

The story of my legs — a long and winding road to a good outcome

Manfred Amelia

When I was younger, for many years I suffered all kinds of illnesses, including pneumonia, scarlet fever, diphtheria, mumps and tonsillitis. I never went to hospital — my mum cared for me at home. I think that is why my lymph nodes worked overtime; you can't keep working at 100% all the time without some form of collapse! The nodes in my right groin began to stop working properly.

My mother noticed that my right upper leg was a bit bigger than my left one in a school photo when I was 6 years old. Really, my whole upper leg was slightly bigger. It was quite a worry to my mum, but all the doctors we visited could not give us an answer why that had happened to me.

When I was about 10 or 11 years old, I was very pale and anaemic, and a doctor gave me a course of 12 liver injections to build up my red blood cells. When I received the first one, I fainted. You can imagine I did not look forward to having 11 more. They worked wonders, however! I got my colour back, and never had any more serious sicknesses.

For the next 30-odd years, my upper leg only slightly increased in size. But then in the 1970s, my right ankle started to swell up during the day. It went down overnight, but from day to day, the swelling increased. The swelling slowly progressed up my lower leg and, finally, after about 2 years, I had full-blown elephantiasis as they referred to it at that time. You can get an idea of its size by looking at the top of my leg in *Figure 1*.

I went to many doctors and finally to a specialist and he told me the only way to fix it was to "prune the excess" as he called the operation.

The problem was I am a Jehovah's Witness and could not accept a blood transfusion so the specialist got quite annoyed with me and said nothing can be done for me.

The surgery and infection

In 1975, I was referred to doctor Gwyn Morgan. He told me he could operate on my leg without a blood transfusion. He had performed this operation in England, but it would be the first of its type in Australia. He ordered a special knife from England, which he used to separate the swollen tissue from the skin and underlying muscle.

The operation lasted for 7-and-a-half hours and was performed on my lower leg from the knee down to the top of my foot (*Figure 1*). You can see that all of the tissue above my muscles was removed right down to the muscle and then with the special knife, they shaved some of the skin from what they had removed and grafted it back on to the bare leg muscle. Things went wrong, however. Straight after the operation, I vomited a great amount of blood. An endoscopy showed a stomach ulcer, which now was bleeding badly.

Due to the loss of blood (and the fact I did not wish to receive a transfusion), my toes started to go blueish, so the clinicians had to remove the plaster cast from my leg that encased my skin graft (and stopped any more swelling from occurring). After a couple of days, a lot of the skin graft turned black, which had to be removed bit by bit. Interestingly, it did not hurt as I had no feelings in my leg (I learnt later that all of the sensory nerves were removed when the tissue was removed). In the meantime, I built up my blood cells with iron injections, but it took about 3–4 weeks to fully recover.

The skin graft was still a problem. The surplus skin could not be used after a while, so the clinicians had to take more skin from my right upper leg (in those days, the skin taken was quite thick and left a lot

of scarring). Altogether I had three more operations to take more skin to replace that on the lower leg which had died. This was not a quick process. We had to clear up many infections so the healing process took over 3 months, even in the hospital.

We tried many things to control the infection in the leg. We even used the afterbirth from the placenta of newborn babies to keep the leg moist and help healing. It seemed to work. Dr Morgan then suggested that a solution that I think was either acetone- or saline-based could control the infection. So we bandaged my leg with the diluted acetone solution and it started to heal very quickly and finally we could proceed with the much-needed skin grafts.

After quite a few months, I had my leg pinned up in the air. Finally, once the pin was removed, I could lie down properly with my leg stretched out resting on the bed. Oh what a relief! Two things were a challenge to me, however. Firstly, I had no feelings in my skin grafts as there were no nerves there, so it felt like my leg was always in the air. Secondly, I could not move my leg; it was so long suspended that to try to move it was incredibly painful.

A physiotherapist told me not to worry and that I needed to tell my brain that I still have a leg! He told me I needed to start exercising it. So during the night I told my brain to move my leg. I started wiggling my toes, then moving and eventually lifting my leg. After an hour or so it worked perfectly.

So when the physiotherapist came the next morning, he said "start by wiggling your toes". I quickly told him: "I can lift my leg!" He then said: "No, don't run before you can walk. You have to take it step by step!"

