Glenda Outhwaite is a retired Production Manager for a travel goods company.

In this article, the author describes her 15-year experience of living with leg ulcers. She explains the challenges these ulcers have brought in her daily life and the particular problems with pain management she has encountered. The author describes how different approaches to manage these ulcers have worked, and the most successful treatment to date.

Patient story: the challenges of living with a non-healing leg ulcer

My first experience with a wound that never seemed to heal began in 1997. It started as a scratch on my leg that only required a plaster, but it soon became larger and more difficult to dress. This was to be the first of three long-term leg ulcers I developed over the past 15 years. With each ulcer, I have had different experiences of treatment and services, which I will share — together with their impact on my life — in this article.

Impact on daily living
In the years I had these leg ulcers, my life totally changed. My thoughts were always about the ulcer and of where I could go to get help. The ulcers impacted on my social life, as the smell of the wound just before a new dressing made me reluctant to go out or meet people. Cooking meals had to be quick and easy because I couldn't stand for long periods when my leg was painful. This affected my diet and I became anaemic at times over these years. Even simple things like having a shower would become a drama as keeping the dressing dry — using large kitchen tidy bags and elastic — was easier said than done.

The thing I found hardest about having non-healing leg ulcers was how difficult it was to get around. When doctors suggest having dressings changed three times a week, they may not always realise how difficult that can be when you have mobility issues. I was constantly worrying about how far I would have to walk when I got to the doctors, how long I would have to sit in the chair and wait to be seen, and if I would be able to get out of the chair. I also had to walk to the pharmacy for medication. I always said it took me two days to recover from these dressings; so when dressing changes were every second day, there was no time for recovery.

Lastly, after doctor appointments, trips to clinics and battling with pharmacy assistants, the last thing I wanted to do when I got home was clean. Therefore housework suffered and I felt that the house was in a constant state of disarray. After a while this would get me down too; it was just another thing that made me feel helpless.

Finding help
Initially, I went to the doctor for help with my ulcer, and had my leg dressed at the doctor’s surgery. However, after a few months it had not healed, and I presented to the emergency department at my local public hospital because I had just had enough. The hospital doctor suggested scraping back the wound with a scalpel, which I agreed to. During this procedure I was not given any pain relief, and it was so painful that I couldn't face going back for this treatment again. Following this I was always thinking ‘Where can I go to get help?’ I found that having an ulcer took over my life; it was never out of my mind.

One day I heard a talk on the radio about the success one medical team were having using manuka and jelly bush honey to heal ulcers. I started using both honeys straight away but all they did was keep the wound clean, with no sign of healing after three months. I also found applying the honey was extremely painful. I would put the honey on the wound with some gauze over the top and then wrap a bandage around the lower half of my leg. I know not to do that now! The gauze stuck so badly sometimes it would take hours to get it off and it was very....
painful. I used to do this every day. A few minutes after bathing the wound and applying the honey, the wound would be stinging and this would last for up to two hours. After giving up on the honey regimen, I had community nurses attend me for some months. They applied melonin, combine and a securing bandage, but never a compression bandage.

My treatment continued without success until I was seen by a different doctor at the hospital, who knew of and referred me to the ulcer clinic at the Royal Brisbane Hospital. This clinic uses a multi-layer compression bandaging system (Profore®, Smith & Nephew) in ulcer healing. I went to the clinic at the hospital once a week to get my leg redressed and after eight months of this treatment, my ulcer was finally healed.

Further treatments
In August 2009, I developed my second ulcer, but fortunately this time I discovered the QUT Health Clinics in Queensland. A nurse told me about the clinic after I had an operation for a hernia that took a long time to heal, and I called them straight away. When I arrived at the QUT clinic, I immediately knew I was in the right place. It is so well run and so easy to access; you can always find somewhere to park, get into the lift and be seen straight away. Things like that make life so much easier. You wouldn’t believe how hard it is when you have to find a parking spot and then walk and walk to get to where you have to go, especially when you’re in pain. The wound healing service itself was second to none, and in comparison to my experience with the previous ulcer, it was like having a healing miracle performed on my ulcer. The ulcer was fully healed in one year.

My third ulcer developed in February 2014. Each ulcer has always been in the same place on my leg, so two months after this third ulcer appeared I requested a second referral to the QUT wound clinic. However, on this occasion my doctor declined to make the referral, stating that he could treat it successfully. However, it continued to grow from two small coin-sized ulcers at the top and bottom of my previous scar, to an ulcer approximately 20cm x 10cm half-way around my leg. The pain from this ulcer was the worst I have ever had.

Coping with pain
Going to the pharmacy and asking for painkillers was the most stressful thing I had to do while my leg ulcers were healing. I have lupus and already suffer badly with the pain from osteo- and rheumatoid arthritis; so the additional pain of the ulcer pushed me to breaking point. I felt as if pharmacy staff were treating me like a drug addict when I asked for paracetamol and codeine. I am in my 70s and found it insulting to be constantly questioned: ‘Why do you want these pain killers?’ ‘How many do you take in a day?’ ‘Where is the pain?’

I asked my doctor to give me a prescription for pain relief and was prescribed tramadol, which I found less helpful than the paracetamol and codeine. When I returned to the doctor’s surgery, another doctor looked at my leg — which was by this time inflamed from my knee to my ankle — and prescribed me oxycodone, which only made me feel calm and tired. I had found that codeine was the most effective pain killer for my leg ulcer.

Final success
After six months of visiting the doctor for dressings three times a week without improvement, I finally got a referral to the QUT clinic. At this point the pain was like nothing I had ever experienced before. The skin around the ulcer was inflamed and swollen, and it was getting bigger every day [Figure 1]. I began treatment at the QUT clinic again in October 2014. Initially the ulcer was dressed with a Profore bandage twice a week because it was so messy and painful. However, after two weeks it only had to be done once a week. The pain went away almost immediately and I now have no pain at all. It is now the beginning of November and the ulcer has already started to close in. It’s wonderful; the compression bandage gives instant relief from the pain.

Conclusion
I feel so fortunate to have the QUT wound healing service, with the knowledge, dedication and kindness of its nurses, and all the other people who work behind the scenes. The staff there really listen to you. On reflection of my negative experiences, I don’t think I was listened to at all by the doctors. I feel I shouldn’t have waited so long to access treatment, but every day was such an effort. I was so exhausted and desperate by the time I was seen. Now, after everything I’ve been through, I know that I need to stand up and make myself heard; I feel stronger and more confident.

While I still have trouble getting around, the QUT clinic is set up in a way that makes it easy for me to access. Best of all, I know that as soon as I am seen at the wound clinic, I am on my way to getting my ulcer healed and that is the biggest relief of all.