

Matt Carter's story

1- Symptoms and Diagnosis

I was diagnosed with oesophageal cancer in August 2014 at the age of 48. During the six months prior to that I noticed swallowing food had gradually become harder, which I put down to indigestion so largely ignored it. Steadily I ate less and less, opting for softer foods thinking it helped to alleviate the discomfort. Eventually I couldn't even eat small meals, choking and coughing, bringing food back up. That's when I went to my GP. Six weeks later and after a change of GP I was asked to attend an urgent endoscopy at the Churchill hospital. The examination revealed a lump in my lower oesophagus, which ten days later was confirmed to be cancer.

After the endoscopy I don't remember leaving the hospital, both my wife and I were completely stunned. I didn't want to look it up on the internet knowing it wouldn't be good for my state of mind, preferring to talk with the experts at the Churchill first before jumping to any conclusions. As it turned out that was the right thing to do for me as our first meeting with our Consultant surgeon, although hard and sobering, left me feeling confident I was truly in excellent hands. It's better to know exactly what's what than speculate or guess. Waiting was the worst thing. It seemed to take weeks to go through the various scans and tests to devise the right treatment plan for me. At each stage not knowing if the cancer had spread or not. To help cope with all of the waiting we decided to spend our valuable time doing nice things. Walking, visiting family and friends, going to the cinema, anything to enjoy the time rather than worry about tests out of our control. Yes, it felt sickening before each meeting to discuss the results, but I went in thinking if it's not good news I wanted to know what could be done and then get on with it. At first, I found talking with close family and friends very hard, but it really helped, most importantly, to dispel what felt like a stigma or personal failure to have this horrible cancer. Being mindful not to be negative, we found their response incredibly supportive.

On reflection, throughout 2014, I shouldn't have ignored the symptoms for so long and talked with my GP much sooner and been more assertive. The clinical team at the Churchill did a brilliant job. My reassigned GP was brilliant too and still is. Facing up to the cancer early on with my family and friends was extremely hard but a very important step. My wife, family and friends have been there for me at every stage, I feel so humbled. Nevertheless, staying positive at every twist and turn is extremely hard but absolutely the only way to stay focused on beating it.

In my next account I will describe the treatment I went through including chemotherapy and radiotherapy, how it made me feel and how I coped with it.

2- Matt Carter's Journey Continues

This is the second of a four-part series sharing my experiences of coping with oesophageal cancer. In the first part I described events leading up to diagnosis and in this summary, I outline my treatment plan and how it worked out.

It was a tough time meeting with the oncologist to discuss options which seemed limited and simply daunting. A few weeks after diagnosis, as tests and various meetings unravelled, I was eventually offered a place on a national trial funded by Cancer Research UK called 'NeoScope'. Again, the waiting was the hardest thing, but for me the decision to go on the

trial was an easy one. When the chips are down it's time to do whatever it takes. The trial involved prolonged chemotherapy for eleven weeks instead of six on the highest dose I could physically cope with. This was coupled with high dose radiotherapy overlapping the last five weeks of chemotherapy. With modern drugs and targeted radiotherapy being much safer these days I signed on the bottom line. We all know that chemotherapy is not a summer picnic, but I found the first few weeks surprisingly bearable. Listening carefully to the advice of nurses helped an awful lot, with the do's and don'ts of it all and knowing I could call my specialist nurse (ANP) for advice and support.

At first the weekly infusions and daily tablets felt intense but soon became a routine. I made great friends with a cheerful character in the chemotherapy suite who has a worse cancer than me. That was really sobering, and he's still here today fighting his corner.

The key to it all is REST, not doing too much, keeping warm if it's cold, cool if it's hot, relaxing as much as possible, being distracted with family, friends, TV, films, books, puzzles, painting, music, anything to be preoccupied. Carefully follow the pill plan, always seek advice if unsure and avoid people with colds! My wife looked after me throughout, making sure I didn't miss any tablets and keeping my spirits afloat. I found the worst of the side effects to be nausea and fatigue, both manageable with medication and sleep. For a day or two after infusions I had subtle tingling sensations in my feet, hands, lips and tongue, with bizarre hot sensations when touching cold surfaces, although these faded away. Side effects are inevitable but nothing to be afraid of. The radiotherapy wasn't too bad either, being more of a trial having to get there five days a week. However, after four weeks of radiotherapy and ten weeks of high-dose chemotherapy I was on another planet. It was the toughest time, but the end was in sight and I kept telling myself 'I'm beating it'. Another survival tactic was to get washed and dressed every morning telling myself 'look-good-feel-good', which really helped.

