### Biography

Graeme Heward was born in Ashby near Scunthorpe in 1961, the second son of a steel works electrical engineer/semi-professional footballer, and a seamstress. Aged three, he had a brief existence in Sydney Australia, returning to Lincoln where he was educated at Branston Secondary Modern School, moving to Manchester in 1983 to pursue a career in physiotherapy. All rights reserved. This book or any portion thereof may not be reproduced or used in any manner whatsoever without the express written permission of Graeme Heward.

#### Cast of Characters

Lesley – My partner of eighteen years.

Elliot – My older son.

Sam – My younger son.

Cheryl – My physiotherapist colleague at PhysioSport.

**Professor Jarrod J Homer (Prof H)** – Head and neck surgeon, Manchester Royal Infirmary (MRI).

**Sarah Spencer** – Professor Homer's secretary and 'ex-Miss Long Legs of Great Britain'.

**Philip Bryce** – Specialist head and neck Macmillan nurse, Manchester Royal Infirmary.

Mr El-Kholi – Ear, nose and throat surgeon. Wythenshawe Hospital

Mr Jonathan Hobson – Ear, nose and throat surgeon.

Professor Nick Slevin – Oncologist, Christie Hospital

**Roz and Brian** – My neighbours at PhysioSport.

**Debbie Elliot** – Nurse specialist at Christie Hospital.

Mark Openshaw-Blower (Mark OB) - One of my closest pals

Jim Quigley (Jim Quig) – squash buddy.

Mr Mani – Head and neck surgeon, Wythenshawe Hospital.

**Miss Cook** – Oculoplastic and orbital surgeon, Manchester Royal Eye Hospital (MREH).

Mr Qureshi – Oculoplastic and orbital surgeon. MREH

Bob and Liz – Friends and neighbours (driver number 2).

Mr Palimar - Ophthalmologist, Warrington General Hospital.

Mr Tim Blackburn – Maxillofacial surgeon, Manchester Royal Infirmary.

Nurse Barbara Farimond – Specialist maxillofacial Macmillan nurse, Manchester Royal Infirmary.

Mr Sateesh – Visiting maxillofacial surgeon, Manchester Royal Infirmary.

**Mr Masimo Maranzanno** – Visiting maxillofacial surgeon Manchester Royal Infirmary.

Mr Dharmasena – Oculoplastic and orbital surgeon. MREH

**Mr Scott Rutherford** – Neurosurgeon and skull base specialist, Salford Royal Hospital.

Andrea Wadeson – Skull base nurse specialist. Salford Royal Hospital.

Jake Shackleford – School friend of Elliot's and triathlete.

George Francké – University friend of Elliot's.

Phil – My neighbour at home.

**Brian** – Patient and friend (driver for rides).

**David Thompson** – Oncologist Christies

Sarah, Tarin, Iwona & Oliver – Prosthetists at Aintree & North Manchester Mr Omah Gawagzeh – Occuloplastic Surgeon. MREH

The names of certain people who may not wish to be identified have been altered or not used to protect their anonymity.

### Index of terms and abbreviations

Abutments- Small titanium screws with a central thread for magnet attachment. A&E: Accident and Emergency department.

Adenocarcinoma: Cancer affecting mucus-secreting cells.

**Bell's Palsy**: Viral infection affecting the Facial Nerve causing temporary or permanent loss of facial function.

**Benign tumour:** Cancerous growth that can enlarge but not spread to other regions of the body.

Auscultation: Listening for sounds with a stethoscope.

Blepharitis: Blockage of tiny oil secreting glands at the base of the eye lashes.

**CT scan:** Polo mint-shaped machine taking 3D X-ray images of the inside of the body, particularly useful for looking at bony areas.

**Cannula:** Needle inserted into a vein that can be used as a means of administering fluids or drugs on multiple occasions.

Cauterised: Method of using heat to seal tissues.

Cellulitis: Bacterial infection affecting the inner layers of skin.

CCG: Clinic commissioning group

CLL: Chronic Lymphocytic Leukaemia.

Contrast medium: Radioactive substance that shows up readily on scans.

**Dactocystogram:** X-ray test with special dye to look at the course of the tear duct.

**Drafting:** Reducing the effort of cycling by riding very close to the rear wheel of the cyclist in front. This can reduce a rider's effort by up to 40%.

EMG: Electromyograph. Measures muscle response to nerve stimulation

**Endorphins**: Hormones released in the brain in response to pleasurable activity. Helps relieve pain and stress.

**ENT:** Ear Nose and Throat.

**Eustachian tube:** Short tube connecting the middle ear and nasal cavity for equalising ear pressure.

**Fascial tissue:** Packing tissue of the body. Helps support and keep the tissues in definable sections.

Granulation tissue: Ground tissue at the commencement of tissue repair.

HSP: Henoch-Schonlein Purpura.

Hypertensive: Higher than normal blood pressure.

**Intubation tube:** Inserted during an operation to maintain the airway to provide oxygen.

Lactic Acid Threshold; Point when the body can no longer sustain the processing of lactic acid, a byproduct of exercise.

Lester Jones Tube (LJT): Pyrex glass tube used in the place of the tear duct.

Linear accelerator: Specialised machine for emitting X-ray radiation.

Lymph node: Contains immune cells which help fight infection

**MR scan:** Tube like machine with giant magnets that creates an image of internal structure of the body, especially useful for soft tissues.

Malignant tumour: Cancer cells that can spread to other areas of the body.

MRI: Manchester Royal Infirmary

**MDT meeting:** Multidisciplinary team meeting when various medical specialists discuss complex cases.

MRSA: Methicillin-resistant staphylococcus aureus

**Mutated:** In the process of cell replication and division the genetic code is very slightly altered.

**Neuropraxia:** Temporary loss of nerve conduction caused by damage to the outer layer of a nerve

**Oculoplastic and orbital surgeon:** Pertaining to the eye and surrounding tissues. **Oncologist:** Specialising in the study and treatment of cancer.

**Ophthalmologist:** Eye expert.

Orbital cellulitis: Inflammation and swelling of the tissues around the eye.

Parotid Gland: Largest saliva secreting gland.

**PEEK:** Strong plastic like material used in my nasal reconstruction. Commonly used in the aviation industry for its strength and lightness.

PTSD: Post Traumatic Stress Disorder

Proptosed: Projecting forwards of the normal position.

Prosthetic: Artificial device used to take the place of normal body tissue.

**Radiotherapy:** Exposing cells to a controlled radioactive substances to destroy a cell's DNA (genetic code).

**Sinus:** Cavities in the skull bone to lighten the bony structure and add resonance to the voice.

Skull base: Bony shelf that support the brain.

Stent: Small tube used to maintain the patency of a tube, artery, vein or duct.

Stoke: Vascular block or bleed causing damage to brain cells.

Suture: Stitch.

**Trophic Stimulation**: Method of feeding nerve signals to floppy muscles in time rejuvenating them

Vertebral Artery: Major vessels in the neck supplying the brain.

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#### Riding With The Alien

## Chapter 1 2010. Eye Watering

30 October 2010. It was a beautiful day, driving south from Manchester on the M6. My partner, Lesley, and I were heading off for a long weekend in Bath to celebrate her forty-seventh birthday. On our way down we called in at Warwick Castle, Stratford-upon-Avon, then stayed overnight near Gloucester before spending a couple of days in the fabulous city of Bath. While driving, I noticed my right eye was watering. I wasn't unduly concerned. Perhaps a touch of conjunctivitis, I thought. I'll leave it to settle by itself. Maybe it will be gone in a few days.

I was oblivious to 'the Alien' that had entered my life.

Several weeks later, the eye watering was still troubling me, so I purchased some Chloramphenicol, an antibiotic fluid available without prescription, from a local chemist.

With still no change in my symptoms, I decided to see my optician, a friend and patient of mine. Despite being forty-nine years old, I hadn't succumbed to wearing spectacles just yet, so I was an infrequent visitor to his clinic. Ian examined my eyes and reported that it was most probably conjunctivitis. All was normal apart from the watering. However, the problem persisted.

By December, my eye was still watering. Perhaps my GP could identify the problem? Antibiotic medication was prescribed but this made no difference.

At short notice, I'd booked with a friend to go skiing for a week. By this point I was becoming a little concerned about my ability to see clearly. Prior to departure, both my eyes were really sore, so I went to the Accident and Emergency (A&E) department at the well-respected Manchester Royal Eye Hospital. There, I saw a nurse practitioner who examined my eyes thoroughly before consulting with her doctor colleague. I had blepharitis, a common condition of folk my age. Ironically, it's known as 'dry eye'. I thanked her and felt confident this was the cure. Eye drops and daily cleaning of the margins of my eyelids, where there are small oil-secreting glands at the base of the eye lashes, did seem to settle the acute redness. However, the eye watering continued.

In January 2011, I returned to the A&E.

'I feel as if my tear duct's blocked.'

Following a similar examination to before, the response was the same: 'Blepharitis. We'll refer you to have the tear duct tested.'

One month later, I attended the examination. By slipping a fine plastic tube into the tear duct situated on the lower eyelid on the nose side, the doctor was able to test its patency. Once the tube was correctly sited, he squirted a small volume of saline solution through the tear duct. The left duct felt different to the right. On the left side the fluid quickly made its way through to my nasal cavity and down my throat where I could immediately taste the saltiness. On the right it seemed to well up before going through. I brought this to his attention.

'Probably a blockage and it's cleared now. You're discharged', said the doctor.

I thanked him and left, hoping and believing it was as simple as that.

It was now mid-March, and the problem was persisting. I'll go back to my GP, I thought. The familiar story, there wasn't an available appointment with a GP who I knew so I saw a new doctor.

Twenty-five years ago, I'd had a sinus operation to widen the small tubes that drain the sinuses, a bilateral nasal antrostomy. It had been largely successful, not requiring me to return to the Ear Nose & Throat department (ENT). Whenever I suffered a cold, the right sinus was marginally more affected than the left, but it was nothing I couldn't cope with. I explained the reason for my visit, adding that I sensed a pressure on my eye, like a heavy cold would produce.

'I doubt very much that your eye problem has anything to do with your sinus as it's a huge cavity', said the GP. 'Try this steroid spray for a month'.

