

Date: July 2011

Story submitted for publication from TVT Mum member Karen

Hello everyone,

my name is Karen H, I am 53 and live in west London.

My story begins in August 2010, I had a cystocele repair (grade 1 - mild) and Gynecare TVT put in for mild incontinence, like many of the ladies on here I believed my consultant that it was a routine op and would be fine. I did not do any homework/research and had no idea how bad complications could be, I read the bit about erosion in the leaflet the hospital gave me and thought it won't happen to me.

I expect you can guess whats coming next, I had the op and recovered well, but this sharp thing was digging in me - I thought it was a nylon stitch. It was extremely uncomfortable so driving or sitting on a hard chair was not great, the only really comfortable position was lying down in bed !

I hung on expecting an appointment from the hospital at 8 wks, went to see my GP at 11 wks to ask her to cut this stitch as I couldn't stand it any longer, she looked & asked the nurse in and said she wouldn't like to in case it was important & I should phone up and ask for an app. at the hospital .So I was finally seen again at 12 wks.

Got an appointment for the following week, to be told by the consultant that it had eroded & that it was my body rejecting it. Looking back I think my GP must have had an idea it was the tape - what stitches are blue?

The consultant said he would rebury the tape in a small operation and it would probably heal this time, so 7th December I went into hospital again as a day case.

Had the op was sore but ok for 2 wks then the agony started, it was very sore and inflamed I could hardly walk anywhere - great just before Christmas.

My sister who is a retired physiotherapist asked if I had any anti inflams - which I had from the August op, so started taking them. Things calmed down a bit, till 7 January when I happened to bend over and had a sharp pain - which made me go ouch out loud. That evening I examined myself and sure enough I could feel the tape it had eroded exactly 4 wks later.

In a way I was glad this had happened, because I could not endure this kind of discomfort, how could I carry on normal life feeling like this? This made me start looking on the internet for solutions, at the same time I had this dreadful feeling of panic that I had this thing in me and it was a terrible mistake.

I went on the Topix forum, and found Lorraine on TVTmum, and read as much as I could as my follow up appointment with my consultant was looming on 27 January. I was not going to go in blind and trusting.

I went to see my GP again, and said did you realise you were looking at an eroded tape and

its happened again, she said no, I have seen lots of ladies with TVTs but not erosion. I told her I wanted it out and did she know of anyone who did removal, she said she would make enquiries. I went back the following week and was told that I would have to ask my consultant - I had the distinct impression that she had been told don't get involved let the consultant sort it out.

Saw the consultant, he examined me and confirmed it had eroded, then told me he hadn't done the op as he had been called away on an "emergency" and if he had done it it would have worked. I asked if I could have it taken out, he said it was not necessary if he took a section out the rest would support my bladder and I would "probably" still be continent, perhaps I was not assertive enough/ I didn't feel as if I was getting anywhere so I agreed and explained that I was in the middle of selling my house and could I put it off till April - he agreed and I went away thinking you are NOT operating on me again there has to be another alternative.

So at the beginning of February I spoke to Lorraine, who gave me the best advice - if you can afford it go abroad and have it out. The notice board was not running then, so I didn't really go on the site much. Instead I emailed a lady I met on Topix who had just had mesh removal (Gynecare prolift) by Dr Raz.

She is a nurse, and so I trusted her opinions, and evaluation of Dr Raz.

I emailed Dr Raz who replied so quickly, then I started the process of arranging an operation abroad. It really is not for the faint hearted - it took a lot of determination and the support of my husband, but on May 12th I had full tape removal at UCLA.

Whilst recuperating there and on the net I met the lovely Liz R - who had full tape removal in the UK 3 days before me. We have been in contact ever since and she has been so supportive plus we talk about our recovery symptoms.

Its now 6wks since the removal, and I have waited this long to post as I wanted to have a true picture of my recovery, and if I can help any one I will gladly.

A big thank you to Lorraine and for this website, otherwise we would all be in a dark place now. Xx

More on my mesh removal..

Did you have travel several times to see Dr Raz?

I only went the once, because I was an international patient his secretary (Jean) arranged the consultation & examination, ultrasound, and then a final consultation with him all for one day, then it was surgery the next day, its so different from the NHS where weeks go by.

Before that, though I had to go through their international patient system - where you are assigned patient number and given a "self pay" price for the surgery. You then pay, arrange

a date for the surgery, then have to complete tests here (bloods,ECG,chest xray, significant med history from your GP) fax those off to Jean.

As for his success rate I haven't got figures, but he is good. On his final consultation he said to me " I am 90% certain you will be continent after this operation". I asked how he could be sure, he said its the way he takes it out and also the fact that he has done so many, obviously it depends on individuals medical history/ problems as to the outcome.

I have to say for me it was hard traveling back - 10 hr flight catheterized with leg bag , when really all you want is your own bed. But I asked for assistance at the airports and they were great - wheel chaired everywhere.

Its now 7wks, and things are alot better, its taken a while for my bladder to get back towards normal, I still have minor leakage but no worse than before I had the TVT fitted, and so long as it gets no worse I can live with that (started doing pelvic floor exercises in earnest).

Please join our support group on the message board

<http://tvt-messed-up-mesh.org.uk/phpbb/>