I lost my sense of taste and appetite but, positively, I found eating physically easier as the weeks passed by. Sipping cool water felt good. At the end it took 4-6 weeks to recover, including my various senses, and clearly the tumour had shrunk. In fact, I enjoyed a small roast turkey lunch with family on Christmas day which I hoped might happen. That was truly amazing.

Further tests were scheduled to see if the cancer had shrunk or spread, determining whether surgery to remove the tumour was possible or not. Again, a totally nerve-wracking time. After rigorous testing I was told I could elect for surgery if I wanted it. Although exhausted I was determined to do whatever it took so gladly accepted the offer.

In the next part of this series I describe the operation and my time in hospital.

3- *The Penultimate Step*

In this third part of four, I describe my time in the Churchill hospital under the knife. The operation was followed by four days of intensive care and a week recovering on the Upper GI ward.

Leading up to the operation I was scheduled for the full oesophagectomy, a highly invasive procedure requiring access to the entire body cavity via a 'shark bite' lookalike incision from the belly button around the left side under the ribs and up to the shoulder blade. In certain circumstances a smaller keyhole operation is sufficient but for me full access was needed. The aim was to completely remove the tumour located at the juncture between the lower

oesophagus and the stomach, requiring the entire oesophagus to be taken out and the stomach to be reconstructed. It's a daunting thought for anyone to contemplate but given the alternative I felt extremely grateful to have this option and simply wanted to get on with it.

On the day of admission my wife stayed with me to the final door, a really hard and emotional moment for both of us, even though we had utmost confidence in the surgical team because we knew that my surgeon has a 100% wake-up rate.

The operation was well described. I felt very well informed. Receiving the general anaesthetic was the last thing I remembered, opening my eyes some nine hours later in an intensive care bed.

My surgeon being the absolute star he is, immediately phoned my wife to tell her I was ok. She didn't hold back the tears.

Perhaps the biggest surprise was waking up with eleven tubes and drips poking in all directions. But that didn't stop the team getting me out of bed two hours after the operation. I sat up sipping water watching a six nations rugby match while peddling slowly on a small exercise bike.

My wife was allowed to see me straight away which made me so happy.

I don't recall having any acute pain whatsoever with only a few aches and awkward moments trying to move about. Yes, the drugs are strong because they need to be, but I didn't experience any serious pain to worry about. On day two I was sipping tea. The ICU consultants and nurses were amazing, so incredibly professional and caring.

Arriving on the Upper GI ward was a great relief. It felt like recovery was just around the corner. The team on the ward are simply fantastic. I'm also so grateful to friends and family travelling to see me, mostly in a haze of gentle hugs and drugs, though I do remember dignified assisted showers with Hilda 'the shower queen', what a Trojan she is! Another star visiting me was Jackie, ex- oesophageal cancer patient and founder member of OOSO who now inspires me to work with her to help others through what are very difficult times.

Ok the food wasn't the best memory nor the disrupted nights having regular checks receiving medication, but I felt increasingly better and within a week it was time to leave for home.

Since my days on the ward two years ago the clinical team have introduced an advanced recovery programme called 'ERAS' (Early Release After Surgery) which aims to help patients recover even faster and seems to be working really well. My overall stay lasted ten days and now the typical duration is around seven to eight days.

I'm pleased to say my time in the Churchill was a good experience. Yes, ok I had a tough few days, but given the seriousness of the operation my story is testament to the brilliance of our NHS. And yes, there are always things that could be done better, but those fantastic people saved my life and thoroughly deserve honest, heartfelt positive feedback.

However, the white-knuckle ride isn't quite over. In my next and final part, I describe the outcome of the operation, the pathology of removed tissues and my prognosis - warts and all. I will also describe recovering at home including dietary tips, exercise, the do's and don'ts and the things to be aware of.

4- And finally ...

In this final instalment I describe what happened after my oesophagectomy bringing matters more or less up to date.

Being discharged from hospital was a relief in one way, wanting to get home and basically relax and recover under my own steam, but it was a difficult moment leaving the safety of the hospital where they looked after me so well. Being able to phone our ANP (Advanced Nurse Practitioner) or the ward for advice was a great comfort and we knew our surgeon wouldn't hesitate to step in if something urgent cropped up. Also reading OOSO's booklet was a great help, preparing us for the return home and what to expect.

