

Introduction

I was asked recently by Matt if I would write an account of my experiences as a carer for my wife, Carol, during her “journey” from original diagnosis, through all the medical treatment and procedures, leading to surgery and post op recovery.

Inevitably her experiences are the counterpart to mine as her carer - from Carol’s emerging symptoms, the shock of the diagnosis in early 2015, through the cycles of chemo and tests prior to surgery in September that year, and then the road to recovery and subsequently learning to live with a “new normal”.

For that reason, talking about my experiences requires me to describe Carol’s. While this is our personal story, some if not many of the elements that are covered may be familiar to others reading this note, or will become so sometime in the future.

There is a lot of really helpful material and pointers available today on the OOSO website. Yet as I think back to nine years ago, there was no “how to” handbook to follow as I endeavored to give Carol my best support as she coped with her illness, treatment and fears.

I knew that my role was, and remains today, to be by her side, sometimes literally, and to provide as much support at both an emotional and a practical level - in the latter case looking for specific and tangible actions/things I could do - as seemed appropriate at each stage so as to help Carol deal with whatever specific issue she was facing at that time. All without overcrowding her if possible.

My aim was to offer help wherever possible, and not wait to be asked. Sometimes doing the right thing involved trial and occasional error on my part.

One practical step taken by me throughout this journey has been to accompany Carol when seeing the consultants (Nick Maynard, her Surgeon, and Nicola Warner, her Oncologist) or other members of the team. I would take a discrete note of what was being said and discussed, so that afterwards we could talk about what had happened during the appointment. I would play back what I had heard after Carol had first done the same. We would then reflect on what it had meant and the next steps.

I quickly realised that in addition to supporting Carol, my sitting in on such sessions would help me understand what was on the horizon in her treatment plan, and to think about what aspects of support I might need to be providing.

Symptoms and diagnosis

To begin at the beginning. Carol was physically very fit - a tennis player, walker and frequent visitor to the local gym for her Pilates and other fitness classes. Always a slim individual, her slender waist and weight hadn’t rung any alarm bells. It was when she started to have eating difficulties and regurgitation of food that she approached her GP who, as there was no improvement following some prescribed anti reflux medication, referred Carol to Stoke Mandeville (the main hospital for Buckinghamshire) in Spring 2015 for an endoscopy.

It was on that day, while in Stoke M, that Carol was told of the tumour at her gastro oesophageal junction and of the plan to refer her case to a consultant at Stoke Mandeville.

Sadly, this was taking place while Carol’s mother was extremely unwell in hospital up in Scotland. On the afternoon that Carol was being told of her diagnosis and next steps, we already had plans in place to travel up to Glasgow to visit her the next day. It was on hearing these arrangements, that a CT scan was carried out on an urgent basis the same day as her endoscopy. It was a rushed day and evening with little time for us to process what was happening.

Carol and I discussed what to do and made the decision not to tell her mum about the cancer. We timed our trips north at a point in the chemo cycles when she was coping with the side effects. Isabel died a month before Carol’s surgery without ever knowing.

We did tell her brother who lives up in the Cairngorms, and I told my brother. We asked our son and daughter to come over to our house from their respective homes in London for lunch. They knew something was “up” but didn’t know what. Carol and I had discussed how to approach telling them the news. We decided it was best to be open and so we explained what had been happening, the diagnosis and that over the coming months there would be further tests, chemo sessions and hopefully a decision that the cancer could be treated /operated on. We all did our best to look at and talk about the positive possibilities even if we each had private fears about the prognosis and whether the cancer had been found early enough or whether the treatment and surgery would be successful.

Slower time, our close friends were told about the diagnosis but in a low key manner.

Tests and treatment

Carol was referred to Nick Maynard and the team at the Churchill, where we quickly realised how fortunate we were to be in such good hands.

Following a laparoscopy in May (which required an unplanned overnight stay at the Churchill to reopen, bleed and re-suture the umbilical wound), and then a subsequent review with the Consultant Oncologist, Carol progressed to the next stage - three cycles of “neoadjuvant” chemo at the specialist unit on the Stoke Mandeville site. The aim was to shrink the tumour prior to any surgery. The first cycle began in early June.

Travelling to Stoke M from Marlow was never straightforward - generally at least a 45-minute drive on relatively narrow roads that wind across to the other side of the county. We would soon realise that the journey by car to the Churchill mainly on the M40 was much easier taking little more than some 35 minutes.

I would drive Carol to Stoke M for a session of infusions starting in the morning. Each session lasted much of the day, with Carol usually one of the last group of patients to leave, always with a bag containing various tablets to be taken as part of the chemo cycle and to help her cope with its side effects. Taking advice from a friend, I created a log and checklist of what medicine had to be taken including when and how it should be taken (e.g. with food, after food etc) to ensure that we stayed “on plan”. (I adopted the same approach after Carol was discharged, following her surgery).

Fatigue and significant nausea followed the first and the subsequent chemotherapy cycles.

