



SOCIAL DEVELOPMENT COMMITTEE

SURGICAL IMPLANTATION OF MEDICAL MESH IN SOUTH AUSTRALIA

Old Parliament House Chamber, Old Parliament House, Adelaide

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(OFFICIAL HANSARD REPORT)
PARLIAMENT OF SOUTH AUSTRALIA

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MEMBERS:

Dr R.M. Harvey MP (Acting Presiding Member)

Hon. C. Bonaros MLC

Hon. E.S. Bourke MLC

Ms P.M. Luethen MP

Ms D. Wortley MP

WITNESSES:

CHELSEA

EBONY

JACOB

JOHN

SHARON

[Via videoconferencing]

426 The ACTING PRESIDING MEMBER: Thank you for appearing before the Social Development Committee this afternoon. Due to the current situation concerning COVID-19, the committee has resolved to exclude strangers from the gallery. The proceedings will be broadcast to the public online via the Parliament SA website.

A transcript of your evidence today will be forwarded to you for your examination for any clerical corrections. Should you wish at any time to present confidential evidence to the committee, please indicate and the committee will consider your request. I advise it has been resolved that names of doctors, specialists and hospitals involved in individual cases should not appear in evidence. Witnesses, media attending today and all listeners via the internet are asked to abide by these determinations.

Parliamentary privilege is accorded to all evidence presented to the committee and therefore protects the witness from any legal action arising in regard to that evidence; however, witnesses should be aware that privilege does not extend to statements made or documents circulated outside of this meeting. The committee will consider any documents presented to it and will determine whether the documents be received and form part of the evidence.

I advise for the purposes of the transcript that your evidence today is being heard via video link. I further advise for the transcript that the following people are present in the room in Old Parliament House for the hearing of this evidence, which for the moment is just us.

I will introduce the committee now: to my left is the Hon. Emily Bourke, member of the Legislative Council; Ms Dana Wortley, the member for Torrens; and Mary-Ann Bloomfield, who is the research officer for the committee. My name is Richard Harvey and I am the Acting Chair and member for Newland. To my right is Ms Robyn Schutte, the committee secretary, and to my far right is Ms Paula Luethen, the member for King. If you perhaps start with an opening statement, if you like, then we can get into some questions after that.

SHARON: Good afternoon to you all. My name is Sharon. I present this document as my account of the effects and impact that medical mesh has had on my life. Since having this procedure on 6 March 2015, my life has never been the same. It has progressively got worse over time and continues to be today. I have had reoccurring urinary tract infections, which happened from the very start and continues to happen, with many more problems occurring since this operation took place. I have attached a separate list for reference, which I believe you have access to.

When discussing the procedure for 6 March 2015, being for an interior repair and a suburethral sling and cystoscopy, I was never told of any side effects. There was never any mention of it being mesh or even a mention of it being a permanent device. He said it was a quick and easy procedure, worked well for stress urinary incontinence, and a quick recovery. This procedure has turned out to be the complete reverse. Yes, maybe I should have asked more questions, but I put my trust and life in this man's hands, thinking he would have my best interests at heart. Can I ask where his duty of care and professional advice as a gynaecologist and surgeon was? Scary stuff, to say the least.

After this procedure occurred, my recovery was nothing but eventful and painful. Fluids were pushed excessively and I had a large atonic bladder and trouble voiding. I remember passing some blood while trying to void and being in a lot of pain and discomfort and required re-catheterisation on several occasions. I had a catheter left in on discharge for another week.

During the week after being discharged, I presented myself at the outpatients at the local hospital with my daughter and a very close friend who drove us, feeling very unwell and having blood and some clots in my catheter. I had a urinary tract infection and was treated with two courses of Noroxin. I was feeling very worried and anxious about it all.

I feel that I have been robbed of my old life and have been emotionally, financially, physically, mentally and sexually scarred for life, not to mention the impact it has had on my personal, social, employment and family life. I am not the same person. In the past 4½ years, I have had multiple scans, ultrasounds, blood tests, UTIs, PRP injections, colonoscopies, an endoscopy and multiple other things as well—too many to mention.

Financially, having to cover the ongoing medical bills for all these appointments and medication has had a crippling effect on my life, my partner and family, which has created more debt and stress on our everyday lives. I recently had a part removal of this foreign-body mesh on 14 November 2018 after seeking further advice from another urogynaecologist. It was pulled too tight and I also had a lot of scar tissue. He removed part of that device but it really hasn't helped that much since.

I was employed in my workplace as a supervisor and loved my position. My income has been a big loss to my partner and I. I had my first appointment with the Royal Adelaide Hospital mesh unit—I know you said don't mention the hospital—on 27 August 2018, after quite a lengthy wait. I understand there are a lot of people who have serious problems and need to be seen sooner and that the clinic is only new. This new clinic has been progress, of course, for all mesh-injured patients, and we did get an apology from Greg Hunt and a register put in place for future mesh and other devices last year, but what about the thousands who are already suffering from these devices?

There just seem to be brick walls standing in the way of many other avenues that we need help and support with now; for example, disability pensions, healthcare packages, carers' pensions for the many partners who are trying to adjust also, and access to our super regarding the mesh nightmare that many of us live with now every day of our lives. There are numerous things that could be done and everyone that is involved in the creation and use of these products needs to be held accountable so it never happens again.

Following on with my current health problems, I now have issues with my hips, and incontinence with bladder and bowel, which is embarrassing and life changing as it creates a problem not only at home but also dealing with many issues of finding toilets urgently when you have to go out. At 53, I now wear incontinence pants for both urine and faecal problems—definitely not where I saw myself being at this time of my life.

My depression is a lot worse and my physical activity and weight gain are also a contributing factor. I also have brain fog from the numerous amounts of medication I take. I have trouble with walking, sitting, standing, stairs and can only pace myself differently each day. I now rely heavily on my partner to do almost everything, as I no longer can manage normal day-to-day chores. This has been extremely hard on John. He has given up his full-time employment to help me. My life has changed in so many ways, and it has left nothing but devastation on every level. It is not only my eyes that are crying now for so many reasons but my whole quality.

I have so much more I could say but am feeling very gutted and sad for myself and the many other victims of this mess. I hope and pray that no-one else has to endure the pain and the

adverse reactions that so many of us have, worldwide. How dare these health professionals tell us it's not the mesh. I understand they take a code of practice, but what about their duty of care to their patient? I no longer have the same faith left in this health system we have in place at the moment and truly challenge where our rights are as a consumer. Thank you for listening.

427 The ACTING PRESIDING MEMBER: Thank you very much; we very much appreciate that. Ebony, would you like to provide your statement now.

EBONY: Yes. I write this letter as my firsthand experience that mesh has had on my family, in particular my loving stepmother and my devoted father. She is a loving, caring, energetic, loyal and fun woman. She enjoys life and all it has to offer. I have seen the effects of mesh greatly impact her quality of life, particularly over the last two to three years, as she has been forced to stop work due to the issues mesh has caused her physically and mentally. She enjoyed her retail job, often telling us stories of her customers through the day, whom she loved having chats with, and of the displays that she would spend her days so lovingly creating.

Over this time I have seen a decrease in joy and happiness not only from her but also from my father. The burden from the medical costs and government's incompetence and beyond has financially left them high and dry. Ongoing costs of medical appointments, medication, travel to and from appointments all over the place are just ridiculous. With no help, it's just appalling. Thoughts have been thrown around of selling their beautiful property as they can no longer financially afford the repayments. Both are very keen gardeners and have put their heart and soul into their gardens, veggie patches and more. I would hate for them to have to give up everything they have and continue to work so very hard for.

Some days I see her and I just wish that I could take it away from her. She is not the person that she used to be and, unfortunately, she can't do the things she wants and once used to do with no troubles at all. I can see the pain in her when she walks, sits or even moves, and it is not fair for anyone. While I might not be the most knowledgeable person when it comes to mesh, I understand what it is and how it's affecting people. Thousands and thousands of people are without work and in pain every day of their life, unable to really live and without the quality of life that any human so truly deserves. It pains me to say that she is one of these people.

She is my stepmother but she has never treated me anything less than her own. I know she wants to help me in every aspect of my life and my partner as we grow together and start new stages. One day we hope to have children, and it upsets me to think that she might not be able to play with and love them the way I know she will and wants to.

Mesh has so clearly impacted her life in every single aspect of it. I wish that her and others fighting this battle can get the help that they need and so truly deserve. Financially, the government and the healthcare system need to step up. The medical industry also needs to lift their game, recognising that it really is an issue and that these people need the medical assistance without the price tags.

