

At the beginning of this health issue I was 58 years old and recently widowed. Being self-employed, I am responsible for ensuring my business stays open and economically viable, I operate a small Cosmetic and medical clinic.

Appointments are often back to back from 7am till 7pm, 5 to 6 days a week. I am booked 3 to 4 months ahead, which means attending any specialist appointments is not only difficult, but also has a direct and indirect cost to myself and the business. On top of this I am a Registered Nurse and work at the local hospital on weekends and any other days where I can.

I have always been a very physically active person, being involved with a local exercise group involving intense gym sessions, weightlifting, and extensive running sessions in our local sand dunes and park areas.

Because I was enjoying my fitness sessions so much, I decided on presenting myself to a Gynaecologist due experiencing slight urinary leakage on running down the steep hills during my exercises and did not want this to worsen.

Upon my initial visit, I was diagnosed with 2<sup>nd</sup> degree uterine descent, 2<sup>nd</sup> degree cystocele, and a small rectocele, and was advised to have a hysterectomy and repair operation. Because of my profession and medical history as a Registered Nurse, I researched the mesh involved in these procedures and found them to be very controversial. I then brought this to the attention my doctor and strongly voiced that I did not want the mesh. My Doctor then emphasised that with the level of exercise I do and how active my lifestyle was, he would not be doing the right thing by me if he did not use the mesh.

He did not inform me of any side effects of the mesh, or state any history of complications involving the mesh; therefore my initial investigations were dismissed, as the doctor described the operation to not involve any issues, meaning the complications for a hysterectomy were overlooked. Due to the respect and trust I “had” for our medical industry, I signed a consent form, under the impression a “professional” had confidently dismissed the concerns I voiced.

Following this I underwent the procedure for the vaginal hysterectomy which involved anterior and posterior repairs, and bilateral sacrospinous colpopexis for my prolapse and urinary stress incontinence. There was a first degree descent of the vaginal vault so an Anterior Elevate system was used to support the bladder and undertake bilateral sacrospinous colpopexis. A posterior repair was then performed for the large rectocele.

During my recovery I was very compliant, as being on my own and self-employed the need to get back to my business was paramount, ensuring I followed all precautions and gave my body the correct rest. Around the 7<sup>th</sup> to 9<sup>th</sup> day of my recovery I began to experience pain generally caused by sitting in an upright position for longer than 10 to 15 minutes, Naturally I assumed this was part of the healing process and tried to remain laying and resting on my lounge in the hopes this would help my body heal.

During my post-operation visit I certainly had pain on the left and right side of my pelvis. Even driving to the postop visit, I realised I could not sit comfortably in my car, and by the time I arrived to the doctors after an hour’s drive I found myself in excruciating pain, this pain was unbearable to the point of nearly being in tears. This pain was noted during my visit, identifying the upper, right, back area of the vagina as a specific region of acute pain.

This pain continued, and I found myself unable to sit at work for any length of time. This prompted me to try a variety of oral pain relievers, however none of these resulted in relieving me of any discomfort and I ceased taking any. I also found myself experiencing a period of bowel incontinence for a few months after the procedure, and out of concern I eventually had a colonoscopy that showed nothing and this incontinence eventually resolved itself.

After further advice that I could potentially still be in the timeframe of naturally healing, I waited for my situation to hopefully improve and my body to heal, I found the pain and discomfort to be unrelenting and I returned to the Gynaecologist who informed me that this was definitely his doing from the operation, but expressed to me that he himself could not identify the reason why or how. He felt that perhaps he needed to remove the Sacrospinous Colpopexy anchors and also some of the mesh. This caused me great concern and distress to consider having to undergo another procedure as I had already taken 6 weeks off post operation, and was advised that I would need to take another 3 weeks off.

However, at the mercy of our medical professionals and the constant level of excruciating pain I had no choice but to have the operation, even though I do not have loss of income insurance as it is very expensive for someone such as myself who is self-employed, and I was informed it would take 2-3 months to activate, therefore I had to accept that I would receive no income for this time off.

After the second procedure, the pain was definitely still present and unrelenting on the left side. I discovered the pain to now be unbearable whilst in a sitting position, and found it could only be tolerated in an upright standing position, the only relief I found was when I was lying down.

I stressed all this to the Doctor and also emphasised that the amount of time I had to take off work was absolutely unacceptable due to the compounding losses of my business.

It was at this stage I was then referred to a pain management Doctor, the first string of specialist appointments causing my business to suffer further and me trailing multiple prescriptions. I was prescribed 100mgs of Gabapentin, I took this for weeks in the hope of some improvement but found no relief from my pain.

I was also sent for an MRI in North Sydney, which is three hours away, meaning I would have to suffer through 6 hours of pain whilst driving there. The results from the MRI indicated pudendal nerve decompression.

I returned to the Gynaecologist who expressed that he needed a second opinion, and from the advice of the pain management Doctor I was sent back to Sydney to see a Professor who specialises in pudendal nerve damage and pelvic issues. This of course caused even greater distress to me, as I would be losing more income, more days off work, more 6 hour return trips in serve pain to Sydney, and the embarrassment of cancelling clients I had previously postponed. Going to Sydney meant costly accommodation, painful travel and the demise of my business reputation.

After seeing this Professor in Sydney he explained to me that my acute pain was definitely due to my original operation and that it was pudendal neuropathy. He instructed the first course of action would involve undergoing a series of Hyaluronic acid injections as close to the damaged nerve as possible. The aim is to restore the damaged nerve and cause the scar tissue to split away. I have currently had six of these injections with no desirable affect or improvement. The "direct" cost for these injections has amounted to \$6,000, a fraction of the indirect cost on my business and loss of income.

Currently I have 3 options; firstly I could trial a neuromodulator which I am very apprehensive about. Secondly I could pursue pudendal nerve decompression surgery via the trans-gluteal approach, or I could attempt surgery with an American surgeon that has experience in this area, he would also be removing the remainder of the mesh and anchor. This third option is yet to be discussed in depth with the surgeon, and would cost me an estimated \$25,000.

This journey of chronic pain and discomfort has exhausted my ambitions of living a fruitful life after the death of my partner of 40years. The direct medical cost and chronic pain married with the indirect suffering of my business has compounded to the point, any kind of blissful retirement in my mid to late 60's has most likely been robbed. I found great solace in my active lifestyle of exercise before this incident, so much so that if the reality of this outcome had even merely been impressed on me I would not have considered the operation. As a registered nurse I took confidence in my ability to use my networks for sourcing sound medical advice, however given my current situation like many others, this is clearly not what I have encountered. I pray for those with no medical background who are seeking the same advice I did. I am not one to shy away from the challenge of hardship, so I will persist to actively manage my business and family under these circumstances. However I am deeply concerned that there is an ill-informed industry actively operating under a serve lack of knowledge, an industry which every individual entrust with their health and well-being, and rightly should considering the so called accrements and cost associated with these "professionalise". There is no doubt in my mind that the anguish caused from the dismissal of my concerns raised, and the mental, physical and finical outcome of this scenario has been a contributing or accelerating factor to the deterioration of my heart. This has already left me in hospital once, requiring immediate surgery to have a stent put in.