

Women's Health Presentation

Transvaginal Mesh Implants

Seven years ago Olive contacted me through my husband after reading a news article he'd written about mesh. I am forever thankful she did.

Before we knew each other, we were both struggling to come to terms with constant pain and crippling side effects of a surgery that was supposed to 'change our lives'. We both suffered from stress urinary incontinence, and as a result of a mesh tape implant called a TVT-O which is a (tension free vaginal tape – obturator – we lost the lives we once knew.

Today we are the best of friends, united in a common aim, to ensure no other woman is put at risk from the polypropylene mesh implants, which have devastated hundreds of thousands of lives across the world.

Many of us had been told we were 'unique', that the life changing injuries we had suffered had never been seen before and were blamed on everything but the mesh. When we found each other, we realised we were not unique. We were victims of one of the biggest medical scandals of our time. Many of us have been spoken down to, vilified and dismissed and told our pain was 'all in our head' – some of us were even referred for psychological treatment.

What happened to us could easily happen to you too. We were all just like you, wives, mothers, grandmothers, sisters and best friends. We worked and looked after our families and homes, just like you. The one thing those responsible forgot to take on board is that women are resilient, we fight back when wronged, and we are utterly tenacious.

Women's health issues can be a tricky subject. We live in a time when porn is widely available, but try and have a conversation about vaginal health and people run for cover. Nobody wants to say the V word. Despite the fact more than a third of us will develop urinary incontinence it's not something that's openly talked about. Many will suffer in silence for years before seeking help. And usually, the specialists you see are men.

Most of us were told that our embarrassing leaks could be 'fixed' by a 20 minute procedure that would change our lives. It certainly did change our lives, and not for the better! I need a wheelchair to get about, Olive relies on crutches, and so do many others.

Most of us certainly were not told about the complications we might suffer, or given a choice of other safer procedures such as; physiotherapy, which can cure or improve incontinence in 80% of cases. Most of us weren't offered medication, bulking injections or traditional repairs using stitches such as Burch Colposuspension or an autologous fascial sling, which uses your own tissue to make a sling, both have the same efficacy as mesh, and if they fail, you are not left with a permanent petroleum based piece of plastic inside you.

Most specialists did not even think they needed to tell us that they were putting plastic inside our bodies. We were assured we were getting the 'gold standard treatment'. We were not told that in fact as many as 40 per cent of us could suffer catastrophic nerve damage by the metal butcher hook like trocars used to place the plastic mesh implant blindly in our groin. We weren't told that the mesh tape could harden, twist and slice through tissue and organs. That it could cause auto-immune responses as our bodies fought to get rid of the foreign bit of plastic – the same stuff that water bottles are made of – the same tape that ties up your newspaper bundles – the same plastic that is used in millions of every-day things. And very few of us were ever told that once implanted, those mesh devices were virtually impossible to remove – it is like trying to remove chewing gum from hair.

We weren't told that many of the specialists we saw had received funding at some time from the mesh manufacturers who made billions selling plastic mesh kits. Mesh tapes would save the NHS around £200 per person because they would no longer have to use such experienced surgeons to do natural tissue repairs and there wouldn't be the need for a few hours extra in hospital. We weren't told if you were one of the unlucky 1 in 5, the results could destroy your life. Because if we were told all of those things, who in the world would take that chance?

Some of us knew there was a huge problem the moment we woke from surgery. We were in agony. We couldn't walk, or move properly. The pain was excruciating. Others have taken time to realise mesh has left them badly injured, and some have learned it can take 10, 12, maybe even 15 years for the problems to emerge.

Then something wonderful happened. One woman Linda McLaughlin had the courage to speak to journalist Marion Scott, and her editor Jim Wilson had the wisdom to forget worrying about the icky subject of vaginas, and publish the story. It was a revelation.

Marion told us that her phone had been ringing off the hook with calls from women across the country. She put us in touch with each other and it was a bittersweet introduction. None of us wanted to think of other women suffering as we all were but at last we had found each other, someone to share our pain, our anger and frustration. And that is how Scottish Mesh Survivors was born almost six years ago.

Within a very short time our numbers grew to hundreds. Marion sat us down and told us straight that we were in for the fight of our lives and if we didn't have the stomach for it, we should walk away quickly and try and get on with our shattered lives. But if we decided we were going to fight, she would back us all the way, and she has. She demanded that the then Health Secretary Alex Neil meet us and see for himself the dreadful injuries we had suffered, and he agreed. We got on a bus and went through to the Scottish Parliament, not knowing what to expect, and we just spoke from the heart. It was scary, it was sad. It struck a cord with politicians from all parties who realised this was not a political issue, it was a medical scandal. Surgeons had not been reporting the side effects and complications because it was voluntary, so on paper, it looked as if these mesh implants were doing a good job. We were the evidence that things were not right.