On the ward a duty consultant visits patients every morning to review their progress, but they won't commit to a discharge date more than a day or two in advance. They need to be sure the patient is well enough to go home. So, being released can happen suddenly and the patient's family need to be aware of what's going on and to be prepared for it.

The day before leaving hospital the consultant said I might be allowed home and, sure enough, the next morning he signed off my release. Leading up to discharge, physiotherapists made sure I was able to walk a reasonable distance and to get up and down stairs safely. In addition, dietitians talked me through a booklet outlining the kinds of food I should eat and how often.

I was well enough to walk out of the hospital to the car waiting by the front door and, with care, I was able to climb into the front passenger seat. Driving wasn't an option and in fact I didn't drive for about six weeks after the operation. We checked with our insurance company who confirmed I wouldn't be covered if I caused an accident during that time. Besides, I was still on painkillers and quite drowsy. Common sense must prevail. Ask whoever drives to avoid potholes, go slowly over speed bumps, and take corners carefully. It all helps.

It was such a relief to be back at home in familiar surroundings and close to my wife. She has been incredible throughout, supporting me when I needed it but giving me space to do things for myself and not fuss over me too much.

My sense of appreciation of life was intense that day and has remained the same since.

Because I love food, I wanted to choose my meals but it's vitally important to follow the dietitian's advice and the tips in the OOSO booklet. Soft foods at first, little portions and often. Six small meals a day spread out two hours apart. However, just after two weeks at home I was eating toast (brown seeded granary bread); duck eggs being a high protein favourite; grated cheese on baked beans; full fat milk in tea; cream in coffee and soups and so on. I was also keeping high protein seed bars and packets of nuts in my pocket for snacks.

Within three months I was eating small portion, full English breakfasts and roast dinners.

Drinking alcohol in sensible amounts is fine and sipping away at a couple of pints of an evening is a pleasure! A small alcoholic drink before a meal seems to help relax the new stomach and allow food to pass through more smoothly.

Now, two years on I've regained 20lbs of the 40 lost and cut down from six small meals a day to three with occasional snacks. Don't eat too much or too quickly as either may cause 'Dumping syndrome'. This is effectively a pain in the stomach minutes ahead of a quick trip to the loo.

I also carry a pack of dextrose tablets which really help if I eat something too sweet that leads to headaches and extreme tiredness, almost like a diabetic reaction. Dextrose tablets from any chemist seem to help curb these effects, though I rarely get this problem now.

It's important not to lift anything too heavy. For me, a kettle at first was enough and even now I don't lift more than a small travel case or a lightweight bag of shopping. Twisting is a real problem for me, causing acute pain around my scar so I avoid any sudden movement or unnecessary strain. The to and fro' movement of hoovering or mowing a lawn can be awkward so don't attempt too much too quickly. Digging in the garden is a definite 'no no' for me.

My scar has healed incredibly well and has almost disappeared, yet I still get pains around my ribs where the nerve endings have been cut, though it's rarely a concern.

I came off strong painkillers within a month of returning home but still keep prescription soluble cocodomol for occasional bad days. It's important to visit your GP and keep in touch should you need anything. Recently, I started quarterly B12 injections at my local surgery to help boost energy levels, and I take a daily Centrum 'performance' multivitamin tablet high in iron and B vitamins.

Sleeping has been fairly easy using three or four pillows to prop me up. This helps reduce reflux during the night, as does not eating three hours before bedtime. Sleeping on my right side seems to cause reflux so I tend to sleep on my back and left side now the scar is less painful.

My mobility has improved with regular short walks, but I still struggle to cycle or swim as I used to, though I'm sure with determination and practice things will improve.

We're not so bothered about travelling these days. Being with family and friends is the most important thing. Even so, we have been abroad to the States, Iceland, Norway and Ireland, and travel insurance hasn't been a problem. 'Insure and Go' give us a normal family deal so long as our GP has it on record that I'm fit to travel and nothing has changed.

The pathology results that were fed back soon after the operation were reassuring. The surgeon removed the whole tumour including two cancerous lymph nodes leaving no apparent cancer cells behind.

The risk of the cancer reoccurring is low for me which is truly great. However, cancer of the oesophagus is known to be aggressive and anything yet could happen. For that reason, though we still plan for the long term we very much live for the day.

My overall quality of life is good although quite different to what it was. Recovery has been slow but sure, feeling increasingly better by the month, and two years on I feel extremely fortunate to have had a second chance. The most important things are to stay positive and enjoy life.

I hope you find these experiences helpful in some small way and thank you for taking the time to read my story.