

**Senate Community Affairs Reference Committee on the Number of Women who have had Trans vaginal mesh and related matters inquiry.**

**Terms of Reference**

**1a. Who has had transvaginal mesh implants and 1b experienced adverse outcomes.**

My name is [REDACTED] I am 62 years old former Registered General Nurse.

On the 13/07/2009 I had a Vaginal repair for the repair of Uterovaginal prolapse, cystocele and rectocele with mesh. Where the uterus was pushed back up and [REDACTED] and [REDACTED] mesh inserted and sutured. Straight away I had pain which is to be expected post-operatively but it did not diminish at all. I was very careful post-operative and still the pain remained.

On the 22/07/2009 I went and saw my GP as I was having pain and my anti-inflammatory medication was altered to reduce the pain and the rash I had developed. I returned to the GP on the 29/07/2009 due to a continuation of the pain. I returned on the 11/09/2009 and was seen by my G P due to the pain. She performed a pelvic examination and found I had prolapsed and she referred me back to my first gynaecologist.

On the 30/09/2009 I was seen by my first gynaecologist for severe pain the result of the uterus coming down. She immediately booked me in for surgery.

On the 16/10/2009 I had a Laparoscopic Assisted Vaginal Hysterectomy performed by my first gynaecologist. The pain continued and was very strong felt like the front of me was being pulled to the back

On the 03/02/2010 I was seen by my first gynaecologist for the pain that I was having on the right side of Vagina and radiating to my anus. I had a pelvic examination and nothing was found

On the 15/03/2010 I was seen by my GP who wrote a letter to my first gynaecologist.

On the 16/03/2010 I was seen by my first gynaecologist who performed a pelvic examination and found that the right pelvic floor muscle was in spasm. I requested a referral to [REDACTED] a Women's Health Physiotherapist that I had seen in 2006 to learn how to do pelvic floor exercises.

On the 22/04/2010 I commenced seeing a pelvic physiotherapist at [REDACTED]. She did a pelvic examination and commenced me on a dilator. She also recommended that I start hydro therapy which I did

On the 04/10/2010 I saw my G P who wrote mental health care plan so that I can deal with my anger about the dodge surgery, not being able to nurse and the effect on my sex life. The pain that has tainted my last two years.

My pain has been present since the initial operation prolapsed in September 2009. I had the LAVH on the 16/10/2009, but the pain on the right side remained.

It felt like that the front and back was being dragged together and something sharp pushing into the top of my leg. I was more comfortable in the morning getting worse after I had been standing and walking for long periods. The pain was reduced by lying down. The pain score can vary from .5 to 5 over a day. I know that the pain isn't a large score but it is long term and can be a deep resonating pain at times you don't know what to do with yourself.

I commenced having internal physiotherapy in April 2010. I used a dilator and then a vibrator as a dilator to stretch the right side. I commenced hydrotherapy in October to relax and strength the pelvic muscles. It gave some relief but there was still the dragging sensation front to back. The pain felt sharp and rough as if something was being pushed in. The pain was also worse when I was sitting upright in a chair or driving, it depended on the tilt of my pelvis and I could not stand for long period. I avoided sex as it gave me pain during and I can end up with a deep resonating pain for days after.

I couldn't work and eventually I had to let my registration lapse as I wasn't able to do the mandatory updates required.

I desperately needed to have help as my life was just counting the hours until I could have my next lot of pain relief.

On the 11/10/2010 I went and saw a Psychology to discussed issues related to my pain and my life. It was a time I could be me and vent as I tried not to burden my family.

I finally got my GP to refer me back to the Gynaecologist and saw my first gynaecologist on the 2/11/2010 she listened to me with regards to my pain. She tested me for Vulvodynia and found that I was negative and planned to do an operation to separate mesh from the pelvic floor. [REDACTED] my husband, all my sisters and children family thought I should get a second opinion. I had wanted my first gynaecologist to admit that there was a major problem with the operations she had performed by the fact that it needed a third operation.

I saw my physio therapist on the 02/12/2010. I ended up quite sore after the manipulation of my pelvic floor. She gave me an article on the failure of mesh. This was the first time I became aware that it wasn't my fault and there was a problem with the mesh and the operations they were performing. I also obtained the names of 2 gynaecologists and booked in to have a second opinion.

I saw my second gynaecologist on the 01/02/2011 he agreed with me that I should have had my uterus remove in the first operation. He stated that he always removes it when he does the repair.

On the 14/02/2011 My second gynaecologist performed a division of the right anterior [REDACTED] mesh at the level of vaginal sulci. Both mesh arms were identified and excised with good mobility and a check cystoscopy.

This has reduced my pain to a level that I am no longer considering ending my life. I am still having pain but at a reduced level. I still have difficulty with sex and must make sure I have pain relief before and know that that I will have increased pain for two days after. I am very careful on what seats I sit on as hard seats push the mesh into my soft tissue and I will have walking after. This is a major problem with driving long distances as we have had my husband father living 4 hours away and we have had to make many trips as he was elderly.

