

Being a carer – a personal view

Matt (OOSO Trustee) asked me to write up my experiences as a carer for my partner before, during and after their treatment for cancer of the oesophagus. This is my perspective on our story, everyone's experiences will be different, but I hope this is helpful to people going through something similar. I have anonymised this, so I have used the pronouns they, their, and them.

1 Diagnosis

My partner originally visited the GP in early 2019 as, like many people do, they were suffering from acid reflux. Like most people presenting with this symptom, they were initially given a proton pump inhibitor (PPI, Omeprazole in their case). But the symptoms continued so our GP referred them to a specialist, Dr. Margaret Myszor. After many scans and probes, they were eventually told that the diagnosis was cancer of the oesophagus, but fortunately, it was still at Stage 1. Like any cancer diagnosis, this was very scary, but we were reassured by everything we were told. I was particularly concerned as cancer of the oesophagus was one of the many things that my father had when he died in 2001. We had been told then that this cancer was rarely survivable – in most cases, it was diagnosed too late to be treatable with the knowledge at the time. The actor John Thaw was diagnosed shortly after my father died and himself died the next year. The diagnosis brought these memories forward.

2 Treatment – Decision on which treatment pathway

The cancer was at Stage 1 and small. The next decision was what treatment pathway to use. The Multi-Disciplinary Team (MDT) concluded that there was no need for my partner to undergo radio- or chemotherapy, which was a great relief. As well as the cancer being stage 1, a key factor was that they judged my partner as young and physically fit – their 4-day-a-week gym habit, healthy eating and regular walking came to the rescue. Their surgeon was Bruno Sgromo, whom we visited twice before the operation to prepare us. He deliberately made sure the second appointment was the last of the day – he wanted to give us as much time as we needed for the momentous decision to go ahead with the chosen treatment. We left comforted that we had made the right decision and were incredibly grateful for his generosity with his time. Bruno told us that he would be doing the operation using keyhole surgery. As this is far less invasive than the traditional surgery involving opening the ribcage, the recovery time, though still months, would be reduced. It is also generally the case that there are fewer complications after keyhole surgery. He also emphasized that they were young and fit – that had them walking on air as we left the consultation!

They also spoke to Liz Ward, the dietitian, and to Anne Phillips one of the specialist nurses, about the operation and post-operative care.

3 Treatment – The day of the operation

The operation was in July 2019. Check-in time was 7 am. As we live in Reading and traffic can be very unpredictable up to Oxford, we stayed in a hotel near Headington the night before the operation to be near the hospital. We arrived at the Churchill early in the morning and were briefed by Bruno, the anaesthetist, and the nursing staff before I said goodbye and left them to their care. Bruno called me around 4 pm to say that the operation had gone well, and they were recovering in ICU. I was allowed to visit them there, but I'm not sure they remember much of that as they were still heavily sedated and on morphine.

I visited every day of their stay. They were in a shared ward for the first couple of days then moved to a single-bed ward, which was much easier. You could see the improvement each day. Notable highlights:

- From the physiotherapy being able to walk along the corridor and back.
- Progressing from jej-tube and light liquids to pureed food.
- Not pressing the morphine button as soon as the 5-minute timer ran out. Though when the pain was heavy, they did develop a clock-watching habit so as not to miss out!

4 Discharge day – 7 days later

There were many things to go through on the day of their discharge from the hospital. The nurses had to be sure that they could self-medicate properly. Just daily warfarin injection in their case. Then we both had to be trained on the feeding machine (yes, I do know it's called an infusion pump!). In all, there seemed to be about six different people who needed to sign off on the discharge, so instead of leaving around 2 pm, it was eventually around 6 pm. To top it off, the printer in the department wasn't working properly and they couldn't use that from another department. Some parts of the discharge note for our GP practice that should have been printed were handwritten on micropore tape stuck over the bits that didn't work. It looked like a forgery! Luckily, the GP practice had known us for 30 years, so they joked about it but accepted the letter....