I explained: "No. I can lift it." So I did. I lifted it right up. You should have seen his face! His mouth was wide open. "What did you do?" he asked. I explained how I had moved my leg the night before. You should

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Patient perspective

have heard him: “I am glad that not all my patients are like you; I would be out of a job.” I was very proud of myself. Finally, I went home. It was quite an experience after spending so much time in hospital. The world came alive. The sounds, the air, the birds ... all of the things you take for granted all of a sudden are like new.

Maintenance of my leg

First, I had to keep bandaging a little patch the size of a ten cent coin on my inner ankle. It finally healed up. To maintain general control, I was told that for the rest of my life I have to soak my leg at least once a fortnight for up to two hours in warm water and then my wife had to first rub it hard with her hand and then ‘descale’ it carefully with a small metal fingernail cleaner to remove the soaked loose skin and debris. It is amazing how much skin came off. After the scaling, we brushed it with a soft brush and soap. It always bled in some spots so then we had to cover that with a bandage for a day.

I found and used a variety of creams, but it seemed that nothing worked better than good old Vaseline or petroleum jelly. In my opinion, other creams seemed to have a range of white or coloured pigments in them, which seemed to ‘clog up’ the skin graft quicker and make it appear unhealthy.

Then to gain further control of the upper part of my leg, I had several more

operations. I had three long cuts needing about 100 stitches each, and the surgeons scraped out as much as possible of the underlying swollen tissues above my muscles. These operations were done at three different times and the areas allowed to heal before proceeding to the next operation. I think even in those days we did one trial of liposuction which was not very successful.

So now my upper leg had reduced quite well, but during the following years it slowly grows bigger again and we tried to keep it under control the best way we could by massaging it (at my age, I don’t want any more surgery).

In 1985, I developed, how can I call it, bubbles or nodules around my ankle (Figure 2). I had some of them removed surgically, but they still grew and I had to keep them rigorously clean otherwise the areas between them started to smell.

Finally, Dr Morgan suggested another operation and so the skin around my ankle was operated on to remove most of the old skin graft and put a new one on. This worked well and the pappilomas went.

For all those years and the years since, I kept my leg in what I would call ‘good condition’ with the help of my wife — together we kept soaking, scaling and cleaning it. You definitely need a spouse/partner or committed carer to do this well; no wonder that those who don’t fare poorly.



Figure 1. After the final reduction operations.



Figure 2. Pappilomati on the shin and foot.

New ideas and new directions

In 2007, I developed a small oozing leg ulcer on the right side of my ankle. It grew to the size of a five cent coin and no matter what I did, it did not heal. I suffered for about 7 years and no matter what I tried (be it creams or antibacterials), nothing seemed to work. It appeared that I had no infection in the wound, according to the doctors. But then I noticed something.

Occasionally, I suffered an attack of cellulitis. If it was a mild one, I got away with just taking paracetamol. But if the infection was more severe, I took antibiotics. I noticed that the oozing of my ulcer was reduced, but as soon I stopped taking antibiotics, it oozed again. Of course, since I did not want to take antibiotics all the time, we went back to bandaging again.

Then I had an idea. I wanted to try something unorthodox — my doctor was not too keen on this idea and I would suggest you do not do this without them knowing.

I opened an antibiotic capsule and mixed it with some sterilised water, then added to a cream and applied it directly to the ulcer. Believe it or not, this stopped the oozing very soon, in about a week or so, and not only that; it started to heal and formed a skin. I had to stop applying the paste when I have to soak and clean my leg and that does open up the wound a bit. But when I applied the paste again for a week, it healed and closed the wound very quickly. I did not have any cellulitis attacks for a long time.

But all good things sometimes come to an end. Unfortunately, my little leg ulcer did come back. Again, it is very persistent. I am trying hard and ardently using my antibiotic mix to heal it, but so far it is very stubborn and it won’t heal. I love to experiment though. I’m doing only one thing different at a time so I know what works for me! But what I notice too is that if I put on a couple of kilos in weight, it oozes a bit more!

At the moment, I am 73kg. My ideal weight should be 69–70kg, so guess what I’m up to next? I like my food and my cooking. My wife is a good cook, but because I really love cooking and experimenting with food she is quiet happy to let me do the cooking. Maybe I should only do the cooking and stop the eating!

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