

Submission to Senate Community Affairs References Committee

I am writing this submission as a result of my personal experience of the effects of transvaginal mesh implants.

Name and contact details

Name

[REDACTED]

Address

[REDACTED]

Date of Birth

7/9/44

Contact number

[REDACTED]

Email address

[REDACTED]

State New South Wales



Postcode

2035

Terms of Reference 1: The number of women in Australia who have been impacted

1. Have you or a family member had a transvaginal mesh implant?



If Yes, please share your experience:

pro-lapse caused me to get mesh implant, however I was not advised of this before the operation. Drs advised that I would get key hole surgery. ~~This~~ I was advised the operation would be 17/5/07. However this was canceled and rescheduled to 6/9/07. This was canceled and op. was done March 2012.

2. Have you or your family member experienced adverse side effects as a result of the transvaginal mesh implant?
(full details are provided at Terms of Reference 5, below)



If Yes, please share your experience:

Constipation and trouble controlling urine.
-feeling unwell and sick in the tummy.
-bloating, causing unsettled sleep patterns.
strain on mental health as unable to leave the house incase of toilet accidents.

3. Have you or your family member had the mesh removed or made attempts to have the mesh removed in Australia or elsewhere? (full details are provided at Terms of Reference 7, below)

Yes

No

If Yes, please share your experience:

4. Do you have any suggestions or recommendations about changes to laws, policy and practices in relation to transvaginal mesh implants or similar products?

Yes, I would not recommend anyone getting this done in the future.

Terms of Reference 2: Information provided to women prior to surgery about possible complications and side effects

1. What information was given to you or your family member prior to surgery to implant the transvaginal mesh?

I asked [REDACTED] to explain to me through a picture what surgery ~~that~~ he is going to do. I have included a copy of the picture where he advised me he was going to do key hole surgery. Labelled number ①. I was advised it would be day surgery and I was in hospital for 2 weeks.

2. How was this information provided to you? (eg. brochures, verbally, websites)

Through a picture (see picture 1)

3. Do you have any suggestions or recommendations as to what information you think women should receive before they receive a transvaginal mesh implant?

Again I would not recommend for this to be done to anyone in the future.

Terms of Reference 3: Information provided to doctors regarding transvaginal mesh implants and possible complications and side effects

1. What is your experience of doctors' knowledge of transvaginal mesh implants, complications and side effects?

Not to my knowledge did the Dr know anything about the side effects or complications.

2. Have you found information about transvaginal mesh including complications and side effects that your doctor (GP or specialists) was not aware of?

The Dr did not tell me about any side effects or complications, only seeing what other people have gone through I related my side effects to the mesh.

3. Do you have any suggestions or recommendations about what information you think doctors should be provided with in relation to transvaginal mesh?

I feel it is the Dr's responsibility to be aware of complications and the materials he is using. More research should of been done to prevent complications and further damage.

4. How could women adversely affected by transvaginal mesh implants tell their stories to doctors?

The Dr's need to listen and accept that the product they are using is causing damage and lifelong heartaches. Many times I have felt like the Dr did not want to listen and take responsibility.

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Terms of Reference 4: Any financial or other incentives provided to medical practitioners to use or promote transvaginal mesh implants

1. Do you know of or do you have evidence of incentives being provided to medical practitioners to use or promote transvaginal mesh implants?

No

2. Do you have any suggestions or recommendations about the provision of incentives to medical practitioners for using or promoting transvaginal mesh implants?

It's wrong! The patient would have no idea it's happening.
You would not have the operation done with that product.

Terms of Reference 5: The types and incidence of health problems experienced by women with transvaginal mesh implants and the impact these health problems have had on their lives

1. This is the opportunity to tell your and/or your family member's story about how transvaginal mesh implants have affected you and your family. These impacts do not have to be limited to health issues but may also extend to issues around relationships, finances, employment or any other part of life that has been affected.

See attached.

