

Pressure ulcers an SCI person's Achilles heel

Anyone who has ever had one will know how quickly they develop and the potential impact they can have on your quality of life. SIA Trustees Raquel Sigantoria and John Borthwick want to know your views on what can be done to prevent them from occurring and, if they do occur, what treatment you feel works best for you?



Raquel Sigantoria
Below: John Borthwick

Raquel writes...

John and I have been accepted as Patient Representatives onto a panel to oversee the production of new NICE Guidelines on Pressure Ulcers over the next 18 months. NICE (National Institute for Health and Clinical Excellence) is the independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health.

Both John and I have personal experiences of pressure ulcers. We know that this type of injury can have devastating repercussions and is a major concern for many who have catastrophic injuries. We represent everyone who has sustained a pressure ulcer whether they are SCI, nondisabled or have complex multiple injuries. Our role is to ensure that the patient's voice is heard and represented when the new National Guidelines are drafted and later published.

Why is it important?

Pressure ulcers represent a major burden of sickness and reduced quality of life for

people who experience them, affecting not just the individual but their families and their carers. There is currently no nationally-collated data on pressure ulcer incidence, prevalence or the true financial costs to the NHS, although estimates put this at billions of pounds annually. Worryingly, the rate and severity of pressure ulcers in the community and care homes is unknown, but we do

know that pressure ulcers have been associated with a two- to four-fold increase in the risk of death in older people in intensive care units.

Why do we need your help?

I sustained heel ulcers within 24 hours of becoming paralysed aged 11. They became infected with MRSA and I required various skin grafts over a three-month period on bed rest. When I was 21, I sustained a sacral ulcer which ended up requiring surgery. During this time many treatments were tried to heal the ulcer, none of which were successful, mostly due to the fact that the real cause of the ulcer had not been properly identified. John and I know what did and didn't work for us, but every person's experience is different, especially as much depends on their individual circumstances. In order to represent as wide-ranging a view as possible we would like to hear from you about your experiences.

What do we want to know?

We want to know if you've ever had a pressure ulcer or cared for someone who has. How old were you, how 'bad' did it become and how long did it take to heal fully? What treatments did you undergo? What worked, what didn't? Have you ever received guidance or advice on how to avoid getting a pressure ulcer and what to do if you do get one? Where did you get the advice?



Prevention

What sort of things help prevent you from developing pressure ulcers? It could be equipment, techniques, education or nutrition to name a few.

Cause

What do you think caused your pressure ulcer? Pressure? Friction? Moisture? A device?

Assessment

How good are your treating team at assessing your risk of developing a pressure ulcer? Do your clinicians respond when you have said you have had a pressure ulcer? Do they treat that area as being more susceptible to further breakdown and categorise you as a higher risk? How much is it left to you to inform clinicians or do they take the lead?

Treatment

Were you given options as to the treatments available and the pros and cons of each? Did the treating health team favour conservative management over surgical intervention? Do you feel this was correct with the benefit of hindsight? What type of treatment did you have?

Quality of Life

One of the most important factors for a person with a pressure ulcer is their quality of life and how it is affected by having a pressure ulcer. Equally important is how the treatment affects their quality of life for better or worse. Some say most pressure ulcers are avoidable. This, in my experience is correct. We need your views to help inform the public at large of the pitfalls we face and how this really can become an injury that need not occur.

Raquel Sigantoria

Editor's note: Whatever your experience, please email sia@spinal.co.uk or write to SIA at SIA House, 2 Trueman Place, Oldbrook, Milton Keynes, MK6 2HH