

## **My Cancer Journey – from Despair to Elation**

### **Pre Diagnosis**

In April 2023, I started to notice that I was having some issues eating food. Initially I didn't think a lot about it but through the following month it steadily got worse and I knew (at least my wife told me in no uncertain terms) that I had to go and see the Doctor.

I managed to get an appointment with my GP on 6 July 2023; he diagnosed "reflux" as being the issue but to be on the safe side he would send me for an endoscopy. After a week, notice of the appointment for the endoscopy came but it was for some time in January 2024. My symptoms were getting worse; I was regularly bringing back food. I returned to our GP's and saw a different Doctor. He didn't go against the original diagnosis although he put me on to the 2 week pathway and I was able to have an endoscopy at my local hospital (Milton Keynes) on 03 Aug 2023.

### **Diagnosis and Despair**

The endoscopy was not a pleasant experience, I could see the screen showing an obstruction in my oesophagus and also more worryingly they could not get the camera passed the obstruction and into my stomach. Biopsies were taken and I could tell from the faces of the medical team there, that this was potentially a major issue.

I was panic stricken as I waited to be told the results by a MacMillan Cancer Nurse (Michelle). Michelle confirmed that there was a Tumour in my Oesophagus, but said it was not necessarily Cancer, the biopsies would determine that. She also explained that, because they could not get passed the obstruction, the next step would be for me to have a CT scan.

I was devastated with this news, as was my wife; my biggest fear had come true. Some fifty years earlier my father had died from Cancer of the Stomach. My father's death (he was only forty and I was a young teenager) had left a lasting impression on me. I could only think that history was going to repeat itself.

The wait for the CT results was difficult to say the least. My mind was doing overtime and I was trying to reconcile what I needed to do and get sorted before I died, not knowing how long I had left (weeks, months, years?). At the next appointment the Consultant confirmed that it was Cancer but the CT scan was not clear enough to size the tumour or to determine how far the Cancer had spread. I would need to have a PET-CT Scan at the Churchill Hospital in Oxford.

It was now time to tell our family, what a difficult task that was, how do you tell your nearest and dearest that you are dying of cancer. We did this over a FaceTime call; all I wanted to do was curl up in a corner and cry. As always my wife was there to bolster and help me through it.

The appointment for the PET scan came through fairly quickly, another not so pleasant experience as I was made mildly radioactive for the scan. The journey home was difficult as I needed to stay as far away as possible from my wife in the car (because of the radiation) and our journey home would take over an hour. Apparently, the risks of radiation to the patient and others after a PET scan are low, and for only a short time, but I wanted to be careful.

Anxiety grew further over the next 2 weeks as we waited for the results of the PET scan. We met with another consultant (Mr Saka) and Michelle the Macmillan Cancer Nurse. Mr Saka confirmed that I had a Tumour at the base of my Oesophagus and it was Cancerous, the Cancer had also spread into the Lymph Nodes in my chest and abdomen. He also went on to say that the cancer was inoperable, at which point my heart sank and I found it impossible to listen to what was being said, I thought I was dying! At some point I became aware that there were 2 treatment options being offered both aimed at improving my quality of life. The first option was to have Chemotherapy and Immunotherapy (at Milton Keynes Hospital) the second option was to put my name forward for a clinical trial in Oxford. My wife immediately said yes to the clinical trial, Mr Saka had to ask

“is this what you really want Andrew”. I had nothing to lose and possibly more to gain by joining the trial so agreed to it, in the background Michelle mouthed “good choice!”.

### **Treatment**

An appointment came through to meet with Dr Lizzy Smyth on 18 September 2023 at the Churchill Hospital in Oxford, she duly told us that I was eligible to be accepted onto the Star 221 trial and went on to explain the trial protocol etc. There were two arms to the trial, the new trial drug or the control arm, there would be a random selection as to which arm of the trial I would be allocated to. Dr Lizzy also confirmed that both sets of treatment were aimed at improving the quality of my remaining life, the cancer was inoperable and my current life expectancy was 1-3 years. Inside I sank to even further depths of despair, given this information I couldn't help but think is it really worth putting myself through the debilitating treatment that I knew Chemo was?