These are people, human beings, and to not help them when they are in desperate need unless they pay the ridiculous costs associated is outrageous. The fact that they cannot admit that they have done wrong is unbelievable. Some of the people we have spoken to and sought assistance from have given no compassion and have left her feeling like there is no help. From what I believe, this device of mesh or similar material is still being used after being banned in many countries. How have we got it so wrong?

I am only the ripe age of 24, and I have absolutely no faith in doctors and beyond because of this mesh experience. I, myself, facing much fewer medical problems, am really so cautious now, seeking second opinions and doing so much research into any little detail I am told. I should be able to trust these people. It is not only their job but their duty as health professionals to care, and far too many of them only care about the money they will receive and not the person's life in their hands.

Writing this I am truly upset, thinking that she may not get the quality of life in the future that she deserves and that her and my father's dreams of becoming grey nomads might be just a dream. While they are struggling in probably every aspect of their lives, they both continue to

help everyone around them. She is the most helpful, giving and selfless person I have ever met, and I love her to the ends of the earth. Thank you for listening.

428 The ACTING PRESIDING MEMBER: Thank you very much, Ebony. John, would you like to provide your opening statement now?

JOHN: Sure. Good afternoon. My name is John. I am the husband of Sharon. I present this document as my account of the effects of medical mesh and how it has impacted on myself and my wife. My wife was a healthy, energetic and hard worker whose dedication to her job in retail sales and work ethics made her a trusted employee. She loved her job, and they in turn loved her. She has not been able to work since May 2018. Since her operation in 2015, I have witnessed a steady decrease in her functionality, and this was almost immediate from the time of the operation. The impost on our life in relation to her health and the continuing, spiralling issues related to mesh have impacted us both personally.

I have found the mesh to have consumed our lives—and, in fact, that every day will pose another issue which will either be a recognised ongoing problem or something new. Mesh has now placed us in a difficult financial position, exhausting all our savings to provide a path to clinics, specialists and the like, all of whom do not come cheaply. It has affected our sexual intimacy, which I believe is probably normal, according to the doctors, and has been the cause, I am led to believe, of marriage and relationship breakdowns. I thank God that both of our deep love for each other is sometimes the only thing that we hang onto.

Another issue as a spouse or partner—and I think I probably speak for not only men but poor women who are now afflicted with the ongoing saga of mesh—is anger. It is anger against the medical profession—and sometimes that word belies itself in its relationship to doctors, but that is another conversation. Anger is directed to the issue of the lack of recognition by some doctors that mesh itself causes issues and serious problems. So often I have sat in doctors' rooms and have had to swallow their rhetoric: 'No, no, no, these issues are not caused by mesh,' or 'You can't blame the mesh, as it's still under investigation.'

On a number of occasions a well-known gynaecologist told us it 'only affects a handful of women'. I am not a violent man, but on that occasion I could have become one. How dare he? I know three other women that are affected by mesh just within my circle of friends. And what constitutes a handful? I was angry and still am. The lack of empathy, coupled with blind refusal to admit that the medical fraternity has got this one wrong, sticks in our throats. We are left to carry the can for a system that to this day, I am led to believe, is still implanting mesh that has since become banned in many countries.

This anger spills over at the financial gain by medical practitioners, which has probably not done any good with regard to current practices or moral medical ethics. We know that exists, but this is not the essence of the debate, although it is an influence perhaps. I merely wish for it to be noted that, all being human, financial greed can be an influence on some decisions made.

The future plans of any couple are exciting as they look to the future—plans to retire by the sea and travel to places not just limited to many other capitals. All these plans pale, now, into insignificance as we battle the ongoing medical issues, various treatments and continual specialist visits. Whilst we still wish for our dream and hang on to the 'one day', it seems a long way away.

The mesh saga has had a huge impact on our lives as well as our life in general. I am now very disillusioned by the medical system. It has shown me over the last five years that not many doctors have been made more aware about the mesh and its ramifications. My wife's operation was a debacle, with nursing staff carrying out patient care completely opposite to the doctor's instructions, causing issues and complications from the start.

I implore that the medical fraternity be forced to be accountable and re-educated about mesh complications and the effects they have on patients. They need to fully inform future patients of every aspect of mesh and the operation, something that was not explained to my wife. I also implore the government to recognise its faults and shortcomings with regard to the matter, laws relating to recognition of this to be genuine, having it listed somewhere as an urgent issue, to help relax laws relating to accessing super funds for treatment. I am sure cabinet would rather this than the pending onslaught of the strain on our current malfunctioning medical system. Surely, using our own funds has far more benefit than impacting on our already under stress public medical system.

I hope for everyone's sake that, going forward, changes for the better for affected people will be made. In closing, mesh has ruined my wife's life and our life together. We are both left in a holding pattern that seems to have no proper outcome. Mesh equals money, and duty of care has taken a back seat. I thank you for listening.

429 The ACTING PRESIDING MEMBER: Thank you very much, John. Chelsea, would you like to share with us your opening statement?

CHELSEA: Yes. This submission is to recount the dreadful experience and impact medical mesh has had upon my beautiful mother and our family as a whole. In addition to this, my aunty is also a victim to medical mesh. Prior to the implantation of medical mesh, my mother was an enthusiastic, active, selfless loving and reliable individual, who would take everything that came her way in life by the horns. This included going to my netball games each weekend, actively participating in my school events, going for walks, dropping everything for anyone close to her who needed help and also upholding such dedication to her full-time retail position that she held for 14 years.

She was one of many women who had suffered with some incontinence after pregnancy and was convinced by our local doctor that the implantation of a sling would be a quick fix and that she would have a speedy recovery after surgery. My mother was never debriefed the way a patient should have been before an operation. This includes her never being informed of any potential risks or told that it was in fact medical mesh made of polypropylene that was being inserted. It was instead described as 'a sling' that would support the bladder.

On the day of her operation, on 6 March 2015, my mother begged the nurses in our local hospital to call her surgeon due to the fact that she could not urinate and was in a great deal of discomfort. The nurses were also left with incorrect instructions for her after-care post operation and told mum she needed to be drinking copious amounts of water so they could determine whether she was able to pass urine. However, she was only supposed to be sipping water at that particular time, we later found out. This complete lack of care caused the bladder to strain and bleed.

From this point, she had a catheter inserted, which she was then sent home with, for about three weeks. During this time, it was taken out and then inserted again on multiple occasions, which caused countless UTIs and blood in her urine. At the time, she gave the situation the benefit of the doubt that this was caused by the poor after-care after surgery. We were all yet to discover the horrific path that mesh was going to drag my passive mother down at this point.

Since the implantation of medical mesh, it is an understatement to say that my mother has never been the same person. Her positivity has declined rapidly with each ongoing health issue she faces day in and day out, not to mention the increasing amount of new problems that surface on a regular basis. Most recently, my mother has been trialled on so many different types of pain medication to keep her chronic pain level somewhat at bay, but her memory, energy, mental state and physical abilities are declining rapidly each and every day, which is unfair on her and also us as a family because it makes each of us more helpless in the sense that there is no definite solution to this problem.

In addition to this, my mother's GP of 28 years was also a friend outside of the local clinic and had supported my mother a huge deal until the issue actually regarded medical mesh. Her doctor now claims my mother does not exercise enough and that her health issues are not caused by mesh whatsoever, which is appalling. She refuses to listen to her the way that she should to the point where my mother leaves appointments in tears.

To conclude, my recommendation is that all medical mesh devices should be banned worldwide. Training doctors and/or surgeons need to be still trained in the old method, if the body rejects the surgery, where native tissue is used. There also needs to be greater support available for medical mesh victims, as they have had to form their own groups due to the lack of care from treating professionals on this issue. Thank you for listening.

430 The ACTING PRESIDING MEMBER: Thank you very much, Chelsea. Jacob, would you like to share with us your statement?

JACOB: Yes. I am writing this letter today to describe my experiences with mesh when I first met my partner's mother two years ago in May 2018. She was still trying to push through a great deal of pain and hold down her job in retail when I first came into their lives. We only just met

at the time, so I didn't know much about what was going on yet. At the time, I was staying with my partner on her mother's property in their granny flat. Almost every day, I would notice her coming home from work around lunchtime or earlier due to her severe pain levels. Sometimes she was unable to make it there, which is how I knew it was bad as my partner had always said her mother has incredible pain tolerance with most things she had dealt with medically.

The more time I spent with her mother and got to know her the sooner I learnt that she was clearly struggling with more than just her physical incapability. Due to everything going on, she was also going downhill mentally. Fast forward a few weeks down the track, she had to actually make the difficult decision to leave her job after years of loving what she did for a living. She was now unable to complete tasks most of us wouldn't even think about.

