Two women share their incredible stories of diagnosis and treatment to raise awareness and help other women - Cambridge EndoCare at Spire Cambridge Lea Hospital.

Tuesday 29 March, 2022

The specialist team at Spire Cambridge Lea Hospital, led by international expert Mr Mohamed Mabrouk, is celebrating becoming fully accredited by the British Society of Gynaecological Endoscopy (BSGE) and recognised as centre of excellence for the diagnosis and treatment of endometriosis. Two patients have shared their inspirational stories with the aim of helping others access a diagnosis and treatment.

Endometriosis affects 1.5 million women in the UK; it can be a chronic and very painful condition which is difficult to diagnose because of variations in symptoms. Some patients require surgery and if the condition is advanced, surgery can be complex requiring a team approach involving many surgeons with the necessary expertise in this particular type of procedure and condition. This type of multidisciplinary team at Spire Cambridge Lea is led by Mr Mohamed Mabrouk, Consultant Gynaecologist and endometriosis surgeon with a special interest in endometriosis and advanced laparoscopic surgery.

Mr Mabrouk explained:

"Endometriosis is an incredibly tough, debilitating and little known about or understood disease which is sadly common. Now this hospital is recognised as an accredited centre for endometriosis management, it will help more women from across the region access a diagnosis and the care they need. Sadly many of our patients have suffered for the majority of their life with painful symptoms, so I feel privileged to work with this great team who can treat different degrees of severity of endometriosis. Everyone is experienced and devoted to helping women overcome endometriosis and have a better quality of life, living as symptom and pain free as possible."

Cambridge EndoCare – the diagnosis and **treatment team**

All too commonly for many patients, by the time it is diagnosed and operable, the endometriosis may have spread to their bladder, bowel, ovaries or ureters. Mr Jonathan Morton is a colorectal surgeon who works with Mr Mabrouk to remove endometriosis tissue in the bowel. Mr Nikesh Thiruchelvam is a consultant urologist who assists patients who have endometriosis in their ureter or bladder. Often all three consultants are involved in the same operation as a patient undergoes endometriosis tissue removal from multiple areas.

This was the case for **Sarah Mercer**, from Cambridgeshire, who underwent surgery at Spire Cambridge Lea Hospital last November to remove endometriosis from her bowel and ureters. She also underwent a hysterectomy to remove pre-cancerous cells from her uterus. Sarah explains:

"If my endometriosis had been diagnosed and treated earlier, my life would have been very different. I wish, as a young girl, someone had said to me: 'Very painful periods are not normal so let's look into it.'"

I was extraordinarily relieved when I was finally diagnosed. Over the years I'd been told many times my pain was part of life as a woman. Now I know, no pain like the pain I suffered is normal and that is why I'm keen for other women to learn from my story.

I had very heavy, debilitating and painful periods from a young age which I lived with throughout my life. Fortunately, I gave birth to a 'miracle' son but despite several rounds of IVF, my endometriosis was not diagnosed and I was unable to conceive again.

Eventually the pain became unbearable and I suffered IBS. More worryingly I started to find blood in my stools. I was dismissed by my GP after initial investigations, but eventually I consulted a GP who specialised in Women's Health. She immediately thought I had endometriosis of the bowel and so investigations began.

Blood tests were carried out and revealed I had inflammation and an indicator for ovarian cancer. I was referred for an urgent ultrasound at Spire Cambridge Lea Hospital where the radiologist stated I had endometriosis, and my bowel and uterus had fused together.

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Scan Me:

The first consultation was different to anything I had ever encountered. Mr Mabrouk listened to what I had to say; it was such a relief to be listened to and validated. He explained all of the treatment options and I chose medication to control my symptoms. For a while it was wonderful, the pain was manageable but then my symptoms returned and seriously impacted my quality of life and time I was able to spend with my family. I had another MRI which showed I had a lot of endometriosis, deep in my bowel, my uterus and the top of my vagina. I also had Adenomyosis inside my uterus (a condition where the inner lining of the uterus breaks through the muscle wall of the uterus).

