

## Silvia's story, December 2019

**Age:** 26

**Diagnosis:** Achalasia

**Treatment:** Laparoscopic Heller Myotomy (Padova, Italy)

**Note:** My diagnosis and treatment took place in Italy (Varese and Padova). I am now London-based and am under the care of an excellent Upper GI team at St Thomas'.



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

One day in September 2010 I tried swallowing a mouthful of my dinner, and it remained stuck in my chest area, similarly to how a big lump of bread can stay stuck if you don't chew it properly. I was 17 at the time and I'd just started my final year of secondary school. I didn't think much of it that first time, until it started happening more often during subsequent meals. I thought I was just being greedy and eating too fast, so I tried slowing down and chewing more, but it made little difference. Eating started to become painful, because of the pressure caused by the food that remained stuck at the entrance of my stomach. My parents were very confused and told me to eat slower. This continued for a month or so, until my parents decided it was time to pay a visit to our GP.

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

Sadly, my visit to the GP didn't result in an achalasia diagnosis – but in a misdiagnosis of anxiety and an eating disorder. With hindsight, this outcome isn't surprising: I was a young girl in her teens telling a GP that she couldn't eat – a GP who'd probably never even heard of achalasia, or at best studied it in a textbook many moons ago. I was fortunate though, and my parents believed me over the GP when I told them that I really wanted to eat, but just wasn't able to because of the pain. They probably perceived the hunger that I'd started experiencing because of this unwelcome diet!

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

I received a preliminary achalasia diagnosis very soon (about 3 months) after my initial symptoms manifested. This is unusual for someone with achalasia, and I consider myself extremely lucky! Given the failed GP appointment, my parents decided to book a private appointment with a specialised GI consultant. After I'd described my symptoms, he immediately suspected achalasia, which was confirmed by a barium swallow (esophagram). It was fortuitous that I'd landed on a GI consultant who'd already treated achalasia.

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

The GI consultant recommended I get a Laparoscopic Heller Myotomy. His rationale was that it would give me long-lasting relief (between 15-20 years) from my symptoms, which was ideal given my young age. He also dissuaded me from less invasive, but also less long-lasting interventions such as dilation and botox, as they could make a Myotomy more complicated.

The prospect of a long operation under general anesthesia absolutely terrified me. I distinctly remember telling my Mum that I wouldn't let surgeons and their tools anywhere near me! I'd decided that for the time being, the pain eating caused me and the effect it had on my weight and wellbeing, weren't worth the risks of an operation. Sadly, the less invasive POEM operation wasn't standard practice back then, or I would have jumped at the opportunity!

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

Following my diagnosis, my symptoms rapidly worsened. I was experiencing severe pain every time I ate, and drinking liquids started becoming difficult. I continued losing weight, and by February 2011 I'd lost about a stone. Even if I tried eating little bits of high-calorie foods throughout the day (just like a rabbit, my school friends joked), I just couldn't keep the weight on. Given the impact the condition was having on my wellbeing, and the severe pain it caused me, I realised the time had come for me to get the dreaded operation.

The Laparoscopic Heller Myotomy was carried out in a specialised Achalasia centre in Padova (Italy), which is internationally renowned for its research on the condition. Before getting the ball rolling with the operation, I got an endoscopy and manometry. Both are somewhat unpleasant procedures, but required to fully confirm my achalasia diagnosis, and to get the necessary findings for the operation.

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

The operation went very smoothly, and I was kept in the hospital for 4-5 days. During the last few days in the hospital I started eating soft foods; that first time swallowing without pain was just incredible! I slowly regained physical strength, and by the start of Week 3 I was back in school, preparing for my Baccalaureate, and slowly reintroducing foods as per my prescribed plan. My most coveted memory during recovery was the first time I had a pizza: it was bliss!

A couple of years after the operation I developed heartburn, for which I was prescribed Lansoprazole, which I took on and off for the best part of seven years. Five years after the operation I also developed esophageal spasms, which are painful contractions of the esophagus that feel like a heart attack. Needless to say, getting into the care system in the UK was a very perplexing, complicated and frustrating experience - and I'd like to thank the Achalasia Action community for their tips and support throughout it. I am now under the expert care of an upper GI team at St Thomas'.

Nearly a decade on from my operation, I still happily eat most foods, no longer take Lansoprazole (just Gaviscon), and rarely experience spasms. This is mostly due to me modifying small but important lifestyle factors such as: no longer eating grapes or giant couscous, eating a heartburn-friendly diet, and avoiding sleeping on my tummy - all tips that have come from the achalasia community! If you have any questions about my story, feel free to contact me on [silvia.davey@achalasia-action.org](mailto:silvia.davey@achalasia-action.org)