My journey pre-Kshar sutra

At time of first diagnosis, I was 44 years old

December 2021 – I recall the exact moment I felt a fissure form whilst having a bowel movement. I knew for sure it was a fissure as I'd had one many years prior. Through sheer bad luck this led to an infected anal gland. This then led to a fistula forming above my anus. I was admitted to hospital for seton placement which I was to have in place for 2 months. I spent 3 days in hospital waiting for the procedure which would be a very quick one, during which time I had many pain killers that lead to constipation – that would come back to 'bite me in the bum' later. The procedure was horrific for me. I felt as though I had been abused. I had bruising on my rear that took several weeks to heal, I was unable to sit down at all and when I finally felt I could, it was for short periods and always with the aid of a donut. The first bowel movement after surgery literally felt like glass and all subsequent bowel movements made me very nervous. Sitz baths became a part of my everyday life.

January 2022 – I had just become accustomed to life with the seton, but developed a new abscess about an inch from the site on my right butt cheek. I called the hospital for advice and was advised I'd have to admit myself to have this lanced. So I did. They also removed the seton a month earlier than was meant to occur, but at the time I was very grateful and thought I was healed of the fistula which was why it was removed. The lancing of the other abscess left me with a concave open wound the size of a 10 cent coin that took weeks to heal. Once I ran out of the dressing supplied by the hospital, I purchased my own. At $3 per dressing that I had to change every single time I went to the bathroom – an expense that would continue for many.

I later learnt that the abscess they lanced was just a boil and not on the same side as the fistula. I did not need to have this procedure at all.

February 2022 – I have a catch-up appointment with the registrar at the public hospital I had my procedure at (on Valentine's Day of all days lol). I explain to them that since the procedure I have had a lot of seeping from my anus and was advised this is normal mucus and nothing to worry about. I reiterated that the amount that was seeping was absolutely not normal – again she said it was normal. I repeated it 3 times before giving up! I leave feeling helpless, unsure of what to do about the seeping. I continued with the sitz baths and constant wearing of dressing/sanitary pads.

April 2022 – I felt a new abscess forming on my left butt cheek this time. And it was a monster! It felt as though it was as big as an egg. Needless to say, I was in absolute agony and I was devastated at the thought of another surgery. At this time, I was waiting for an appointment with one of the best colorectal surgeons in Melbourne and did not want to have any further procedures until I had spoken to him about all my options. I went to the emergency ward and was advised I would need another procedure which would leave me with an open would 10 times bigger than my other!! I refused this and requested antibiotics, then headed home to battle this myself and find a way for the abscess to break out and drain. I've had boils before, I knew I could do it even though this one was way more intense. I also knew infection could spread through the body – hence the antibiotics. I spent over a week in bed fighting it (I felt as though I was fighting death), had endless amounts of sitz baths alternating various things: salt, Dettol, potassium permanganate. I even put a thick mud mask on the area to draw it out. This helped to peel away layers of my skin and allow the abscess to push its way out through a tiny hole. I then requested my GP cut it a little bit more to allow it to drain. Yes, it was a horrible week, but I would rather that suffering then the suffering that would have ensued had I allowed them to operate again and lance it so brutally. This small incision ended up remaining open and seeping until I went to India.

June 2022 – My mental health was at its lowest point ever. I reached a point where I was constantly on the verge of tears. Literally. The tears were below the surface just waiting to pour out. All. The. Time. I was surprised at how I reacted to things, I would watch a slightly sad moment on TV and would burst into uncontrollable tears, heaving and sobbing. I am a naturally bubbly person who laughs a LOT and appreciates all the things! So, this threw me. I saw no way out. My passion is my family and travelling. I was taking up my quality family time feeling blue and was unable to travel due to pain and the bathroom care required. I tested the waters by taking a small interstate trip, but was so limited in what I could do. I also got another abscess whilst away. Luckily the wound was still open and it burst and kept draining. If I did not have an open wound constantly draining it, I would have had to have at least another couple of procedures, I'm sure. I was also spending a small fortune on the dressing still. I would estimate I'd be well over the thousand dollar mark in total with what I'd spent on them. I was so careful to keep the wound clean as I don't think I could have coped with any other issues. I also knew this open wound was a temporary fix, but was unsure of what the answer was. It was like I was holding my breath, hoping the wound would stay open until I found a solution.

I had received an MRI referral from the public hospital (which I had no idea someone had booked me in for) and received my first actual test for this issue.

July 2022 – I woke up one day and wondered how other countries treat fistulas, and started scouring the internet. Somehow, I ended up discovering Kshar Sutra. This was the first sign of hope I felt since I developed the horrid thing.