Never have I ever seen anybody lose their quality of life like my partner's mother has. She was a bubbly woman with the way she would talk to people and experiencing life for what it was. Her energy is now almost completely gone, so she is unable to be the social butterfly that even I once knew her as. Doing a quick trip to the shops for a few things, home is her prison and mesh is her sentence. These devices should never have been put in anybody unless they had been tested for the long term. These devices need to be completely banned not only in Australia but globally.

I recommend that we need to notify the women and men who have these devices implanted experiencing major health issues and have no idea why. The doctors still lying to them and saying it's due to other medical issues need to be held accountable for this, seeing my partner's mother having to live with the pain she does each day and the uncertainty of what her future is going to hold.

431 The ACTING PRESIDING MEMBER: Thank you very much, Jacob. The committee has a number of questions for you. I have one, initially. Perhaps Sharon might be best placed to answer that. Would you perhaps like to elaborate a bit more on what extent you were made aware of the potential for complications and those sorts of things when this procedure was initially discussed with you?

SHARON: He told me that it was the best thing since sliced bread and gold standard and that they haven't really had any issues to date. It was very effective for stress urinary incontinence with a quick recovery, hence going back to work in a short amount of time. I trusted him because this surgeon had also done my hysterectomy back in 2009. I had been seeing this man for several years, so I trusted him. I should have asked more questions, but I didn't and I regret that every day.

He didn't really tell me that it was a permanent device. He explained it as a little bit of tape that created a hammock for the bladder. I also believe, since having the part removal, that it was pulled too tight. It actually felt like a really hard rubber band was pulled to extreme tension. You could actually feel that on my left side.

There was a lot of scar tissue, so they also divided that while they removed the piece of foreign body. I didn't know that it was made of polypropylene, hence it breaks down with oxygen. It's a nightmare. It should never have been used. I had no idea what it was made of. He didn't tell me that. I feel like he didn't give me all the information that I needed, and I trusted him anyway and signed without asking any more questions.

432 Ms LUETHEN: First of all, thank you, everyone, for delivering your statements today. I'm sure that took lots of courage, and you must have a very loving family to all do that, so thank you. Sharon, may I ask, during the initial consultation before the first operation, did the doctor discuss with you whether it could be removed in South Australia if you were unhappy with the results?

SHARON: No, he didn't. I had no knowledge. I went back for my three-month post-op, but I also was put back in hospital just for short afternoon visits to try to void because I couldn't urinate properly. He didn't actually tell me it was a permanent device and that it couldn't be removed, the type of device I have inside of me.

I have had four different urogynaecologists' opinions, and they have told me it's like taking a jackhammer to an old concrete rebar slab; it's way too dangerous. It's so embedded. I've got no choice. They can offer me physio, pelvic floor pain management and psychology. I'm doing

all of that, but the pain is significantly worse. Next month, I start pain infusions to see whether that can help me, but mine can't actually be removed.

433 Ms WORTLEY: Sharon, can I firstly say to you and your family that I'm so sorry you're on this journey. Thank you for coming today to deliver this evidence before the committee. I would like to go to the section in your statement where you say you had the first appointment with the Royal Adelaide Hospital mesh unit on 27 August 2018. You said it was after quite a lengthy wait. Can you tell us about how you made the appointment, how long you had to wait and what happened at that first appointment?

SHARON: I made that appointment with the knowledge that the mesh clinic was open through my GP. I rang and made the appointment, but they said that the wait was quite lengthy and they were doing it by the seriousness of the actual patient. I waited eight months for my first appointment.

434 Ms WORTLEY: Eight months.

SHARON: Yes.

435 Ms WORTLEY: At that first appointment, can you tell us who you saw and what was the outcome? Have you had follow-up appointments since, and how long did you have to wait for those?

SHARON: My first appointment was with the gynaecologist—

436 The ACTING PRESIDING MEMBER: We don't need the name. That's okay.

SHARON: Am I allowed to name him or not?

437 The ACTING PRESIDING MEMBER: No, it's probably safer not to.

SHARON: Okay. It was a man I saw who was the urogynaecologist in the mesh unit at the Royal Adelaide. That was in August last year. He has now retired, so I only actually saw him once. He told me that there was no chance of having a removal done because of the severity of the way it was embedded. It is fully embedded in my tissues. He did say that they know where the main nerves are, but there are little nerves obviously coming off those as well, which they would do more damage, and it would possibly kill me trying to get the device removed anyway.

I am still having regular appointments with the psychologist, and she has been really good. I stopped seeing the pelvic floor physio because I started bleeding. Every time they do an examination, it makes me bleed and I am in severe pain for a few days after that. That is ongoing and it just stirs everything up.

I have seen the urologist once and I am booked in on 25 August to have a urodynamics and a cystoscopy done at the Royal Adelaide Hospital. I also am under a The Queen Elizabeth Hospital pain specialist, so I start my infusions for pain next month at The Queen Elizabeth Hospital.

438 Ms WORTLEY: So, it was 27 August 2018. It's 12 months on and you are about to start the pain treatment and have some more tests; is that correct?

SHARON: Yes, but I have been treated with pain medications prior. I become tolerant to it because I have such chronic pain. I am using Valium suppositories, Endone and Palexia. Gabapentin I have just come off of because of the severe side effects, but I have a whole list of medications I take. You can't function. I go to say something and I forget totally what I am going to say. I can't think straight and I can't remember things. It is like fog brain.

439 Ms WORTLEY: So, Sharon, in the lead up to your first appointment with the mesh clinic, you had already had a number of tests; is that correct?

SHARON: That's right.

440 Ms WORTLEY: And they were through the private system?

SHARON: Yes.

441 Ms WORTLEY: And then you took those along with you to the mesh clinic and that's where they made the diagnosis that removal wasn't a possibility because of the severity; is that correct?

SHARON: That's right.

442 Ms WORTLEY: Was there any consideration given to going interstate or even overseas in relation to having that looked at?

SHARON: I actually took it on board and sent my medical records to a surgeon in America. He sent me back a quote and said that he believed he could do it. I would still have a lot of complications, hence nerve damage and pain for the rest of my life, but he believed it would get rid of the foreign body reaction causing further infections. I spoke to the doctors about this and they advised against it. It is in excess of \$50,000, so I would need to sell the property we have to access that sort of money. Hence, I would have to just put my life on the line, whether it would be successful or not—that's a fifty-fifty chance.

443 Ms WORTLEY: Sharon, I have just one other question in relation to the mesh unit at the Royal Adelaide Hospital. At your first appointment I think you said you saw the urogynaecologist and then you had other appointments, I'm assuming. Were they on the same day, or did you have to wait for the other appointments with the psychologist and the pelvic floor physio?

SHARON: Yes, I actually had to wait. They weren't the same day: they were probably eight weeks down the track. Now, I have been having regular appointments with the psychologist because I am severely depressed because I'm not the person I used to be, I'm not that person anymore, and I'm having a hard time adjusting to that mentally.

444 Ms WORTLEY: Thank you to you and your family for having the courage to come forth to provide the evidence so that perhaps going into the future there will be things put in place.

445 The Hon. E.S. BOURKE: I would also like to echo what other members have said about appearing before the committee today. I appreciate that it must be very difficult, but thank you for sharing your story. I don't think anyone could put any price on the physical or emotional pain you and your family have gone through, but just so that we know as a committee roughly how much you have invested at a financial level for your appointments and procedures that you have gone through already, are you able to highlight how much you think that would have been so far?

SHARON: I would say it would be, for all I have had done—for example the PRP injections were \$500 a session, the surgery in a private hospital was over \$5,000 for part removal of the sling, hence I can't get a healthcare card because we were over the threshold by \$38. Whatever test I have had done—MRIs, ultrasounds, the transvaginal specialist ultrasounds that are done in North Adelaide—and my medication alone, some of that isn't on the PBS, so some of them are \$54.

It has been, I would say, thousands. I have redrawn on our loan, hence it's created more financial problems, thinking I could seek and find and fix this dilemma, but now I realise that's not possible. Hence, the mesh unit did say that there were some surgeons interstate that could possibly help some patients but that wouldn't be an option for me.

446 The Hon. E.S. BOURKE: I guess, from what we've been hearing from witnesses who have appeared before this committee is that, unfortunately, your story is a common story. Witnesses have said that they have gone to see the doctor and were told that this was the easy procedure, the quick fix that was an easy option to take. I'm aware that you weren't able to receive any information in 2015 but, from the network that you have created since that time, are you aware of people who are going through this procedure receiving information from their GPs before they go through with the procedure?

