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"A Different Light"

A Different Light –24th June 2023 – “People look at the person within, not what they are wearing”

It's been one of those times when you think. “Hell's teeth- what is going to happen next?!” I used to think that gout was the jokey punishment for aging aristocrats who have imbibed far too much in the likes of foie gras and other such rich food, while guzzling litres of port. But when you actually get gout, it is not a laughing matter, I can tell you!

It started off with a vague ache in my left toe on a Monday. My mobility, which is very limited these days anyway, quickly declined into an agonised shuffle, as I moaned and bleated to anyone who came near me- and when they did come near me, they didn't stay for very long. Normally you don't take much notice of your toe- but during a gout attack your big toe quickly becomes the centre of the universe, with all it's gravity channelling pain to the inner sanctum of the toe joint. By the Saturday I was seeking advice and relief from my brother who has previously suffered from gout before, and as a doctor, I thought he may be the ideal candidate to provide gout help. My brother kindly prescribed me Prednisone and I was thrilled with the thought that the gout would be relieved in the next few hours. But alas, while this is the first line of attack for most sufferers, for me this just didn't take. To add to the slings and arrows that gout was sending my way, my dear ninety-year-old mother passed away, and while she had a peaceful death in her own home with my two brothers, it is nevertheless a very sad and significant time in one's life. In reflecting on my mother's passing, I realised that one of her many outstanding attributes was an abundance of positivity and optimism that just seemed to radiate from her. I did my best to channel her positivity and optimism over the next few days.

As someone with a very visible disability and someone who is unashamedly vain, I have always been very particular about what I wear. On the morning of my

mother's funeral, I went to put my shoes on and with horror I realised that there was no way my gout ridden foot was going to fit into my shoe. I sat there looking at my foot which looked like a small piglet on the end of my leg. I couldn't believe that I was going to attend my mother's funeral wearing slippers. Could things get any worse? Days later, there was still no respite from the continuing pain emanating from my left big toe. Back to my GP who declared that after a course of steroids, the gout should be far more reduced than what it was and that I needed to go to the Emergency Department and get it tested for other explanations to what was happening to my toe. My wife and I inwardly groaned imagining hours of waiting at Whangarei Base Hospital. We were, however, pleasantly surprised when we were seen relatively quickly. They had to test the fluid in my toe which meant my toe had to be aspirated. This involved inserting a needle into the big joint of my big toe which was not pleasant. I cannot keep still at the best of times, let alone when a large needle is being inserted into my toe. Thankfully they offered me gas on which I hyperventilated wretchedly, while a second nurse held onto my shin with both hands. My medication was changed to colchicine. The gout seemed to start to settle, when I suddenly endured bouts of severe diarrhoea, reminiscent of Niagara Falls. This is apparently a common side effect of colchicine. A trade off if you like between gout and gastro side effects. I opted for the gout as the dehydration was making me look and feel like a walnut. Another week later I was scheduled to go down to Auckland to take part in a Mihi Whakatauki to be welcomed as a member of the newly formed Whakapuawai; a task force group to advise the New Zealand Health Group on how to implement Enabling Good Lives into their organisation. I felt humbled and honoured to take on that role but also appalled and horrified to still be wearing SLIPPERS! However, despite my anguish of having to wear such inappropriate footwear, no one has batted an eyelid. Not at the funeral, not at work and not at the Mihi Whakatauki. Is it because people don't really look at what you wear; they look at the person within? Or is it that when people see a disabled person that's all they see? That a disabled person can either be wearing a tuxedo or a poncho and it would be all the same to them? No, I am going to take a leaf out of my mother's book and take the positive angle – they're looking at me, and the person within- and thank goodness for that!

Jonny Wilkinson is the CEO of Tiaho Trust - Disability A Matter of Perception, a Whangarei based disability advocacy organisation.