I finally see the colorectal specialist and come armed with a million questions which he kindly and clearly answers. I explained that whilst the hospital I was dealing with was fabulous, there was no continuity of care. I saw different people every visit, no one explained the true extent of how serious a fistula could be. No one explained anything!! I had to go and do my own research. From that I learnt that there are many types of fistulas and treatments. He showed me the MRI results and advised I had a complex fistula. He also advised I would need another seton placement to drain the existing abscess, after which he would re-assess as to which procedure would follow (most likely a LIFT). I was advised his rate of success was 80% (but I would have to wait a year for my private insurance to kick in and enable this surgery).

Had I not just learnt about Kshar Sutra I would have found that statistic to be hopeful, but now I just found it unacceptable. The recurrence rate was appalling – sitting around 50%. I asked the surgeon what his opinion was on KS and he chuckled at me (as I knew he would) and said it was the same thing as a seton. While the concept is similar, there is a different method used with KS than the seton used in Western medicine. He was adamant that since there is no science behind it, it could not work any better than Western methods, completely disregarding that there is science behind it, just not in Australia. Whilst I was not surprised by this reaction/response, I was still enraged by it. Why is it that some believe if it's not curable by way of Western medicine, it's not curable at all? How can all other methods of healing be discounted so readily when there are years of success stories and evidence? Why are doctors averse to recommending other methods of treatment alongside theirs? I was seeing an excellent Chinese acupuncturist who had been practising for over 30 years. He provided me with herbs to imbibe, provided acupuncture and cupping all over my body, advised me of what to exclude from my diet, encouraged me to do pelvic exercises, and to become accepting of this as having a sad or depressed state of mind would not aid my recovery. He is of the belief that we can heal from the inside out, which I too believe (and something you would never hear from a Western doctor). But I had to consider that a fistula needed something else on top of this. Enter Kshar Sutra.

I am in the midst of learning about this treatment, but so far I have come across a couple of similarities to what my acupuncturist taught. One example of which is food. No meat or chilli for example. I assume this is in part to help bowel movements, but also to help 'eat clean' and eliminate the body of foods that will perhaps hinder healing and cause inflammation. Common sense, right? When I posed this to a couple of the doctors I saw (ie I asked if there were foods to avoid), I was met with an instant 'no'. Not even a pause for thought. It still blows my mind really. Doesn't someone in the field of medicine enter that particular field to help people heal? If so, how could you *not* be open to other methods of healing combined? I know that's a very idealistic way of thinking, but it also just seems logical! I am open to all methods when it comes to treating myself, why isn't everybody? Anyway!

Another thing that astonished me was when I queried the surgeon about my initial seton placement. I was advised prior to the surgery that I would be examined under anaesthetic, and dependent on what they found, they would either place a seton or do a fistulotomy. No MRI. No ultrasounds. I didn't question that; I just put my faith in the experts and went along with it. When I asked the surgeon as to why I was not tested, which would have given an accurate picture of what was happening internally and would potentially lead to accurate treatment, I was advised there was a lack of MRI machines. Ummmm. He was an excellent specialist in his field, but to say that was disheartening. If it wasn't something that was so serious, I would perhaps be more understanding (maybe), but this is a chronic issue that takes a lot away from people, and here the doctor is telling me that they essentially just guess their way through by probing instead of scanning. What the!!!

I want to be clear that I am not anti-Western medicine as I fear I sound super negative! That's not the case at all. It's the experience I had/am having with the fistula that has led me to feel so disheartened. I was also blown away by how far we've come in medical science, yet we still don't have an answer for fistulas. Humans are so complicated!

Back to Kshar Sutra. I somehow ended up finding video testimonials on YouTube from all over the world (the first one was by Norma from Canada who created the support group on Facebook). Everyone talking about their horrendous experiences until they discovered KS treatment. It was the first time I felt a glimmer of hope. I ended up finding and joining the support group on Facebook and the more I read, the more I felt myself take a huge sigh of relief (along with the MANY tears of gratitude for finding others who understand and not feeling so alone for the first time). There was a whole network of people out there who had been through what I had, who had been to India for the treatment, who shared their success and/or horror stories to others around the world. It provided me with a wealth of information – recommendations for doctors, accommodation, travel tips, all of it!

The success rate of KS is said to be over 95% (most documentation report 97%) - which by definition is a cure and vastly different to the 80% I was quoted by the specialist. The rate of recurrence is said to be about 3% - again vastly different to the recurrence rate of Western methods which sit around 30-60% mark depending on procedure. I have yet to read an example of incontinence as a result of this treatment, where the risk when undergoing a fistulotomy for example varies between 6-40%. That blew my mind!!! What in the world is going on that Western medicine hasn't welcomed this method with open arms! How infuriating. I'm one of the lucky ones who is in a situation where I firstly have access to the information needed about KS, and secondly can actually afford to go have the procedure done! Ok I'd go into debt, but I have the choice and knowledge when too many don't.