SHARON: I've actually got a sister that's also been fitted with a device—from a different manufacturer to what I've got—but she wasn't told either any of the risks or factors that could happen. She is now in a situation where she's got chronic pain, hence affecting her job. She takes a lot of pain relief, but she is having a lot more time off work at present because of the issue she's got with it.

My GP of 28 years I actually left two weeks ago, crying. I felt really let down because she knows the type of person I am, and we have had such a good friendship along the way because

she has been my GP for so long. She told me that it's not the mesh that is causing my problems; it is lack of exercise, because they know that exercise is good for pain. I understand that. The issues I have with my hips, leg, groin, UTIs, they have told me are all separate issues, which, okay, I will accept, but these issues have been created since having the mesh put in, and I believe my problem started from having mesh.

I had no problems. My job was hard and physical and on the go all the time. I was a dresser in a giftware and homeware store, so I dealt with a lot of furniture displays, moving shelves, setting up, which I loved dearly. I have never not worked in my life, so even trying to adjust to that and knowing there is nothing I can do to fix this situation is hard to comprehend. It is hard to get your head around that.

447 The Hon. E.S. BOURKE: Thank you, Sharon. I really do appreciate your feedback.

448 Ms WORTLEY: Sharon, I am just wondering whether you have been in touch with the various mesh support groups in South Australia.

SHARON: Yes, I have, but I have to be honest with you. I find it very overwhelming, so sometimes I distance myself because I feel like my whole life is consumed by mesh. There is nothing else. I get up every day and I wear those consequences of that decision I made back in 2015. I feel overwhelmed at times by the amount of people out there that are affected. You read what is on those social support sites, which is awesome and I am so grateful they are there, but at this point I feel consumed and overwhelmed, and I think that creates worse depression for me at this part of my life. I don't know that that will always be the case. Who knows? But at this point in time it is. I am struggling, big time.

449 Ms WORTLEY: I am sorry to hear that.

450 The ACTING PRESIDING MEMBER: Thank you very much, Sharon, and also to your family for sharing your stories with us today. It is undoubtedly a very difficult but also an incredibly brave thing to do. It will no doubt benefit other people. Thank you again, and we all wish you all the very best.

SHARON: Thank you all for listening.

[Videoconference concluded]

WITNESSES:

GORDON

EUNICE

ELSIE

SARAH

451 The ACTING PRESIDING MEMBER: Thank you very much for joining us today. Just before we get going, we have the option to live broadcast to the public just the audio online, or not. We are comfortable leaving it entirely in your hands as to whether or not you are comfortable to do that. I understand, Sarah, that you would prefer not to.

SARAH: No.

452 The ACTING PRESIDING MEMBER: Are other people comfortable? We can not do that.

ELSIE: It's alright; I can cope.

EUNICE: Yes, that's fine.

453 The ACTING PRESIDING MEMBER: You are fine with that? Okay. We will just need to make sure, Sarah, that when we get to the question and answer that we turn the live stream off when you are answering. So to protect the privacy of individuals, the oral evidence given at today's meeting by Sarah will not be broadcast live on the internet. Ms Wortley, would you like to move that?

Moved by Ms Wortley.

Seconded by Ms Luethen.

Carried.

454 The ACTING PRESIDING MEMBER: Thank you very much for appearing before the Social Development Committee this afternoon. Due to the current situation concerning the COVID-19, the committee has resolved to exclude strangers from the gallery. The proceedings will be broadcast to the public online via the Parliament SA website unless the committee resolves otherwise.

A transcript of your evidence today will be forwarded to you for your examination for any clerical corrections. Should you wish at any time to present confidential evidence to the committee, please indicate and the committee will consider your request. It has been determined that, when hearing from individuals presenting personal evidence, only first names will be recorded in the transcript and subsequent reporting. Additionally, I advise it has been resolved that names of doctors, specialists and hospitals involved in individual cases should not appear in evidence. Witnesses and the public attending today or listening via the internet, including media, are asked to abide by these determinations.

Parliamentary privilege is accorded to all evidence presented to the committee and therefore protects the witness from any legal action arising in regard to that evidence; however, witnesses should be aware that privilege does not extend to statements made or documents circulated outside of this meeting. The committee will consider any documents presented to it and will determine whether the documents be received and form part of the evidence. All persons, including members of the media, are reminded that the same rules apply as in the reporting of parliament. Again, I would like to advise that the hearing will be broadcast on the Parliament SA website.

I will now introduce the committee. To my far left we have the Hon. Emily Bourke, a member of the Legislative Council; Ms Dana Wortley, the member for Torrens; and Ms Bloomfield, the committee's research officer. My name is Richard Harvey and I am the member for Newland and also the Acting Chair for this committee. We have Ms Robyn Schutte, the committee secretary, and to my far right is Ms Paula Luethen, the member for King.

Thank you for coming in today to share your stories with us. Perhaps, Elsie, we could start with you, with an opening statement.

ELSIE: Good afternoon and thank you for the opportunity to share my mesh journey. My experience with mesh is that it is cruel and barbaric and should never be implanted. I believe the number of people adversely affected following the implementation of medical mesh to be far greater. This is because symptoms may take years to become an issue. Myself and my two daughters have had mesh implantation surgery. Two of us did not experience issues until much later.

We go in trusting that the surgeon is going to be up-front and honest with us. Sadly, this is not the case. We are not trained medical professionals in these medical devices and are totally reliant on the honesty of these surgeons. In 2004, my GP at the time highly recommended this new surgery as I had had a prolapse from a total hysterectomy in 2002. My pelvic reconstruction surgery involved a J&J TVT-O for mild incontinence due to a cystoscopy and a J&J mesh for a bowel prolapse and permanent sutures for vaginal prolapse. I was given no other options, such as native tissue repair, etc.

The surgeon explained that there were no reported adverse effects with mesh and that he had only ever had one issue with a TVT-O—gave the lady a trim and all was well. There was no explanation that there was a mesh implant with arms for the bowel. This was to give me a new quality of life, or so I thought. Initially, I only had minor discomfort with intercourse and tummy pain, but as the years went by the mesh for the bowel prolapse was becoming lumpy and uncomfortable. My GP then sent me off for a colonoscopy due to his concern with the lumpy mesh. The report just confirmed that it was mesh. I continued to experience pain, discomfort, ultrasounds with no results, reflux, etc.

In 2009, I started to have difficulty lifting my leg in the car—driving a manual car—and could not sneeze or cough without pain killing me. I wish I had known then about the mesh arms implanted into my ligaments. Assuming it was my hip, I went off to an orthopaedic surgeon. I had a bone infection as a child, leaving me with a femoral head flattened. I was blaming my hip. The surgeon commented that there was no arthritis but if he went in further, he should find it. I had a hip replacement in 2010, with no improvement. I then proceeded to spend countless dollars on physio and hydrotherapy, all to no avail.

Inflammation from the bowel mesh, permanent sutures and the TVT-O result in continued pain, making normal activities very difficult. When I was out visiting or at work, I would always be looking for cushioned chairs and was not able to stand for long. I struggled going to work, at times using up all my sick leave. It was all very frightening. My new quality of life had turned into my worst.

In 2017, I went to another physio for strengthening exercises for my hip and very quickly realised that any progress with my hip was resulting in a big increase in pain inside my pelvic region. Alarm bells started ringing—mesh. Enter Google. Googling the word 'mesh' quickly identified symptoms I was suffering from. Joining mesh chat groups, I have become very wary of the issues attached to partial removals.

The bowel mesh was not only painful but was getting worse, finally protruding into my vagina, making intercourse impossible. This resulted in no sexual relations with my husband, causing huge stress on our relationship. My husband referred to it as 'the cheese grater'. After years of anxieties, not knowing what was causing my symptoms and having to do my own research, I am very fortunate to have a GP who listened.

My GP referred me to a gynaecologist in South Australia. While I found him to be honest, in that he had not removed a TVT-O, when I said that I was having pain on the side of my pelvic region I was informed that that was not where the TVT-O is attached. What he did not acknowledge was that the arms from the bowel prolapse mesh were attached to the ligaments on the side of the pelvic region.

I was prescribed antidepressants without being told that they were antidepressants and was referred to a physio to desensitise the pelvic area. How do you desensitise protruding mesh and overstretched deteriorating mesh arms? I was offered removal of the bowel mesh and sutures but declined.

The mesh clinic would have been by far my first preference, but as they are not doing total removals I decided that, with pain and time not being on my side and needing a total removal, I would go interstate. Having been offered a separation package at work, I was able to access money to go interstate. It is so very distressing when your only option is to draw on your retirement funds for surgery knowing you have no means of replacing it.