I would have preferred a referral as well but agreed that if my symptoms didn't improve within a month, she would refer me to ENT.

'While I'm here', I said, 'I'm approaching fifty. Will you be contacting me to have a health check?'

I'd never had a health check or prostate examination. I've never been keen on needles or lots of fuss, but it was a mild concern to me. Physically, I was extremely fit and outwardly I appeared healthy.

'Why? Do you think you've got a problem?' said the doctor.

'No', I said. 'I thought that was the reason for having a health check – to check.'

'Well, you can have a blood test for prostate-specific antigen, a marker for possible prostate problems, but it isn't a sure-fire test. You've probably got your own blood pressure machine. Why don't you take it yourself?'

This was far from the proactive response I expected. As a medical professional myself I tried to 'walk the talk'. I looked after myself, took regular exercise, ate well, didn't smoke, and hardly drank. Perhaps she thought I was wasting her time.

A month later, the problem was still there. My eye was continuing to water and the feeling of pressure hadn't subsided. If anything, it was greater than before. There was a slight gap starting to form on the inside of my eye where the eyelids meet, as if a cyst was forming. Lesley, who had been relatively unconcerned up to this point became suspicious of something more serious. I took no chances on being fobbed off a second time, so wrote to the doctor asking for a referral to ENT.

Two months later, I had my appointment at Withington Hospital with Mr Potoula, an ENT consultant. I had a choice of several local hospitals but chose Withington as it was there, I trained as a physiotherapist in 1983-86. The large Victorian hospital with its Florence Nightingale wards had largely been demolished fifteen years ago to make way for a community hospital that was modern and up to date. Mr Potoula took my history and examined my nose. The swelling had developed towards the nose side of my eye and there was a noticeable pain in my right sinus. Within seconds of looking up my nose with a special scope he declared that I would need an operation 'but first, let's have a CT scan'.

I thanked Mr Potoula and left with Lesley. It had been eight months since the onset.

The scan, on 12 July at Wythenshawe Hospital, came through more quickly than I'd expected. I had also worked there as a physiotherapy student and my sinus operation was there in 1986. It was good to be somewhere familiar.

A week later I was reviewed in clinic. I was now under another ENT consultant, Mr El-Kholi. I saw his colleague, who had a student nurse with him. Over his shoulder, my scan was visible on screen. I was used to looking at scans of backs and necks but not skulls. Despite that, I could see there was a black egg-shape situated to the right of my nose overlapping my right eye orbit (the bony socket the eye sits in).

'You have a mass in your sinus Mr Heward. We need to do another scan - an MR scan - to find out what it is', said the doctor. By now the pain was

increasing, my eye was being visibly pushed out of my head and I had difficulty breathing through my right nostril.

The following week, I had the MR scan with a special dye injected into my vein to highlight particular areas. By coincidence, I knew the radiographer, Richard, from a previous scanning department. After the scan he spoke to me in a solemn tone.

'It will be reported on tomorrow.'

I drove away from the hospital in a blur, my mind racing with a myriad of thoughts. No? Can't be?

In the event, the radiologist who interprets the scan had been on holiday, so I had to wait several extra days before getting any news. Mr El-Kholi's colleague rang me.

'The tumour is benign'.

Huge relief. My mum was staying with me at that time so I went immediately to give her the good news. My boys and Lesley were the next to be informed, then friends. Mum had come to stay so I could help her own rehabilitation from a recent stroke. It had been early May when I'd visited her in Lincoln, where she lived with her husband of twenty years. It was the bank holiday when Prince William and Kate tied the knot. Mum loved all that stuff.

The previous week she'd had a blood pressure check at her GP which registered pretty high considering she was on anti-hypertensive medication. I'd suggested she obtain a home blood pressure machine to take more regular readings.

'While I'm over, I'll show you how to use it'.

Which I did. But on Sunday morning she wasn't quite herself. By midafternoon she'd had a stroke. Fortunately, her husband noticed something was wrong and called me. She was slumped in a chair, unable to speak or move her right arm. Within seconds I knew what had happened. The emergency services were there in minutes, and we were in Lincoln County Hospital via a blue-light ambulance ride within forty-five minutes. Lesley, Dave, her husband, and I stayed with her most the remainder of that day, returning the next morning.

Initially, every word she said came out as 'whey'. With some gentle persuasion I had her repeat some nursery rhymes. Learnt from infancy, they are deeply embedded in the brain's memory. I've never been so pleased to hear 'Baa Baa Black Sheep'! It helped get her lips moving, formulating words and was a welcome boost to her confidence when she could hear the correct words coming out. It had made us smile and laugh – four adults, so pleased with a simple nursery rhyme.

Lesley and I had driven back home to Manchester in the knowledge that she was in good hands, returning twice that week to be with her. She was making good progress but had difficulty with nouns, telling the time, names and counting money. I knew that this period of time was crucial to her recovery. Small episodes of stimulation and patience would be required so I had her over to stay with me for weeks at a time, playing pairs with a pack of cards, doing picture puzzles, naming objects in the garden, counting money and going for walks. The investment paid off as she conjured up a fantastic recovery. She's a pretty determined lady.

I was in clinic again. By now, the pain was really bad.

'On the way out', I said, 'if I see a porter at this hospital with a knitting needle, I'll be tempted to let him have a go'.

The doctor laughed and said the operation would be as soon as possible. The tumour was growing exponentially, filling my right nasal cavity and deflecting the nasal septum dividing left and right sides of the nose. I looked in the mirror. Using a torch, I could see the grey mass part way up my nostril! Come on, come on. How much longer would I have to wait?

17 August 2011. The morning of the operation to remove the tumour, I met another consultant, Jonathan Hobson, young and colourful. He and Mr El-Kholi would perform the two-hour operation together. I walked down to the anaesthetist's room feeling somewhat nervous. Mr El-Kholi sat with me while the theatre was prepared. I had always been a keen squash player, and nothing could be better than to treat the world's best players. My fellow physio, Cheryl, and I had looked after the national championships for the last decade, several British Opens and the World Open. Some of the best players were Egyptian and I knew Mr El-Kholi was too. Egyptian squash players are revered in their own country like premiership football players are here. I mentioned that he should look after me carefully so I could do likewise with his fellow countrymen, and I believe he did. Just at that point he started to talk statistics. There was a 95% chance of my tumour being benign, but these things 'can turn nasty'.

My symptoms had improved immediately on coming round from the anaesthetic. The pain had gone, I could breathe more easily, and my eye was almost back to its rightful position. I was discharged that evening. It was Wednesday, so I took the following two days off work plus the weekend and returned to my South Manchester physiotherapy practice on the Monday. Some of my current patients wouldn't even be aware anything had happened to me. I would be seen in clinic two weeks post-op for check-up and the results of the biopsy.

The following week I started back at squash. Life was getting back to normal. Fabulous!

## Chapter 2 2011. Enter The Alien

31 August 2011. Lesley wanted to come with me to the clinic review. I was feeling pretty confident as the op had gone well and the odds of 1 in 20 were pretty good. Jonathan greeted me. Would you both like to come in?

'No, I'll be fine by myself'.

'Sure?'

'Yep'.

I sat down with Jonathan and a fellow doctor. I started by saying how fantastic I felt and what a great job they'd done. Without realising, I was making Jonathan's job much harder.

'I'm afraid the tumour's malignant.'

It didn't quite sink in. We chatted for a short while then I asked him to repeat the malignancy bit again. He inspected inside my nose for several minutes then started to talk cancer. Tears started to form. I couldn't believe it.

He took my mobile number and said he'd contact me to arrange a meeting once he'd discussed my case at The Christie, a world-renowned cancer treatment and research hospital in Manchester. He also gave me the number of a Macmillan nurse, if I needed to talk to someone. Despite my devastation, I thanked Jonathan. He'd delivered the news in the kindest possible manner. Lesley knew immediately there was a problem from my expression and body language as I emerged from the interview room. I can recall her shocked look.

'What's wrong? What's wrong?'

We walked a few yards away from the clinic waiting room to sit in a corridor where we could be alone. With my head bowed to cover the tears I blurted out the news. What was to become of me? Was I about to die? No one knew. The roller coaster had begun to roll.

Lesley was fantastic, saying just the right things. Her father had died of a heart attack twenty years previously, and her brother seven years later of unremitting multiple sclerosis. Lesley had seen suffering and had suffered herself. I wondered if I was to be the next male in her life to depart. We returned briefly to Lesley's home where I had a hug from her mum, Beryl, before I carried on home, a twenty-minute drive away. I wanted to tell my two boys Elliot, then nineteen and Sam, seventeen, before I could announce it to the world. Elliot had his girlfriend Debora with him. We had a group hug while I spluttered out the news followed by a prolonged hug from Elliot. With Sam I did the same. My mind was a jumble. I can't recall the conversation accurately. Earlier, at the hospital, I'd discussed with Lesley whether to tell people the real truth or spare them the harsh reality. There was simply no choice. It was too big a deal to hide. The boys, who clearly found it very upsetting, preferred my total honesty and I didn't want to hide anything. Talking about it at the time and in the future proved to be the best way for our family and Lesley to cope with all that was to be thrown at us.

That evening I drove halfway to Lincoln meeting my mum and her husband Dave, coming in the opposite direction. We exchanged the passenger, Mum, and continued our journey back to Manchester. I waited until we were driving back to deliver the shocking events of the day. I was concerned how Mum, who was still recovering from her own difficulties, would take it. She was prone to tears at the best of times. By me continuing to drive it somehow helped her keep those emotions in check until we arrived home. She took the news better than I'd expected. Inside she was devastated.

'How could it happen to you? You've always looked after yourself. Why couldn't it be me instead?'

I went into work the next morning as usual, ringing my closest friends between patients. I was 'in bits' on the phone. I'd start the conversation okay, then break down. I couldn't use the 'C' word. It was too raw, so I referred to the tumour as the 'Alien'. I never thought it would be me, at my age, as fit as I was. I ticked none of the boxes.

I informed some of my patients. They'd followed my progress and respectfully needed to be told the bad news. The same went for the guys and girls at my squash club. There was universal disbelief. Talking about it helped me, though I can understand why other people might wish to avoid the issue.

