

Transvaginal mesh problem grossly under-estimated

True picture finally beginning to emerge

THIS is the view of leading Vic consumer health advocate, Health Issues Centre (HIC), following an online Facebook survey* targeting thousands of women nationwide who have undergone pelvic mesh implants to treat stress urinary incontinence and pelvic organ prolapse.

In just three weeks 1,250 women have completed the survey.

Of these, a shocking 58% say they have been adversely impacted, citing problems such as chronic incontinence, abdominal pain and pain during intercourse. Sadly, for a quarter of these women, the impact of the implants has led to a breakdown of their marriages or personal relationships.

Just 38% of the respondents believe they made an informed choice to have the procedure.

Of the women who sought remedial medical assistance, slightly over 10% reported this made things better while 40% reported it made no difference and 11%, that it made matters worse.

The remaining 39% were told that nothing could be done for them.

The HIC has undertaken its research to better inform its submission to the current Senate Inquiry, established by Senator Derryn Hinch. The inquiry has been set up to attempt to estimate the extent and impact of mesh implants in Australia.

Commenting on the overwhelming response to the survey, HIC CEO, Danny Vadasz, says he has no idea 'how much of the iceberg has been revealed' so far but believes there could be considerably more given that HIC is currently averaging over 100 survey responses per day.

"Even if we were to receive no further responses, I think we have already demonstrated that this is a significant public health problem which has been grossly under-estimated - in terms of numbers of women as well as the severity of resultant health problems.

"What we are seeing is a catastrophic failure at all levels of the health system to protect the well-being of thousands of women - the lack of due diligence by the TGA in approving the device given the risks; culpability of manufacturers who despite plenty of evidence of adverse reactions overseas, continue marketing their products; the government which does not have a central register of how many procedures have occurred and how many products have been sold and finally, those surgeons who continue to practise the procedure without informing their patients of the risks and the irreversibility of the implant.

"Clearly a lot of questions need to be asked!"

Mr Vadasz says while transvaginal mesh has been seen by the medical fraternity as having 'revolutionised' surgical options for women with stress urinary incontinence and pelvic organ prolapse, the collateral damage for women when it goes wrong, is just too high. "We are calling for the classification of mesh to treat either of the conditions to be upgraded to a higher risk status so the patient consent process reflects the consequences when there are complications."

Mr Vadasz attributes the success of the HIC survey to its ability to provide women with strict anonymity. "Women are reluctant to self-identify given the personal pain and heartbreak they have undergone and the intimate nature of their disclosures.

"We felt it was essential to create a safe place for women to disclose the full extent of their experience without having to sacrifice their privacy. In fact, this was all that was necessary to release a tsunami of feedback!"

Despite the number of women coming forward, Mr Vadasz believes that the problem will continue to go underreported given that many women do not associate their symptoms with their mesh implants. On top of this, many have been told by doctors there is no causal relationship.

"This has been borne out by the significant number of survey respondents who told us they were unaware that the pain and problems they had suffered for many years could be linked to their mesh implant. Some have cried at the realisation with one woman declaring, 'Now I know I'm not crazy'."

Here are some of the more harrowing comments on the HIC Facebook page:

"My specialist told me it was all in my head. He got angry with me and said: "I suggest you stop focussing on the vagina, and get on with your life" in a dismissive and irritated tone. Doctors I have seen since have not been forthcoming on what they can see, it is like they are trying to protect the medical fraternity by not telling me fully what is going on or helping me find treatment."

"I was told the mesh cannot be removed. I had complications from the moment I came out of theatre. I needed a complete reconstruction but was refused and offered the TVT as part of a study or to put up with consequences of a grossly oversized baby that was a face presentation and a complete episiotomy after he became stuck. I now suffer urge incontinence and a partial vaginal prolapse. I wish I'd never had the TVT done!"

Mr Vadasz is calling on women who have had an implant (or believe they may have) to complete the HIC survey:
<https://www.facebook.com/pg/UnderstandingPelvicMesh/about/>

*More information about the survey The Health Issues Centre is one of several organisations invited to provide input into the senate inquiry into the extent and impact of Transvaginal Mesh Implants (TVM) across Australia. Currently there is little information about the number of women who have undertaken the procedure and less about those who have suffered from side-effects. In order to understand the magnitude of the problem and gain insight into the impact on these women, the consumer health advocacy conducted a highly targeted nationwide survey.

Using the centre's Facebook page to create interest and an online survey, the survey targeted 14,000 women nationally.

The questions are as follows:

- Have you undergone a transvaginal mesh, tape or sling implant as treatment for urinary incontinence or pelvic organ prolapse?
- Do you continue to have undiagnosed symptoms of chronic abdominal pain or urinary incontinence?
- Do you feel you were fully informed before agreeing to the procedure?
- Did the procedure satisfactorily resolve your health concerns?
- Could you specify any adverse impacts you may have experienced?
- How would you rate this adverse impact - discomforting, severe, debilitating, unendurable, none of these.
- Have you sought medical assistance to rectify the problem?
- Did your doctor/specialist confirm a causal relationship between your symptoms and the mesh implant?
- If you were offered remedial treatment, did it change your condition?

While launched only three weeks ago, 20,000 have engaged with the survey and 1,250 surveys have been completed. Over 14,000 people have viewed the Facebook video.

The findings to date show that:

- 1,250 women have completed the survey
- 73% of the 1,250 respondents have undergone mesh implant. Another 8.4% aren't sure.
- 40% of respondents believe they were not fully informed before agreeing to the procedure. Another 21% felt they were misled, leaving only 38.5% that believe they had made an informed choice.
- Only 43% women considered that the procedure had resolved their related health concerns.
- 58% say they have been adversely impacted. Of these, 76% cited incontinence, 58% abdominal pain, 55% pain during intercourse and 25% breakdown of their marriage or other personal relationship.
- 33% of women reported their adverse impact as "discomforting" while 32% said it was "debilitating" and 12% "unendurable".
- While 62% of these women sought remedial medical assistance, only 10.6% reported this made things better. For 40% it didn't make any difference while for 11% it made matters worse. 39% were simply told there was nothing that could be done.

48% of respondents were over the age of 60.

More about HIC ... it is a not for profit Vic based consumer health advocate which encourages better health outcomes by encouraging consumers to become involved in their own health care and ensuring the health system is responsive to their needs.

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