The surgeon recommended the removal be done in two operations—the first being the removal of the bowel mesh and inflamed woven sutures. I was told that the mesh should never have been used for the bowel prolapse and that it should have been the native tissue method. At this point, I was told that the arms from the mesh were attached to ligaments. As the mesh curled up and deteriorated, those arms were pulling harder and harder on the ligaments.

In February 2020, I had the first round of surgery. Although my previous surgery note stated that I had had total removal of my ovaries, some of my ovary had been left behind, which was later confirmed with a biopsy. The mesh, along with the arms, were totally removed, as were the sutures. Two weeks later when I was getting into the car, I realised that I had just lifted my leg in without supporting it.

I couldn't stop thinking about the pain, wasted years and all the money that I and the taxpayer had wasted. Pain from the TVT-O still greatly restricts my normal activities and is still having an impact on my life. I am now waiting for the removal of the TVT-O later this year. My daughter has complications with a J&J TVT-O—J&J Gynemesh Prolene. Following surgery and without her knowledge, the surgeon inserted a J&J Gynecare Prolift.

Just as we have the right to a safe work environment, it is essential that the mesh clinic provide a mesh-safe environment for all mesh victims to attend and be seen by medical professionals who are not pro mesh. My daughter attended the clinic recently and was informed that she was not bad enough for removal, prescribed antidepressants and referred to a physiotherapist.

Mesh victims are in trouble long before they attend the mesh clinic, and to be told that you are not bad enough for removal is psychologically damaging. How does the mesh clinic define 'bad enough' for the removal of mesh: unable to function, unable to work, unable to care for your family, marriage breakdown, losing your home, or totally reliant on welfare or medication, with no quality of life?

Mesh victims need professionals who will listen and make themselves aware of all possible complications attached to each particular implant. It's imperative that we have access in South Australia to credentialled medical practitioners for the removal of medical mesh, to be offered complete removals of implants, not partials, and to provide accessible support for patients and families following adverse outcomes.

As with my family members, we have not had one notification that we have mesh implants. There would be thousands of mesh victims not contacted, leaving many mesh victims and their GPs not knowing that they have mesh or being aware that the symptoms they are experiencing are mesh-related. It is essential to establish a South Australian register for mesh implant recipients, including a prospective and retrospective audit, which includes the public and private hospital sectors. This is the only way to get a true picture of the long and short-term adverse effects. There need to be regular follow-ups following implantation.

Education and information need to be truthful and very comprehensive, with all options available to be able to make informed consent. There needs to be education of medical practitioners in the adverse symptoms of mesh to be able to accurately make mandatory reports and treat patients. Non-mandatory reporting results in an unreal picture of issues with mesh. We are not medical professionals and are reliant on Dr Google, Facebook and chat groups, as the medical profession is a closed shop.

We need to know the possible complications of our mesh implants so that we know the surgeons we are seeing are addressing our problems. The unnecessary psychological stress in prescribing antidepressants and telling victims that their pain isn't real: how do they possibly know? Do they have a mesh, a foreign body, implanted in them? The anger you feel when you hear this, when you have experienced the pain from mesh and then the relief after removal, is indescribable.

A register providing all previous implants, types of implants, methods of implantation and possible complications with nerves or ligaments: this information, supplied to both patients and their GPs, would prevent costly unnecessary tests and procedures, saving personal budgets and the health system hundreds of thousands of dollars. To be offered complete removal of implants and not partials in South Australia by credentialled medical practitioners would essentially mean that we have a safe mesh clinic that is meeting the needs of all mesh victims. Thank you for giving me this opportunity, and I just hope, in doing so, it helps others.

455 The ACTING PRESIDING MEMBER: Thank you very much, Elsie. It's very much appreciated. Eunice, would you like to share with us an opening statement?

EUNICE: Good afternoon. My name is Eunice. In March 2008, I had a TVT-O implanted at the local hospital. This operation was supposed to happen in July 2007, but it was abandoned because the surgeon punctured my bladder in two places trying to implant the TVT-O in me. I was having issues with incontinence. I played netball and had to change myself at half-time because of bladder leakage throughout the game.

I went to see a gynae at a local hospital, and he told me that he could fix my incontinence by putting some tape in. The procedure was day surgery, and the only warning I got was that it could puncture my bladder, which would mean having to wear a catheter for about a week. I agreed to the surgery and went in in July 2007 but, as I said, my bladder was punctured twice. I say that because it just shows how blind surgeons are going into the body when they're putting this mesh in. They are not seeing where it's going.

Allowing for healing, I went back in to the hospital in March 2008 to have the tape inserted. This time, the operation was successful. At no time was I told that the product was mesh, made of polypropylene, could not be removed, could have any adverse effects—nothing. My journey with mesh had begun.

Initially, I had no issues with the implant. My incontinence appeared to be fixed. Unfortunately, over the next couple of years, I began getting pain in my pelvic area and lower tummy area. I underwent numerous investigations. I was told I had IBS, diverticulitis, scar tissue pain and then bladder pain. Nothing eased the pain, though, and I was also becoming incontinent again.

In May 2015, I went and saw a urologist regarding my pelvic pain and incontinence. In October 2015, I had a cystoscopy, during which time the specialist noted that mesh had eroded through my vaginal wall. She excised this in November 2015. I was flabbergasted, as I had no idea when I had had mesh implanted.

I originally thought that it must have been put in when I had my hysterectomy and a Burch procedure in 1995. I did try to investigate this on Google but my papers had all been destroyed as it was 10 years prior, so all medical records were gone. It did explain why my partner, Gordon, could feel something sharp during intercourse. We had asked about this previously with my doctor and we were told that it was probably a stitch that hadn't dissolved but that it should go away. Once the mesh was trimmed, it did go away and the reason for my pain was at least partly diagnosed.

In October 2016, I had terrible pain in my back, near my left kidney. It was thought I had a kidney stone. I had tests done, but there was no stone. The pain increased and was also in my pelvic area and vagina. I was unable to work and I was put on various pain medications. There were visits to various specialists but no-one could help me. My GP was at a loss. I was diagnosed with chronic pelvic pain. Mesh never entered into the conversation.

We were watching a TV show called *The Project* and it aired a segment with Derryn Hinch that discussed mesh and the damage it was doing to women. It stated that women may not even know they had mesh, as it was also called tape. I could not believe it. I contacted the support group shown on the segment, the Australian mesh support group. Through this group, I met up with some women in South Australia who were also living with mesh. This meeting was truly eye-opening and heartbreaking at the same time.

The only option spoken about at that time for removal of the mesh was going to America, but that was certainly out of my reach. I was suffering from pain, incontinence, constant thrush, rashes on my forearms and generally feeling unwell. I was still not able to work and the only

reason that our financial situation was not dire was because I had income protection on my superannuation. I dread to think what would have happened if I didn't have that.

Through the chat on the Australian women's mesh support group, I learned there was a doctor in Sydney who had trained with an American doctor in the removal of mesh. I contacted this doctor and went to see him in Sydney. He stated that he would be able to remove my mesh but I would have to wait a while as he was waiting on equipment to be able to do this. I was prepared to wait. I was just so happy that this stuff would be out of my body.

There were other doctors mentioned on the support group who were going to be able to remove mesh, but I continued with my Sydney doctor as I believed he had been trained in America. I no longer had private health insurance as we could no longer afford it. This meant that I would have to pay for the removal. My daughter organised a fundraiser for me.

I got a call from the doctor and I went over to Sydney in November 2017 to have my removal done. My partner, Gordon, has been with me throughout this whole journey. We both went to Sydney as I would need help after the operation and I was told that I should stay close to the hospital for about 10 days after the operation in case anything went wrong.

I knew when I had the operation that they had got the mesh out as soon as I woke up, because I actually felt well. I had no pain. The operation had gone well. The doctor advised that he had got all the mesh he could see—he couldn't say he got it all, just all that he could see. He saw where the mesh had been trimmed on the left side. He also said that the mesh on my right side had eroded into the urethra and had created a fistula with the vagina. It was all inflamed.

I came home after 10 days and was feeling well. I had very little pain. You would be right in thinking that I should be back at work, feeling fit and healthy and not have any pain. The trouble with mesh, though, is that there is so much damage done putting it into the body. My pudendal nerve is damaged. I am on 225 milligrams of Lyrica morning and night for this pain. I am on Palexia 150-milligram slow-release tablets for pain. I am also on Cymbalta, which is generally used for depression, but in my case it is being used for pain.

I have been trying to get back to my full-time job building schedules for people on the phones in Centrelink, Medicare and Child Support. Up until two weeks ago, I had worked myself up to 26 hours per week. I generally do not get through two weeks without having time off for pain. I am seeing a psychologist, a pelvic floor physiotherapist and the pain clinic, all through the mesh clinic.