The following day I drove the usual twenty minutes into work at 6.30am for a 7.00am start, crying all the way. What songs would I have at my funeral? How will it all end? How will I die? What about my lovely boys? What about Lesley? I was just turning my life around after years of discontent in a marriage followed by divorce. This was a cruel blow. Lesley felt cheated, fearing a future without me. I never resorted to looking for information on the internet. It wasn't that I was in denial, it was just better for me to be fed only positive information at this stage. Remaining optimistic was important to me. Lesley and the boys found that if I was upbeat, it was fine for them to be upbeat too.

The following weekend I'd arranged with my Mum and Lesley for us to visit my aunt near Exeter who I'd not seen for many years. It was an opportunity to see my cousin who is a GP in Exeter. It was good to talk it over with someone who had medical experience. This area of medicine was uncharted territory for me. While we walked along the pebbled beach, Mum collected a couple of pebbles she liked the look of. One pebble she would take home to her house the other stayed at mine and is still by her bedside, next to a bible. Over time, the enduring nature and resilience of pebbles would become qualities I should strive for. We returned home to Manchester a day early so I could meet Jonathan and my Macmillan nurse at The Christie on the Tuesday morning. The roller coaster was picking up speed.

Despite living close by and regularly driving past, this was my first visit to The Christie. As I approached the entrance, I almost had to pinch myself. Was this really happening? We sat down in the outpatients department. I glanced around. I must have been the youngest person there, apart from Lesley. I was as fit as all of them put together. There was no outward sign that it was me who harboured the alien.

We met Jonathan in a side room. He'd discussed my case earlier with colleagues. I had a sinonasal intestinal-type adenocarcinoma. Basically, cancer of the nasal lining. This cancer was so rare it didn't have its own classification so was grouped with the one most like it – intestinal. It was decided I should have a full body PET scan (Positron Emission Tomography). They were looking for metastases, secondary cancer deposits, anywhere in my body but especially in my bowel. I mentioned that my father was presently fighting bowel cancer. I had no suspicion I had any other problems, especially with my bowels, however, I'd already been proved wrong by not suspecting cancer in my sinus. Furthermore, Jonathan added – saving it until last, as I'm sure he felt uncomfortable about broaching it – 'it may have spread to your brain'. The roller coaster was in full flight as I contemplated the devastating consequences.

The following week I had the PET scan. A young chap took me through to the research centre at The Christie, run by The University of Manchester. He explained the procedure, injected me with radioactive glucose and left me in a darkened, silent room for an hour. I was to stay quite still so the glucose wouldn't be attracted away by any muscle activity from the intended target, Alien offspring. I was told to empty my bladder before entering the scanner.

Three days later I was back in The Christie's Outpatients. Things were happening quickly. I had a new consultant, Mr Jarrod J Homer, a head and neck surgeon. Lesley and I were called into one of the small consulting rooms. In came one of Mr Homer's colleagues, Mr Mani, and he explained the extent of the problem.

The Alien had eaten its way into the shelf of bone supporting my brain, the nasal cavity and fractured my right eye orbit.

'We will need to remove your right eye. It's no good leaving it if there is any chance the cancer could have spread to your eye'.

I felt sick inside.

'But my eye's fine,' I countered. 'I've got normal vision'.

Mr Mani paused then made a quick assessment of my eye movements. He seemed pleasantly surprised.

'We need you to have a further MR scan'.

We had performed a wicked turn on the roller coaster. Lesley and I left the room arms around each other as Lesley burst into tears. A nurse came over and asked if she was okay.

'Would you like a room?'

'No. That's kind, we'll be okay thank you', I said, turning to Lesley. 'That's great! I have the problem and you get the sympathy.'

We were able to laugh about such events. Very often it helped to relieve the pressure. The PET scan thankfully proved negative. As far as anyone could detect the mass in my sinus was the only tumour.

That afternoon I had an appointment with one of the senior doctors at my GP practice. I wanted to keep him updated about my tumour situation and make him aware that I was unhappy with his colleague's attitude when I'd asked previously about the health check. I didn't want to get bogged down in anything other than an informal notification. I had a much bigger fight on my hands with the Alien. I also thought that their cooperation and help at a later date might be essential. As it was, he listened, made no comment about her conduct, offered me the routine health checks, wished me good luck and suggested that The Christie would now deal with me.

That wasn't quite how the hospital saw it. A patient's care was a partnership between their GP and the hospital. I didn't take up his offer of a health check as anything they could have found would have been more than superseded by the seriousness of the Alien intruder. I had enough on my plate.

The Macmillan nurse very kindly invited Lesley and me for a coffee and chat at her ward in Wythenshawe Hospital, on 20 September. By now I had many questions to ask. After the news of losing my eye, Lesley and I had talked about prosthetic eyes, how realistic they were and that very often no-one could tell. By putting my hand over my right eye, I could reproduce my future visual field and acuity. Could I do my job? Could I drive? Could I continue playing my sport? I didn't want to lose a perfectly good eye but if it meant surviving, I'd have to.

We sat down with my nurse. She was blunt.

'Basically, you'll lose your eye, have facial disfigurement and you will not be able to have a prosthetic eye'.

I was totally gutted to the point that I questioned if I could deal with an operation at all. I asked how long I'd have if I didn't have the op.

'Maybe four weeks for it to fully enter your brain,' she said.

It must have been hard for Lesley to hear me ask that, but I had to weigh up everything. Do I go out of this world at least looking normal or do I tolerate mutilation? Could I handle mutilation? She estimated the op would be ten hours long. The nurse wished me luck as we left. We walked back along the long hospital corridor. We were once again in disbelief. When would the torrent of bad news stop coming? The roller coaster roared.

Lesley would often wonder how I was feeling. Fortunately, I was happy to share my emotions.

'It's easier for me,' I would say. 'I know how I feel. It's worse for you having to imagine what it's like'.

Being a handsome couple, it concerned me what I would look like after the operation. Lesley never openly flinched at the thought of being landed with a guy who was suddenly disfigured. Our feelings for each other ran deeper than skin. My charisma would get me through! Ha ha! One of the girls at the squash club once described me to my face as 'boring'. Anyone having low alcohol consumption was clearly assumed to be so. But life with me was anything but boring. It was a great life and I'd had great life experiences. If I had to bow out now, then that was my destiny. I had no regrets.

If I was to survive, how was I going to cope with facial disfigurement? What would it be like walking into a room full of people I didn't know? How would new patients feel when I met them for the first time? Eye contact is such an important means of communication. How could I make eye contact with someone

when really, I would prefer to hide my face? To spare my embarrassment, people might look away. An eye patch wasn't the answer for me – that belonged to pirates with parrots. I thought I would wear glasses permanently to hide the lot. That would deal with the physical affects. The psychological impact would be harder to hide. That could be very destructive, seriously affecting my confidence and self-esteem. I knew there was a society for help with such disfigurements, but I wasn't ready for that just yet.

Lesley worried how she would feel, suddenly faced with a partner with significant facial disfigurement. Coping with the acute problem was one thing, living with me for the rest of her life might represent something else. She was already experiencing stress, anxiety and frequent migraines as she tried to stay strong for me, my boys and Mum, and her own family. She never resorted to comparing my fate with that of her father and brother. Rather, she drew on them spiritually. It was not about religion.

Three days later I would have my MR scan with contrast dye. This was a critical scan. The best images are obtained by being as still as possible. To help that process my head was in a special brace. I was becoming an old hand at scans. The MR scanner is a long narrow tube some people might find claustrophobic while the CT was more like a polo mint. I used to practise at home, lying as still as possible, keeping my breathing shallow and regular. The images were good.

### Chapter 3 Together

During this torrid period, I had huge support from family, friends, fellow physios, squash mates and patients. Elliot, my older son, was back at Manchester University studying medicine and Sam was in his final year of A-levels at our local state school in Lymm. We had a policy of talking about the whole thing, even making light of it. As long as we talked about it openly at home, the boys had very little requirement to converse about it outside our 'special' group. Their friends were probably too young to offer meaningful help anyway. Thankfully Elliot and Sam are best mates so had each other and their respective girlfriends, Debora and Viki for support. A note was made at their educational establishments that my life was 'up in the air'. I was keen not to be responsible for destabilising theirs. Honesty had certainly been our best policy. They knew there were no more shocks coming, other than the ones I expressed following any consultation, and they were up to date with everything. Elliot, Sam, Lesley and I wanted life to carry on as normally as possible. It seemed our best self-defence policy.

My squash mates at Bowdon Squash Club were great. I wanted to carry on in just the same way as always. Most of the guys and girls knew my situation by now and had monitored my progress throughout. With my watering eye, I had difficulty seeing clearly during games. Squash, being a fast sport with a small ball, meant having good visual acuity and picking up the ball as early as possible was essential. Squash players don't generally make excuses, especially the professionals. It's a very gladiatorial sport, fighting for space on the court, looking for an advantage.

As I couldn't afford to lose my 'remaining' eye I was wearing protective eyewear during every match. Several people I knew had had close shaves with eye injuries but I didn't know anyone personally who had lost an eye through squash. The eye orbit is a perfect shape and size to funnel in the small rubber ball. As I played my games, at crucial points I would imagine this was me against the Alien. I had to win. That short rally was a microcosm of my whole life. I felt as if I was practising for the big fight, which was a now only a few days away. There were two guys, Mark and Jim, who I played squash with on a regular basis. Both were a similar age to me. Mark I had known for at least twenty-five years, a successful solicitor. His life somewhat mirrored my own, divorced (now remarried), two kids. We each knew we could rely on the other. Mark came from a public school background, well-spoken and suited. We always shook hands to greet but not this time. I was in floods of tears as we hugged. Mark had read my mind. He was already putting in place a power of attorney in case it all turned to 'rat shit'. I could trust Mark with my life. He would sort things for my lads in the way I would have wished. He was already executor of my will.

Jim was likewise successful in his job and had two kids. He was a big solid guy, difficult to manoeuvre and see around on a squash court which was always the subject of some banter. On my drive towards the club to play Jim, I was already in tears. Jim had arrived before me. He could see as I walked towards him with my head slightly bowed that I was struggling. He hugged me and I needed that. I knew he had dealt with friends in a similar situation to me and not all had had a positive outcome. Jim kept it simple and in perspective.

