

The impact on living with a chronic leg ulcer from young adulthood

KEY WORDS

- ▶ Chronic leg ulcer
- ▶ Compression
- ▶ Pain management
- ▶ Quality of life

Leg ulceration affects 1.5% of the adult population and the management of these wounds is costly to the NHS (Guest et al, 2017). The impact to individuals quality of life has been frequently reported and the literature documents that lower limb ulceration can affect a wide range of patients quality of life including self-esteem, pain, sleep, social isolation, physical mobility, less vitality, restricted social function, and restrictions with social interaction, work capacity, and psychological well-being (Herber et al, 2007; Hopman et al, 2016; Persoon et al, 2004; Green et al, 2014). Even though many practitioners are aware of these factors and try to empathise with the individual patient, at times the true impact of living with a chronic wounds can be overlooked or even forgotten, as the nurse focuses on the clinical aspect of wound care. This article will share a personal account from a patient who has been suffering from leg ulceration for over a decade. The aim of this article is to raise the true individual impact of living with a chronic wound and to try to ensure this remains paramount in the minds of all practitioners caring for patients with lower limb ulceration.

My name is Tracy Goodwin and I am 38 years old. I have 2 children, 2 dogs and along with my husband, I run a business. I have been living with a chronic leg ulcer for almost all of my adult life. At the age of 20, I suffered a deep vein thrombosis (DVT) while pregnant with my first son that, despite blood thinning treatment, re-occurred. Afterwards, I was left with throbbing and aching in my left leg, needing pain relief on a daily basis. I was also left with silvery, paper-thin skin on my left ankle.

A few years later, I had a simple knock to the same ankle — and that became the ulcer which has been the bane of my life ever since. It was just a tiny cut to my inner ankle that refused to heal and for several weeks, I tried to carry on as normal (albeit with smelly exudate running into my shoe). After a few more weeks, I was sent to the hospital to have it dressed. I hadn't even heard of leg ulcers and had no concept of the affect that such a small wound could have on a person's life. The ulcer healed after 12

weeks which, at the time, seemed like a lifetime — what I would pay now for a 12-week healing time! However, I was left with an even worse throbbing venous pain in my left leg and very thin, delicate skin on my ankle.

I went on to have my second child in 2004. During the pregnancy, I had to inject myself with a blood thinner every day as I was on lifelong blood-thinning medication by this point. When my children were 6 and 1 years old, I unfortunately suffered a second knock to the same ankle in the same place. The wound became infected and very quickly went from the size of a small dot to the size of a 50p piece (*Figure 1*) and I received IV antibiotics in hospital for several days. Nevertheless, the ulcer did not heal. It closed over for a matter of weeks a few times, but never permanently.

I do not have any pre-existing medical conditions, I wasn't overweight when this all started and I have never used drugs — I've not even smoked a cigarette — I have just been unlucky. Obviously I am overweight now, which

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Figure 1. The leg ulcer quickly grew to the size of a 50p piece and became infected



Figure 2. The second X-ray revealed a broken 5th metatarsus of Tracy's left foot

I know doesn't help but it is no great surprise given the fact I cannot exercise much. I have a busy home and work life and I am a bit of a comfort eater. In all honesty, living with a chronic wound, you need a lot of comfort. I have tried to lose weight over the years (2 years ago, I lost 3 stone) but unfortunately, it never seems to make any difference to the ulcer.

There seem to be some pre-conceived ideas about leg ulcers: A) they only happen to old people. B) they can be healed with maggots and Manuka honey. If I had a pound for every time someone has suggested these to me, I'd be rich.

LOW SELF ESTEEM

Living with a chronic wound has affected my life in every single way. First and foremost, it has affected my confidence. People wear nice clothes or shoes to feel good about themselves — I cannot do that. For many years, the only shoes I could wear were flat backless mules or, to fit over the four-layer bandage, flip flops in all weather — including snow. I cannot wear shorts, cropped trousers, skirts or dresses without my leg and my highly unattractive compression stockings being on show. It makes me feel old and ugly.

My foot and toes have actually changed shape because of the ulcer. I have spent so many years walking on the side of my foot that the ligaments have shortened and I find it hard to straighten my foot. This results in my left shoe being worn down more quickly and extra pressure being put on my left knee and hip

meaning that I now suffer with back problems from bad posture.

ANOTHER FOOT INJURY

In June 2016, I started suffering from a pain on the outside of my left foot. At A&E, I was told that it was soft tissue damage from walking on the side of my foot. I attended physiotherapy sessions and applied ice as directed but it continued to get worse. Four months later, I visited the GP and requested that I have a second X-ray. On this occasion, it was discovered that my 5th metatarsal bone was broken (*Figure 2*) and because I had been walking on it for several months, the two parts of the bone had come apart completely. I was given an air boot cast to wear but unfortunately, the bones didn't fuse at all. The pain from the broken bone is bad and affects everything I do, even walking around the supermarket leaves me in pain. The bone needs to be fixed but the surgeons are reluctant to do it because of the risk of bacteria getting into the bone from my ulcer. Currently, I am seeing the plastic surgeon who carried out a re-cell skin graft. It is very frustrating because I am positive that the bone was broken because of the knock on effects of the ulcer yet the ulcer is also the reason that the bone cannot be fixed.

