What is Asherman’s syndrome?
Asherman’s syndrome is a condition in which adhesions or scar tissue develops inside the uterus, sticking the front wall to the back wall of the uterus, obstructing or obliterating the endometrial cavity where a pregnancy develops.

Asherman’s syndrome usually develops after a surgical procedure on the uterus such as a D&C (dilatation and curettage), termination of pregnancy, evacuation of retained products of conception after a miscarriage or retained placenta, or more extensive surgery such as a myomectomy (operation to remove a fibroid). It is usually made worse if there is an infection, and is much more common than many doctors accept. It is not always caused by poor surgical technique and is an unfortunate consequence of some procedures.

How do you know you have Asherman’s syndrome?
Most women with Asherman’s syndrome will notice that their periods become much lighter than they were before the operation and sometimes the periods stop altogether. Many women also experience significant cramping and pain at the expected time of their period, especially if they don’t see any loss at all.

How common is Asherman’s syndrome?
Asherman’s syndrome is much more common than many doctors think and many are not prepared to consider the diagnosis as a result. The estimates of the proportion of D&C procedures that cause it vary from less than 1% to up to 5%. If you have had surgery and your periods are lighter than they were before, it is certainly worth checking it out.

How is Asherman’s syndrome diagnosed?
The easiest way to diagnose Asherman’s syndrome is by a hysterosalpingogram, an x-ray examination in which contrast medium is introduced into the womb which shows up on x-ray and will show an absence of contrast medium or a filling defect in areas of the cavity which are obstructed by adhesions.

How does Asherman’s syndrome affect fertility?
In the worst case, Asherman’s syndrome can affect fertility by obliterating the cavity so there is nowhere for the embryo to develop, or it can make the endometrium so thin that implantation cannot occur. Adhesions can also block off the fallopian tube so that sperm cannot gain access to the egg to fertilise it.

How is Asherman’s syndrome treated?
The diagnosis is confirmed by hysteroscopy and can also be treated by hysteroscopy using microscissors to divide the adhesions. It is best if this procedure is done by a surgeon who has plenty of experience in treating Asherman’s syndrome, since it can be made much worse if the hysteroscope is introduced in the wrong place, creating a false passage which is surprisingly easy to do. The more experienced surgeons will do this under x-ray or ultrasound control to ensure that they are in the true cavity of the uterus.

Unfortunately the adhesions often come back and it is essential to have high dose oestrogen treatment to encourage regrowth of the endometrium after the adhesions have been divided to reduce this risk. A stent or contraceptive coil is also often left in the uterus to help to prevent adhesions from re-growing and to break them down when the coil is removed.

The prognosis for most women with Asherman’s syndrome is good and we can improve the uterus in most cases. Sometimes however the uterus is so badly damaged that the endometrium has been completely lost. In these cases the only option is to resort to surrogacy.

Mr Adrian Lower FRCOG
Consultant Gynaecologist

Angela’s story
My journey started in December 2004 when my first daughter, Freya, was born on 7th December. She was five weeks premature due to my waters breaking early. I saw her for seconds before I was whisked into theatre. My placenta wouldn’t come away, so they had to manually remove it. Two weeks later I had a visit from a midwife who was concerned that I still looked heavily pregnant. They admitted me into hospital as I had retained placenta. Nine weeks later, after seeing my GP with stomach pains and constant bleeding, I was in hospital again still with retained placenta. All these D&Cs resulted in scarring of my womb and for the next two years I didn’t have a period. I was referred to a consultant, who diagnosed Asherman’s Syndrome. We then proceeded to try and it, I had a hysteroscopy and a coil inserted for six
In May 2007 I gave birth to a beautiful baby girl after a twenty four hour labour. I was then rushed straight into theatre to remove a retained placenta (where the placenta has attached very deeply in the endometrium) which was done by D&C. Two weeks later I was rushed back in to remove more retained products. Nobody ever warned us what the consequences of these two surgeries could be.