These two guys were like rocks, enabling me to offload my grief and distress on each of them knowing they were resilient enough for it not to get to their own core. I couldn't do that to my lads, Lesley or Mum. They were too close and vulnerable for that.

My brother Nigel was two years older than me, unlike me in character but vaguely similar in appearance and height but not portliness – he's a bit overweight and also a bit of a 'Jack the Lad'. Even he phoned to check on me. Despite his father and me having cancer he was in no hurry to stop smoking, after all, neither my father nor I had smoked. That's justification enough and the logic that only other committed smokers might comprehend.

I had moved to Manchester from Lincoln when I began my training as a physio at Withington Hospital. It was a brilliant period of my life. Following my mother and father's acrimonious divorce, I lived with my mum and brother in Lincoln. Subsequently, Nigel had moved into his own place. I was working for Barclays Bank after A-levels, having drifted into banking because I didn't really know what else to do. By the first six weeks I hated it. It felt like a prison. It was my first real taste of work and, perhaps not having grown up with sisters, I found the girls difficult to deal with.

I was enjoying playing squash and football during that time until I had a knee injury. I saw a consultant who referred me for physiotherapy at the local hospital. In a eureka moment, I thought this is the job I want to do. I wanted to

make a difference to people's lives and do something useful. I would need biology O-level, which I studied for at night school. I was still working for my banking exams too, but my heart wasn't in it. I applied to Nottingham School of Physiotherapy but was rejected. To help my chances and prove I had the determination, I started the biology A-level. At the local college they taught part A of the syllabus one year and B the next. I couldn't wait that long, so I taught myself the missing year.

I applied to Withington School of Physiotherapy where I was interviewed by Mrs Oldham and Mr Whitlow. Both had a good sense of humour and easy manner. This place felt like home. As I was seated waiting nervously to be called in, I even bumped into a girl, sister of a football mate, who I knew from Lincoln, studying in her third year. I didn't even know beforehand that she was a physio student. What were the chances of that? Perhaps it was a good omen?

Several weeks later I received the letter postmarked from the hospital. I opened it with Mum. I'm in!! We hugged. My delight was tinged with sadness for her, as she would be on her own at home from now onwards. My father wasn't pleased.

'Giving up a good job, your car, your future, and a cheap mortgage. You fool'.

But, for me there were more important issues in life. I knew it was the right step. Years later he didn't mind availing himself of my new-found physiotherapy knowledge when he had the odd injury from playing tennis or for his achy knees.

There were forty students in each year at Withington. I was one of two lads in my year group. Thank goodness for Martin who had a great sense of humour and could share a male joke that you couldn't necessarily do with the girls. Our class were fantastic with none of the bitchiness of the bank. After qualifying, we had periodic reunions and it so happened that recently, as these scans and examinations were going on, we'd had a reunion in Manchester.

One of the girls had recently died which was very sad. The law of averages dictated that one of us would be dead by the time we all reached forty years old. As yet, the full extent of my problems were not yet known. It was sunny so I'd applied sun cream to my face. After thirty minutes the cream was irritating my right eye. Another thirty minutes on and my eye was streaming. The girls rallied round with antihistamines. I was in so much pain I don't know how I drove home. At a later date, by email or text, they would all know the devastating news.

Cheryl had worked with me for the past ten years at PhysioSport, my practice. I first met her at a postgraduate course in Southport in 1995. I thought

then that if ever I needed a physio in the future she would be someone I'd approach. She lived in Manchester, and I knew some of her friends so would occasionally enquire about her. Suzanne, my previous colleague was leaving to set up home with a guy in London to have their baby. Perhaps Cheryl would be willing to fill the position? This proved to be the perfect transition. Cheryl was married at that time. A more reliable person you could not hope for. She played squash, enjoyed running and had a similar approach to life as me. Later we would see each other through difficult times and divorces. Cheryl was like the sister I never had, and she had followed my eye situation from the beginning. When she heard the news, it was malignant she was in total disbelief, spending the whole day crying. Cheryl would increase her hours for the six-week period I would be off while recovering from my surgery. I'd been told I would be able to work through the radiotherapy. PhysioSport was hers if the worst happened.

Several people had offered me financial support if things became sticky. I was hoping to return to work fairly quickly, but it was very nice to know I had that buffer if things didn't go to plan. Self-employment was precarious in that respect, particularly as I had no insurance cover for long-term illness. I had considered this type of insurance, but it seemed to me that making a claim was almost impossible and policies only paid out after a protracted period of absence. I preferred what I thought was a more positive approach by investing my limited resources in my own health and fitness.

By now the news was out. Squash players from all over and ex-patients were sending in emails, texts and cards. It was hugely reassuring to have so many kind messages of support. Whenever I met someone, male or female, it was heart-warming to have so many hugs. I used to ask if it was okay to take some of their healing power as we did so. I believe I took some of their strength with each hug.

### Chapter 4 At The Sharp End

My first meeting with Mr Homer, the head and neck surgeon who would perform my operation, followed a multi-disciplinary team (MDT) meeting on the morning of 29 September, when my case would have been discussed with colleagues of various medical disciplines. Mr Homer was, I'm guessing, eight years younger than me and slimmer, self-assured, and smiling. There was a small posse of people including Mr Mani, Debbie Elliot, a specialist head and neck nurse, Lesley and me in the small side room. He went through the details of the operation – incision sites, length of op and hospital stay – leaving my eye until last.

An incision would be made through both my eyebrows, crossing the bridge of my nose, down the right side of my nose then under my nose, spreading out to both left and right (where the top of a moustache would be). They would go in through my forehead frontal bone to remove the tumour in its entirety.

A portion of the sheet of bone that divides the upper sinus from the brain, the skull base, would be removed, together with the associated layers of tissue surrounding the brain, the dural lining (meninges). The dura would be replaced with fascial tissue from the outside of my thigh, where there is a nice strip to harvest, and secured in place with a plastic and titanium plate. Any tissue the tumour had come into contact with would need removing, including the specialised lining of the nose, turbinates (bony fins inside the nose that humidify and filter the air) and the nasal septum that divides the left and right sides.

'The op will need a whole day of surgery and you will be hospitalised for about seven days', said Mr Homer. 'And there's a possibility we may be able to save your eye'.

This was the first piece of good news in weeks. I didn't ask percentages. Any percent was a bonus. I thanked both Mr Homer and Mr Mani and left feeling confident they would do their utmost to help me. Despite the gruelling details, I left a happy chap. All things are relative!

My operation was scheduled for two weeks' time, Friday 14 October, and I would require another MR scan on 6 October. This would define the full extent

of my surgery. The surgeons would need to remove all the cancer plus a little more – a clear margin. My Alien would be gone. At that meeting they asked if I'd been involved in industrial woodcutting, apparently the main cause of this type of cancer, perhaps the result of dust or resins from exotic woods. I had done a few DIY jobs including laying solid wood floors but that would be insignificant compared to the exposure in a joiner's lifetime. Perhaps it had something to do with my sinus op in 1986? Whether it did or did not would have little bearing now.

I never asked, 'Why me?' It didn't serve any positive purpose. I had the Alien, and I would have to deal with it.

Sporting biographies were always of interest to me. I was always keen to know what made such people special and what motivated them to be the best at their particular sport. A good few years ago I had read the book 'It's not about the bike' by Lance Armstrong, the American Tour de France cyclist, since disgraced. It's an inspiring book about Armstrong's battle to overcome testicular cancer and return to winning the Tour. As my own story unfolded, I could relate to some of the experiences he described.

The week of my operation I had a pre-op check and met Philip Bryce, a specialist head and neck nurse. Philip was about 6 feet 4 inches but not at all physically imposing. He answered any remaining questions I had. The operation would take place at Manchester Royal Infirmary (MRI) and not Salford Royal which had been proposed if neurological support was required for the brain aspect. I took that as a good sign.

Shortly before my op I saw my neighbour Roz, who lives next to my practice, speaking to her through my upstairs window that overlooks their garden. She read my situation in an instant. Detecting all was not well, she cut the conversation short and walked round to be with me. Her husband Brian had suffered from leukaemia and, more recently, sublingual (mouth) cancer. She knew only too well the turmoil I was going through. Brian had fairly recently endured a fourteen-hour operation and recovered to enjoy his life. I regarded Brian as a Trojan of the highest order. What that man had not endured is not worth repeating. I hoped if he could do it, then so might I. He was an inspiration and reassurance in my uncertain world.

I thought back to those initial consultations. Would things be different now had the Alien been spotted earlier? Mine was a very unusual and rare tumour. 1 in 100,000. I had symptoms of blepharitis, which may have acted as a red herring.

My symptoms had been relatively insignificant – a watering eye. There was nothing to be gained from looking back. No 'if onlys'. I was here now.

I slept well the night of 13 October, having had my last drink of water at 9.00 pm. Lesley drove the short distance to MRI and parked up for the day. There was no way she was going to leave that hospital until I came round after the op. We registered on the first floor, 'hospital bag' in hand and took our seats in reception.

Following some minor confusion, as there were two Graemes on the list, I was met by Ross, a reassuring anaesthetist. He explained the procedure, as he would have done hundreds of times before. I had no complicating medical history. I would be catheterised because the op was longer than six hours and it would be necessary to monitor my fluid levels post-op. A new experience for me, slightly eye-watering, but at least I would be out when they inserted the tube. Next Mr Bhatt and another registrar, Mags, met me. They guided me through the consent form, possible stroke, meningitis, infection, loss of eye and death.

Another patient had been fitted in for surgery before me so I would be down at eleven-ish allowing just that little longer to agonise. I changed into my op gown following our final hug and waited. Lesley occupied the time doing a crossword, occasionally plying me with a clue. The time had come. The porter arrived, collected my notes and walked Lesley and me to the entrance of the corridor leading to the operating theatres. We kissed and traded 'I love yous'. Lesley wished me luck and I disappeared with the porter to the anaesthetist's room not realising it was the last time I would ever smell Angel, the perfume I associated with my special girl.