I was accepted onto the control arm of the Trial and treatment would take place every 2 weeks. On 10 October 2023, we attended the Churchill Hospital, I was fitted with a PICC Line and treatment started. Every visit would follow the same pattern, I was weighed, my height was measured and 6-8 files of blood were taken. Treatment consisted of the following infusions:

- Immunotherapy – Nivolumab 240mg
- Chemotherapy – Oxiplatin 160mg
- Chemotherapy - Folfox (Bolus) 800mg
- Chemotherapy - Folfox (Pump) 5000mg (administered over 48 hours)

After the first 3 infusions were complete (which took 4-5 hours) I was fitted with a pump with the final infusion which would be administered over 48 hours. There were also a number of medications administered to counteract the numerous side effects of the treatment.

After the first treatment, physically I felt ok, mentally I was still struggling with the enormity of the diagnosis and would the treatment actually do anything. A District Nurse came to our home after 48 hours to disconnect the pump and redress the PICC Line, there was a concern over the PICC line as there was a discharge from the entry point. We were later to find that I was allergic to the nickel clip which kept the line in place and also my skin was allergic to the standard dressing used (both issues being resolved 4 weeks later).

Initially the only reaction to the treatment was continuous hiccups. This was a red flag to me and more reasons to worry, after my father had had his operation he had continuous hiccups, which brought back difficult memories. I convinced myself that the treatment wasn't going to work. Sleep didn't come easily with my mind working overtime and I was scared of pulling my PICC line out, I was so tired! On reflection, with so much going on it was a very stressful time, and not surprisingly we were worried throughout.

A week later I was due to see Dr Lizzy, unbeknown to me this had been cancelled (to cut down on my travelling). I can't fault the receptionist, she was very persistent with the person who should have informed me about the cancellation and insisted that I was seen by at least a Specialist Nurse (Sheba). Sheba was very quick to apologise and calm me down. Having told her of some of my worries she insisted that I should see Dr Lizzy. Within half an hour I was in a consulting room with Dr Lizzy, I explained about the hiccups and insomnia. Dr Lizzy could see and commented on how stressed I looked. She immediately put my mind at rest, the hiccups were a side effect of one of the anti-sickness tablets (Dexamethasone), and I was given a different prescription for a very small dose of Olanzapine. That night I had the best sleep I had had for several months and the hiccups stopped.

The fortnightly visits to Oxford for treatment (9am to 4pm) continued, with the side effects becoming more and more noticeable and it always followed the same pattern. By the time I got home on the day of treatment and the day after, my temperature would be sky high. By the second day my temperature would be back down to normal but I was shattered and found it difficult to drag myself out of bed, I had no appetite and found it

difficult to concentrate on anything (sometimes feeling quite nauseous despite anti-sickness medication). About a week after treatment I would start to feel more normal.

At this early stage I was still struggling with swallowing, I could only manage semi liquid food. My wife became an expert in making soups and mushed up food. As December approached I noticed I was finding it easier to swallow food so we experimented (with Dr Lizzy's encouragement) with foods; scrambled eggs, crisp breads and cheese, fruit yoghurts, shepherds pie all worked well. Everything seemed to be so positive and heading in the right direction.

Mid December 2023, my PICC Line became blocked, no blood could be taken from it nor could any fluids be pushed in through it. The only answer was to remove it and insert a new one in my other arm.

Later in December, further issues developed, my white blood cell count became too low and I was unable to receive Immunotherapy and Chemotherapy. I panicked, did this mean the treatment was not working, would my tumour start growing again? Unfortunately I was given this news in the Day Treatment Centre by a nurse, saying that treatment wasn't possible today. I was close to tears and feeling devastated, I thought it had all been going so well. The original plan on that day, as my wife was working, was that I would go to Maggie's (a charity supporting all cancer patients and their families) across the road from the Churchill and wait to be picked up. As I entered the building I broke down in tears, thankfully 2 of their counsellors (Mary and Alex) were there and they very quickly reassured me that it wasn't the disaster I was imagining. Dr Lizzy was in touch the next day and prescribed a course of injections prior to the next scheduled treatment.

Treatment resumed in January 2024, as my blood cell count had returned to acceptable levels. There was even more good news as the latest CT scan showed that my Tumour was shrinking and the Cancer in my Lymph nodes was also receding. I was elated to say the least. Several discussions during my consultations with Dr Lizzy, centred around how awful I felt after immediately treatment. It was decided that I should have the dose of Oxiplatin halved, I knew I had to trust Dr Lizzy but I couldn't help but wonder if this would impede the further reduction in the Tumour.