Two weeks ago, my pain flared up and I have not been back at work. I am spending a lot of my time in bed as it is one of the only ways to ease the pain. How long this flare up will last is anyone's guess. There is no infection; it is just that muscles have tightened and I'm in pain. These years living with mesh, especially since the partial removal in May 2015, have been horrendous. It has affected every aspect of my life.

I was an active, fit and healthy woman who enjoyed life to the fullest when this mesh was put in me. I had a wonderful, healthy intimate life with my partner, Gordon. I enjoyed playing sports, I walked every evening up to five kilometres, I loved my job and my attendance was good. This mesh has left me so that I can no longer walk any distance without pain. I cannot stand for extended periods of time.

My intimate life with Gordon is non-existent. We do not do much socially; friends and family know that I cannot attend events a lot of the time. I have a grandson who is six and he only sees me as being basically bedridden; I can't do the things with him that I want to do. I am not the partner, mother, sister, grandparent, friend or employee that I want to be.

I truly believe that I would have died if I didn't have the mesh removed. It is poison and I dread to think of the women who do not realise that they have this inside of them. This needs to be banned. Doctors need to be held accountable for continuing to put this into people knowing what side effects could happen and knowing that it can't be removed. Thank you for your time today.

456 The ACTING PRESIDING MEMBER: Thank you very much for sharing that with us. Gordon, would you like to share anything?

GORDON: Good afternoon. My name is Gordon and I am the partner of Eunice. I am speaking here today to let you see how mesh has affected my life as the partner of a woman affected by mesh. I have seen my soulmate, wife-to-be and outstanding woman go from being a healthy, happy person who would walk up to five kilometres an evening, enjoy playing her netball and be social and active, and a lady who loved to be outdoors and travelling—her family had a hard worker who rarely missed her work—to a lady that can spend days at a time in bed and in pain.

The first that I had heard of mesh was when Eunice came home from a specialist appointment and said that the doctor had found mesh had eroded into the wall of her vagina. Eunice didn't know where the mesh had come from. We had known there was something in her vagina as there were times when we were having intercourse and I would feel something sharp.

Eunice had asked a doctor about this previously and was told it was probably a stitch that hadn't dissolved when she'd had incontinence fixed years before. The doctor cut and removed the piece of mesh, and that was the end of everything wrong with Eunice—that was what I thought, anyway. Unfortunately, a month or two after this, Eunice was in dreadful pain in her pelvic area. She went to doctors and the specialists but no-one could find out what was going on or why she was in this pain.

One night, while I was watching *The Project* on TV, there was a segment with Derryn Hinch about the mesh. This was a profound moment for us, as we had no idea about this poison that was in fact not approved by the FDA as a standalone product. Eunice has been in her bed for weeks, months. She never took any painkillers, but now we can't find a painkiller that will sustain her pain for a whole day so she can work or walk or do her everyday living. I have been to numerous doctors' appointments with Eunice and to see her dismissed and treated like she is crazy is heart-wrenching.

We flew to Sydney in 2017 to have the mesh removed by a so-called expert. We thought this might change things for the better—and it hasn't. I have watched this outgoing, vibrant lady who just wants to experience life end up bedridden at times, sad and upset, doctors not being able to help her. She has numerous infections and is on daily medications. We have had our lives turned upside down. We always had a very healthy sex life, but this has been affected by the mesh so that it is non-existent. We don't travel much or far. We don't socialise like we used to—and all because of this mesh made by Johnson and Johnson Ethicon.

I listen to Eunice talk with the ladies about their experiences in the support groups she is in. It is heartbreaking to hear that these women are taking their own lives because of the pain, that men are leaving their wives and partners because of the lack of intimacy, that women are unable to play with their children or grandchildren, that women are unable to work because of the pain. This shouldn't be allowed to happen. This mesh needs to be removed from the market and never used in people again. Thanks for your time.

457 The ACTING PRESIDING MEMBER: Thank you very much, Gordon. Sarah, would you like to share with us your statement?

SARAH: I wish to highlight the physical and emotional impact I suffered as a direct result of a failed vaginally implanted mesh device. I was told it was a simple, safe, non-invasive, effective procedure. It was very complicated, unsafe, extremely invasive and ineffective. I was told it was gold standard. It was cruel, savage and barbaric. I was told it will greatly improve your life. Mesh destroyed my life. We migrated in 2003, sponsored by the SA government boasting world-renowned quality health care, investing large sums in the Australian economy. We called SA home. Beautiful Adelaide fulfilled all my dreams.

Prior to mesh, I participated in several outdoor activities and helped run a successful family business. Mother to four, I was the rock they relied on and socially had numerous friends, and my main passion was dancing. Life was good. In 2014, attending a routine Pap smear, my new gynae, like a jack-in-the-box, popped up having detected urinary stress incontinence, a condition I never complained of or sought treatment for. With no study into my voiding history, no urodynamic testing and no counselling on less aggressive treatment, he said, 'I can fix it.' I didn't get time to think before I signed and was rushed out. However, back home closely monitoring mild and managed both symptoms, I concluded they didn't warrant surgery, so I cancelled.

In 2016, I received a reminder a follow-up Pap was due. Surgery far from my mind, the slick, manipulative master asked, 'Why didn't you proceed with surgery?' Expressing fear of

surgery, he played on my fear, saying 'If you don't proceed, your symptoms will progressively deteriorate and then you will be too old to have it done.' Jack-in-the-box struck gold. He said, 'I see a polyp in there that will need surgical removal,' adding, as if doing me a favour, 'I may as well do both procedures together.' I describe this like a dentist filling a tooth who, while in there, says, 'I might as well remove your tonsils.'

On my back, strapped, vulnerable and half naked with legs spread, I was in no position to argue. Seeing me hesitate, he reassured, 'The outcome will greatly improve your quality of life.' Brought up to believe doctors don't lie, I trusted he had my best interest at heart and I signed, totally unaware of any risks. Inexcusable that an unqualified registrar used me as a lab rat in a blind procedure.

Like a lamb to slaughter, I went into surgery full of hope and returned bewildered and broken, with multiple adverse surgical injuries, when careless, misguided, five-inch razor sharp trokar hooks, like butcher's hooks, ruptured my bladder, caused severe internal bruising and swelling, catastrophic tissue and nerve damage and punctured four pelvic exit wounds, when only two were required. Yet, when I questioned this, I was told, 'Oh, that was a mistake,' conveniently omitted from the op notes. Told, 'You won't go home until you void,' I was sent home on a catheter, and having failed numerous voiding trials I remained catheter dependent.

My injuries include—there are too many to read out; it will take too long—mesh erosion, acute groin, pelvic and vaginal pain, chronic inflammation, coccyx nerve spasm, sciatica nerve damage and obturator nerve damage, amongst others, all symptoms I never had before mesh; all with devastating consequences, leaving me suicidal. If lucky to get to the loo on time, it was an absolute nightmare, as sitting mesh obstructed the flow so I had to stand, peeing like a man. Even finished residue pee would run down my legs and I would have to return three and four times to the bathroom.

I felt I was dying a slow and agonising death, when mesh jagged edges shred my insides. Intolerable, unrelenting bladder infections felt like a rugby ball wrapped, set alight in burning fuel between my legs. I had given birth to four babies with big heads and the pain was nothing in comparison with mesh. Adding to the trauma was discovering the polyp he used as bait to lure me into surgery turned out to be a small cervix polyp, normally removed without surgical intervention. More upsetting, my SA top urogynae said, 'You were never a candidate for aggressive surgery. It was totally unnecessary and inappropriate for your condition.' Repeatedly, I rang my gynae, but he refused to take my calls.

In desperation, I consulted multiple mesh-happy, proud fellows of RANZCOG, but each visit was fraught with tears and frustration when they downplayed my injury, branded me hysterical and dismissed me as an irritant with a 'too bad, get over it' attitude. Likewise, the hospital response was appalling: 'Well, you signed the consent. Admit it, you signed the consent.' I begged to be readmitted, but I was reduced to tears when they said, 'We have patients dying here and you want a bed.'

Witnessing my distress, a sympathetic nurse rang my gynae seeking an urgent appointment on my behalf, but he refused. She asked why. He said, 'Patient has gone through the public health system.' That was his decision, not mine. I wanted it done private; he wouldn't do it private because I didn't have private health cover. I said I wanted whatever he put inside me removed, but he said, 'Impossible.' Learning I had been implanted with a permanent device made from the same plastic used to manufacture school chairs, Coke bottles and wheelie bins, was shattering.