It's a good job we have a big car as the boot was full of the feeding machine, several boxes of feed cartons, and a large variety of medication and bandages.

When we got home, we set up the feeding machine. Unfortunately, we didn't do it exactly right as it didn't work when we started it up. The team at Abbott's call centre were brilliant and they dealt with our panic call at 10 pm patiently and efficiently. The quick phone call soon had us right.

5 Post-treatment

5.1 Post-treatment medication

After leaving the hospital, they were on several medications:

- Warfarin, to prevent blood clotting. This was a daily injection that they needed for 5 weeks. The discharge nurse joked that it was normally 4 weeks however my partner had 'got lucky' as the late afternoon prescription fulfilment meant they were just past the cutoff point and they gained the extra week of self injection for free!
- Painkillers, principally codeine. Although effective as a painkiller, they did suffer from nightmares while taking it. These went away after they stopped taking it, which was after a few days.
- Creon. they found that the more of this they took, the easier it seemed for food to move to their stomach. In consultation with the specialist nurses and dietitians, they learnt that this should not be related, so the difference was psychological. However, as with all things medical, the patient's mindset and thoughts make a significant difference. They were referred to a gastroenterologist who recommended to stop using it.
- Laxative to get them going again early post-surgery.
- Imodium (Loperamide hydrochloride) for occasional attacks of diarrhoea.

- Acupuncture. they found that this was helpful with digestion. The first session with the acupuncturist was entirely fact-finding, reviewing the consent form and answering my partner's questions. There was no hands-on work. There followed 5 acupuncture sessions at which point the acupuncturist suggested a pause and see how things go over the next few months. My partner's diarrhoea and other digestive issues calmed down significantly. Although acupuncture is not on the NHS list of treatments, my partner's experience shows the effect of the patient's mind on recovery. To use the phrasing used by GPs: some people find it helpful.
- Multi-vitamins to make up for the reduced vitamin intake from food, particularly vegetables.
- Probiotics to try to restore the gut microbiome.

5.2 Off the feed!

A major milestone was when they no longer needed the feeding machine. No more did we have our nights soundtracked by its "whirr-whirr" every few seconds for the 11 hours it took to dispense the feed. But this was only possible as they were able to eat more. This in turn was aided by a small procedure to stretch the pyloric valve. This is quite common after an oesophagectomy to allow food to move through to the gut.

5.3 Mental effects

With the high doses of morphine while in hospital, it's not surprising that they were, to say the least, a little out of it. They recovered quickly once off morphine, though as noted above they did get nightmares while taking codeine – which the body metabolizes into morphine. They stopped the codeine early despite its highly effective pain-killing skills as they were determined not to get dependent on it. A balancing act as high pain is a barrier to the body's recovery. They replaced it with paracetamol. It took a couple of months before they were fully back to normal. We realised just how easy it is to get addicted to painkillers after such major surgery.

5.4 Physical recovery

Before the operation, Bruno had told us that pre-keyhole surgery it usually took around nine months for people to recover, and with keyhole surgery it took around two months less.

With not being able to eat as much, there was inevitable weight loss. At one point, they were back to their wedding weight, which most people having been married for nearly forty years would be quite pleased with but as they are fairly small, this needed the attention of the dietitians. I'm sure you have all heard the advice – eat several small meals not just three big ones (my partner remembers the incredible powerhouse OOSO founder Jackie Beaumont telling us 8, 10, 12, 14, 16, 18 – the hours of the day for eating), focus on calories, so starch and protein rather than vegetables as they can fill you up without providing the necessary calories. One thing that helped was, at the suggestion of the dietitians, using a smaller plate so the portions didn't seem so small.

One result that we did not expect was that while before the operation they could eat anything, afterwards they found several foods caused problems. These included dairy (and they loved cheese), red meat, most seafood except white fish and salmon, and anything in the onion family. So, we have discovered the delights of soy milk, soy yoghurt (which also works as sour cream for Mexican food), and vegan cheese. For a while we thought they had a gluten intolerance as they found bread caused a reaction, but we realised that they could eat pasta. Now we have found breads that work for them, and they can tolerate more types, even if in small amounts.