### **The Operation**

I continued with my fortnightly treatment and consultations till mid-February. At this consultation, Dr Lizzy told me that the last CT Scan showed virtually no Cancer in the Lymph nodes and my tumour had shrunk so much it was barely measurable. She had also been discussing my case with Professor Markar and that they were of the opinion that an operation was appropriate to remove what remained. I was on cloud nine as I left the Churchill that day.

I met with Professor Markar at the end of February and he confirmed what I had been told by Dr Lizzy, he gave me even more hope because he said that he didn't operate on people unless he was sure that he could cure them. Before the operation could take place he wanted to run more tests including a laparoscopic investigation and an endoscopy.

It was around this time that we discovered OOSO, how fantastic it was to meet and talk to Matt and others that had already undergone the same procedure that I was facing. It gave both me and my wife hope and reassurance that we were doing the right thing.

The results of the investigation came back and the operation (an Esophagectomy) was set for 31 May. I continued with treatment till the end of March and my PICC Line was removed, how wonderful it was to be able to shower without a plastic sleeve on my arm.

The pre-operative care and advice I received from the Churchill's staff was second to none. I had appointments with Dieticians, Physios and Specialist Nurses all offering help to prepare for the operation and also what to expect post operation. It was clear I needed to be as fit as possible for this ordeal and I set about trying to get to the target set by the Physio of walking 5km at least once a week, set exercises, eating more protein than

carbs and improving my lung capacity through use of a Power Breath (supplied to Churchill Hospital by OOSO!). I achieved all of the targets set with the exception of the exercises set, of which I managed only a few.

The operation day arrived I didn't have time to become apprehensive as I was first on the list, actually I was the only person on the list. I said another goodbye to my wife and don't remember any more of that day once the anaesthetic had been administered.

### **Recovery**

I woke up the next day in CICU, I felt very woozy but in surprisingly little pain. I can recall that my allocated nurse was very attentive as I drifted in and out of sleep. I was conscious and amazed at the number of tubes that were either putting stuff into me or draining substances out of me. At some stage (I am not aware when) I suffered a one off episode of Atrial Fibrillation (AF). Whilst in CICU I was encouraged to sit out on the first day, walk around the nurse's station on the second day, and twice round the nurses station on the third day. I can remember thinking "you've got to be joking" when I was first asked to go for a walk, with all the drains tubes etc. but with my dedicated nurse in front of me and the Physio behind it was all possible. Kudos must go to the Nurse who held my hands and encouraged me all the way through this activity.

Four days after the operation I was moved to the normal ward I became aware that I had a Jej line fitted which fed me over night and I felt so bloated in the morning. The overnight feed was causing problems with my Diabetes and as well as my normal medication I was now being given Insulin. I was introduced to the lovely and legendary Hilda who helped me have a shower. I will also never forget the 2 lovely young Physiotherapists, at our first meeting they showed me how to escape from Hospital and on our second meeting I was to do "the stairs". Going up 2 flights of stairs was relatively easy, coming down was a real challenge but eventually I achieved it. This all meant I could go home!.

### **Elation**

At home I found that I could not easily get in and out of bed, so the first week or so I slept in a reclining chair. The overnight feed continued to be an issue, my dietician agreed to halve the dose and after 14 days we stopped altogether and the Jej line has since been removed. As I write it is just over 2 months since my operation, eating has become easier, small amounts but regularly. I have returned to my walking regime with a target of 5km at least once a week (currently I'm at an average of 3 km a day). I am now taking no medication (including no diabetic medication!) or painkillers, only an anti-reflux tablet at night. I have also lost 36kg since the first visit to my GP, which is quite normal for patients in this situation.

Around 2 weeks after arriving home I received an excited phone call from Dr Lizzy and a week later one from Professor Markar both giving me the same news, the latest tests show that I am currently clear of Cancer. I am so grateful, elated and happy to be alive and well with the prospect of so many more years ahead with my family and friends.

I would like to finish by paying tribute to the skill and expertise of: my Surgeon (Professor Sheraz Markar), my Oncologist (Dr Lizzy Smyth) and all the team at OUH. The care and dedication shown towards me during this journey has been incredible, I cannot speak highly enough of them.

I must also mention my wife who has been unstinting with love, encouragement and support every step of the way, it is difficult to imagine what she has been through but I think it is fair to say she must have been to hell and back again. Those of you that know me well will know how important my family are to me, they have given me the motivation and determination to get through this journey.