Finally, I saw my gynae and I asked, 'What material did you put inside me?' With a blank stare, he feigned ignorance and said that he didn't know. He prescribed HRT and I asked for how long, thinking it would be a week or two. He said, 'For life.' I was shocked, as going through the menopause I consciously made a decision not to take HRT. Now I was put on it for life. Asking why, he said, 'To prevent erosion and organ perforation.' Seeing me gasp in shock, he said, 'As you were told before surgery.' A blatant lie.

Had such risks been disclosed, I would never have consented to this filthy, flawed product, nor chosen to play Russian roulette with my life and put my marriage and my family's happiness at risk. However, in pain I didn't confront him because I was afraid to. I was afraid of his

angry hands inside me, but he never examined me and he never offered any follow-up care, so I said to him, 'What happens now?' He said, 'See your GP,' and I was discharged.

My GP admitted he knows little about mesh complications, besides why should already overworked GPs be expected to clean this chaotic mess made by incompetent gynaes who do the damage, wash their hands and walk away? In addition, a senior doctor flew into a rage when I mentioned mesh. He said, 'Stop talking about talking about mesh; your symptoms are not mesh-related. You never had mesh.' I said, 'I had a TVT.' He said, 'A TVT is not mesh,' sneering.

Furthermore, an openly hostile top gynae in the clinic said, as if no big deal, 'A bladder injury is not uncommon, you know.' Another risk that wasn't disclosed to me prior to surgery. Staring me down he said, 'I believe you had words with my colleague.' I said, 'Your colleague said my TVT wasn't mesh.' He said, 'Well, we don't call it mesh here in South Australia, and we must defend our colleagues.' When I asked who defends the mesh-injured I was shown the door.

Seeking a gentler approach, I consulted numerous female doctors, charging astronomical fees. The first doctor I liked but she witnessed me struggle, she heard my horrific experience talking about mesh erosion, and yet in a report she still wrote, defending mesh, 'May patient reap the rewards of her TVT.' Then a pain specialist misdiagnosed me and when I returned with the proper MRI diagnosis she said, 'Well, we don't always get it right.' Male or female, their only concern was defending mesh. Like a virus, they wanted rid of me and fobbed me off with antidepressants and strong opioids, leaving me zombie-like and unable to function. Today, these are the doctors who are running the mesh clinic.

Worn down and with symptoms escalating, my only option was removal. Removal is extremely difficult, with some surgeons comparing it to removing chewing gum from hair or rebar from concrete. The mesh clinic still claims partials are acceptable, when ongoing injuries do not support that assessment. If they had a large splinter in their privates causing acute pain, rendering them immobile and sexless, would they choose to have it partially or fully removed?

I know many SA mesh-injured women who were promised full removals, costing them thousands, only for their pain to return, and scans showed that their surgeons conned them and didn't do full removals—but they didn't tell them that—leaving them financially broke, devastated and suicidal. I couldn't take that risk.

In 2017 I had a full removal by a very skilled Melbourne surgeon, who found the mesh misplaced and bunched up in a string, very lateral to the obturator nerve bundle, and I have obturator nerve damage. Pathology found evidence of foreign body reaction, yet doctors still say, 'Foreign body reaction; not mesh-related.' Up to date, I have spent \$70,000 going around on this merry-go-round, funds that we had saved for our son's future.

Mesh-free I sat for the first time peeing, crying like a baby out of happiness. Yet, begrudging SA doctors said to me there was no need to go interstate, there were plenty of SA doctors equipped to do it, one throwing my removal notes across his desk and shouting at me. He said, 'I was just as qualified.' He offered me a partial; I didn't accept his partial. I had a full removal and he was angry—very, very angry.

While I will never regret having the removal, the damage done at implant is irreversible, meaning this nightmare never ends, but I am more upset that I am unable to lift my grandchildren. How can I explain that to crying toddlers? I don't seek sympathy as I am not the worst injured. I speak to raise awareness of the sheer depth of this disaster: ignored too long, too many lives ruined, marital breakdowns and too many children left without functional mothers. I speak for thousands crying with nobody listening; some permanently disabled and in wheelchairs and with sticks, and others losing bladders and rectums, not forgetting those who have died from sepsis or suicide.

Shame on doctors who take the oath to do no harm and shame on those who do nothing to prevent it. If mesh was implanted in any man causing catastrophic damage and pain so bad he couldn't urinate or sexually perform, mesh would have never been approved. If I was a car and my radiator leaked, I would be recalled, refitted and made new again. Even faulty airbags and Whittle jackets with defective zippers are recalled.

Since the federal/state inquiry found women ignored and treated appallingly, the handing down of recommendations and the opening of the mesh clinic, nothing has changed, it's business as usual. As we are sitting here, you can be sure there is some woman with her legs in stirrups being implanted with mesh, totally unaware, having been told, 'Don't worry. It's a new, safe mesh.' There is no safe mesh.

The emotional cost is catastrophic. Out of shame I stopped socialising, but the most traumatic experience was when something sharp stabbed us during intimacy, resulting in excruciating pain, oozing blood and foul discharge. Educated by Catholic nuns, prickly wire mesh was not my idea of playful sex. However, me fearing pain and he amputation, we abstained. Anyway, it put a terrible strain on our marriage.

Mesh stole my career, my happiness, ability and passion. It shattered my hopes and dreams and put an end to quality family time and travel plans. On pain-free days I see a glimmer of my old self, but incontinence 24/7 is traumatic. I have developed a rash to diapers but I have to wear them. In the heat, one day I left them off. Bare butt, signing for a parcel, without warning the floodgates opened. I blamed the puppy, but the postman went beetroot. Recently at my son's wedding, I lost control and performed a Riverdance as guests scattered.

I agonise over horrific memories, resenting not only doctors but myself for being so trusting and gullible. I don't sleep, but dozing, I awake with a jolt, thinking it was a nightmare. Feeling my urine-soaked diaper, I am reminded this nightmare is real. Recently, the mesh clinic asked me, 'What do you want?' I want to live pain-free. I deserve to live pain-free. I want to dance. I want to run after my grandchildren, enjoy intimacy and enter old age with dignity and not a useless, smelly piddle pot. I want my life back.

I struggle to make sense of this filthy business rife with corruption and the blind-sighted ignorance of the TGA, RANZCOG and the government, which have lost total control of overzealous, greedy gynaes who abuse the system and implant at an alarming rate, the motivation of greed and profit too great not to jump on the bandwagon. But when things go wrong, nobody wants to know. Nobody is accountable, and those telling the truth are labelled 'troublemakers'. As a builder, if I build a defective house and someone is injured, I am accountable or I risk my licence. Why are doctors above the law and never accountable? You all failed women. It should be a standard requirement to protect women. The sense of betrayal grows.

An honest and respectable Queensland doctor who never used mesh rightly said, 'Why worry about registering and credentialling for something that should never be used in the first place?' It just gives them the green light to continue this form of female genital mutilation, clearing the way for the next generation to be harmed. You can keep talking, you can hand down recommendations, open clinics, establish registers and credential doctors to remove mesh who can't even insert it without causing catastrophic harm, but you can't change the mindset of those who put profit before health when it is not in their financial interest.

In a compliant health system that turns a blind eye to unethical practice, making a mockery of the profession, who will oversee that these doctors adhere to new registers and credentials? They already know they are doing wrong, but they keep doing it. Despite Federal Court findings, four of the nine pelvic products deemed defective, including the Johnson and Johnson TVT Exact that I was implanted with, are still sanctioned by the TGA and remain in use in Australia.

In July 2018, the NHS in England and Scotland put a pause on vaginal mesh. Why not Australia? Why are we so slow? Are we not worth as much as English women? How can setting up registers and credentials fix the problem when mesh is the problem? Eliminate mesh, you eliminate the problem. You have the power. I heard the TGA say, 'Only government has the power.' When we spoke to the minister he said only the TGA has the power.

You have the power. It must come from the top, because as more and more as mesh-injured come forward, we are gaining strength. We will not go away. We will not be silent until you do what is right: ban, pause or suspend mesh and show that you care. Thank you very much.

458 The ACTING PRESIDING MEMBER: Thank you very much, Sarah. We have time for a couple of questions. The member for Torrens.

459 Ms WORTLEY: Thank you to all of you for having the courage to come here today and tell your harrowing stories about the journey you have had with mesh. Sarah, if I may, and anyone else who would like to contribute, the mesh clinic has been mentioned on a number of occasions today. What is it that needs to change with the mesh clinic so that the women who are attending or want to attend get the treatment that you believe they deserve?

SARAH: They don't care. The doctors in the clinic don't care.

