## Sarah's Story

## Sarah had reached desperation point with long-term chronic painful and heavy menstrual cycles, so in May 2021, she has a Novasure endometrial ablation, D&C, and tubal ligation with Filshie clips. She was just 26 years old.

I was experiencing periods that were anywhere from nine to 18 days long at a time; multiple days of very heavy bleeding and crippling pain. Every cycle I was taking anywhere between 30 and 40 pain pills and tranexamic acid (to try and lighten the bleeding).

My entire life revolved around my period, and there were very few days in a month where I could comfortably do anything without fear of bleeding and pain, so that pretty much ruled out holidays, most outdoor activities, and staying over at friends' houses. On my worst days I couldn't be away from the house for more than an hour at a time. My sex life was pretty terrible too, and my self-esteem was impacted. My iron levels were chronically low, eventually requiring an iron infusion in 2020.

No cause that could be found for my period issues, and none treatment was effective, so I asked the doctor if I could have a hysterectomy (in 2016) but was declined due to my age and not having children. I said I was childfree by choice but was told I would 'change my mind' and to keep waiting. I was told my "periods may come right after you have a child, anyway."

Eventually, I ended up with a great GP who was very proactive and respectful of my choice to not have children. After seeing two gynaecologists, one finally agreed that I had waited long enough and thought about it enough, and he discussed the NovaSure ablation option with me, saying that hysterectomy would need approval from the medical director because of my age.

He thought the ablation was far less invasive and an easier recovery so we should try that option first instead of going for the bigger procedure. I also had serious reservations about the Filshie Clips, ultimately preferring removal of my tubes, but was not provided with an alternative to this method. He really downplayed any risks of the endometrial ablation and said that I was "overthinking most of my concerns".

Following discharge after the procedure, no followup appointment was scheduled; I was told I didn't need one. This doctor never saw me again.

While the potential risks were explained to me there was also lots of information about how successful the procedure is. I expressed repeated concerns but I was told it would be very rare to have any real issues after the fact and the majority of women found everything much more improved after the procedure. After my procedure, my periods never stopped. They were definitely improved and while they were still painful, they weren't as bad. During the first six months, I considered the ablation reasonably successful, and any niggles were due to not having fully recovered; at least that's what I thought.

After the first six months things have gotten progressively worse. Ovulation has become really painful; I get awful electric shock-like pains that travel down my legs; and it feels like someone has scissors on my fallopian tubes for a few days each month. I have had pain in my lower back sore since the procedure, and nothing helps or makes it go away; I'm always in pain now. Using my abdominal muscles can cause pain in my pelvic area, especially around my tubes, also with coughing and sneezing.

Each period I have is slightly worse than the last, and I now fear it will get much worse than it was before. I experience random throbbing pains in my cervix that take my breath away and the pain is getting harder to manage each time. I tried to go back to the specialist only to find he had retired six months after I saw him. His replacement was unfamiliar with the procedure and focused on the pain being my clips; he performed an ultrasound in which he noted my endometrium was surprisingly active. There was no indication from him that the ablation could be causing the issues; he quite literally shrugged his shoulders and said, "that's weird I don't know, it's pretty rare to have these issues."

After finding the Facebook group, and seeing that thousands of other women are experiencing what I am experiencing, I finally felt like I had some answers about the past year of my life and that, sadly, I am not experiencing something rare or unique at all. The only solution is a hysterectomy, which has left me even more upset knowing I should've just had that in the first place.

I don't know anyone who has had the procedure for whom the ablation didn't eventually fail or cause long-term complications. I don't understand how this procedure can continue to be performed with the narrative being that 90% of women are happy with the procedure, it's quick and easy, yet there is more information coming out that shows this isn't true.

Now I am waiting to plan a time next year to get a hysterectomy and finally be done with my monthly terror. My major concern now is, am I able to wait that long? What if I end up needing something more urgently?