After reading and reading and reading, I narrowed down my search to two particular doctors who had the most mentions within the group, the most experience, highest success rates and loveliest

manner. The doctors' manner was almost as important as their skill to me. It is daunting to even think of flying across the world to undergo a treatment for a chronic issue in a personal part of the body, so having someone be gentle and caring is vital!

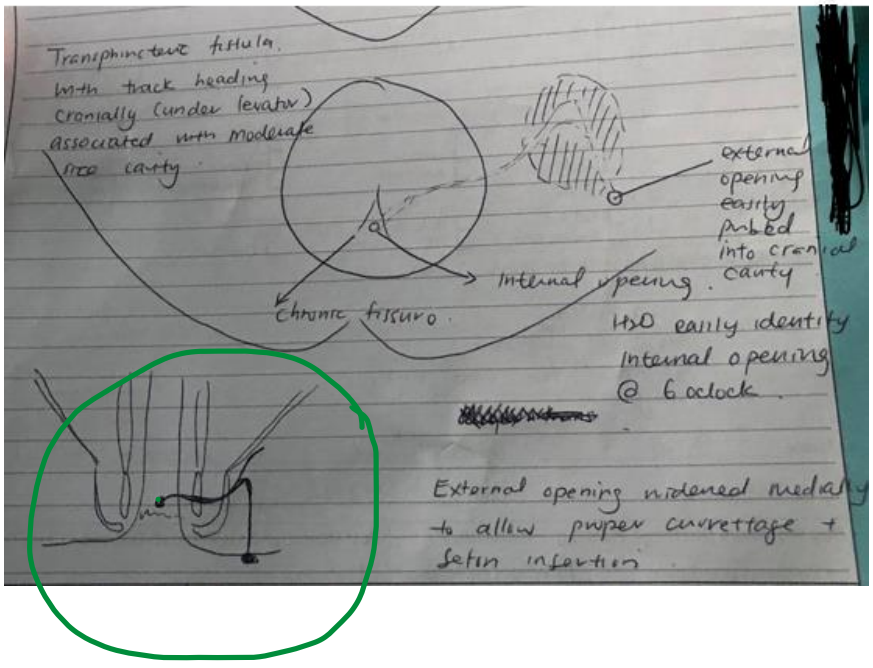
After looking at all my options, researching Kshar sutra endlessly, reading and watching numerous personal experiences, I made the decision to go to India in October 2022. Once I decided to go, it was all systems go. So much to plan and do before going.

End of July 2022 – I had been bleeding for a couple of months from the track and I couldn't avoid it any longer. The bleeding was becoming scary. I had to admit myself in to hospital. I was so disappointed that I could not hold out until October, but I also did not want the fistula to expand anymore and potentially spread to a place that makes it more difficult to treat and cause more long-lasting damage. I was adamant I did not want any surgeries, ideally just another seton placement to assist in drainage until I begin treatment in India. I messaged the doctor in India and asked for his advice but did not receive a reply. A couple of days later I admitted myself to the hospital.

I didn't have to wait long at the hospital; I was sent in to do preliminary blood tests and was sent back out to the waiting room to wait for results within an hour or so. In that time, the doctor in India replied to me. Of all times to receive a reply, it was within that 1-hour window where I was concerned about whether or not I should go ahead with any procedures that may or may not interfere with his treatment. An omen indeed! I explained the situation and the doctor advised me that if the hospital feels I need a seton, to do so and he will remove it when I arrive in India. So that's what I did.

Without the doctor saying as such directly, it was clear that the initial seton from December was removed too early.

At 7am I was woken in the hospital to find 7 people staring at me and was expected to be coherent and alert as the surgeon explained what they would be doing. I once again felt like a body part and not a human being. The doctor advised they would be inserting a seton (as below) and would do a curette of the fistula tunnel.



The surgeon then advised I would need a further procedure a couple of months later which would have a 60% success rate. This again differed to what the specialist had advised earlier – I am unsure why.

This reinforced my decision so much more that India was the right path for me.

August – October 2022

Planning for my trip was overwhelming! I was lucky enough to have Long Service Leave available to me as I'd been in my job for 11 years.

I researched the treatment extensively and prepared for every detail of my trip. I read everything I could find on forums, all previous comments and posts on the support group, all previous first-hand experiences, all recommendations for hotels, transport options, all of it.

16th October 2022 – fly out of Melbourne on Thai Air business class. Had to fly business class as I cannot sit for long. Small fortune that a dear friend paid on my behalf. The flatbed was a blessing. It was a spacious way to fly and definitely helped. I was very emotional all the way though due to leaving my family in a worried state. They understand why I have to do this but of course were concerned. This ain't no holiday! Little did I know how wild and wonderful the ride would be.