There were several doctors, technicians and the porter who made small talk, keeping it jovial and relaxed. It was there that I was able to draw on all of those well-wishers. They were all in there with me. People had lit candles that day and it seemed like all the churches in South Manchester had been regularly praying for me. Mum had lit a candle in Lincoln Cathedral with a friend. I was grateful she was not alone one hundred miles away from the action where the mind can play tricks. I was as fit as a fiddle and looked perfectly fine. My right eye had served me well. I thanked it. Through a small gap in the double doors, I had a glimpse of a body on the slab in the bright theatre lights with lots of staff in their greens. That would be me very soon. Staying as relaxed as possible to keep my blood pressure from rising, the cannula was skilfully inserted into a vein in my left wrist. I could see the clock was at 11.00 am and then I was out.

Lesley distracted herself as best she could by reading magazines in reception on Ward 9 or taking a short walk. Jim, my pal, called by to keep her company for a while before Elliot arrived, following his afternoon lectures, and Sam joined in after school via a lift from friends of mine. They waited until 7.00 pm for me to appear.

On coming round in the recovery suite the first thing I said was, 'Lesley and the boys will be waiting for me on ward 9'.

It was a struggle to speak with my dry mouth and the morphine, but they were at the forefront of my mind. In that short period before drifting off again I knew I'd survived and was capable of speech and rational thought.

When Mr Mani found the threesome, his first words were 'we've saved his eye'.

Lesley gave him a big hug, kissed him, and thanked him very much. The boys chatted to Mr Mani about the details of the operation and thanked him. He was an inspiration to two budding doctors. I recall seeing Lesley and my boys for a brief greeting.

'They saved your eye, Dad'.

Then I drifted off again. The boys used my phone to send a group text to all my concerned well-wishers that evening.

I spent the whole night on the recovery ward being carefully monitored. The night seemed to last forever, punctuated by blood pressure checks, ear temperature readings and the shining of bright light into each eye to check my pupil reactions. As I was the only patient on Recovery, I was getting personal attention, which was reassuring. My lips were bone dry and as I moved my tongue in front of my top set of teeth I felt to my surprise, a forest of string in my mouth. The moustache incision was inside, not outside my mouth, extending from one side to the other. It had enabled the surgeons to retract my face away while attending to the deeper nasal and check tissues. My upper front teeth, right side of my nose and face were numb. I had warned Lesley and the boys that I could well look like a car accident victim. With my eyebrows shaved, replaced by a line of fine stitches, stitches by my right eye, bruising and tape to keep my nose in place, I didn't disappoint them.

The following morning, I was moved onto Ward 9. MRI was in the process of being modernised and I was fortunate enough to be in the new section. I was semi-recumbent in bed with the backrest permanently at a 40-degree angle to lessen the gravitational pressure in my head, face and brain to reduce swelling. I would have another five days and nights in that uncomfortable position, unable to roll onto my side or stomach. Not surprisingly, my vision was initially very blurry. Despite the bed angle I could see only the ceiling as I was moved first to one bay then to another. Apparently the first was too lively. I needed to rest.

The team came to see me that morning. The op had gone to plan, and all was well apart from a concern over my fluid balance and cerebral (brain) salts. My mouth was so dry. I was permitted only a sponge on a stick dipped in water to moisten my dry swollen lips, otherwise I was nil by mouth. A morphine pump activated by me pressing a small button gave regular pain relief for the first few days. The morphine was an effective painkiller but made me feel very nauseous. I had double vision on everything to my left, which I'd been warned about. If it didn't resolve, I could have glasses to correct it. Lesley, Elliot, and Sam were my only visitors that day. That's all I wanted and all I could cope with. I made little contribution to the ambience of the ward. I was happy to listen. There were seven beds with me in the middle of the side having only three. Organ transplant patients occupied the beds opposite. Despite feeling pretty awful it was interesting for me, from a medical point of view, to listen to the various doctors talking and to the patients' thoughts and conversations. It was an insight into patient/nursing psychology.

The following day was much the same. My mum and brother, who had made the journey from Lincoln that morning, my boys, Lesley, and Jim came to see me. While they sat around my bed, I was content to close my eyes and listen. As Mum held my hand, I could sense her weeping. Seeing me in such a state hurt her dreadfully. I tried to reassure her.

'I'm doing OK, Mum'.

Desperate for a drink, that evening, I was allowed to take sips of water. During the night, feeling dehydrated and dry, I took a sip. Either the water or the alteration in my head posture stimulated vomiting. The side rails on the bed prevented me leaning over though I knew even that movement was too much for my delicate head. I couldn't turn onto my side either, because of the tilted backrest, so the fluid just flowed onto my chest and bedclothes. Within a few minutes two nurses had come to my rescue.

The team continued to monitor me on their daily morning ward rounds. The drip was removed, painkillers and antibiotics discontinued. Mr Bhatt and Brian, my nurse, removed stitches in my face and packing from up my nose while the stitches in my mouth, being of the dissolving kind, remained in situ. The right side of my nose and cheek were still numb as was my forehead, extending backwards to the top of my head. There was an additional MEDPOR (plastic and

titanium) plate supporting my right eye, which had replaced the bony eye orbit removed. The plate was intentionally put in tight on the basis that following radiotherapy my eye would sink back into its socket. For now my eye was proptosed (forwards of its natural position). Double vision on my left side remained, so much so that I didn't know which of the two tea mugs to go for!

I was up and about by midweek, five days post op, and contributing to the ward banter. What an amazing transition!! Lesley collected me from hospital on 24 October, ten days following my op and perhaps a stone lighter. The ward staff had without exception been fantastic and I thanked them all for their professionalism and care. I was hugely indebted to the skill of Mr Homer and the team who had saved my eye and, more importantly, my life. I said goodbye to Peter who was in the next bed to me. He had laryngeal cancer brought on by excessive alcohol consumption during his navy days. Now his voice box had been removed, communicating was awkward but amusing to both of us, like playing charades with me doing all the guessing. My mum, who revelled in the business of cooking and caring, had been installed at my house and was eagerly awaiting my arrival. She would stay with me for six weeks in what was a symbiotic relationship. She helped me recover as I helped her by walking, reading and setting cognitive tasks.

One of the complications of my op might have been cerebrospinal fluid leaking from my nose that was clear and salty. It was a concern while I was an inpatient and would indicate that the plate and plug supporting my brain might have failed. The first evening home I felt the saltiness on my upper lip, then I felt it again. Not wishing to panic I contacted the ward. Within four hours of leaving, I was heading back to MRI via a lift with Mark.

False alarm. The most likely cause was tears rolling from my right eye, also clear and salty. Having no facial sensation, I hadn't detected the fluid until it reached my lip. Phew!!

I had had a massive operation, survived and was home. Despite pain, numbness, double vision etc things were looking up for me. For Lesley, Mum and my boys their pain and suffering was easing too. The stronger I appeared the less they worried. Keeping life as normal as possible was to become a recurring theme and a coping method for all of us. If I was positive, then those around me could be positive. When I felt well enough to laugh, we all laughed. Elliot and Sam's youthful perspective and vigour with their less complicated lives were a constant stimulus for my recovery and I was pleased my traumas were not impacting on their lives too much.

# Chapter 5 Fitting In

Over the following six weeks, I was seen weekly at The Christie. My recovery was going very well. The double vision was now only at my extreme left and upward. My facial scars were healing nicely, in response to daily massaging with Bio Oil and good nutrition. The bone growth knitting my skull made it feel as if I was developing a horn on my forehead. I had extended my ability to walk up to an hour and I was back on light indoor cycling. Only two weeks post-op I was comfortable driving short distances. I needed to keep an appointment diary for so many visitors spread through the day, one lot in the morning followed by a sleep at lunchtime and another lot during the afternoon. It meant I could enjoy every visit and not be too tired. Any remaining time, I was on the phone to folk interested in my progress. I would introduce Mum as the housekeeper, likening it to Downton Abbey. Quite rightly, she used to complain how much time I had spent chatting each day and pointed to my need to rest and recover. It was a nice time with her, one we'd never have had but not for our respective misfortunes.

An unpleasant odour accompanied me at the time, like sweaty feet. Some days it was more noticeable than others. Lesley was very sensitive to this and commented that I could invade a whole room and certainly a car. In a reversal of normal physiology, the smell was coming from my nose. I made a point of apologising in advance to unsuspecting visitors.

Gordon, 83, who was a father figure to me, was a frequent visitor. I first met Gordon when I worked at a central Manchester private physiotherapy practice in 1987. He never married, had only a few close relatives but had lots of friends and many godchildren. Gordon was an intelligent man who could play the fool when he wanted to. He would have fitted in well with the characters in the Goons. We had a similar sense of humour. Our friendship grew and he became godfather to both the boys and spent at least one week each summer away holidaying with us. Following my parent's divorce my own father became a distant figure and remained like that despite having two sporty grandsons to engage with and love. Gordon more than made up for any deficiency and I was always proud to introduce him as a major figure in my life.

Gordon affectionately referred to me as the 'leader of the Viking ship'. I was physical and mentally strong. He saw me as a decision maker with lots of energy, looking to conquer all before me. Inside, I felt I was still that strong warrior. Outside, I bore the scars of my recent battle.

For my first review at The Christie, 'Gentleman Jack' collected Mum and me. I'd known Jack for twenty-five years, a lovely man and friend of Gordon's. I suspect he was a great dad too. As I walked into the main entrance with my eyebrows not fully grown, my scars visible and the tissues surrounding my eye swollen, I felt I 'fitted in' now. It was obvious who had had the cancer. On each attendance I would have a chat and 'decrusting' with the ENT medical staff. This entailed a long pair of pliers passed via either nostril back into my nasal cavity to remove crusted snot. With or without a topical anaesthetic it was an unpleasant experience performed by one of the registrars, Mr Mani or Mr Homer, using a probe with a light source or head lamp. Lesley always cringed at the procedure which lasted up to thirty minutes each visit. It was worth the intrusion to be able to breathe more easily afterwards. To maintain my clear sinus in between hospital visits, four times daily I would inhale steam and suck a bowl of warm salty water up my nose.

My oral stitches, forming an internal moustache, had not dissolved so needed removing with scissors. That gum area is sensitive anyway, and felt more so following the op. The dozen or more stitches were tight. Threading the hard nose of the scissors under the stitches against my sensitive gums was absolute agony. Mr Mani and Debbie Elliot worked together cutting perhaps three stitches at a time, paused for a minute or two to allow me to compose myself, then resumed.