It was too late to do anything that would help ourselves, but we were determined that no other women would have to suffer as we all had. After taking advice, we decided to make good use of the Scottish Parliament policy of involving people. We drew up a petition and submitted it to the Public Petitions Committee, asking for an independent mesh inquiry to examine just how safe these implants were, asking for operations to be suspended until they could be shown to be safe. We asked for changes to be made so it was mandatory for doctors to report complications and adverse effects. We wanted a register so implants that were causing problems or not working could be easily identified and action taken. We wanted properly informed consent to be introduced so women were told the facts and we wanted our toothless medical watchdog the MHRA to reclassify mesh implants as high risk.

We called our campaign 'Hear Our Voice' and we held up posters and got used to telling television cameras our stories, but still some surgeons kept using mesh implants. Without mandatory reporting and recording of complications there was no real data to show how bad these devices were.

But now we had hundreds of other women in our group, and instead of listening to officials who were telling him mesh was good, Health Minister Alex Neil chose to believe the evidence he saw with his own eyes and in June 2014, he requested a suspension of transvaginal mesh use in Scotland.

There were tears that day as we sat in parliament and realised we were part of something that was going to make a difference to other women's lives, for generations to come.

We faced stiff opposition from surgeons and we suspect some of their anger was due to the fact they had never had women challenging them before, and with such success. But our campaign was being listened to and we were moving forward. At that point, Scotland was applauded. We were leading the world and taking action when others had failed to do so. Other countries were looking at what we were doing, and they were taking notice.

Alex Neil ordered officials to launch an independent safety review, and promised patients would be at the heart of everything. He was furious that the doctors had failed to lodge complications. He promised that nobody who had a vested interest in mesh would be appointed. We believed him. Unfortunately, he was moved and Shona Robison took over...

We had to fight tooth and nail, literally, to get the changes that were so desperately needed. The inquiry went ahead, but virtually everyone else appointed had a vested interest in mesh. We were lone voices once more, desperately preaching to the already converted. We drew up patient information leaflets and even had to fight to have the word 'mesh' included in them. We insisted women had to be told the whole truth and nothing but the truth. That way, they could make their own mind up and decide whether they wanted to take the risk and have mesh. We went up against the most powerful pro-mesh surgeons and organisations, including the medical watchdog which – contrary to what most people think – it is not a government body but a mostly industry funded body – and gradually, we began moving in the right direction. We even won a convert in the expert group of surgeons, Dr Wael Agur decided that using mesh was no longer a safe thing to do, and now he teaches others how to use native tissue.

Just as we were about to reach our goal, suddenly everything changed and from being a country leading the way, Scotland suddenly found we were retreating. The Chair of the independent review resigned weeks before her report was due, and she was replaced by the medical director of one of the two Scottish health boards which had decided to flout Alex Neil's mesh suspension. For ten months we were excluded from meetings, and the report that was on track to do the right thing became a whitewash. We took our concerns to Ms Robison but it was to no avail. We resigned from the review group, and so did the expert Dr Agur who no longer used mesh. Almost 100 MSP's from all parties signed their name to refuse to support what was described as Scotland's whitewash mesh report. The outcry over the way the review behaved has prompted an investigation and we await that report.

In December 2017 the Public Petitions Committee Convener Johann Lamont led a passionate Chamber Debate about mesh implants. It was an emotional day for us listening as our 'Three Meshkateers'; Neil Findlay, Jackson Carlaw and Alex Neil, and politicians from all parties spoke on our behalf. The Committee is due to publish their report at the end of August.

We gave evidence to the Australian government, and they and New Zealand followed the lead we had started and today virtually no mesh is used there. Sadly, Scotland lost ground, and while mesh manufacturers have paid out over £3billion in compensation to women in the US, since the mesh suspension we fought so hard for was introduced four years ago, NHS Glasgow and NHS Edinburgh have continued to implant around 500 more women. We have worked closely with Westminster and politicians there and two weeks ago were delighted to see NHS England has suspended mesh use, at least until the review headed by Baroness Julia Cumberlege publishes. She announced 'We must stop exposing women to the risk of life-changing and life threatening injuries.'

We still have much work to do. Europe has now recognised that all mesh can cause serious injury and has reclassified it to the highest risk category. Despite that, our medical watchdog has failed to protect women. It breaks our heart that we still hear of women being advised to go ahead and have a mesh implant - they are told it's not the same mesh they've read about in the papers - it's a 'good mesh' or it's a tape or a ribbon. Well please believe us when we tell you there is NO GOOD MESH - mesh is mesh - it is all made of the same polypropylene plastic and if it goes wrong, the results could cost you not only the lifestyle you once enjoyed, but also your life - as some women have found to their cost.

There are currently 502 mesh cases in the High Court in Edinburgh, and recently, mesh manufacturers failed in a bid to get our cases thrown out - they have no shame.

The mesh scandal has been compared to the Thalidomide scandal. Not by us, but by the Thalidomide victims who came to parliament to support us and encourage us to fight for the truth.

We hope you leave today knowing more about mesh, and more about what can be achieved when women work together. We did not choose this journey. It chose us. Indeed, the strong friendships we have all made since mesh happened to us would never have happened at all if it hadn't been for this scandal. Would we change a thing? Yes of course we would. If we could only turn back the clock and know what we know now.

Please see our website: <http://www.scottishmeshsurvivors.com/> for more information.

The fight goes on...

Best wishes

Elaine & Olive