AFFECT ON YOU

Prior to the implant I had a prolapse. So I saw [REDACTED] and he told me he would do key hole surgery to repair it and i would likely be overnight stay (see diagram). If I had known what they were really going to do I never would have agreed to it. ①

I was on a waiting list so had to wait several years. After the operation there were complications and I had to stay in hospital for a while. When I woke up from the surgery I was in pain. It felt like something was stitched too tight, or something was caught as i felt pain in my lower back everytime I moved. I couldn't use my bowels, I couldn't eat and i felt sick, my blood pressure was high. After the operation [REDACTED] explained to me what they did (see diagram). He told me about the mesh implant and that it caused bruising to my bladder. ②

When I came home from hospital My health was much worse after the operation and I because of it.

i kept needing to urinate, can't sneeze or cough as I lose control,

and my bowels were still not functioning, I need to go but then can't

had to wear a pad all the time as it was leaking

sleep disturbances, difficulty getting to sleep and getting back to sleep

high blood pressure

lost weight

still feeling sick

feel not confident to leave the house

I kept going back to the doctors to try to fix things.

I did several programmes to get some relief with the urine problems such as Pelvic floor programme, i had to hire an Internal Electrodes - Vaginal Probe and did a Urodynamic Study. These were a waste of time and money as there was no change after everything.

AFFECT ON FAMILY

It has been very difficult on my family as I often feel like I burden them with the brunt of it. I take my frustration out on them, and feel like all I do is feel miserable and consumed by the health problems. They are supportive and help to keep me going when all I want to do is crawl back into bed.

MENTAL HEALTH

Affects my lifestyle because of my health problems. I often feel trapped and isolated as I am embarrassed about not making it to the toilet in time and having to wear a pad all the time. It is difficult to want to leave the house. I am always worried about being close to a toilet and carrying a

change of underwear in case I don't make it. I worry that I smell when my bladder leaks and I feel ashamed.

These health problems with my bladder and bowel cause me frustration and create mood swings and which makes me snap at family and friends and I just want to crawl in bed and cry. My quality of life is low. I had plans to travel to Ireland and see where my ancestors lived, but that dream has been taken away from me.

Some days I don't feel like getting out of bed, but with my urine and bladder issues, I can't even do that.

RELATIONSHIPS

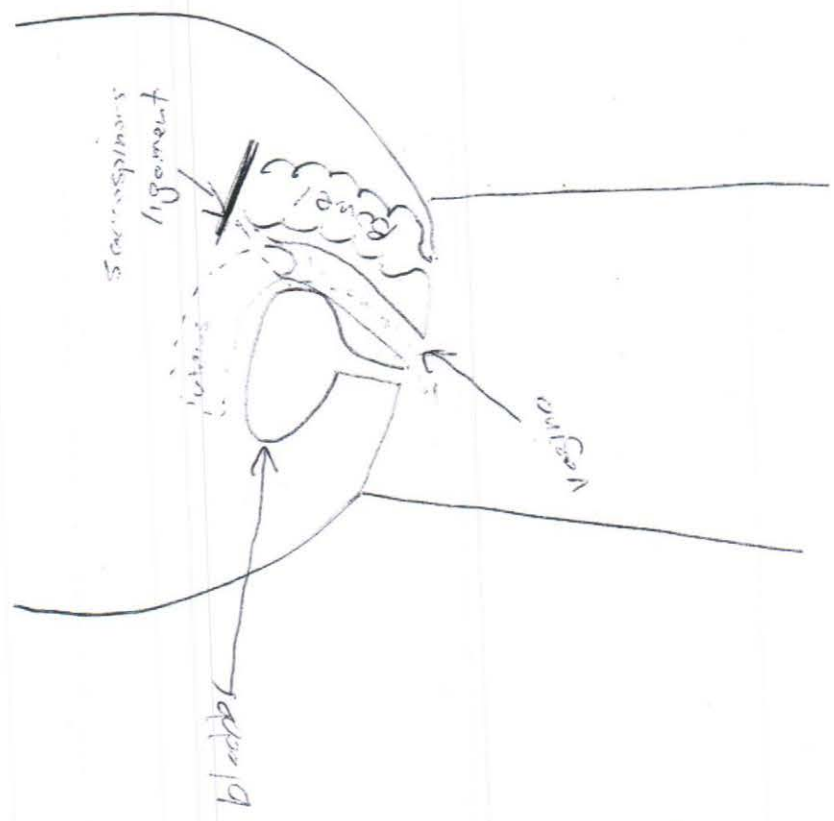
After I recovered from the operation, I tried to be intimate and used lubrication but it was incredibly painful and felt too uncomfortable to continue. I have been unable to be intimate with my partner of 40 years since the operation. This has put an enormous strain on our relationship. If you can't have intimacy in life then life is pretty miserable. Where is the quality in life.