At a further clinic meeting I was told that my olfactory nerve, which is responsible for smell sensation, had been chopped. My sense of smell had gone forever. Unless the nerve could regrow through a plastic and titanium plate (unlikely!), it wasn't coming back. Unfortunately, having no sense of smell also affected my sense of taste. I was a functional eater, not a cuisine guru. The dumbing down of those senses forever was sad, but not in comparison to saving my eye or my life. It was worth the trade-off and with my poor cooking skills might even be considered preferable! Apparently following this sort of nasal surgery, the sweaty feet smell from my nose was a normal occurrence and nothing to worry about. I was, of course, oblivious to the odour.

It felt as if Mr Homer and his team had given me a second chance in life. With my physiotherapy rehabilitation skills, I was able to maximise my own recovery, making good progress in a relatively short period. Radiotherapy would be my next hurdle, so I was keen to regain my strength before embarking on the next challenge. I had mixed messages regarding radiotherapy. Mr Homer thought it would be plain sailing while others warned of the tiredness, sickness, and depletion of the immune system.

Following a review with the ENT team at The Christie, in early November, I was seen by an oncologist (cancer specialist), Dr Lee. She was a straight-talking Chinese doctor who had very little change of facial expression. She explained that radiotherapy was recommended in my case. The radiation beam would interfere with normal cells and cancer cells as they divided, mopping up any rogue Alien cells that may have escaped the surgery while the normal cells would largely recover in time. I was advised to have thirty fractions (individual sessions). Most breast cancer cases I had come across were fifteen fractions and I knew of no one having more than thirty. I surmised mine was close to maximum. Perhaps it was the same dose just over a longer period depending on the cancer's speed of growth.

'You may have perhaps diminished vision or blindness in your right eye,' said Dr Lee.

The radiotherapy beam had to pass so close to my eyeball and the optic nerve, the information highway that exited the back of the eyeball, that damage might occur.

'We may melt the bridge of your nose. Your pituitary gland, which is situated towards the base and back of the brain, may be affected and cause loss of thyroxine and testosterone levels. You may get cataracts later in life'.

Despite feeling as if I had been punched in the face, I thanked Dr Lee and re-joined Jack who had once again provided us with a lift. Jack and I were both stunned. I was offered a DVD to watch at home which described the radiotherapy treatment, being both informative and reassuring. I had time to think about radiotherapy before my next Christie appointment and consultation with Professor Slevin, the oncologist who featured on the DVD.

To put a positive spin on it, I couldn't imagine why they would save my eye in an operation only to lose it undergoing radiotherapy. Surely it must have been discussed at the MDT meetings, well before my op? I felt I was slowly being stripped of vital senses: now my endocrine (hormone) system. Again, I had no choice. I couldn't let the Alien off the hook now.

### Chapter 6 Radiotherapy

The following week I met Professor Slevin and Dr Lee, with Lesley and Elliot. Nick Slevin had a nice manner and a sense of humour. He explained the pros and cons while we looked at the MR scans, dismissing the prospect of pituitary gland involvement, which was a relief. I felt he was checking to see if I was up to the task.

'We are very fortunate to have a special machine here at The Christie,' said Professor Slevin. 'We can bend the X-ray beam'.

This was great news.

'It will take me several hours and a physicist two days to plan your treatment'.

It was a huge investment of time on just one patient though I thought I was worth it and said so to his amusement. Even the stoic Dr Lee laughed. Consultations like these are hard enough to handle so a bit of humour especially when instigated by the patient must have made their task that little bit easier.

My first radiotherapy session was planned for 2 December. Prior to this I would need a further MR scan and the creation of a face mask to keep me in the exact same position for each radiotherapy session. Radiation to this area would be millimetre sensitive so a blast through the wrong tissue could be devastating. After a lull, the roller coaster was once again picking up speed.

In mid-November, I had both the mask-making and MR scan. The scan would form the template for guiding the X-ray beam through the appropriate tissues. Once again this was with a contrast substance injected to highlight specific tissues during the scan that required a cannula to be inserted into a vein in either my wrist or hand. This needle with a tap could then be connected to a pump in the scanning room to deliver the contrast medium at the desired moment. Inserting that needle takes some skill and practice. I've been told my veins are like drainpipes. On this occasion the radiographer tapped my hand, fiddled, and poked several times until eventually the watching supervisor nodded. Some practitioners were better than others. There was blood all over on this occasion. Following a sip of water and a short pause in the reception area to recover, I was ready to resume.

It's important with radiotherapy that the same tissues get irradiated exactly the same on each occasion. To enable this, permanent small dot tattoos are marked onto the patient's skin as reference points when adjusting the linear accelerator (machine that delivers the high energy X-ray beam) into position. In my case there would be one dot on my central low chest with the remaining landmarks marked up on the mask looking something similar to a crash test dummy.

After lying under the X-ray simulator machine while a radiographer marked my face, I was off to the mould room to form the mask. I was positioned face up on a similar hard plinth, a laser light bisecting my body. It was like a scene from a James Bond film. I lay as still as possible while three technicians lifted a prewarmed sheet of plastic with pre-set clips around its edges, over my face and shoulders. I had only a ping pong ball-sized hole that corresponded to my nostrils, enabling me to breathe while the technicians moulded the plastic into contact with my tissues. The mask allowed me to be positioned in the exact same position day after day while I had the radiotherapy.

I returned to the simulator room where they confirmed it was a good fit and continued preparing the mask with lines and dots. Lying as still as possible, remaining calm and shallow breathing would be my mantra for the next two months if the radiotherapy was to be successful.

My eyebrows had started to regrow, disguising the scars apart from across the bridge of my nose where I had a 'W' appearance. I referred to it as my 'Harry Potter' scar. My right cheek was moderately swollen and my right eye continued to bulge forwards by approximately five millimetres. I had been told my eye would sink back into its socket following the effect radiotherapy would have on the fat that surrounds the eye.

I was reassured when I bumped into a fellow squash player, Chris Lee, a physicist working at Clatterbridge Hospital who prepared patients for radiotherapy in a similar manner to mine. He expanded on the process of bending the X-ray beam which all sounded amazing. Radiotherapy was a daunting process, so any comfort was greatly appreciated.

With radiotherapy looming I felt I could have gone back to work but, to give myself the best chance of recovering, I stayed off on the advice of Mr Mani and Debbie Elliot. My first session was a Friday. I would have sessions at The Christie each weekday for six weeks, apart from Christmas Day. I was in Suite 10. To

create consistency, as far as possible, my sessions would be on the same machine with the same team of predominantly female radiotherapists who were all very kind. Each day they would ask how I was feeling and note any skin changes. The irradiated tissue would include my upper palate, just above my upper lip, nose, right cheek, right eye orbit and the deeper sinus tissues. To get some of the rays out they would have to go through some sensitive tissues including my brain. I gargled daily with sodium bicarbonate to offset potential soreness in my mouth. My moustache bristles disappeared, and I developed burns on my tongue and suffered facial redness. Initially the sickness was eased with the same anti-sickness medication pregnant women take. The fourth and fifth weeks I had to resort to steroids then hung on for the last week knowing momentum and the sight of the finishing line would carry me over.

Sam, my younger son, had just been offered a conditional place at Manchester University to study medicine. It was the best piece of news and brought tears of relief to my eyes. I knew now that if I was not to survive both my sons were on a career path of their choice. Both had expressed an interest in the physiotherapy profession before focusing on medicine. My advice to them was to gain that extra grade at A-level and study medicine if they had the ability. There were more job prospects and the remuneration and opportunities greater. Furthermore, I didn't want them to be physiotherapists just because I was. It was their choice.

Both my lads kept it together completely during these tough times. Thankfully they were very close and had each other for support. Their interest in playing sport had provided a natural distraction from my tribulations. I was very proud that they both chose to go into such a worthwhile profession and one allied to my own. They needed no reminder how important their role would be in the future. For years, our mealtime discussions had focused on my interesting patients, anatomy, physiology and the like. I had been feeding them. Now they were feeding me. How good did that feel!

Statistics state that one in three people will suffer some form of cancer. If I had the cancer for the three of us, that would fulfil the odds leaving Elliot and Sam free. I was happy with that thought but it's never that simple. I was also aware of genetic predisposition in certain cancers. Cancer treatments will also evolve so by the time my boys reach my age, the available treatments will hopefully have advanced enormously giving them a better chance than me.

Each radiotherapy session started with a few pleasantries, a review of any symptoms then confirmation of my personal details, name, address and date of birth. The neck rest that was used originally in the mask making was inserted into a slot in the solid plinth. I laid face up corresponding to the neck rest while the therapists made adjustments to my head, shoulders and legs. My positioning was critical. Once in the desired posture the mask was placed over my face and clipped into position. I couldn't move. Not that I wanted to. I felt like Han Solo from Star Wars, when he was encased in a sheet of carbon, leaving an impression of his face on the surface. I could breathe only through the 'ping pong' hole.

Each occasion the whole plinth was adjusted: up three, across two and back two clicks. The markings on the mask had to match up precisely with the room's laser lights. Two radiotherapists would set me up, double checking the adjustments.

'Okay Graeme? Back in a minute.'

Then a siren would sound signalling the start of treatment. Everyone disappeared from the room though they were able to view me remotely on CCTV. The huge linear accelerator whirred into action with its distinctive hum as the arm changed position, paused and then fired its high energy X-ray beam with a 'zzzzzzzzzzz'. There were about fourteen different phases enabling the machine to alter its angle of attack. The treatment phase took about five minutes. If the radio were playing, I would estimate it would take one and a half musical tracks to complete. The set-up phase took about eight minutes and unclipping two minutes. Once the machine had completed its firing the girls would be in pronto to unclip the mask. It was so good to hear their footsteps as it heralded an end to the claustrophobia. For the first three sessions and weekly thereafter I had modified CT scans to check I was maintaining the identical position (perhaps an extra five minutes in the mask). Professor Slevin always seemed pleased with my progress when he reviewed me in the weekly reaction clinics.