Mr Mabrouk made it clear he would never pressure anyone into surgery which he didn't, but I needed to come to terms with my diagnosis and what it meant. Mr Mabrouk was with me every step of the way and after another MRI to check, the endometriosis was found to have spread to my ureters on both sides. Together we decided surgery was going to be the best route because damage to my ureters could affect my kidneys. During this entire process, Mr Mabrouk was wonderful and very reassuring, which helped when making such major decisions.

Three surgeons, one key-hole operation

On 6th November 2021 I had a hysterectomy and my uterus was removed. Mr Morton, removed the endometriosis from my bowel and carried out a disc resection of my bowel. He is another lovely consultant who listens and is empathetic.

Mr Thiruchelvam successfully removed the endometriosis from my ureters, doing a fantastic job using key-hole surgical methods.

I kept my ovaries, so I did not have to go through menopause, apparently it is important to preserve them if possible.

Medication and symptom free

I'm currently medication and symptom free! I've got my life back . . . you don't realise how much pain you have been managing until you have none, it was such a part of my everyday life.

I felt different immediately after the operation. It was such a relief and I started to get energy back. Four months post-surgery and I feel like a new person which has had a huge and positive impact on my home life. I am now able to be there for my child and for my husband, which makes such a massive difference.

I can't stop thanking Mr Mabrouk, Mr Morton, Mr Thiruchelvam and the specialist nurse Kate who checked on me all the time whilst I was recovering in hospital. They are so invested in their patients and they really do care."

Claire James from Rushden, Northamptonshire explains her journey:

"I didn't know I had endometriosis. It wasn't until Mr Mabrouk explained following my MRI, drawing with a pen what was going on, did I see it. I called it **my Spaghetti Bolognese insides** because that is what it looked like. I had endometriosis in my bowel, five large fibroids pushing down on my bladder and I needed a hysterectomy. All my symptoms suddenly made sense, the irregular bowel movements, the constant need to pee and the pain that would leave me in agony on the floor were no longer disconnected symptoms. They were caused by endometriosis and Mr Mabrouk said that he could fix all the issues I had lived with for over 10 years.

Last November I underwent surgery at Spire Cambridge Lea in the care of Mr Mabrouk and Mr John Morton, who did an amazing job reconstructing my bowel. I had 13cm of my bowel removed, along with five large fibroids (the biggest being over half a kilo) and a hysterectomy, but my cervix and ovaries were left in place.

I was extremely anxious before the operation, terrified I was going to require a stoma. I had backed out of a procedure in another hospital before, so this team was aware I needed to be kept busy with no waiting around. No sooner than I had arrived, I was dressed in a gown and prepared for surgery which was a huge success. I can now drive for two hours without a break, I sleep for over 10 hours undisturbed, and my life has transformed. I have started to cycle again and no longer need to find a convenient hedge every few miles.

For over 10 years I've been thinking it's normal to pee three to five times an hour, all day and night. I put it down to one of those things women put up with after childbirth. However, I was wrong and that's why I wish to share my story so other women do not keep on going with conditions and symptoms that are not acceptable. The care I received was wonderful and although I avoided surgery for as long as possible, I

am now living my full life."

Neil McCullough Hospital Director at Spire Cambridge Lea stated:

"Many of our patients have waited years for a diagnosis and that is why I'm proud of Cambridge EndoCare at Spire Cambridge Lea Hospital. The accreditation demonstrates we have a recognised and experienced team devoted to our endometriosis patients, so they can access specialised care and support whenever they need it. As well as Mr Mabrouk, the team includes a specialist nurse, a pain management specialist, a specialised radiologist and the vital supporting consultants in other specialties including colorectal surgery, urology, uro-gynaecology and reproductive endocrinology."

Ends.

Notes to editor:

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About Spire Healthcare

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