ANY OTHER

i have always enjoyed going to my family tree meetings each week and volunteering at the library, but since the operation it has been extremely difficult. I have found it hard to stay focused and enjoy my research and social side as I am constantly worried about whether I will have an accident and not make it to the toilet or soil myself. I am left feeling isolated and alone.

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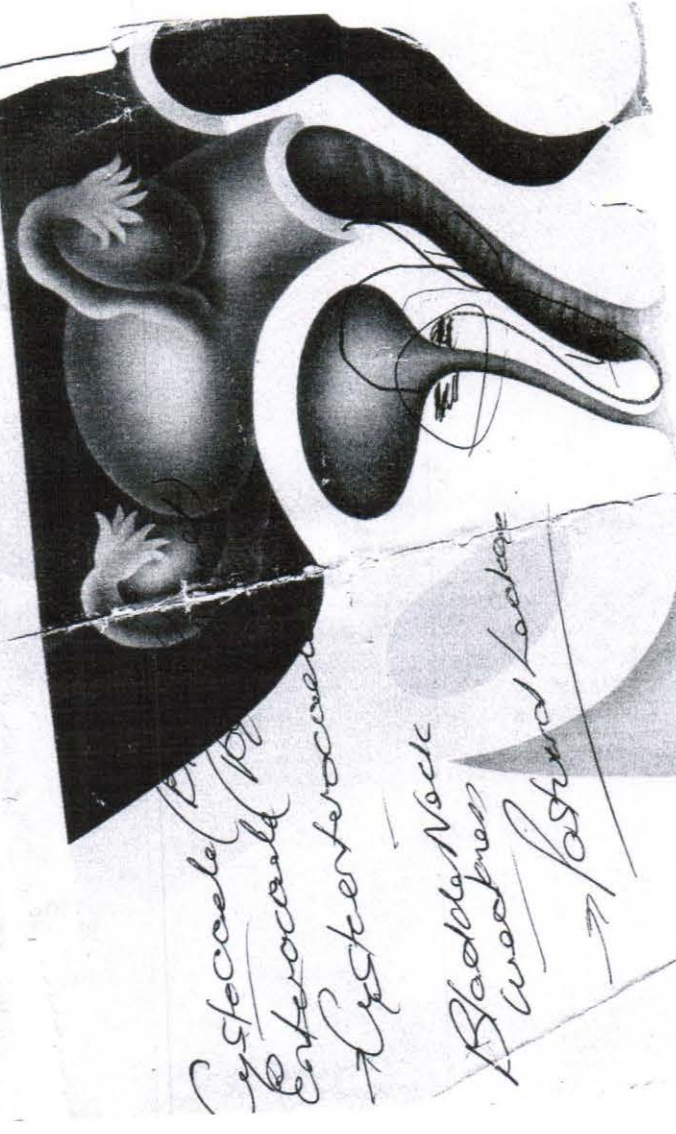