As time went on my periods never returned. Each month I would get all the symptoms and the pain would become agonising, I couldn’t even walk or sit down properly. Different GPs insisted there was nothing wrong as blood tests showed my hormone levels were fine and an ultra sound didn’t show anything unusual. When our daughter turned one we started trying for another baby, I was 36 and I felt I didn’t want to wait too much longer for number two. Even though I wasn’t getting my periods my GP said it was still fine to try, but as each month went by the pain became increasingly worse. After persisting for eighteen months I was eventually offered a hysterosalpingogram, where dye is injected through the cervix into the uterus and an x-ray is taken to check for any blockages. After a few very painful attempts they were unable to get the dye through. Someone in the room mentioned that my cervix could be blocked by scar tissue, however my consultant and GP both dismissed it.

Finally in February 2009 I was booked in for investigative surgery. This was when we received the devastating news, they had found severe scar tissue all over my womb which was blocking my cervix and gluing my uterus walls together.

The consultant told us that my womb was useless and that the scar tissue could not be removed (they perforated my womb in the process of trying). Basically, there was no cavity for a baby to grow, I was infertile and that surrogacy was our only option. When I got home I went straight onto the laptop and googled “scar tissue in the uterus”. That was where I found www.ashermans.org – it was such a relief to find the group with its wealth of information and support.

Through them I found one of only a handful of AS specialists in the UK. He concurred through a 3D ultrasound (a routine scan won’t detect it) that I had severe Ashermans caused by over aggressive D&Cs. He gave us a 50/50 chance of conceiving naturally after corrective surgery, a hysteroscopy and a course of hormones. Unfortunately, my scar tissue was so aggressive it grew back within three months. Over a period of time I had four hysteroscopys and one failed round of IVF. We went through so much emotionally and financially it was heart breaking. After the IVF, I was told that my AS was one of the worst and most aggressive cases seen, the scar tissue was literally growing back within a couple of weeks and was given the crushing news that my AS was just too extensive.

Then incredibly, in December 2009 my periods started to return, the left hand side of my uterus had started to heal itself. I had another hysteroscopy a few months later and discovered I was pregnant in August 2010. We were so shocked and overjoyed, but very nervous at the same time. Sadly it wasn’t meant to be, we lost our baby at sixteen weeks to placenta previa, a condition caused by all the damage from the scar tissue. I had twelve units of blood transfused and almost died. I then had to have another D&C two weeks later to remove retained products. After that, we were informed another pregnancy would be life threatening. My AS returned with a vengeance so I took the decision to have a hysterectomy in June 2011. By then we needed to accept our circumstances, allow ourselves time to grieve and enjoy life with our wonderful daughter who we are so lucky to have.

I know now that there is a 25% risk of developing AS from a D&C two to four weeks after delivery and that this increases with each D&C. I discovered the hard way that AS is very under diagnosed (it is undetectable in a routine scan) and that sadly, not many doctors or nurses are trained to look for it or they are told that it is very rare. In actual fact it is estimated that 5% of D&Cs cause Ashermans.

The good news is that when it is detected early enough the results can be different. I certainly don’t want to scare anyone with my story, mine was an exceptionally bad case! I am still actively involved with the AS website in helping to raise awareness and nearly all the women I have met though it have gone on to be successfully treated and had their longed for baby.

In February 2010, I fell pregnant, but at my twenty week scan was told that my cervix was opening. I was on the verge of losing another baby. I received a trans-vaginal stitch, but less than a week later was back in hospital as my cervix was still opening. All of the internal operations I had had over the years had weakened it. Again, I spent three weeks in hospital, but on 6th July 2010, Amelie was born asleep at twenty four + three due to cord prolapse. Again, the placenta was removed in theatre.

I researched and found a doctor in Liverpool, who performed trans-abdominal cerclages to prevent women like me from losing any more babies. I had mine done on 21st September 2010. However, unbeknown to me it caused my Ashermans to return. It took over a year to be diagnosed. One doctor tried a hysterectomy but it didn’t work. Then I found the Ashermans group on Yahoo. There I learnt of a specialist in London. I saw him and despite my age (43 at the time), he agreed to treat me. I had a hysterectomy in May 2012. In July of that year, I fell pregnant. The next thirty eight weeks were the most frightening ever. I had a new consultant. She was sympathetic and she scanned me regularly to ensure the pregnancy was progressing as it should be. On 4th April 2013, I delivered a beautiful baby girl by caesarean section. We called her Thalia and she weighed 6lbs 6oz. She is our fourth child; Coby and Amelie are forever with us in our hearts.

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