The first day of radiotherapy I was distressed by a bright blue light I could 'see' when the machine was firing. I'd always understood that the beam was invisible. Apparently, this was caused by activation of neurones in my eye or optic nerve when the beam was in such close proximity. Scary!

Each day I would mentally chalk off one day, playing little mind games with myself to make it seem shorter. So... 'This time next week, I'll have one week to go' when, in actual fact, it was two weeks from today. Perhaps a week was a

manageable chunk with a weekend's break in between? I completed the course on Friday 13 January – lucky for me.

I texted my well-wishers: 'Got my nose over the finish line 2day. 30 radiotherapy sessions completed! All told it's been a marathon ordeal, but I believe I'm now cured. I've got my life back and my eyesight (may need further op later this year)!! Onwards and upwards. Progress scan in two months. No more roller coasters for me please!! THANKS 4 being there with me, esp at the beginning. I'll be catching up with u all soon. Much love. XXX'.

I had completed the challenges. I would return to work on 23 January. It made such a difference fighting it together with the support of family and friends. But, while it was great to finish, I didn't feel well enough yet to go out celebrating. I'd lost my appetite, perhaps through radiotherapy-induced nausea. I felt the roller coaster slowing. Ten days recovery would be sufficient and enable me to go back to work in good time for Cheryl to cover the National Squash Championships in mid-February while I covered the practice, which would be less tiring. That sweaty feet smell was unfortunately still around. I asked if it was okay for me to book a holiday.

On a daily basis, while attending for radiotherapy at The Christie, I was conversing with other patients and their relatives. Their stories, and seeing young children arrive for their sessions, sometimes made me feel thankful mine was not worse. I had spare time on my hands during my six weeks of mandatory rest. I was feeling too sick to be at work or to play sport, so I decided to paint a picture for The Christie. I'm not really an artist but I wanted to say thank you to the staff who had helped me. A friend of Lesley's who worked at The Christie passed a photograph of it onto the Arts, Design and Environment Committee for their consideration – I've never heard back from them. I wonder why?!

People often said how brave I was. I never felt that at all. I'd not made any brave decisions. They had all been made for me.

Having had the okay from Mr Homer, I booked with Lesley, her two boys (Josh, twelve, and Elliot, fourteen) and Lesley's mum, Beryl, for a week abroad in July.

# Chapter 7 The Christie

For the past 100 years The Christie has been leading the way in cancer treatment, research and education. More than 40,000 patients each year pass through this hospital, one the foremost cancer centres and the largest single-site in Europe. While it serves approx 3.2 million people locally, it also cares for patient from the rest of the UK that account for 26% of the current case load. Satellite radiotherapy centres in Oldham and Salford have supplemented the Withington site in South Manchester since 2011 and there are 400 or more clinical trials taking place at any one time. New projects include the new £28.5 million Manchester Cancer Research Centre, Maggie's Centre providing non-medical support and creation of the new high energy proton beam therapy service. The Christie holds a string of awards and accolades for innovation and numerous world firsts.

The Christie charity provides enhanced services over and above NHS funding to improve patient and carer experience, facilitate high quality research programmes, encourage, and support innovation in service development and promote and support the educational development of staff.

Richard and Mary Christie were the pioneers of the hospital we know today. They were instrumental in establishing a cancer centre in Stanley House, Oxford Road, Manchester in 1892. The Cancer Pavilion and Home for Incurable (the 'incurables' was deleted from the title very early on) was part-funded by the legacies of wealthy Mancunian inventor Sir Joseph Whitworth and Daniel Proctor. The centre added Christie to its existing name in 1901, in honour of Richard's, first president of the hospital and Mary's contributions.

A decade later, enthusiasm for radium treatment to be made available in Manchester was growing, though it was expensive and somewhat unproven. Following local appeals for money, a small radium institute was created at Manchester Royal Infirmary, the Manchester Radium Institute, later renamed the Holt Radium Institute.

With increasing demand, the Holt Radium Institute and The Christie were running out of space, so in 1931 both moved to their present site in Withington and began joint management. Lord Derby and Lady Elizabeth Holt performed the opening ceremony. The Holt Radium Institute and The Christie formally merged in 1946, two years before it integrated into the newly formed NHS.

During the Second World War, much of the radium was safely stored at the Blue John Mine in Castleton, Derbyshire.

A research department, the Paterson Laboratories (later the Paterson Institute for Cancer Research) were built next to The Christie, in 1962. Its founder, Dr Ralston Paterson put together a team of physicists and clinicians in the 1930s. Paterson and physicist H M Parker developed a method of treating cancerous tissue with radium which was adopted internationally. The protocol became known as the 'Manchester Method'. Indeed, Dr Paterson's wife, Edith, conducting research at her own expense, became world-renowned for her work. Later, the research department acquired funding for the new build.

The Joseph Holt Brewing Company have been very generous benefactors of The Christie since Edward Holt's contributions to form the radium institute at the beginning of the 20th century.

# Chapter 8 2012. Stalling

Though I'd expected to feel very tired throughout radiotherapy I was surprised the tiredness was so persistent. Being younger and fitter than most patients when I started this process, I felt that I should fare better.

On the weekend prior to going back to work, I felt really lethargic. I phoned Cheryl to delay my return to work. On the Sunday, I noticed my elbow, hand and ankle joints were stiff. Viruses can cause these types of reaction. Perhaps the radiotherapy had depleted my immune system?

The following day I was similar, if not worse, with the addition of hundreds of small bruises on my buttocks, legs and arms. Lesley insisted I call the GP. I felt too weak to make it to the surgery so a doctor from my GP surgery came to my home. My blood pressure was extremely high and she thought the rash might be a sign of HSP (Henoch-Schonlein Purpura) an auto-immune condition, though she had never seen it in an adult before. She spoke to Warrington General Hospital, supplied me with a note and off I went with Mark in the early evening to A&E. The roller coaster was picking up pace.

Being admitted to hospital can be a lengthy procedure and this was no exception. By midnight I had agreed with the doctor that I could go home if my urine was clear of protein though she really wanted me to stay. I'd had enough of hospitals and preferred the comfort of my own bed. A deal's a deal. There was protein in my urine, so I thanked Mark as he left.

It was suggested that I'd be seen by a consultant the following day to eliminate any kidney damage and most probably discharged. The following morning, Dr Ooi, whose specialism I'm not sure I ever knew, immediately recognised the HSP signs and symptoms. By now, my joints were very stiff, swollen, and painful and I was feeling dreadful, requiring painkillers. I was told the condition was self-limiting and would eventually go.

HSP is a condition that usually affects children, often the result of an upper respiratory tract infection and is thought to be an abnormal response of the immune system. I stayed in hospital a further day though the day case ward for orthopaedics was totally inappropriate for my condition. There were patients, doctors, surgeons and nurses milling around constantly when I needed some peace and quiet. No one visited me that day. Every likely visitor was either ill or for one reason or another unable to make it, no one to help me with my thoughts or decision-making. My right eye became really painful that night and the surrounding tissues ugly with swelling (orbital cellulitis). As my double vision increased, fearing the loss of my eye, I sensed I was drifting in the wrong direction. Once again, the roller coaster was twisting.

The following morning, I suggested to the medical staff that I transfer to MRI. I spoke to Sarah, Mr Homer's secretary and arranged for Bob, my friend and neighbour, to collect me. But, despite Sarah's efforts, MRI was full, so I had to remain at Warrington. I was immediately transferred to another, more suitable ward, under the care of Mr Jonathan Hobson, the ENT consultant who performed my original operation at Wythenshawe. What a happy coincidence for me that Jonathan had recently moved there. He remembered me and had a good handle on my history. Following a CT scan, a constructive chat and starting on intravenous antibiotics, I felt much more at ease. He said he would speak to Mr Homer.

Bob, now retired, arrived to pick me up following my failed attempt to transfer hospital. He was distressed to see me in this lifeless condition which was at complete odds with the many times we had played so energetically on the same squash team. An experienced father of three, I felt reassured he could fight my corner if I needed help.

Robbie, a fellow squash player and skipper of the over-45s Cheshire squash team, came to see me a couple of times while visiting his dad in the ward above mine. Robbie was often my roommate for twice yearly county matches.

The following day I felt improved and was well enough to visit Mr Palimar, ophthalmologist in clinic. My ability to walk was limited by muscle stiffness brought on by the HSP reaction so I took the wheelchair taxi. Porters are always good to chat to. There's always a Northwest football team, match or signing to discuss. In the clinic there was quite an audience as Mr Halliwell, ophthalmologist, joined Mr Palimar to listen to my history. Having a medical background helped me enormously in these situations. I could rattle off an accurate history with all the medical terminology, making life easier for all. Each day I was seen in the excellent ophthalmology department, as my eye situation settled and the following Monday, I was allowed home, though the bruising and swelling of my legs and arms remained.

Sixteen years previously I'd had a short spell on that same ward. I'd had a headache and lethargy for two days. During the second night I developed a splitting headache, neck stiffness and pain on exposing my eyes to sunlight (photophobia). I thought I might have meningitis, which was subsequently diagnosed. I'd asked my then wife, Sue, to check me for skin bruising, which was clear, then called the GP. A doctor from a local practice took two seconds to make up his mind to call an ambulance. Thirty minutes later, in A&E, I was in too much pain to talk at normal volume, so I whispered my details to save the reverberation in my head. I remember being wheeled to the assessment ward, grateful that the floor layers had created a smooth surface. I had viral meningitis, much less serious at my age than bacterial but with pain I might have associated with my head being run over by a truck. I spent four days as an in-patient, two with my face and eyes covered with a pillowcase. Fortunately, I had no lasting effects and returned to light work the following Monday and recovered fully within a month.

30 January. It was good to be back home again, but the respite didn't last long. I continued to feel sluggish and woke the Friday morning with my eye in a swollen and painful state, once again experiencing marked double vision. I rang Sarah, Mr Homer's secretary, who advised me to make my way to A&E at Manchester Royal Eye Hospital. I phoned Bob for a lift, then packed a few clothes and toiletries while Liz, Bob's wife, kindly tidied up in the kitchen. I was feeling awful. Was it the aftereffects of the radiotherapy, the HSP or an infection somewhere around my eye? It was a mystery.