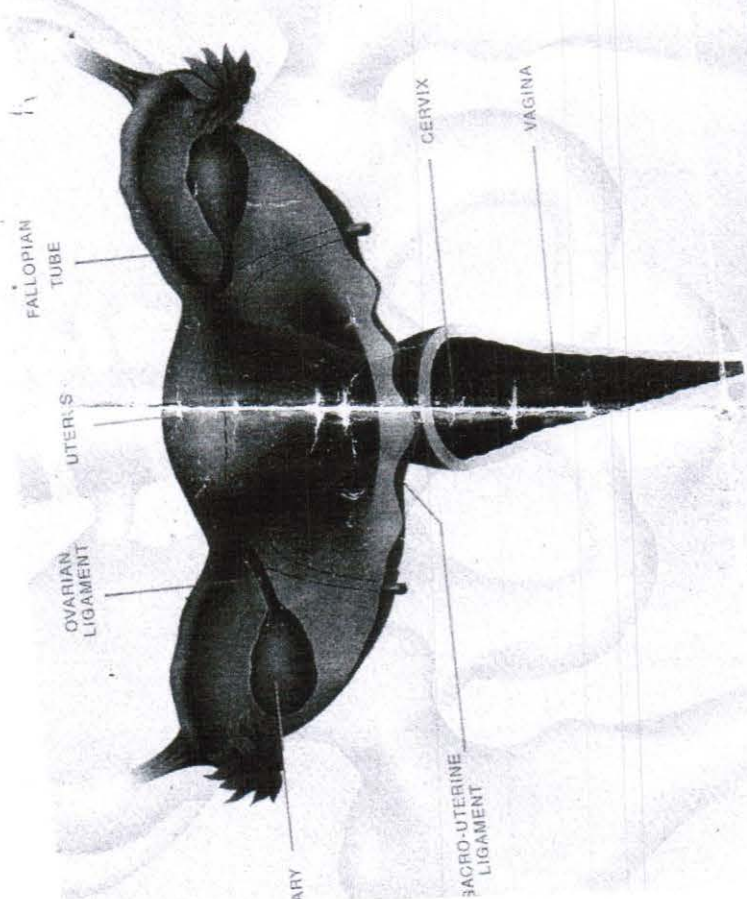
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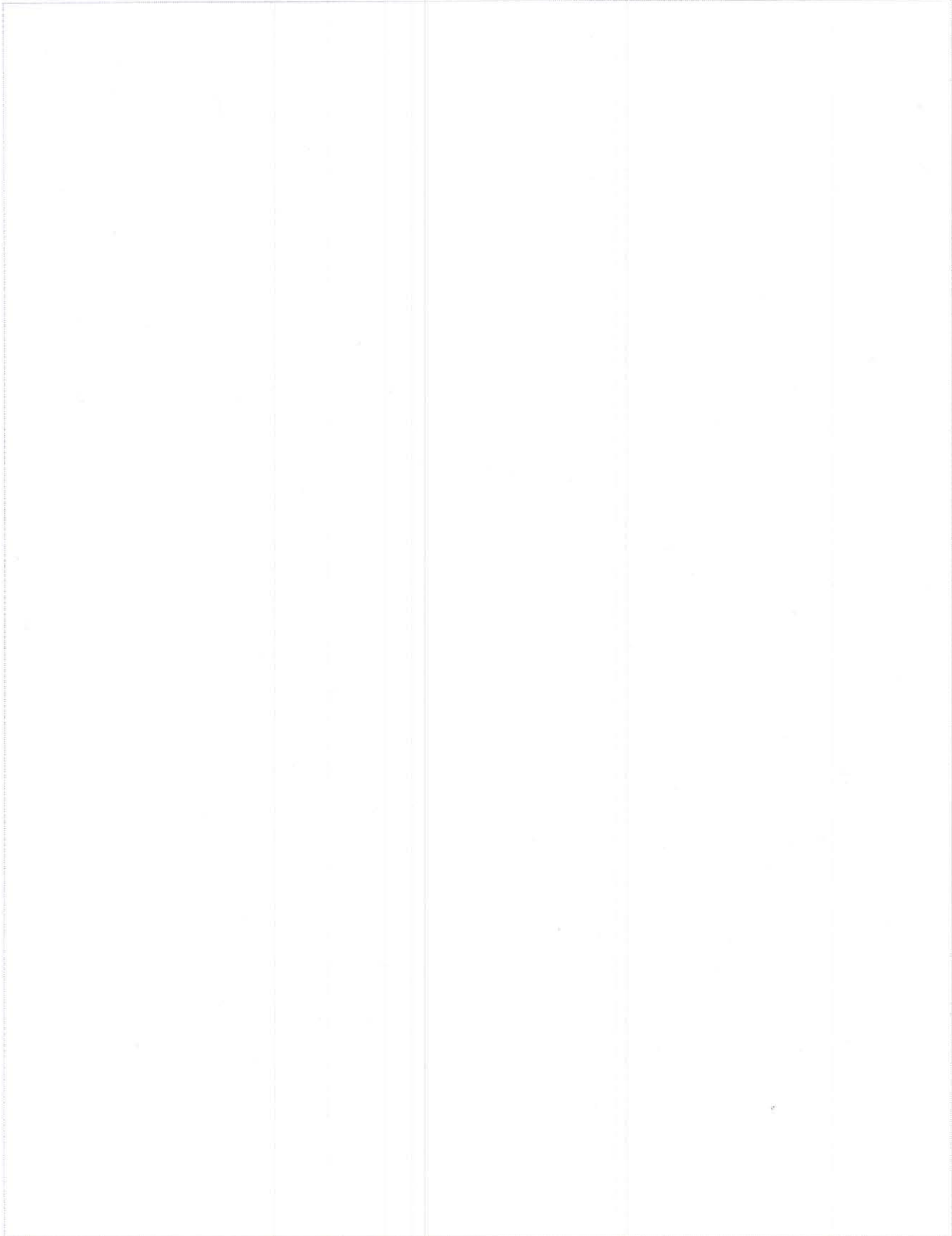
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Terms of Reference 6: The Therapeutic Goods Administration's (TGA) role in a) investigating the suitability of the implants for use in Australia; b) ongoing monitoring of the suitability of the implants; and c) knowledge of women suffering with health problems after having transvaginal mesh implants