I must mention belching. This was not expected, but they find for a while after eating they often have significant wind. This can sound quite painful but isn't and passes (forgive the pun) quickly. Ginger tea and Lindt 70% dark chocolate, which is dairy-free, also helped.

They managed to get back to the gym after two and a half months. The gym kindly offered to suspend their portion of the fees while they were away. They were advised to avoid floor-based exercise, such as Pilates, which they had previously been quite keen on, because of the stress on the stomach area. They were able to do spinning classes, though initially using only around half the calories they had done pre-operation. In early 2020 the gyms closed so we looked for a different form of exercise. We were lucky enough to find a good pair of road bikes ex-demo from a local bike shop and took up cycling. I had been a cyclist before we started going to the gym, but they hadn't cycled since university. We soon found that their limit was around twenty miles because they just didn't have the stamina or energy reserves for much more.

They have had poorer temperature regulation than me for as long as we have been together. We have found that this has become worse since the operation. But they also know that when they feel cold, they need to put on another layer and, often but not always, eat something as they could just be running low on energy. This was urgent as when cold they quickly became light-headed – a new symptom for them.

5.5 Back to work

They went back to work after about six months, with a week-long business trip in the first month. In hindsight, they should probably have waited a while longer as their job was stressful enough without the added load of recovering.

5.6 Adjustable bed

Given the need for them to keep their upper body raised, we looked into and eventually bought an adjustable double bed where each side was independently controlled. Was it worth it? Yes. Though expensive (around £5000, but as it is for a clinical reason you don't pay VAT) it was quiet, wireless-controlled, with separate adjustments for the back and leg sections and the bonus of full-length massage. Now it is a luxury as we find now that they can easily raise their body using a wedge cushion which would have been a lot cheaper. If anyone is thinking of getting one, I would recommend that you avoid one controlled by a wireless remote, as ours is, because the batteries *will* run out at the most inconvenient time. Now, you can usually control them with a phone app, which is much simpler. Failing that, it's not that much of a bind to have a wired controller as you will only use it when close to the bed anyway. Additionally, the Red Cross offer short-term hire at very affordable rates

6 My feelings

As this is supposed to be about me, I should say a few words about my feelings.

6.1 Relief and Gratitude

This might seem odd, but after the initial shock, there was relief on finding out they were at Stage 1, which meant their chances were good. As we moved through treatment and after, we were incredibly grateful to the clinical and other staff for their professionalism and competence. And ongoing, with no serious complications we continue to be thankful.

6.2 Guilt

One response I had that I didn't expect was guilt. Not in the sense of survivor guilt, but at the fact that I could continue to eat as much as I wanted to, while they were eating much less. I did get over this, but it did surprise me.

6.3 Anger

At the first OOSO meeting that we attended, Nick Maynard mentioned that if a diagnosis could be made early enough, before the abnormal cells had turned cancerous, it was possible to treat by essentially scraping out the pre-cancerous cells, thus avoiding the need for a full oesophagectomy and the attendant risks of a major operation and subsequent lifestyle changes needed. I felt real anger at this because it's likely that when they first presented with symptoms this treatment would have been appropriate. Then Nick went on to say that diagnosis was difficult because there can be so many other causes for the same symptoms and many GPs would see one case in their careers so taking a long time to diagnose is normal. We now know that early diagnosis is one of Nick's priorities and that there is significant research into ways of diagnosing early, some of which have been discussed at OOSO Zoom calls.

7 Summing up

A cancer diagnosis is never a good thing. We are lucky in that their cancer was caught earlier than most. We are also lucky that their treatment was carried out and managed by the team at the Churchill, probably the best in the country. Most people who meet them would not guess that they have had such a severe disease unless they are watching what they eat very carefully.

So, yes, it is scary. But it is also survivable. Yes, the operation is drastic, and you will need to make lifestyle changes. But these are manageable, and you will be able to live much as you did before with small adjustments.