

The ups and downs of living with a leg ulcer

have two teenagers, two dogs and I run a business with my husband. I also have a chronic leg ulcer that I have lived with for most of my adult life.

At 20 years old, I had a deep vein thrombosis (DVT) while I was eight months pregnant with my son. Despite bloodthinning treatment, it recurred when he was just six-weeks-old.

At the time, I had no idea of the complications I would suffer in the years to come. I developed silver, papery-thin skin on my left ankle and for years suffered from throbbing and aching in my left leg that needed daily pain relief.

Unfortunately, I got a tiny cut to the inside of my ankle which refused to heal,



Tracy Goodwin.

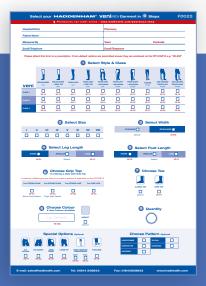
and for several weeks I tried to carry on as normal, despite the smelly exudate running into my shoe. After a few weeks, I was sent to the hospital to have the wound dressed. It healed within 12 weeks, however, the throbbing pain and delicate skin on my ankle remained.

I went on to have my second child, and when my children were aged one and six years, I had a second knock to the same ankle. The skin broke down and the wound became infected. Overnight, it went from the size of a dot to a 50 pence coin. I ended up in hospital on intravenous antibiotics for several days. This time the ulcer didn't heal. Since then, it has closed over for weeks at a time, several times, but never permanently.

In 2008, I was elected for a vein transplant following consultant referral. It ended up being a vein bypass when a blockage was discovered below my knee. The operation was a success, in that it helped alleviate a lot of pain and throbbing (I had been to the GP to ask for amputation this was so bad) but still the ulcer didn't heal permanently.

My foot and toes have changed shape because of the ulcer. I've 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. My left shoe is worn down more quickly that my right. Extra pressure is also placed on my





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My experience



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left knee and hip and I now have back problems arising from bad posture.

I have a broken metatarsal as a result of walking this way. It went undetected resulting in damage that can now only be fixed by surgery, but the surgeon is reluctant to operate due to my leg

ulcer and the risk of infection it poses.

Last year I underwent further surgery so a skin graft could be applied to my wound to achieve healing, but it didn't work. This

was frustrating since the reason the bone broke was because of the ulcer, and it is also the reason the bone can't be repaired. Surely I can't live with a broken foot for the rest of my life?

Living with a chronic wound has affected my life in every single way; it has affected my confidence. I haven't worn heels or strappy shoes for over 15 years. At times, I could only wear flat, backless mules or flip flops (which were all I could fit over the four-layer bandaging), even in the snow! I can't wear shorts, cropped trousers, or skirts without my leg and compression stocking being on display. It makes me feel old and ugly.

My social life is affected as I can't drink alcohol since being on warfarin prescribed after my first DVT. This, in combination with not being able to stand for long, and not being able to wear what I would like, means I avoid going out.

I have tried to stop the ulcer having an impact on my family life, and have spent many days in agony, walking around parks, museums, and shopping centres, walking the dogs and taking the children to clubs and activities.

However, I have had to miss out on

running, skating, swimming, trampolining, dancing, sledging and exercising. Sometimes this was because of the risk of infection, my inability to wear the right footwear or the

fact that high impact activity was too painful. There have also been days when the pain is too much to go out at all. These days have been my lowest.

At its worst, the pain meant I could barely walk and spent 18 months sleeping on the sofa. I wasn't sleeping well, awake with pain, especially after a dressing change. Sleep deprivation is horrible and I wouldn't wish it on anyone. It affects everything; emotions, concentration, diet. I was taking over the amount of prescribed painkillers just to get through the day. I am not proud of this, and am grateful that I now don't need to take as many.

I feel the ulcer has ruined my career.
Before my pregnancy and DVT, I was halfway through my nursing diploma.
Nursing was all I ever wanted to do. I went back to university when my son was one



year old, but I just couldn't cope with the pain of being on my feet all the time during my placement.