The pain has affected how I have been able to be involved with my grandchildren as I have had when lifting them. It has made me feel unwell and stresses that I would normally cope are just too much.

**1c. Who has made attempts to have the mesh removed.**

I will never consider having the mesh removed as it would cause much more damage than have. I have no faith that Surgeons anymore as I feel the ones that I have encounter do not care about me and are only concerned doing the procedure and getting paid and if things go wrong they blame the patient. This my experience.

-The numbers of women involved would not be available as the Surgeons do not even acknowledge that there have been any failures. There is no following up.

-I have no knowledge of anywhere in Australia that is collecting this information. I contacted Shine Lawyers as soon as I was aware that they were considering doing a class action for the failure of mesh in vaginal repairs. I had to contact [REDACTED] Hospital and obtain my operation sheet which showed which type of mesh that I had inserted.

-The changes in the law that I would like to see that if any person required a second procedure to correct the first one. This operation had to be reported to a governing body. These statistics should be Australia wide and this data should be available for people to make informed consent, research and so that compensation can be given to people to get their lives back on track.

**My recommendations are-** The Surgeons should be held responsible for choices that they make with the type of implants that they use.

There could be a web site where there was a review of past performances of surgeons by qualified people.

I would like to see a site on the internet where was a table with the implants on it and the rate of failures and the type of complications that have resulted from their use. How is the patient able to make informed consent with no knowledge?

**2.Important Information provided to woman prior to surgery about possible complications and side effects.**

The information provided to me prior to surgery was very limited. My first gynaecologist said that there had been a problem with infection but that had been fixed by altering the size of the mesh. There was no other mention of any other complications. She did give me a very flash pamphlet produced by the company who produced the mesh. This had no reference to and adverse out comes. Her concern was explaining what she would be doing.

**My recommendation is -**

I would like an honest discussion about the reason for the choice of this procedure. I would have liked to know about the problem that people were having with the mesh. There could have been an Internet site which gives information on the comparison on the procedures that are performed. Recommendations on the reasons for doing one over the other.

**3. Information provided to Doctors regarding transvaginal mesh implants and possible side effects.**

-I have found that they (Gynaecologist) have known about the mesh but have not been very forth coming about the real implications of the mesh are. My General Practitioner knew about [REDACTED] and [REDACTED] mesh but said nothing about any adverse outcomes. Other Doctors in other fields have limited knowledge or none as they are only interested in their own area of expertise.

-I have not found out any information that the Doctors didn't already know they just hadn't said.

- I think that Doctors should be informed of any adverse effects but I have a problem with this responsibility being left to the manufacturers. I think that it must come from a source that has no vested interest. This would then have to come back to the Government. These departments would need to be well funded and have a sense of urgency.-

-For women to be able to have a conversation about the adverse effects of the Transvaginal Mesh with their doctors. The Doctors would need to listen and not to dismiss it. There must be a change in culture with in the medical profession. This could be done when they are training there should be more problem solving and active listening taught.

I think there should be an intermediary so there is someone there to prevent victim blaming.

**4. Any financial or other incentives provided to medical practitioners to use or promote transvaginal mesh implants.**

I have no evidence or do I know that Doctors have been provided with incentives. But I have wondered!!!!

**5. Types and incidence of health problems experienced by women with transvaginal mesh implants and the impact these health problems have on the women's lives.**

-The surgeons did not treat me as a whole person. They were only interested in what I come to see them about. There is no talk about reason for the prolapse and no investigation of any underlying factor.

I would like to see research into underlying conditions. I have wondered if it was due to my work as a nurse with the heavy lifting that involves. If so why haven't my friends had a prolapse, who as well are nurses. I have wondered whether it is genetic as my grandmother on my father's side had a very nasty prolapse. No questions were asked

-Pain was the most disabling side effect of the mesh. It had made me start planning my suicide. I had decided 20 to 30 years of severe pain was more than I could bear. I had started to collect the medications I thought I would need and had decided on the beach I would go to for my last swim. I was very matter of fact about it and this would say that I had severe depression resulting from the pain. That I would think this was a very sensible option. Looking back, I know if the third operation had not been the success it was I would have carried out my plan. I felt that I had no other options.

-I still have chronic pain but at a level that I can have a reasonable life. I am fortunate that I only need paracetamol every day and ibuprofen when I over step what my mesh allows me to do.

- My sex life has been impacted but with pain relief it is limited but my husband is very supportive.

-I can't stand for long periods or lift heavy things. That meant I could never return to nursing. I had finally found the area which I loved and that was Neonatal Nursing. It is one thing to retire because you want to but it is a very different thing to have to give it up because someone else did a very poor job that has effected your health and altered your life.