The days after each cycle were very difficult for Carol. Various anti nausea medicines were prescribed to help her. On one of the days at Stoke M, it was established that Carol’s neutrophil count was too low for the chemo infusions to be given and so the session (which had started with a hydration drip) had to be halted and rescheduled - a hurdle we hadn’t anticipated.

Carol endured these cycles, worrying about her neutrophil count being sufficiently high. Those first three cycles were completed in August.

The teams at the Stoke M chemotherapy unit and at Churchill were terrific - accessible, attentive, caring and able to answer our questions or deal with our concerns with clarity and in terms that we could understand.

On the positives - Carol had worried about the possibility of hair loss as a side effect of the chemo. She asked her hairdresser to cut her hair to a new much shorter style and purchased a wig in a similar style as a contingent option. She asked the team if she could try the cold cap, and took paracetamol before arriving at Stoke M in anticipation of the “frozen head” discomfort that the cold cap might induce. We have both celebrated the cap’s effectiveness in her case - barely any hair loss. We chalked that up as a victory.

On the other hand, and unfortunately, Carol began to suffer from significant back pain in late August. A CT Pulmonary Angiogram was arranged which established that she had a pulmonary embolus (a small clot in her lung). Consequently, a six-month course of daily self administered Dalteparin (Fragmin) injections was prescribed. A new prolonged set of hurdles for Carol - which became even more challenging after her surgery as she lost weight and the nightly procedure became more uncomfortable.

Pre op assessment and surgery

The all important PET scan was scheduled, following which Carol and I met with Nick Maynard to discuss the results, find out whether or not the chemo had affected the size of the tumour sufficiently, and most importantly to establish that surgery was still the plan. It was.

Carol had prepared questions in advance and Nick, as always, made time to go through and answer each one. He explained that it was likely the surgery would involve the removal of her stomach since the site of the tumour was at the junction of the oesophagus and her stomach (a procedure called an extended gastrectomy). Having got her head around the option of an oesophagectomy, the prospect of this alternative was very unsettling and Carol became very tearful. Nick was wonderful. He took the handwritten list of questions from her, and very calmly went through them all without giving any sense of there being any other time pressures or demands on his availability. I will always be grateful to him for that.

A subsequent Pre-op Assessment on 10th September judged Carol sufficiently strong and fit for surgery, and she was admitted to the Churchill at 0700 on 17th September.

We always gave plenty of time for our journeys to the Churchill, to allow for traffic congestion and for time to find a parking space. We left extra early that morning only to discover that there had been a road accident just ahead of us on the M40 a short distance after the Stokenchurch junction. We could see as the traffic inched forward that the motorway lanes towards Oxford were in the process of being closed. Fortunately, we were sufficiently close that we were directed by Highways Agency/Traffic Police onto the hard shoulder and past the incident before the motorway was fully closed (it turned out for several hours). An unwelcome and unexpected hurdle which with good fortune we cleared. We arrived on time.

I stayed with Carol until her name was called and she stood up, gave me a kiss and walked through the door leading to the operating theatre. Not easy for her. Not easy for me. I left and drove back home. I knew this was major surgery and would take a long time.

Our daughter had come down from London to be with me and keep me calm while waiting for news from the hospital. Time passed very slowly that day. I was very grateful for her company. Much later that day it was confirmed that the operation had gone well and that I could return to the Churchill to see Carol in the recovery unit. I remember the first question she asked as she was coming round - had her stomach been removed. It had.

Later that night I phoned the family and updated them that the operation was over and that Carol was being transferred to the ward from recovery.

The days that followed were very much as had been described to us by the husband of one of Carol's friends.

Ken had already recovered from an Oesophagectomy at the Churchill and generously walked Carol through his experiences and described what she could expect. I particularly remember him saying to Carol that "a good day is when one of the tubes gets removed". Carol was prepared for the wound that would run down from the left side of her back across and down her front - she sometimes reverts to it as her shark bite. Thanks to Ken, she was better placed to cope with and take the post operation experience on the ward in her stride. She was very determined to be out of bed in a chair the very next day, walking each day along the corridor whenever possible pulling alongside a wheeled IV stand from which a collection of drips/bags and tubes would hang. Each day Carol took more steps and tubes/drains were removed just as Ken had said. We live in a three floor town house, and so later on she asked to practice going up and down some stairs.

I visited her every day and could see the progress.

Discharge and further treatment

Carol's discharge was delayed a few days, finally leaving early evening on the 30th - after a mild wound infection was treated with antibiotics but also having suffered protracted bouts of diarrhoea.

In planning my driving Carol back home that evening, I had failed to remember the sets of “sleeping policemen” on the back roads to get to the motorway, and the discomfort these bumps in the road might cause her. They did. I’ve never (well hardly ever) repeated that mistake.

In October, the decision was taken to proceed with three further cycles of “adjuvant” chemo.

It seemed so soon after her operation.

Carol’s reaction to the fourth cycle of chemo was very pronounced. She struggled even more with its side effects (nausea, diarrhoea, weight loss, appetite loss, fatigue). Eating was a challenge. I became so worried about how unwell she was becoming that I rang the Churchill and Carol was readmitted. She stayed in the hospital for the weekend and given drips to rehydrate her and help her recovery.

