PRESSURE ULCERS: THE BRUTAL REALITY

Ahead of Stop the Pressure Day on 19 November, SIA is raising awareness of the personal and economic impact of pressure ulcers. Here, we start with a personal perspective – highlighting the devastating consequences, not just on the person themselves, but also their families and relationships.

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I've lived with an 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 as 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 been. 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 manged 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. 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.

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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. 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 happen, and will happen again to someone else.

And that is why SIA works 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 going through what has been one of the most devastating experiences of my life.

> “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.”

IMPROVING EDUCATION

In 2020 it is not acceptable for people to be living with pressure ulcers due to inadequate care and ineffective treatment options. Find out what SIA's SCI Nurse Specialist team will be doing in the months ahead to address this scourge on the lives of people living with SCI.

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It has been said that pressure ulcers are one of the easiest to prevent and hardest to treat problems experienced by the SCI community. This has remained the case throughout my 33 years of SCI nursing.

The skin below the level of a person's SCI acts very differently to the areas of skin above the injury. Sensation is one of the major contributing factors to prevent harm to the skin, so obviously loss of sensation leaves a person more vulnerable to injury. In addition, blood circulation carrying valuable oxygen and nutrients to the cells within the skin is reduced. The reduced elasticity and collagen in the skin also results in it being more susceptible to damage. All these factors also result in delayed healing should damage occur. Add immobility to all this, and the odds are greatly stacked against an SCI person. That said, skin damage is preventable with the right knowledge and support and prevention is always going to be better than cure.

So often a sore that initially starts as an easily reversible red mark goes unnoticed and therefore quickly develops into one of the horrific pressure ulcers that can take months, sometimes even years, to heal. This is at great financial cost not only to the NHS but also to the physical, emotional, economic, and social cost to the person themselves and their family. Close monitoring of the skin, particularly over bony prominences, should be an activity engrained in every SCI person's daily routine prior to getting up and on returning to bed.

If a red mark occurs that when pressed does not change colour or has slow capillary refill (does not return from white to red in six seconds) then this is a Grade one pressure ulcer and needs to remain completely pressure free until it resolves. That may mean a few days of bed rest ensuring no pressure is on the damaged area. As disruptive and difficult as this may seem at the time, it will prevent possibly months or even years of bedrest should the skin then break and develop into a significant pressure ulcer.

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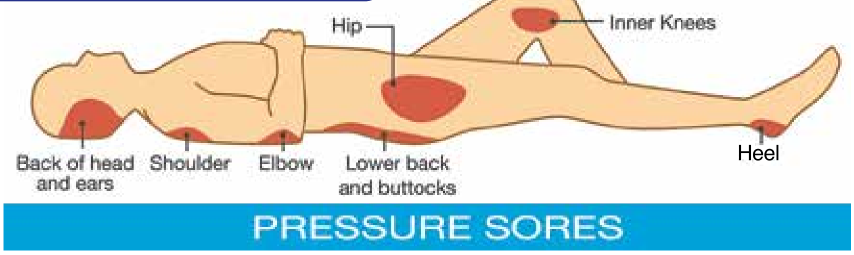
Sir Ludwig Guttmann, the founder of SCI rehabilitation, famously said, "It does not matter what you put on a pressure ulcer as long as it is not the patient." This is still the case today, but luckily there have been advancements in treating pressure ulcers over the years that can help reduce the healing times, if also utilised with pressure-relief methods. Despite these advancements we still hear of SCI people suffering with extensive pressure ulcers that fail to heal and impact negatively on every aspect of their lives, sometimes even causing death from septicaemia. **This is not acceptable**. That is why I am so pleased that at SIA we are focusing our work around the prevention and treatment of pressure ulcers.



▶ *Areas of the body most prone to pressure ulcers*

▲ *These red marks are examples of grade one pressure ulcers and need to be managed immediately to prevent breakdown of the skin*

Knowledge is power and via our SIA Academy we hope to increase the knowledge of those caring for people with SCI with the soon-to-be launched 'Stop the Pressure Educational Module'. We will share more regarding this soon ... so watch this space!

The whole of the nursing team will continue to support SIA's campaigning activities by raising awareness of the plight of SCI people with pressure ulcers and the delays in accessing specialist support to assist with healing. We will engage with relevant stakeholders to drive forward change to allow SCI people to gain faster access to specialised treatments. In addition, we will offer our support and share research and innovation into new therapies and treatments in this area of care.

