

Jamie's Story

I've lived with a spinal cord injury (SCI) for 22 years. I broke my neck at C5/6 at the age of 19 when I dived into shallow waters at an old sand quarry. I hit my head, breaking my neck, and was thankful that my friends were there to pull me out otherwise I would have drowned.

I was incredibly fortunate to be admitted to the Sheffield SCI Centre the same day of my accident, which was remarkable. I know that I received a golden pathway of care by undergoing my rehabilitation in a specialist centre, which not everyone is able to access.

I spent nine months in hospital and during my rehabilitation, I took part in a thorough education programme around all the important aspects of living with SCI. This included the importance of pressure care post-injury, wearing appropriate clothing, checking your skin on a regular basis, using pressure-relieving cushions and mattresses, etc.

Re-engaging with the world

When I left hospital, I wanted to leave that part of my life behind – as much as I possibly could. It was important to me to start re-engaging with the life I had before my injury. I was becoming more independent, enjoying spending time with great friends and my girlfriend – I wanted to disassociate myself with SCI and I was happy to be getting on with my life again.

About four-and-a-half years after my injury, I noticed what I thought was a spot on my buttock. I had probably taken my eye off the ball in terms of checking my skin as frequently as I should have. I didn't think much of the spot when I first noticed it, but it soon opened, and it quickly became apparent that this was not just a spot.

I got in touch with my local district nursing service and they soon realised that the wound was serious. That was the start of what was an 18-month period of my life that I never want to experience again.

Hindsight is a great thing. Looking back, my pressure



ulcer should have been managed better. The nurses were doing the best they could but, without a specialism in tissue viability, their management techniques were not appropriate. I think I also had a misplaced trust in the healthcare professionals I engaged with.

There's an assumption that the people caring for you know best. At that point, I was in my early 20s and I hadn't had much life experience. While I was enjoying a social life, I hadn't re-engaged with the workplace or education. I was living a simple life and wasn't equipped with the skills to challenge the healthcare professionals responsible for my care. I trusted that they knew best.

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It wasn't until months had gone by, my relationships were breaking down and my family started to suffer, that I reached out to my SCI Centre.

I was brought in for an assessment and was told that the pressure ulcer had to be operated on. I was informed that without

surgery the wound would take up to two years to heal. I'm naturally quite slim, so the operation included shaving some of the bony prominence off my ischium bone to enable the wound to heal and prevent the pressure ulcer from reoccurring.

I was in hospital for a month after the operation and then followed a rehabilitation programme so that I could build back up to sitting in my wheelchair again. That took about three-to-four months to achieve.

A profound impact on my life

Throughout this whole period, my quality of life severely suffered. I spent most of the time on bedrest and unless you have experienced it for yourself, you cannot understand how detrimental that is to a

person's mental health. **The impact of the pressure ulcer on my mental health was worse than the impact of my SCI at the age of 19.**

Before the pressure ulcer took hold, I had got engaged. I had so much ahead to look forward to. But weeks and months of lying in bed every day – other than to eat meals – took its toll on all aspects of my life. **My relationship broke down as I couldn't participate in life anymore – I was confined to my room. My world closed in on me and shrunk completely.**

There's nothing more demoralising than being confined to bed when you're not ill. The psychological impact of being in bed day after day and not seeing an end to it and



knowing what you're missing out on, is agonising. Whether you're 23 or 83, you want to be able to engage in life and society. To not have the opportunity to do that was absolutely devastating.

I had no social engagement with my friends and as

I was living at home with my parents and sister at the time, and the situation took a toll on them too.

We talk a lot about the importance of bladder and bowel management and yes, that does have a huge impact on quality of life. But for me, **over the past 19 years the one thing that has inhibited my quality of life more than anything else was that pressure ulcer and subsequent issues related to it.**

More awareness needed

The conservative management of my pressure ulcer wasn't effective, and it was a steep learning curve that general healthcare professionals do not know best when it comes to the care of SCI people. You must be an expert on your condition. You need to challenge when your care is not appropriate. You have to ask for the alternative options or bring people in who are experts in that area of health.

I'm not criticising the nurses who cared for me as I

believe they were doing what they thought was best. But I would have hoped the nursing team would have utilised other experts more quickly, but that didn't happen. So, I'm sharing my story because it is important for others to understand that unfortunately this can – and does – happen again to someone else.

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This is why SIA work with a significant number of people who do not receive the specialist rehabilitation that I had in an SCI Centre. That's why our SCI Nurse Specialist service is so important in district general hospitals and neuro rehabilitation units, where people do receive the necessary education to

manage their own condition. SIA is there to fill that gap – for the SCI person and their treating healthcare professionals. We can also do that through our new Support Network by reaching as many people as possible to really hammer home the importance of pressure care. **I hope that by sharing my story, other people will reflect on their own skin maintenance routines to avoid experiencing what has been one of the most devastating experiences of my life.**

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