460 Ms WORTLEY: So what is it that needs to change?

SARAH: We need mesh banned. Nothing else.

461 Ms WORTLEY: Sorry?

SARAH: Mesh has to be banned. It can't be put in a sensitive nerve-rich area that we need to walk. We need that area to move. It's our movements.

462 Ms WORTLEY: Thank you, Sarah. I understand what you are saying there, but we do have many women who have been inserted with medical mesh and they are being referred in some instances or asking to go to the mesh clinic. I have heard some criticism today of the mesh clinic. What needs to change with the mesh clinic to make it effective for those women who need to access it?

EUNICE: If I may, with the mesh clinic it's very hard for women to go in there and the doctor who may have implanted them is there. I went in to look around the mesh clinic when it first started and the doctor who was there put my mesh in. So it's hard to believe that this is going to be beneficial if you are going to be spoken to by the doctor who did it and who is still implanting mesh. I think that there needs to be staffing there who have a belief that mesh is not the right way to go because they are just being hypocritical. We need someone trained to be able to remove mesh from the women here in South Australia. That needs to be done.

I am seeing the physiotherapist at the mesh clinic and I have to say that I found it a relief to go in and be believed that, yes, you have had a flare-up. We have removal and everyone thinks you should be alright and it makes no difference. It's just the fact that you feel better and it can't do any more damage. So I think there are positives; it's not all bad with the mesh clinic. I think there are definitely positives but I do think one of the big barriers is the fact that doctors are still implanting and treating women who have been mutilated or so badly damaged by mesh, you just can't believe that they have your best interests.

SARAH: But they do tell lies. I always demand a report back when I see a doctor. It's the same in the mesh clinic. They say, 'No, you are not privy to that.' I demand it. But I know when I read it why they don't want me to have it because it's full of lies. Cover-ups. They said I was obese. I am 57 kilos. Why would they say that? It's an excuse for having incontinence. They blame incontinence on women being overweight. She thought I would never see that. Why write it? You don't trust them when they tell you lies. You can't go back to them. I must say the psychologist in the clinic is wonderful. She is really good. She sits there and she listens and she doesn't interrupt but she is the only one I liked.

463 Ms WORTLEY: Do you get access to the report following the consultation? Is that what you were saying?

SARAH: Most women don't ask for it; I do. But I did like the doctor there and she was very sweet. I came home and I put it on the mesh group that, 'I saw a lovely doctor today in the clinic,' and I was bombarded by women saying, 'Don't believe her. She is the one who implanted me. She is the one who ignored me for years.' I didn't know.

464 Ms WORTLEY: What about the wait for access to the various services?

EUNICE: Like I say, I have just had a flare-up; I am still off work, and I was able to get in to see the physiotherapist and the pain clinic. The pain clinic was done over the phone. That was within a week or two, so that was very quick. But to actually see a doctor—one of the gynaecologists—you are waiting months.

SARAH: But it was the doctor in the mesh clinic who said to me, 'We have to defend our colleagues,' so how can I go back to him? He denied everything I said, and then when I asked

for the minutes of the meeting, all their negative comments have been removed. They're not truthful, and they've got away with it for so long it has become normal practice now to deceive.

465 Ms WORTLEY: So what would you like to see change? What do you think the mesh clinic needs?

SARAH: I will fight to have mesh removed or paused—just pause it until you finish your investigation.

ELSIE: Probably with the mesh clinic, why I didn't go there was that I wanted the mesh removed, and from what I've heard, that's still not happening. Also, the pain I was in, and with my life, I just needed to have it done. I encouraged my daughter to go in there, and she got told she wasn't bad enough. And I'm thinking, 'Okay, how do you come up with that decision?' I know she won't go back. That, to me, is devastating, because she is single mum with children, and she is supporting herself.

It is just mind-boggling, because at the end of the day, as the years go by and you are getting affected, it's getting worse and it's getting more restrictive, the only real option in my books to put a stop to it is to have it removed. With my first lot of removal, I have achieved that. I just feel very strongly that in her situation the longer that is put off the worse her life is going to become. I just think it's critical that they get in and remove it; even if it means you don't get any improvement, at least you're not going to keep getting worse.

466 Ms WORTLEY: So would a recommendation involve appropriately qualified surgeons for removal here in South Australia? Would that assist some women?

SARAH: Yes, but can I mention: I know women that have been told by their doctors they are qualified and they can do full removals; they have been butchered. They have been made 10 times worse, because they can't—they can't remove it. It's very, very complex, and it takes years and years of training. These doctors need to go back to RANZCOG and learn how to do it the old way, the way our mothers and grandmothers had it—stitched—but they won't, because they thought this would be a quick and easy fix that would save the health system money, and it's actually costing more in the long run.

These doctors in the clinic, they don't want women going for full removals because they know if they send them for partials they come back for more consultations, more pain med and more partials. I know a woman that had 18 partials. They will keep coming back, because if you have a rusty gate, you can paint it all you like but that rust will keep coming through. It's the same with mesh. They give us HRT to cover it up and cover it up, and they snip here and snip there. That is toxic to the body. It is fighting to get it out of the body, and it will keep eroding. So those poor women keep going back, but it keeps them in business.

EUNICE: I think with getting a specialist in that is properly trained—I mean, they have to start somewhere. But to do partials is not the way to go. A partial removal is not the way to go with mesh. I had that small amount trimmed, and within 12 months I was flat on my back. It is because it is mesh. I've still got mesh in me. I have had a 3D 4D scan, which can show the mesh, and I still have mesh left. It's because it breaks off. It's brittle; it breaks off and it's got sharp edges. It is actually mesh, and it goes dry and brittle when it is implanted in the body.

To take part of that is just leaving it raw on the end, if that makes any sense. It's still going to be cutting; it's still going to be doing more damage. The thing with it is it was eroding into my urethra and it was causing a join; it was joining up with my vagina and the bladder. They were all coming together with a fistula. It's dangerous when things like that are happening.

467 Ms LUETHEN: Thanks, everyone, for sharing your stories with us today. I think, Sarah, it was you who said that initially the doctor had said it was a gold standard?

SARAH: Yes.

468 Ms LUETHEN: Was that the GP?

SARAH: It was my gynae.

469 Ms LUETHEN: We have actually heard, I think, from other witnesses that it is like gold standard, and to me it sounds like a sales pitch. Do you have any idea, or do any of you have any idea, where they would be getting that terminology from, to say that it's 'gold standard'?

SARAH: It was advertised as gold standard.

470 Ms LUETHEN: In actual documentation?

SARAH: We were all nearly told that.

EUNICE: Yes. From what we understand with the sales reps, like you get from your pharmaceuticals and that, doctors are taken to conferences. They have the conferences and mesh was put up. Instead of doing one burch procedure, to put a sling in to lift your bladder and your womb, they would use mesh. They refer to it as a gold standard because they can do five \$2,000 mesh operations before lunch and they have made \$10,000, but for the burch procedure they would probably do one a day, maybe two, so their income is not as great.

SARAH: They compete against each other. My daughter-in-law is a nurse, and she has told me. She hears them talking about it in the canteen—'How many did you do this morning?'—before they go out on the golf course. They are boasting.

471 Ms LUETHEN: What do you ladies believe is the GP's reward for referring these things?

SARAH: It's not GPs.

EUNICE: It's the specialists. They are earning a wage the same as everyone else is. You are going to want to earn the most money you can for the least output, aren't you, so of course they are going to go for mesh. To say it's only 1 or 2 per cent of the population, or whatever they say it is, well being part of that percentage is not a good life.

I think of women who don't know. I would not have known. I would not have known that I had mesh in me. Even when I was told I had mesh in me, I didn't know where it came from. I worry for women older than me who are maybe in nursing homes, who are suffering and no-one knows why they are suffering, because they can't even say, 'Well, it might be the mesh,' because it doesn't show up. That's what I worry about.

SARAH: I spoke at the inquiry in Melbourne. I spoke to the lady from the TGA there, and she said to me, 'We're not getting enough complaints.' So I did some research into that. A lot of the women suffering are elderly; they don't even know how to turn on a laptop. Some of them are illiterate or they are so traumatised by the pain they are going through and on strong medication that has them not functional that they are not capable of complaining. If you mention the TGA to them, they don't even know what the TGA means. They just don't know how to go about it.

472 The ACTING PRESIDING MEMBER: Thank you very much for joining us today. We very much appreciate you sharing your stories with us. I have no doubt it's a very difficult thing to do, and also a very brave thing to do. The evidence you have given will go some way to helping others in our community, so thank you very much. We all wish you all the very best.

THE WITNESSES WITHDREW