1. What experience have you had with the TGA?

Nil

2. What do you think of the current work the TGA is undertaking in this area?

Not known

3. What is needed to improve the work of the TGA in this area?

Not known

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4. Are there other government agencies (apart from the TGA) who could or should have a role in this?

Not known

5. In your opinion, is there anywhere (in Australia or internationally) that does a good job in these areas?

Not known

6. Do you have any recommendations about changes that might be needed to laws, policy and practices in relation to regulation of medical devices in Australia?

I don't believe there has been enough investigation in relation to its use in women and to the risks or problems associated with it. Even after these products were used and women spoke of problems they experienced, these products were still being used in operations. They are still being used today. I think it's a disgrace. These poor women, ruining lives of mothers and women when they know about the problems.

Terms of Reference 7: Options available to women to have transvaginal mesh removed

1. What is your experience of trying to have transvaginal mesh removed?

I was told it is final and cannot be removed or fixed.

2. Do you know of anywhere (in Australia or internationally) where it is easier for women to have mesh removed?

NO.

3. Do you have any recommendations or suggestions about what would make it easier for women seeking to have mesh removed in Australia?

There needs to be a support clinic setup to help the women affected. To provide answers and assistance, both mentally and physically to create hope for their futures. A way to get their lives back, in some way, so that they don't feel alone and isolated. Remember the problems created are delicate subjects for most women to discuss.

Are there any final comments you would like to make?

Please stop using these products NOW.

They are aware of the problems women are having due to these mesh implants, but the women are not told about it before they have the operation. The doctors should be made to disclose the statistics, with the knowledge I'm sure no woman would agree to it if they were told about it before.

Submissions can be made to the Committee in writing by 31 May 2017 and should be sent to the Committee Secretariat contact:

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Phone: +61 2 6277 3515
community.affairs.sen@aph.gov.au

If you would like more time to finalise your submission, an extension can be requested by emailing the secretariat at community.affairs.sen@aph.gov.au or telephone on 02 62773515.