Mary’s story – caring for Tom

I used to work as a GP and retired at the end of April, after a 35-year career in the NHS. My husband, Tom, and I live in a village near Market Harborough in Leicestershire.

In June 2023 Tom was diagnosed with oesophageal cancer and was treated initially at Northampton General and then at Leicester Royal.

You may therefore wonder how I came to be involved with OOSO. – This came about after my neighbour introduced me to a lovely lady who had just joined her art group and who is a member of OOSO and who had had her treatment at Oxford. She told me about the group and I got in touch with Matt, asking if I could join, as there is nothing like OOSO in Leicestershire.

Tom was previously fit and active. He had retired a few months previously, at the age of 66, having spent most of his career as a police officer, latterly as the base manager of the local Police Helicopter Unit.

He had no risk factors – or so we initially thought, although now we wonder if the cancer was caused by his long-term exposure to aircraft fuel. We started to suspect this after learning that 2 other base managers had also had oesophageal cancer, one of whom took over from Tom.

We were having dinner one evening in April 2023 when suddenly Tom had an episode of absolute dysphagia, resulting in water pouring out of his mouth. He had eaten a piece of meat, which had got stuck, and was trying to dislodge it with water. - After 20 min, he managed to get some water down and finish his meal. –

At the time, I found this very worrying but we both assumed that he had eaten too quickly (which he had a tendency to do.) - I decided to watch and wait and a GP friend of mine agreed with this plan.

A few days later, we were in Italy at my niece’s wedding. All was well until the same thing happened during the meat course and it was then that it hit me that he needed an urgent endoscopy.

We somehow got through the next couple of days, with no further episodes of dysphagia. I was, frankly, gripped with terror.

The day after we flew home, I rang Northampton General and managed to get hold of a gastroenterologist – Dr Udi Shmueli -whom I had known since I was a house officer. – I got cheeky and rang switchboard, asking if Dr Udi carried a mobile as I needed to speak to him urgently about a patient.

Udi had a private endoscopy list 2 days later. We have private insurance but, as time was of the essence, I did not even attempt to contact the insurers and I therefore paid for the endoscopy.

Udi found a narrowing in the oesophagus, but thought it looked benign and that it was most likely due to external compression. He said Tom needed a CT scan to investigate further.

Again, I did not bother to contact the insurers and rang round all the local private hospitals with increasing radius from home until I found a slot at a private hospital in Derby 4 days later.

The CT was normal, but then Udi rang me with the biopsy results: One was suspicious. Udi booked Tom onto the end of his next NHS OGD list a few days later and took more biopsies. He still felt the narrowing looked benign at this point but sadly this turned out not to be the case.

The pathologist initially graded the tumour as a T1 – with a very high chance of cure. Udi said that he had never seen a T1 before. In order to stage the tumour further, he said that Tom needed an endoscopic ultrasound, which his colleague could do. Sadly, the ultrasound could not be passed through the narrowing and the tumour was graded as a T3 i.e. much worse than initially thought. I later learned that, even in very skilled hands, the oesophagus is hard to biopsy as it is such a thick, muscular structure – hence the difficulty in getting good biopsy specimens.

We were told that we would be seeing an oncologist and that surgery was not an option, – but 2 days later, we found ourselves talking to an upper GI surgeon from Leicester Royal who said that surgery would increase Tom's chance of survival significantly. As you can guess, we were shocked by this. After the surgeon left the room, we asked the Macmillan nurse who was also present when Tom would see an oncologist. To my dismay, she shrugged her shoulders and said that she had no idea.

As we drove away, I made the decision to transfer Tom's care to Leicester.

We saw an oncologist a couple of weeks later and Tom went on to have chemoradiation for 5 weeks, then a break of 6 weeks, followed by oesophagectomy. Before starting treatment, he had a RIG feeding tube inserted as he was struggling to swallow even liquidised food. He rang me after coming round from surgery and was very distressed – saying "The freak is back on the ward. "– It took me some time to reassure him that he was not a freak and reminded him that the RIG was only a temporary measure and was clearly lifesaving.

Prior to surgery he was seen by the pre-habilitation team, who stressed the importance of physical fitness prior to surgery. Tom thought he was very fit for his age, but the anaesthetist who was running the clinic challenged him to do more. We therefore started working with a personal trainer and bought an exercise bike.

Tom was told that he would not be able to do much by week 4 of treatment, but he proved the oncologist wrong and astounded everyone by still being able to exercise at the same level throughout. I was terrified about the possible side effects of the chemo and radio but the only problem he had was nausea on the day of chemo, which was easily dealt with by ondansetron.

The surgery went well, as did his recovery – until he caught pneumonia the day before discharge, resulting in my having to call 999 in the middle of his first night home.

Tom had 2 goals when he got the diagnosis:

1 To live to a ripe old age with me

2 To play cricket the following season.

I am pleased to report that he has succeeded with goal 2.   I can not tell you how proud of him I am! He has played this year and was the 6th top scorer in his league! Pretty good for a 69-year-old with a history of oesophageal cancer! He is in line to get "Batsman (or rather Batsperson) of the year! As regards to goal 1 – time will tell…

A few weeks after surgery he was offered immunotherapy – the aim being to prevent recurrence – and was the first patient in Leics to fit the criteria as NICE had only licensed the treatment for oesophageal cancer a few months before. He tolerated it very well, the only adverse effect being hypothyroidism. He was on it – 2 weekly – for a year.

As you can guess, I struggled to cope – particularly for the first few months, and needed support from a psychotherapist. My over-riding emotion was fear. I paid for treatment privately. I can highly recommend EMDR!

At one point, I emailed Matt, asking for a chat. He called me later on that day and spoke to me for an hour, after which I felt a lot better. Matt: I can never thank you enough for all your kindness, wisdom and invaluable support.

I felt unable to work for 7 /12 during Tom's treatment My employers were very supportive and did not push me into returning until I was ready. My GP was also very supportive. I wanted to retire on my terms, not on cancers and Tom was in agreement with this. I went back to for 14 months and was glad I did so.

It has been a roller coaster of a ride and we do not know what the future holds, but then nor does anyone. Tom has had a very positive attitude throughout and I am cautiously optimistic, living with hope.