My husband and I set up our own business — he is a heating engineer — and I have done admin for that ever since. It has allowed me to be at home when my children were young, however, it was not what I wanted to do but I don't think I would have been able to hold down a proper job with all the appointments needed and the days when the pain is too much.

Treatment

In addition to surgery, over the years I have tried every dressing, spray, and cream going. I have also been in full strength compression; four-layer bandaging and hosiery kits. The ulcer has shown signs of improvement, but I have stopped getting my hopes up as it usually deteriorates quickly again.

I've also encountered some healthcare professionals who didn't seem too knowledgeable about leg ulcers and compression. For example, one practice nurse applied 4-layer bandaging so poorly that I had to remove it as a result of the pain it caused and was left with pressure damage all over my leg. After my skin graft last year, I was sent home with no compression at all!

I am grateful therefore that in 2003, I met Leanne and her team in Wakefield. We first met when I was diagnosed with a leg ulcer and referred by my GP to the vascular service. I have been under her care ever since.

I totally trust in Leanne and I know that she will do everything she can for me. As soon as a new treatment becomes available. she puts me forward for it.

I have a great relationship with Leanne, which has made a big difference to my ability to live with my condition. Due to my busy lifestyle, Leanne is flexible and fits my appointments in to suit me whenever possible. As I change my dressings at home, if I am ever concerned about my wound. I email Leanne to ask for advice and she will reply or arrange to see me in clinic.

I hate to think how hard coping would be without a trusted professional like her looking out for me. I recently had bad news about my foot and she sent me an email to cheer me up. She doesn't have to do things like that and I cannot tell you how much I appreciate it.

I have a feeling I will have this ulcer for the rest of my life, and hope Leanne is happy to work past retirement age!

My family and Leanne will agree that I get emotional about my ulcer. Tears of frustration that it won't heal, tears of self-pity when people are sympathetic, and worst of all, tears of sadness by the things that have been taken away. I am upset about the life I could have had, the career I should have had, and for the person I should have been. I hate feeling self conscious, disabled and unattractive; I hate that this ulcer has taken away my self-confidence.

I know there are people much worse off than me and when I am down, I remind myself of that. However, having a

My experience



chronic wound that affects my life in so many ways is hard going and I hope that by speaking out I can provide an insight to healthcare professionals of what it is like to live with an ulcer, and let fellow sufferers know that they are not alone. I know I am in the minority having a leg ulcer at my age. I think it is important to understand what the impact of a chronic wound on a persons life is, so it can be minimised.



Dr Leanne Atkin, Lecturer Practitioner at the University of Huddersfield comments:

first met Tracy over 15 years ago when she was referred by her GP with a non-healing leg ulcer. Holistic assessment and vascular imaging revealed deep venous insufficiency. As she describes, Tracy underwent a deep vein bypass which was initially successful but she then developed secondary venous disease. This meant that surgery was no longer an option for Tracy and that her condition would need to be managed with wound care and

compression therapy, possibly for the rest of her life. As a patient, Tracy is compliant with her treatment. Her ulcer is in a particularly awkward position making it even more tricky to heal. We have tried many management approaches. Currently, we are trying additional strapping of her malleolus but it is too early yet to see the impact of this intervention.

A couple of years ago, we changed our approach to the management of Tracy's ulcer. We decided to focus upon reducing the impact of the wound on Tracy's quality of life, rather than chasing the elusive healing. A key component of this has been to give Tracy the skills and knowledge to manage her care independently. She can now cleanse and dress her ulcer, and manage her pain successfully at home, while accessing advice and clinical intervention if needed. This has made living with a chronic wound more manageable for Tracy.

A positive in all this has been Tracy's success at sharing her experience of living with an ulcer with other healthcare professionals at conferences and through publications. Despite being her clinician and working with her closely for over a decade, hearing her speak for the first time about the impact of living with a chronic wound was powerful and emotional and made me consider the patient's experience from a new perspective.

Tracy is now a board member of Legs Matter giving a vital patient voice to the campaign. She makes a real impact when she describes what real life is like when lived with a chronic wound.'