-Financially we are worse off and will have to rely on the aged pension. My husband is on the aged pension and we are also living off savings.

-It has altered how I have been able interact with my grandchildren as I have difficulty lifting and if I did I would be sore for days after. This then means that I must limit the amount of babysitting.

- I have disturbed sleep at night as I tend to have an inflamed pelvis, I must go to the toilet frequently at night to not have an over full bladder which causes pain.

- I now have an elevated CRP. It is no exceptionally high but I just don't feel well. I have been thoroughly investigated for other causes of the elevated CRP and nothing has been found. I wonder if it is my bodies response to the mesh.

- I must be mindful of what I sit on or in. I can't sit on anything cold as the cold tracks up the posterior arm of the mesh which gives me deep pelvic pain. I can't sit on anything too hard as it presses the mesh into the soft tissues and I then have trouble walking when I stand up. I can't sit up right for long periods this means that I have frequent breaks on long country trips. I can't for long a time sewing. This is frustrating as sewing is my special pastime that helps me cope and makes me feel good about myself. Writing this submission has required frequent breaks to recline in my chair to get off the mesh.

**My recommendation is** that doctors must speak to the patient in terms they understand and don't had out flash brochures as

## **6. The Therapeutic Goods Association**

Is an organise that I have had nothing to do with.

How did this mesh get approved? Was it based on research supplied by the companies that make the mesh?

**My hope** for this review that this department or a government department become involved with collecting Data about the failed operations and adverse outcomes. This way they would have information upon which to base their judgements.

### **7. Options available to have transvaginal mesh remove**

I have no knowledge about as I have been able to manage my pain.

I am aware that other people may not have that choice.

I know how long it took my second gynaecologist took to separate the tissues and to cut the right anterior [REDACTED] mesh at the level of vaginal sulci. This relieved the tension the mesh was under after the second prolapse.

To have had the mesh removed would have been a very long operation and I would be concerned about how much tissue would be damaged. There would be a long recovery.

Who would cover the cost? My second gynaecologist require \$2,000 up front payment. I had HBF cover but this was above that.

**My hope is** that there would a government web site that people could go to get accurate information.

This would be about operations that have had adverse out comes and ones that have been found to be successful.

That way we could all make informed consent.

**My summary** – I had an operation for a prolapse that involved pushing up the organs inserting [REDACTED] and [REDACTED] mesh and suturing it in. It failed. Second operation to remove the uterus. Severe pain still present.

The mesh that had been inserted in one place had moved due to the failure of the first operation. It did not go back in to the correct place after the second operation!

The mesh that was inserted was not soft enough I could feel its edge pushing into the top of my leg and when I sat on any firm surface I could feel it pushing into me. It felt like I was sitting on a mesh fly swat!!! I was pulling my front to the back.

I had a third operation performed by another surgeon who cut the front right arm of the [REDACTED] mesh which release the front to back tension. I still had the pain from the mesh itself.

My frustration was with the first surgeon not listening and prolonging my misery and her choice of a procedure that was flawed or that she had left out the removal uterus to save time and make more money by having to do a second operation???

I would like to see that there is a review is done once a repair operation is needed. That way a lot more information would be obtained from all these experimental operations.

I think there should be a website where accurate information on procedures are posted. So that we can give informed consent.

Patients could post any adverse out comes without having to go through a formal complaint. When they are just trying to keep up with life which keeps going

regardless how much pain you are in. Review of the Doctors performance. This is already happening with the generation coming after me.

There needs to be a review of how these products come into the country or are they all fools or are they underfunded? What are there judgements based on? Not data from failed operations like mine as no one has collected that.

I would also like to see research into under lying causes such as heavy lifting, types of deliveries which have less impact on the women and family genetic predisposition. More knowledge of the pelvic floor its function and structures.

## **Hear Say**

1.I was talking to a friend and she was saying that she had to have a prolapse repair. Of course, I told her of my poor outcome with mesh. She said that her Surgeon had told her that she only puts mesh in elderly women who are not sexually active.

This indicates that some Surgeons are aware of the problems of the mesh and are taking measures.

2.My friend went to visit a friend in hospital and she had had a prolapse repair and was in a lot of pain and had mesh inserted.

This indicates another Surgeon either don't know or chooses to insert the mesh for a more convenient procedure.

3.My minister's wife went and had surgery with my second surgeon while I was away sick. I had been going on for years about my issues she obviously had been smiling and nodding at me and not listening. She was about to have her third operation when I stopped going to church.

This surgeon teaches the insertion of mesh so he has a vested interest.

4. I was having blood taken the other day and I mentioned that I had to give up nursing because of mesh. I take every opportunity to mention to woman in my age bracket about my story with regards to mesh. The nurse said that a very dear friend had been on strong antibiotics for over a year as her mesh had been infected since insertion.

This indicates very poor surgical procedure or that this surgeon carries a bacterium.

**Thank you for the opportunity to have my say.**