one.

I served as Secretary of the LAV from 1994 to 2001. In this role I received countless phone calls from others trying

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to find information about this condition, the details of which eluded most medical practitioners. You could always tell if you had somebody enquiring about it on the phone — there would be a stuttering introduction, followed by: 'I'm ringing about limpa ... limba ... lymphoma ... dermia.' Some even commented on their symptoms, one man saying: 'One of my legs is like an elephant's, what's wrong with me?'

The LPEGV had compiled a list of qualified people who were able to help and I was able to refer these callers on to clinics or therapists in their area. When they realised that they were not alone in their quest for assistance and that an end was hopefully in sight, their relief was palpable.

So, back in the present, you can imagine my delight when on opening the invite to the LPEGV birthday party I discovered that the guest speaker

was Professor Piller and that his talk was entitled 'Directions and deviations — a long and winding road to good outcomes for lymphoedema.' I settled back to enjoy the talk — it was a familiar journey — but it didn't take long before I became disconcerted by a word that kept cropping up with regard to the success or failure of individual cases. That word was 'non-compliance'.

It gradually dawned on me that this was something I had been guilty of. It was sobering to think that some 30 years after my initial diagnosis I am still a lymphoedema 'sufferer' (for want of a better word) partly because of my own non-compliance.

At home I consulted my thesaurus and found that non-compliance was variously described as disobedience, rebelliousness, refusal, non-cooperation, and non-conformity. These were certainly characteristics I recognised in myself!

Why do I fall into this category?

I will never forget the time when, after undergoing a course of bandaging and massage in hospital, and achieving a 'good outcome', i.e. a large reduction in the size of my legs, I was confronted by my therapist (a woman who was one of the best in her field and whom I respected enormously) brandishing my newly ordered compression garments, which she informed me I would have to wear for the rest of my natural life.

They bore a startling resemblance to the 'chaps' that cowboys used to wear, but with feet. They were stiff and came equipped with long, even stiffer lengths of wide Velcro, which I was supposed to wrap around my waist to keep them up. All in all they were a frightening sight, but had been custom-made for me at huge expense.

After a struggle, and with my therapist's dextrous use of rubber gloves,

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my lower half was encased in these monstrosities, and I was off home. Almost immediately these truly awful stockings started to creep down my legs until the crutch was near my knees. The result was a discomfort unlike anything I had previously experienced. I refused to go out in public and spent much of the next few weeks in tears. My first episode of non-compliance started there and then.

I live at the beach and one of my chief delights is the early morning walk. But have you tried walking on the beach in compression stockings? It's near impossible. But what are you supposed to do? Avoid exercising? No — go for your walk, come home, have your shower and then put your stockings on. This was the root of non-compliance episode number two.

In time, the unwieldy and hugely expensive chaps were replaced by thigh-high stockings, again custom-made for my different-sized legs. However, problems in keeping them up persisted. Difficult as it is to believe, in those days the solution was roll-on glue — do I really need to tell you just how painfully ridiculous this was? So, onto non-compliance episode number three.

After all these horrible experiences, my question now is, are there any therapists who have lymphoedema themselves? Does anybody else out there know just how awful it is to wear compression garments when the

temperature exceeds 30 degrees and you find yourself spending hot days lying on the couch in front of a fan.

Over the years I have experimented with many of the things Professor Piller mentioned in his recent talk, but, I am at the age where I simply am not prepared to give any more of my time, energy and money to this disfiguring condition.

Rebellion

As a long-standing lymphoedemic I'm a past-master at rebellion. I've spent much of my life rebelling because I can't find fashionable boots to fit my large legs and have to wear trousers because I'm acutely aware that people stare when I wear a skirt. Luckily for me, harem trousers were fashionable in the '60s and straight-legged trousers have recently made a comeback.

After so many years of trying, I have come to the conclusion that it is impossible to find a compression stocking that is comfortable. Surely, someone somewhere should be able to manufacture something that doesn't cut in to your skin at the joints. Even now, I have to strap old shoulder pads on to my ankles before putting on my stockings, simply to get through the day in relative comfort.

Custom-made garments are improving but are very expensive, so although I know better, I darn the holes and wear them past their use-by date. I certainly


can't afford the option of wearing one pair while another is being washed.

Here in Australia, my private health fund in no way covers the cost of podiatry and a monthly massage and I get absolutely no assistance with the cost of bandages, tape, etc.

I lead a full and active life, although I remain disillusioned that nobody has been able to come up with a better and more permanent treatment for lymphoedema than the current regime of compression garments, massage and bandaging.

However, I think I have come up with the solution. Perhaps it's time we stopped trying to work out how to anastomise lymphatics — it doesn't seem to be getting us anywhere.

Instead, we should be researching a spray-on compression garment! This could revolutionise lymphoedema treatment as we know it. Imagine being able to shower and then spray on a skin-like, breathable substance, which would shrink as it dries on your body and provide appropriate compression for the limb. Removal would be easy — simply peel it off or wash it off with soap. There would be no tedious holes to darn and it would also be a boon to those of us with arthritis who struggle to pull garments on and off.

So, my message to Professor Piller is, 'Get working on it and please forgive my non-compliance. I have my reasons!' 

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