

**Michael – Tiverton, Devon UK – May 2020**

**Age: 75**

**Diagnosis: Type 2 Achalasia with a proximal aperistaltic segment**

**Treatment: A Heller's Myotomy recommended but deferred while symptoms remain unobtrusive**



### **History of symptoms:**

Difficult now to give a date when this started, but for several years I experienced at times very intense pressure pain in the mid-thoracic area of the back, particularly whilst lying in bed asleep, and that massage did not really alleviate. This could last for several hours. Around 2010 I developed problems with the back of my throat, a sensitivity that would often make me cough but, on visiting the doctor, he could not find anything.

Then, around 2013/14, I started to find on occasions (sometimes whilst eating but usually not, probably more likely after a sharp intake of breath) that I could not breathe and it would take a minute or two before I could clear my airways and start breathing again. This also started to happen at night. In the summer of 2015 whilst finishing a meal and chatting with someone, I suddenly, violently and involuntarily regurgitated my food, through both mouth and nose. I did not have a feeling of it coming from my stomach and there was no taste of acid. At this point I still did not associate any of my problems with an ongoing eating problem.

### **Initial visits to the doctor**

Prior to 2015 I rarely found need to visit the doctor for my own health, my current doctor remarking on my first visit to him on 9<sup>th</sup> February 2015 that he had nothing on my computerised records other than a broken collar bone (car accident) in the early eighties. Other aspects of my health were however becoming more of a problem (e.g. blood pressure) and it was during a visit later that year that he offered to get me an ENT appointment at the RD&E Hospital in Exeter to see if there was anything that could explain some things. I had explained that there had been an increase in the number of occasions when I had woken up unable to breathe, a feeling of air being trapped in my neck, further occasional episodes spontaneous reflux when eating and a continued irritation in my throat that made me keep coughing to try and clear.

### **Medical progression**

Between 9<sup>th</sup> November and 11<sup>th</sup> December 2015 I had I had a camera placed through my nose that showed nothing obvious except an upper oesophagus osteophyte (which wasn't mentioned to me at the time), a CT scan, which I didn't get any feedback on, a visit to the ENT consultant who decided to send me for a barium swallow X-ray, and the latter taking place, which was the first time that I had a clear indication that I had a significant problem. I was shown the X-rays by the radiologist and could see that the barium liquid was being held in my oesophagus as in a wine glass. The official specification was 'a narrowing at the lower end of the gullet, not looking malignant', and a recommendation was made for endoscopy.

This took place on 23<sup>rd</sup> December 2015 and the gastroscopy report noted "a submucosal lump in the upper Oesophagus: the gastro-oesophageal junction (GOJ) was normal from above and below, although a small tongue of mucosal change was noted in the GOJ: the rest was completely normal: the GOJ sphincter looked tight rather than lax and it was wondered if this was not due to dysmotility" (I had a lot of learning to do to get some understanding of all of this).

This had all happened remarkably quickly, but it then wasn't until the 22<sup>nd</sup> February 2016 that a letter was received suggesting the possibility of a manometry test. On 6<sup>th</sup> April I was offered a telephone consultation concerning this but, following a strong letter from myself listing the depth of

my difficulties, this was changed to a test being conducted on 13<sup>th</sup> May 2016. The test showed no sign of any peristalsis taking place during the process of eating. I then received a letter again offering a (now) post-test telephone consultation but, feeling that this method of consultation would be very inadequate, I finally achieved a face to face consultation with the consultant on 1<sup>st</sup> July 2016 to discuss the diagnosis that he had given in letter to my doctor and within which he had recommended surgical intervention. As a result of my desire to avoid surgical intervention for as long as possible, he agreed to put the decision to operate into hibernation until I would come back to him when the achalasia became too great for me to be able to handle.

### **Post diagnosis management**

A very important part of this for me had been to establish why I had been having these problems. Having done that, my focus has subsequently been on how to manage my situation. I have taught tai chi for over thirty-five years and I feel that this has helped me in managing health problems in general and is continuing to do so with the achalasia. I have a wedge under the top half of my mattress that lifts by head by four inches and this, coupled with two pillows and training myself to not sleep on my back, has reduced the incidence of problems at night significantly. Also, I try to avoid eating into the evening but have a hot milk (contrary to most sufferer's experience) before going to bed, as I find the weight and heat of this helpful to clearing my oesophagus sufficiently for lying down.

I try to eat a reasonable range of things but, generally, food that has both weight and fluidity to it and well chew it. I try to resist dry things, such as biscuits, as these tend to develop a blockage. Otherwise, generally, I eat well. The biggest remaining difficulty for me seems to be the build up of swallowed saliva during the periods between meals. If I am not able to clear this sufficiently before eating it feels like the air within the saliva and its glutinous nature combine to create blockages that are difficult to release and, until I am able to do so, my eating comes to a halt. In the mornings (after a night of swallowing) it usually takes close to an hour with my first cup of tea to get my oesophagus sufficiently clear to have breakfast.

### **Disappointments on the medical side**

In the later stages of my diagnosis two attempts were made to consult with me over the telephone, which I felt was inadequate for helping me understand and discuss the complexities of what I was being told and also potentially facing; there was very limited observation of my dysphagia and are we sure that it is a continuous thing?; since the diagnosis in mid-2016 I have had no monitoring of my situation and do not know how my oesophagus is standing up to the problems; and no professional help seems to be available to discuss and guide me with the management of the problem, other than offer of surgery.