

Informed Consent

LOVE, SEX & RELATIONS

Urinary incontinence is a reality for a large proportion of women after childbirth. It is limiting, preventing women from being physically active. Women live with varying degrees of embarrassment caused stress incontinence. Fortunately, there are surgical procedures which help, but as one woman found, the price might be too high to pay Lynn

Massey-Davis tells why she opted out of the operation to cure her urinary incontinence and why, ten years later, she is happy with her decision.

The notion of informed consent to participate in medical research was, I believe, developed as part of the Nuremberg Code following the trials of those responsible for medical atrocities practiced upon holocaust victims of WW2. The increasingly reliable internet source Wikipedia, defines the concept of informed consent in the context of modern medical care clearly and succinctly as:

“is a legal condition whereby a person can be said to have given consent based upon a clear appreciation and understanding of the facts, implications and future consequences of an action. In order to give informed consent, the individual concerned must have adequate reasoning faculties and be in possession of all relevant facts at the time consent is given”

I am 48 years old like many who have given birth to three children, I have a weakened bladder, sometimes leaking urine which depending upon the context, can be embarrassing. The technical term is stress urinary incontinence in that it only happens when the neck of my bladder is put under stress – when coughing or such like. It is not an uncommon condition and one thankfully which is now easy to talk about, especially since “yummy mummies” like Ulrika Johnsonn have confessed to sharing the same problem.

Like many middle-aged women I give thanks for the new openness,

availability of a range of products and do my pelvic floor exercises with religious fervour and obligatory grimacing. Alongside this I have given up all hope of being able to go to an aerobics class again, fear chest infections as much as the plague and watch with envy when my husband plays on the trampoline with the kids.

As “my problem” as I euphemistically described it, became a bit worse and I changed jobs for one where unfortunately managing toilet breaks became more tricky, I decided to seek medical help. After some tests which were invasive, but sensitively administered at hospital, I was offered surgery in the form of a transobturator tape. The tape is inserted via a small vaginal incision and sits under the urethra and in most cases, dramatically improves stress urinary incontinence. It was a “no brainer” and I went ahead and accepted the offer of elective surgery.



"I decided not to go ahead with surgery to correct my stress incontinence and I have never regretted that decision"

I began to look at the trampoline in the garden with a sense of excited anticipation, it all seemed so easy, or so I thought. Last week, a few days before the surgery was due, I went for the usual pre-operative assessment. I was tested and talked through the surgery and I was given a detailed leaflet to take away and refer to.

Later that evening as I read through my leaflet, I was a little confused about one aspect of it, so I decided to consult a women's health resource on "The 'Net'" to sort out my fears. What I found as a by-product of my search were logs on a few sites from women who had had dramatic and unwarranted side effects from the surgery mainly connected with their sexual health. Having a higher research degree and currently teaching research methods to A level psychology students, I know about the lack of reliability (in scientific terms) of such accounts and how, although distressing, these cases could be of miniscule risk in the overall scheme of things. I therefore trawled the internet for several hours searching for papers and abstracts only from peer-reviewed journals such as *The Journal of Sexual Medicine* and *The American Journal of Obstetrics and Gynecology* to trace the veracity or refute these claims.

A story unfolded however, that made me feel concerned enough to want to go back to the consultant who was about to operate on me and seek clarification. I had uncovered potential side effects of the surgery which weren't mentioned to me at any stage of my care, nor was it listed in a comprehensive table in the leaflet I was given by the hospital covering 12 possible side effects with frequency of occurrence between 20% down to less than 1% incidence.

I found in my search, many papers relating to sexual dysfunction following TOT surgery. The causes of dysfunction were attributed to a mixture of causes both psychological and physical, including pain on penetration and a loss of ability to achieve orgasm through clitoral stimulation (which was the symptom of the poor woman whose distress she had chosen to share with an anonymous website and had sent me on my original search for more "scientific" research.) In one study by Elzevier et al (2008) which was typical of the rest, a study of 44 women who had had the TOT procedure a questionnaire follow-up at 4 months after surgery, 6 of respondents (15.8%) had answered in the affirmative the question:

"The sensibility of my clitoris is less since the operation"

and a staggering 20% reported experiencing pain on intercourse due to vaginal narrowing and 10% of male partners also recorded some discomfort with penetration.

There are of course, degrees of urinary incontinence and some poor women may not feel they have a choice if they want to have a "normal" life. My "problem" was in a different league, so I took the papers to my surgeon to discuss the findings with him. He was aware of the research and response was that when nerves are cut, as they would be during this surgery, then there would be damage which no one could assess the degree to which they would repair fully or not. He was frank and honest and said – sometimes they don't.

I asked if at any stage this potential side effect would have been discussed with me when I was giving my consent for surgery. He said, it would not have been mentioned because being incontinent was of more concern to patients than ability to have fulfilling sex and it was taken as read that this was so with me.

Thinking of widowed relative of mine who had had a good sex life well into her late 70's until her husband in his mid 80's had died, I gathered my papers together and saying to the consultant "I'd rather be wet than risk losing my sex life, see you in 30 years!" I left, with Elzevier's (2008) concluding comment ringing in my ears:

"This study demonstrated that the TOT... could have both a positive and a negative outcome on sexual function and that it is of importance to discuss this issue in informed consent"

The point is that while this procedure is quite literally a life-saver for many women, informed consent has to be just that and I wasn't offered it.

I feel as light as a bird, albeit one with slightly aged and ruffled feathers. Beautiful, sexually-active and grateful for my lucky escape.

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Reference:

Elzevier HW; Putter, H; Pelger RCM; Dleare, KPJ; Venema PL, Lyklama a Nijeholt AAB; **“Female Sexial Function after Surgery for Stress Urinary Incontinence: Transobturator Suburethral Tape (TOT) vs Tension-free Vaginal Tape Obdurator (TVT-O) J.Sex Med 2008; 5: 400-406**