As we went into 2016, the decision was taken that the remaining two chemo cycles should be discontinued on the basis that Carol would not be able to tolerate its side effects. Any benefit of chemo was judged by Nicola and Nick to be outweighed by the negative impact the chemo would have on her.

Recovery, next steps and the “new normal”

By 2017, Carol was eating much better but still only quite small portions. Showing signs of pancreatic insufficiency, Creon had been prescribed - to be taken before each meal and each snack.

And so began an established routine of eating little and often, keeping a close eye on weight with a view to establishing what a new stable weight should and could be.

Carol’s weight began to stabilise around the 46/47 kilo range. However, Carol was still experiencing episodes of dumping, feelings of nausea and intermittent changes in bowel activity. On a cautious basis she returned to physical exercise.

A daily plan developed over time - these days it now comprises Forceval multivitamin supplements, chewable Calceos (a Calcium and Vitamin D supplement), Colecalciferol (a Vitamin D supplement), ferrous fumarate (an iron supplement) together with half yearly (more or less) B12 injections.

Four years on (October 2019) Carol was very much back to her active self, her weight fairly stable, and only occasional dumping/diarrhoea.

Another year later, we reached the five year milestone after her operation. Carol was signed off by Nick from any further routine appointments at Churchill - with the comforting promise and “safety net” from him that Carol could make contact with the team if she had concerns and needed to be seen.

And so here we are - nine years on from the extended gastrectomy - life without a stomach the “new normal”.

Carol is fully active with her Tennis twice a week, Pilates and other classes at the gym, and her Bridge games with friends. The latest addition to her busy schedule is a return to ballet classes.

I still prepare and cook all our meals. Carol is very comfortable drinking fluids and eating (albeit smaller portions supplemented by snacks during the day). We have worked out what foods she is comfortable with and what should be avoided. Carol prefers now not to drink white wine (too acidic) but does enjoy a glass of rosé. Occasionally something (perhaps too large a portion or something too sweet) can trigger a dumping reaction. Sometimes a meal that had no effect one week may trigger a reaction two weeks later.

I still ask her each morning “how’s your tummy been”.

Whenever we go for a long drive e.g. up to Scotland, I still think about where the service stations are in case we need a comfort break. Carol continues to carry a plastic card provided by Macmillan Cancer Support (as do I) with the legend “Due to my cancer treatment, I need urgent access to a toilet. Please can you help?”

We have both found the meetings run by OOSO and always attended by some of the team at Churchill (now held on Zoom) to be extremely helpful, Carol has continued to join these zoom sessions, and has recently volunteered to be someone that Matt can assign as a former female patient who can speak to a new patient if required and would be helpful.

I still have a daily checklist to ensure that Carol (and also me) have taken whatever medication or supplement is required, even if Carol thinks I'm being tiresome.

Carol continues to monitor regularly any weight change, and I try to ensure the maximum calorie and nutritional impact from whatever is on the menu.

Reflections

Thinking about these last nine years, this has been an emotional and a physically difficult extended episode in our lives.

Carol's cancer brought about change for us both.

There is not only an extended period of recovery following the surgery and treatment. There is a further period of time understanding, adjusting to and accommodating what will become the "new normal".

I cannot express my thanks sufficiently to Nick and his team for their skill and care; to OOSO and to Jackie Beaumont (an oesophageal cancer patient herself and the founder of OOSO) who visited Carol on the ward (this was pre covid) and helped her to overcome her fears following surgery and her distress at the removal of her stomach; and to the ward staff and the specialists at the Churchill who individually did the same.

Reflecting on this whole experience, my thoughts include:

- It is a huge shock when someone you love is diagnosed with cancer - you will inevitably be anxious as are they
- Being a carer is best thought of as a real-time process of learning based on how you handle each step of the journey and new experience
- What you do as a carer changes over time
- There are resources that can be accessed and tapped into using the recently redesigned OOSO website and elsewhere
- It is important to find out and access what support is available and draw on that advice
- Listening to other patients and carers at the (now held on Zoom) OOSO meetings really helps
- You will, of course, do the best you can to help, but it's good to have people you can talk to - be that a friend, a family member, someone from the Churchill or from OOSO, Macmillan, Maggie's etc
- It helps to think and plan ahead whenever possible - linked to whatever stage in the journey is coming up next
- Work to a checklist; if you don't write it down it might not happen or happen in the way that you intended
- Your focus will be on looking after your partner/relative/friend but remember it's also important to look after yourself - caring for yourself will help whoever you are looking after
- Stay calm
- Be a patient carer - this is a lengthy journey
- Remember to pace yourself and what you are doing
- This journey doesn't follow a straight line - there will be hurdles to be cleared in order to move forward and there will probably be unexpected turns
- Finally, and without any doubt, we are in extremely good hands with the team at the Churchill and, of course, with the support that is available from OOSO.

Neil Robertson
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