Last but not least, next month the SCI Nurse Specialist service will expand with the arrival of a new nurse with specialist tissue viability experience – there will be more on this in the December issue of ***Forward***!

We can only do this with the help and support of our members, so please get in touch if you have or have had a pressure ulcer and would like to share your story. Email Dave Bracher at d.bracher@spinal.co.uk

UNDER PRESSURE

Dave Bracher looks at the staggering financial costs of pressure ulcer treatment on the NHS – a harrowing insight highlighting the need for action now.

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Billie Jean King famously said that "Pressure is a privilege", Queen and David Bowie collaborated brilliantly to be 'Under Pressure' and, of course, without extreme pressure carbon couldn't be transformed into diamonds. For me, however, since my SCI in 2008, any conversation with the word 'pressure' in it has almost inevitably been followed by the word 'sore' or 'ulcer'.

I first started to learn about pressure ulcers when I found myself actually dealing with my lack of knowledge and a lack of education/awareness training. I was in a neuro rehab centre waiting to be transferred to an SCI Centre when my left heel seemed to literally fall apart – the result of too much time in bed without the simple adjustment of using a pillow to elevate my heel clear of the mattress. The nursing staff at the SCI Centre were brilliant in how hard they worked to help the ulcer to heal, but it still impacted on my rehab significantly and was my first wake-up call to the dangers of being less than vigilant with monitoring my skin.

The situation with my heel also proved that prevention is far and away the most effective way of dealing with a pressure ulcer. In fact, NHS England believes that almost all pressure ulcers are preventable if the correct guidelines and practices are followed, and the Royal College of Nursing (RCN) has recommended that *"all healthcare professionals should be educated about pressure ulcer risk assessment and prevention, selection, use and maintenance of pressure-relieving devices, and patient education and information-giving"*.

Given this approach by NHS England and the RCN, you'd think that pressure ulcers would be a rarity in medical and care settings – an occasional occurrence rather than a regular feature. And yet, the financial implications of pressure ulcers are significant cause for concern for both the NHS and private care facilities. The numbers are astonishing:

- NHS England reports that treating pressure damage costs the NHS more than **£3.8 million every day.**
- The total cost of pressure ulcer care amounts to **4%** of total NHS annual expenditure.
- More than **90%** of pressure care treatment cost is nurse time.
- Somewhere between **1,700 and 2,000** patients per month develop a pressure ulcer.
- A pressure ulcer worsening from grade one to grade two increases costs by **300%**.
- The average cost of treating pressure ulcers ranges from around **£1,200** for a grade one ulcer up to more than **£14,000** for the most serious grade four pressure ulcers.
- Litigation costs relating to pressure ulcers were at an all-time high of over **£20.8m** in the year 2017-18, an increase of **53%** in just three years.
- Cases of nursing homes being liable for pressure ulcers developing have resulted in compensation pay-outs of up to **£11,000** per claim.

And of course, this is only the medical cost. Pressure ulcers have a massive impact on the individual in terms of what they can and can't do whilst the ulcer is healing, affecting all aspects of their life and very often impacting on their mental health as well. The pressure ulcers I've had over the years have dramatically reduced my ability to engage with my family and friends, my ability to work, and on one occasion even resulted in me missing a long-anticipated and much needed family holiday.

Reducing the number of pressure ulcers sustained each year would have a huge impact. Less ulcers would free up nursing time and ensure more beds are available for use, saving vast amounts of time and money. This also means that more patients can be treated, reducing waiting lists and improving organisational efficiency as well as making patients happier because they're being treated more quickly. Patients getting home sooner means they have less time to catch other illnesses and also reduces the likelihood of psychological issues developing.

Pressure ulcers destroy people's lives and cost the NHS billions of pounds each year. The devastating financial and emotional impact doesn't just represent a care or a system failure, it also highlights the desperate need for a more pro-active, urgent and focused approach to treatment options. Current treatments for pressure ulcers are outdated, unreliable and take too long to work effectively, which is why SIA is calling for financial investment and immediate research into the innovative solutions that could either prevent pressure ulcers developing in the first place, or provide alternative, more effective and more reliable treatment options. This investment into new solutions would be transformative for individuals and save the NHS huge amounts of time and money, which is why we want to see decisive action taken now. Only by investing in research and embracing innovation and alternative thinking can we hope to find the solutions to making pressure ulcers a thing of the past.