

# Understanding the differences between lipoedema and lymphoedema

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## Key words

Lipoedema, lymphoedema, misdiagnosis

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## Abstract

An incorrect diagnosis can be a significant event for the individual. Money will be wasted on wrong or poorly targeted treatment, relevant interventions will not be put in place, and there will be a detrimental impact on the person's quality of life. This is my story of a misdiagnosis and what it meant for me as I progressed through 30 years of my life. It is easy to misdiagnose if a clinician does not have the experience or expert knowledge, but it can be highly significant for the person living with the misdiagnosis.

For the past 30 years, I believed the condition resulting in my heavy and misshapen legs was lymphoedema, as this was the diagnosis I was given in 1979 when I was 34 years old. It was not until 2 years ago that I received the correct diagnosis, and this has improved the quality of my life immeasurably.

How did I learn 2 years ago that I had lipoedema? Significantly disabled, I needed to have total knee replacements, yet I had been told in the past I should avoid these at all costs as such operations would only make my lymphoedema more widespread. On the advice of my local lymphoedema management professional, I made an appointment to see another specialist in this field to seek their opinion. As soon as he saw my legs, he said: "That's not lymphoedema; it's lipoedema".

Piller's manual on lipoedema (2009) states: "Lipoedema is a chronic disorder (some might call it a disease) of fat metabolism and distribution which is characterised by its symmetrical distribution normally between the top of the pelvis and the ankles with an appearance similar to jodhpurs."

No one is particularly clear about the aetiology of lipoedema and the incidence or prevalence of lipoedemas. However, some studies have indicated that the condition mainly affects women and the legs.

Why did I carry that misdiagnosis for so many years? There are number of reasons for this, the first being that I did not question it, and nor did my doctors when I told them I had lymphoedema – they assumed I knew what I was talking about. This is patient empowerment in one way, but what if the diagnosis is wrong, as in my case?

Essentially, there was very little known about lipoedema 30 years ago and, even today, I know from other stories that the condition is commonly misdiagnosed as lymphoedema. However, it is surprising these two conditions are confused as there is a range of differences between lipoedema and lymphoedema. Once clarified, it is obvious they are different, as shown in *Table 1*.

This comparison makes so much sense to me, particularly the fact that the feet are not affected. I used to sit in lymphoedema meetings and look at the feet of others and wonder why I was so lucky that mine were of a normal size. Now, of course, I know why.

Perhaps you also have lipoedema, and not lymphoedema, or perhaps you are a clinician now thinking a little more about the differences between the two conditions. I am advocating that any person with a suspicion they may have lipoedema seek an immediate diagnosis and/or a second opinion so that they do not have to experience what I have had to.

I regret that, although I have had this condition from birth (it is genetic), I have only recently learned that many of the treatments I endured in the past were totally inappropriate. For example, I always complained about the cruelty of compression garments, and now I know they are not best used for lipoedema (except for light garments when flying).

I had always wondered why I could not keep weight off and this, as it happens, is one of the most important aspects of managing lipoedema. Excess weight should be avoided by reducing calories and avoiding long chain fatty acids. As soon as I changed my diet, my weight started to reduce and I am now about 20 kilograms lighter than I was prior to the diagnosis and intervention.

There is another important reason for early diagnosis and treatment, which is to enhance normal socioemotional growth. Let me tell you about some experiences I had as a younger person with "big" legs.

I was in my first year at high school and it was the class photo day. Against my unexpressed will, I was made to sit on the front row, so I pulled my uniform down as far as I could to hide my legs. Later, some mothers complained that I should have been at the back where my legs were not on show as, according to these women, I had ruined the photo. And, yes, these comments did hurt me at the time. A few

**Table 1.** Differences between lipoedema and lymphoedema

Lipoedema	Lymphoedema
Soft pliable skin (although some elasticity may be lost)	Harder thickened skin (especially in the later stages)
Tenderness of the skin	Skin not usually tender
Always bilateral (both limbs)	May be bilateral (primary lymphoedemas) but generally unilateral
Usually symmetrical (both limbs)	Usually asymmetrical
Can pick up fold of skin at base of toes (negative Stemmer sign)	Cannot pick up fold of skin at base of toe (positive Stemmer sign)
Feet not affected	Feet often affected (oedematous)
Affected tissues bruise easily	Tissues do not usually bruise

years later, my mother took me to the doctor and mentioned she was concerned that my legs were getting bigger. The doctor told us there was nothing that could be done about them and that I would just have to develop a good personality to compensate.

Perhaps the most critical event occurred when I went to a teacher training college in Dunedin, New Zealand, in the mid 1960s. By this time, I was about 20. Not long after I had started there, I found a message on the noticeboard asking me to see the Dean. She told me I could not possibly hope to become a teacher with such enormous (this was the word she used) legs. I was devastated as this was my chosen career. I agreed to go to undergo physiotherapy, jog, and have medical

tests, in an effort to lose the bulk from my legs. I did all of this to remain at college, and indeed, I lost a lot of weight and developed quadriceps you could strike a match on, yet the circumference of the offending parts of my legs did not budge. After a year of this regimented life, the Dean allowed me to finish the course, but warned me I would be the butt of much cruelty from students.

To a degree, the Dean was right. But I recalled the doctor’s advice and realised I would need to establish graceful interactions with my students. I know “gracefulness” is not a word commonly used in matters pedagogical, but I tried this approach and still use it. One parent told me in my second year of teaching that his daughter (I can still see you, Erin) went home one day well into the first term and said: “Miss Slee has really big legs, but do you know what, they get smaller every day.” These were the days when women teachers were not allowed to wear trousers so there was no hiding any physical imperfections.

However, I must admit that I can remember once when I was less than graceful professionally. I was employed as an itinerant teacher of children with behavioural disorders in Sydney, Australia, during the 1980s. This meant going into a great number of different schools. On reflection, I know that I always carried the expectation that I would be a target for taunts – and I was. I was normally able to ignore any derogatory comments but one day, enough was enough. A slobbish-looking boy about 10 years old called out “hey, elephant legs” as I walked passed him. I stopped, grabbed him by the

elbows, stared straight into his eyes and hissed: “Listen boy, if I had ears like yours, I would never say anything bad about how other people look!” (His ears were huge – more or less like industrial-sized wing-nuts!) This worked and I unashamedly advise the use of this strategy when necessary.

Apart from contributing to socio-emotional stress, a misdiagnosis can cause physical harm. With the best intentions, I have, over the years, had acupuncture, used compression garments, sun-baked, enjoyed hot baths, and swallowed great doses of strong diuretics. All are forbidden activities for people with lipoedema but, of course, I did not know that this was my condition.

Most importantly, I was advised not to have the much needed knee replacements until a wheelchair was the only alternative, because, as I mentioned above, it was considered that surgery would make my lymphoedema much worse.

**Conclusion**

Now that I have two wonderful new knees and am carrying much less weight, a new life is waiting for me. I have just resigned from my tertiary teaching position and intend to resume travelling the world – a pastime I had really enjoyed until my legs and knees had caved in years ago under the strain.

**Reference**

Piller N (2009) *Recognition, Treatment and Management of Lipoedemas: Information for Patients*. Lymphoedema Research Unit, Department of Surgery, Flinders Medical Centre, Adelaide, South Australia



**Figure 1.** Person with lipoedematous legs.