

## **Sue's story, March 2020**

**Age:** 58

**Diagnosis:** Achalasia

**Treatment:** Keyhole HM with wrap

**Note:** My treatment took place at Leicester Royal Infirmary 2015

### **What symptoms did you first experience and when?**

I started to notice the I could not swallow food about 2010, not all the time but at first it was occasionally so I was not concerned about it. It started to get worse and food would get stuck at the top of my oesophagus. Swallowing water did not shift it. It was my ex who suggested I see the doctor about it as he thought it could be cancer (he didn't tell me that BTW). But it was probably a year later (2011) once the swallowing became more of a problem. I was not losing any weight at that stage.

### **When did you inform your GP, and what was the outcome?**

The doctor (De Montford Surgery) was very good and sent me for an appointment with the LRI. They thought it might be a mental issue as the symptoms can be the same but that a Barium swallow would show this up.

I went for that test and it showed my oesophagus was not working properly and they could see the barium getting stuck.

### **When and how were you diagnosed?**

I was given an appointment with a surgeon at the LRI quite quickly after the test and this one was a specialist and was only dealing with patients with Achalasia. He seemed to think I had that and not cancer but I needed to have a camera down my throat to see how bad it was. By this time my eating was getting worse and I was starting to lose weight. The camera test was not pleasant and I opted for no sedation (bad move in hindsight) but they could see from the results that I had a problem.

### **What treatment was recommended to you?**

The surgeon said there were some options to help alleviate the symptoms. One was botox and the other was a dilation. The HM operation was not an option at that time and the wrap was not even mentioned. He told me I had to have some other tests before anything could be done though. It took a long time and a lot of invasive testing before I was offered the HM operation roughly about 4 more years. The worst was having a 2nd camera test (approx 2013) when I was not keeping much down and being sick a lot. I kept my weight on by drinking Prosecco. I told the surgeon this as he was pleased my BMI was so high, he told me to carry on. I could not eat much solid food. Puddings however seemed to go down very well. I told the camera test people that I had a problem swallowing and they gave me sedation this time. They started to push the camera down my oesophagus and it hit the gunk that was stuck at the bottom and I started to choke but they did not

have a sucking device nearby so I started to pull the camera out and they held me down. It was horrendous. They just did not seem to understand about how A affects the oesophagus.

They made me go for another barium swallow. They actually asked me to swallow the thick stuff like children glue, I laughed but they said I had to do it. After I filled the paper bowl with sick they stopped the test.

I then had to have 2 more tests. I do not know the technical terms but one was a wire with balls attached that she put into my nose and down to the bottom of the oesophagus which would not open to let it through. I had to suffer that for 20 minutes. I was in pain but she told me that people never have a nose bleed. My nose would not stop bleeding for 20 minutes after that. It was horrible.

I then had to have a smaller wire in my other nostril (the one that had the 1st test was so sore she could not put it in that one), this was a 24 hour monitoring device which was put down my throat. I explained that I was sick after every meal but she said I had to have it done. Well that lasted 1 hour and I was sick so the wire ended up out of my mouth. My sister had to get it out for me. It was actually traumatic and I refused to have any more done. This was 2014.

### **What treatment did you decide to have, and where was it carried out?**

The surgeon I saw originally was not now available and I was sent to see another who suggested I have the HM with a wrap. I was so pleased as without the wrap you can have problems with acid reflux. Sadly the POEM procedure was not available in 2014. I was given a date for the op at the end of 2014 but this was cancelled. I eventually had the op in March 2015 at the LRI. I was told after the op that they found some bad stuff stuck in my oesophagus so it happened at the right time. The op went well but it was very painful once the morphine wore off. I was sent home the next day and I was back at work after 2 1/2 weeks.

### **How are you managing your symptoms post treatment?**

I can eat virtually anything now except steak or solid meats so its mince for me and sloppy foods are the best. I love a chilli with rice. I only have a major problem if I stuff my food down too fast (old habits die hard). But I did have to go back to the surgeon about my spasms. They slowly got worse after the op. I found that a Gaviscon type liquid helped alleviate the spasms a bit along with alcohol but not wanting to turn into an alcoholic I needed another option. I told my surgeon and he gave me Tildium slow release tablets. These stopped the pain very quickly and were amazing. It virtually stopped the spasms of a while.

I now take Aloe Vera tablets from Lanzarote and they really help the spasms so I don't have to take the Tildium as much. They are really for Angina so I'd rather to be taking them if possible. My surgeon does not understand why the spasms are happening, it would be good to find that out.

It has been 5 years now since the op and I am much better than I was so much so I'm having to watch what I eat as I have put weight on.