This ulcer has had a huge effect on my family life. I have spent many days walking in agony around theme parks, museums, parks and shopping centres or climbing through soft play areas, walking the dogs and taking the children

to clubs and activities. I pride myself on being the best Mum I can be and I will always put my family first. However, there have been many occasions where I have been unable to do certain activities, for example, skating, swimming, running, trampolining, dancing and sledging. This is because I cannot risk infection or wear the footwear required or I have been in too much pain to go out.

MANAGING PAIN AND SLEEP

The pain relief medication also has an effect on me. Thankfully, I am on a much lower dose now but I still take oral morphine and ibuprofen twice a day. When my pain was at its worst, I could barely walk so I spent 18 months sleeping on the sofa downstairs. I wasn't sleeping very well at this time and I spent many a night lying awake in pain (especially after a painful dressing change). Sleep deprivation affects you in every single area of your life but mainly your concentration, emotions and diet. I was taking way over the prescribed amount of painkillers just to try and take the edge off. I no longer have to take as many but at one point, I used to take 8 ibuprofen before I even walked my children to school. I dread to think what damage I could have done to my stomach.

Holidays should be a wonderful time and luckily, I have still been able to travel a bit. One year, we went to Lapland for the day. Before I went, I made sure I was fully prepared with dressings and padding as I knew I would have to wear snow boots. I had to wear a size 11 boot on my left leg as wearing boots my own size was out of the question due to the pain of pulling them on and the pressure on the ulcer.

When we have been on summer holidays, I have tried all different ways of keeping the ulcer dry but nothing has ever worked. We tend to stay in a private villa as I feel extremely self-conscious in public beach areas and waterparks with my compression stockings on. I daren't go on the slides because I am too scared to bang my leg.

THE EFFECTS ON MY MARRIED LIFE

The ulcer has also affected my marriage. Luckily, my husband is very sympathetic as I have many days when I am over emotional and irritable. It is hard to feel attractive when you have a smelly,

painful wound on your leg and I feel guilty as we can't go for a night out like 'normal' couples.

The condition has also impacted my career. I have a Nursing diploma but cannot cope with the pain of being on my feet all day. Luckily, my husband and I set up our own business and ever since, I have been doing the administration for it. It allowed me flexibility when my children were young and being able to cope with hospital appointments, blood tests, not to mention the sleepless nights and drowsiness caused by my painkillers. I would have liked a career in nursing, but there is no point because my leg makes everything so difficult.

HIT AND MISS TREATMENTS

We have probably tried every cream, ointment, spray, dressing, lotion and potion known to man. Throughout the entire time, I have been in full strength compression — first in 4 layer bandaging and then in compression hosiery kits. The treatments work for a while and the ulcer starts to show signs of improvement. But it's always a case of two steps forward, two steps back.

In 2008, I had a vein transplant at Charing Cross Hospital. This operation ended up being a deep venous bypass when a blockage was discovered just below my knee. Although this helped a lot with the everyday aching and throbbing (which was getting so bad that I had asked for a below-the-knee amputation), the ulcer still didn't heal permanently.

ENCOUNTERING IN/COMPETENCE

Unfortunately, I have experienced a few incidents where people do not seem to be knowledgeable enough about leg ulcers and compression. A practice nurse at the GP surgery put a four layer bandage on my leg but her bandaging technique was rubbish. She left me in extreme pain and after a few days, I had to remove it. I was left with huge painful dents all down my leg. Just recently, after the re-cell skin graft, I was sent home with no compression on at all — just a loose bandage around my ankle. This could have jeopardised the success of the whole procedure.

Since 2003, I have been looked after by a team of nurses who I trust. They offer a flexible service whereby I can pop in, phone them or email any concerns. As soon as a suitable new treatment becomes available, I will be put forward for it. This relationship has made a massive difference to my ability to cope with this

condition. It would be much harder if I didn't have health professionals looking out for me.

My account of my ulcer is very emotional and I cry a lot: tears of frustration that the ulcer won't heal, tears of self-pity when people are sympathetic and, most of all, tears of sadness for the things that have been taken away from me. I know there are people much worse off than me and whenever I am feeling down, I always remind myself of that. I know I am lucky to have wonderful family and friends that love and care for me and of course I am grateful that I haven't got any awful diseases that are life threatening. However, having a chronic wound that affects my life in so many ways is hard going and I really hope that I have given you an understanding of what it is like.

I agreed to tell my story because it is less common to suffer from a chronic leg ulcer at my age. It is important to understand that people in their 20s and 30s need to be treated differently to elderly patients so that the impact these have on their lives can be minimised.

CONCLUSIONS

The service and financial impacts of venous ulceration are high on the agenda within NHS England currently. There is an awareness that at times we are failing patients with lower limb ulceration in terms of lack of diagnosis, lack of appropriate assessment and lack of the use of compression therapy (Guest et al, 2015). Whilst we need to raise the standard of care we also need to ensure that we do not marginalise the quality of life impact of venous leg ulceration or think of this only as an older person's disease. Unfortunately, Tracy is one of the few patients with venous ulceration that fails to heal even with appropriate compression, wound bed preparation and corrective venous surgery. However, hopefully her account and reflections of her ulceration will ensure that practitioners keep the patient at the heart of everything we do and that we never forget the individual behind the ulcer.

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