Neil - Salisbury UK - Nov 2019.

Age: 48

Diagnosis: Achalasia – type not assessed. **Treatment:** Hellers Myotomy Nov 2019

What symptoms did you first experience, and when?

In about 2001 I started experiencing chest and back pains about once or twice per month. After a while I noticed these were stemming from the solar plexus area. I knew it was not heartburn, as there was a muscular/ spasm context to the pain. About 2 years later the pains led to odd occasions of impaired swallowing. A further year or two later, my swallowing deteriorated to almost nothing, at least without experiencing great discomfort.

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

I went to my GP in Salisbury, and after 2 visits they referred me to Salisbury Hospital for an Endoscopy – where the Dr immediately suspected Achalasia – I think he was familiar with the condition so that helped get a quick diagnosis. He no longer practices.

When and how were you diagnosed?

I was advised to have a barium swallow and a bit later a manometry at Salisbury. Both confirmed the suspicion of Achalasia. I did note a comment that my 'peristalsis was out of sequence'. I do also recall thinking that the diagnosis is not really very clinical. In the sense that there was/is no blood test or genetic level test to identify the condition. It is often reported that nerve cells are lost in the Oesophagus for people with Achalasia, but this was/is not tested. This said, I have no reason to suspect that methods of diagnosis are not consistent. They certainly seem to be. The upshot is though that the condition remains limited in medical understanding.

What treatment was recommended to you?

I was initially advised to have a balloon dilation. However, I thought I would first try some non-invasive treatments and natural remedies. I tried a therapy called Bowen Technique – this targets muscle membrane rebalance, and is a fairly common practice these days. This combined with some mindfulness, high strength Magnesium and Vitamin B, got me into a state where I could tolerate (mostly) the condition. I also devised a manoeuvre to help me swallow. This comprised: raising my right arm, running my hand across my head, breathing in, and swallowing with a force targeting the roof of my mouth, and imagining my oesophagus was a vertical solid structure; thus allowing the initial force to carry all the way down. We even witnessed this happening on a Barium Swallow. This went on for 10 years or so – somehow just managing.

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

After 10 years of good use, my 'manoeuvre' eventually stopped working. It was a very strange experience. Suddenly I had no 'get out of jail' card. I can now fully appreciate why people go for surgery or a dilation early. It is a pure means to an end. I used Sildenafil (this helps dilate blood vessel to get blood to smooth muscle) to assist with eating; though I am eating mainly soups and well chewed food. No Steaks!! ©

I, just a few days ago had a Hellers Myotomy (HM) at the University College London under Mr Hashemi. I was referred from Salisbury upon my own request. Mr Hashemi is a patron of Achalasia Action and is well experienced in dealing with the condition. I have found his care insightful, diligent and very friendly.

How are you managing your symptoms post treatment?

Given I am only a few days into HM recovery I am doing well. I stayed at UCLH for 3 nights after a 2hr Op. I was awakened by a nurse who offered me a cup of water. My immediate reaction was - OK, this feels fairly painless and on I went to drink it. The only discomfort I felt was in the wounds where the keyhole instruments entered my stomach (6 in total). I had to manage this pain for 48hrs before the swelling went down and it reduced significantly. I have stopped painkillers now. I am on fluids/thin soups only for 2 weeks building up carefully to pureed food. We agreed to do this until my Apt in 6 weeks – we hope to move to solids there after – though I will prob stick to a predominantly soft diet as it doesn't bother me. I can chew, so I can happily blend stuffs in my mouth with a drink. I don't expect to ever be swallowing large chunks of unchewed steak! My current diet includes a daily start of a small bowl of double cream and raw honey (so yummy and about 1000 calories to kick the day off!), a Huel (just Google) shake at lunch (I add a fruit yogurt drink for flavour), and Soup for tea (I usually



add butter to boost it). Luckily my wife likes to make homemade soup- lots of pureed Veg and can add meat/fish. I had pureed pea and ham soup last night – so good! I drink lots of turmeric tea to wash things down, inc a treat of cream chocs in the eve – I suck these and drink with tea so they go down pretty much as fluid.