We parked near to the A&E department and walked the rest, Liz assisting and escorting me as if I was an injured player coming off the sports field. Mr Dhawahir-Scala, who took no time deciding what I should do and where I needed to go, saw us immediately. He left the consulting room for a few minutes, then returned and led us through to the orbital clinic, which fortunately operated on a Friday morning.

Bob, Liz and I sat for a short while before seeing Mr Qureshi and Miss Cook (oculoplastic and orbital surgeons) who arranged a CT scan following their initial investigations. The radiology department was about 400 metres away and the HSP was getting to my legs. My muscles swelled, became painful and stiffened up as I hobbled there and back, making pitiful viewing for Bob who had always regarded me as being pretty fit. What had happened to that fit guy (with limited skill) who ran forever on a squash court? I was admitted. There was no complaint from me, this time I knew I needed help. I collapsed onto the bed in the single-

bedded room with my own en-suite toilet and shower facilities. I was very grateful this time that I would have some peace and quiet. Bob and Liz bought me some fruit and left much happier than the previous occasion in Warrington, confident I would be well looked after. I was prescribed a combination of two antibiotics.

Friday was Mr Homer's operating day and he called in to see me briefly in his theatre scrubs. My symptoms were a worrying development.

'Keep an eye on me please, Mr Homer', I said.

I had eye tests several times, day and night, and the usual blood pressure and temperature observations. Despite having an infection close to the plastic and titanium plate supporting my eye that was responding to antibiotics, no one was confident of the cause. I also received a short course of steroids. I was feeling much better and well enough to be discharged when reviewed by Miss Cook and Mr Qureshi the following Monday. I recall asking Miss Cook if I'd ever be capable of working normally again. Previously in my life I was used to bouncing back from illness. Lurching from one problem to another was new to me.

Mark collected me on his way home from work. Despite continuing the medication for several more days the lethargy persisted, and I felt drained and incapable of doing the simplest of tasks. The HSP bruising had not disappeared. The more I moved, the more the bruising appeared. It was not in my nature and philosophy to sit helplessly with my fingers crossed.

As I would not be returning to work soon, I was reliant on Cheryl to cover the National Squash Championships alone. Colette, who provided some cover when I was off work following my October op, would once again cover the practice for me. Colette trained in the same year as me at Withington and ran a practice a short distance from mine. I was very grateful for their help.

I couldn't yet contemplate going back to my job as a physiotherapist. I didn't feel well enough to expend energy to that degree or commit to regular days. I was suffering with stomach pains too, particularly at night. Was it the HSP, radiation, the medication or something I'd eaten? Before long I had three consecutive days and nights of pain. The oncologists at The Christie had stated previously it was nothing to do with radiation therapy, HSP or a radiotherapy-associated reaction. In fact, the doctor knew very little about HSP, it was so unusual. Sarah tried to admit me to a ward at MRI but there were no beds so I tried to go through the lengthy A&E admittance procedure. I was processed through A&E to the acute surgical ward. I had been on the go for about ten hours and was still sitting in a chair at 10.00 pm. I was extremely tired.

'When will I get a bed'?

'We're still waiting for one to come free', replied the nurse.

In my experience people are rarely discharged during the night and I certainly couldn't sit in that chair until morning. I suggested I go home and return early the following day. Procedure dictated that would not be possible without coming through A&E again. I had to make a decision that would be best for my overall health at this time, so I went home. What a frustrating waste of time and effort!

Later that week the stomach pain intensified. Lesley telephoned Mark, explained the situation and asked that he call round to my home with some Buscopan, a tablet recommended by nurse Philip. When Mark and his wife Debbie arrived, I was in agony. Finding a position to ease the pain was impossible. I returned with Mark and Debbie to their house for the night as there was no way I could manage on my own. I apologised for the choice language as the waves of pain took hold being approximately nine and three quarters on the pain scale.

After an hour or so of writhing in agony the pain subsided. What a relief. Just as I was about to retire to bed I noticed blood in my stools. I rang The Christie's hotline, spoke to a medical advisor and was once again off to A&E, this time at Wythenshawe Hospital.

At 4.00 am, following a thorough examination, blood tests and X-ray I was allowed back to Mark's home. Still, no one understood the origin of my stomach pain.

During the next couple of days I had useful and productive consultations with two GPs, Dr Revell and Dr Rao. The latter arranged for me to be admitted at Warrington Hospital once again, this time on the basis of stomach pains. The orbital cellulitis (eye swelling) didn't want to be left out so reared its ugly head the following day, 2 March.

Dr Chattington, physician, saw me for the HSP and Mr Palimar, ophthalmologist, for the orbital cellulitis. Once again, I was on intravenous antibiotics. I still had the skin bruising on my arms and legs with associated swelling and I was feeling dreadfully ill. There were six guys on the ward, including me. All were confused, apart from me. The nights were awful, broken by either my own intravenous injections or by another patient requiring treatment. Again, I was seen daily for appointments in the ophthalmology department. The excellent ward doctor, Simon Fairweather, arranged an ultrasound scan for my stomach. I was nil by mouth all day only to be told the doctor at the scanning unit wouldn't accept a referral from Simon, only from a consultant. How frustrating! Two days later I had my scan following another day of fasting. The scan results were negative. Good news as far as I was concerned, though I could have done without several days of not eating. To add insult, as I returned to the ward via wheelchair taxi, I mentioned to the porter that I was looking forward to something to eat.

'You know', he said, 'I think one of the nurses might have eaten it.'

And she had. What a laugh. By now the ward's night-time antics were getting to me. Lack of food and sleep and IV injections that were all over the place, when they should have been at eight-hour intervals, were grinding me down. There were two excellent nurses on that ward, Helen and Gemma, who understood my predicament, so I asked them if I could be moved. Later that day, I was relocated to an adjacent bay where, for the next few days I was more comfortable in a bay with four other guys, younger and capable of good conversation and humour.

I described to Sam the events of the previous ward. I've never seen him laugh so much or for so long. I woke one night to see Ken, a fellow patient, stark naked, chatting with the guy in the opposite bed. In came a nurse.

'Come on Ken, back to bed'.

'There's orange juice all over the floor', Ken replied.

'He's fine', said the guy opposite.

'Another night-time commotion and disturbance,' I thought. 'Come on, Ken!'

It wasn't orange juice. Ken had pissed all over the floor. As he returned to his bed he was sure there was going to be a fire, so asked the nurse not to close the ward bay's double glass doors. Ken wouldn't shut up or go back to bed, so he was taken off to the nurse's station for the night. The following morning, I was seated on the edge of my bed eating my breakfast of Weetabix and toast. Ken approached, asking me for a tissue. I handed him the box.

'There you go, Ken.'

'I'd like to spend a penny,' Ken informed me.

'Go back to your bed, Ken. When you see the next nurse, ask,' I said.

'I'd like to spend a penny,' responded Ken.

I repeated my earlier suggestion. Ken turned to walk back with his hospital gown open at the rear. Dangling from his ass was some shitty toilet paper. I deferred eating breakfast whilst I tried to erase that image. Soon, Ken was facing the end of his bed, still asking to spend a penny. He was in side profile to me. Suddenly there was a horizontal projection of shit from the back of his gown. I was definitely on the wrong ward!

I was discharged on 8 March, having had the remaining few days with some good lads and staff on that bay. I was prescribed antibiotics and steroids to continue at home. Charlotte, a kind neighbour, came to pick me up.

There seemed to be little, if any, direct communication between Warrington General and the MRI or The Christie. I specifically asked that when there was some important information from a scan, or difference in opinion, that the information be transmitted to Mr Homer. I even provided his secretary Sarah's telephone number. Perhaps the information was meant to pass through my GPs? Unfortunately, it was frequently up to me to provide all the information. Had I not been medically trained, recalling all the tests, terminology and drug names would have been impossible.

The effects of the HSP were still causing me to feel lethargic. When was I ever going to feel better? I sat on the sofa all day, unable to walk very far and unable to cope with simple everyday tasks. Eye watering prevented me from reading or watching a film and I frequently woke with double vision that prevented me from driving. I couldn't even pack my squash bag, let alone drive there or play. I had degenerated so much. I had seen the light at the end of the tunnel several times only for it to be dimmed. If I couldn't be of any use what was the point of being here? I merely existed. What would I do with myself if I couldn't get out of this hole? I had plenty of painkillers. Not my style. I didn't want such an ending to my life. If I couldn't play a positive role there was no point just hanging on. I felt so low I wanted to die, bring it to an end. It wasn't that I wanted to die but I just couldn't see an alternative way out.

By 25 March I was back at Manchester Royal Eye Hospital, my eye flaring up again. The HSP was still around. Following a consultation with Mr Qureshi I had another CT scan. He asked to keep me in hospital and put me on a combination of antibiotics. The next day he explained there was an infection on the plastic and titanium MEDPOR plate visible on the CT scan. No antibiotics could shift an infection in such a place. I thanked him for his frank honesty. He arranged a meeting between himself, the ophthalmologist Mr Ataullah, Mr Homer and me for the following day. The plate was there for a reason, to support my eye. What would happen to my eye when the plate was removed? There was no possibility of replacing the plate as the surgeons would not want to revisit the site with the addition of scar tissue or to go through irradiated and devitalised tissue. The healing potential of the area had been diminished. I was in a bad place again. Nurse Philip visited me that day. He was brilliant at listening and being there throughout my time. He would text me at weekends to check on my progress and speed things along when he could. I could always rely on Philip. The roller coaster was in full flight once more.

Lesley was with me the following morning when we met in the ophthalmology clinic with the three consultants. I was still feeling awful and was quite happy to sit and listen as the three examined the CT scan and discussed the merits of this and that in medical lingo, some of which needed explaining. Mr Homer turned towards me.

'We'd like to remove the MEDPOR plate from your eye orbit. It could be a bit tricky but it would be best done by chomping at the plate, cutting it into small pieces and removing it via your nostril. It might be difficult to remove the screws. If necessary, we may have to go in just under the eyeball with a small incision, ideally not, as that would be through the irradiated tissues. Hopefully, there will be enough scar tissue built up against the plate to support your eye. If not then your eye would become sunken which is not particularly desirable. The op might even work out for the best!'

My eye had remained proptosed (bulging forwards) since my original operation and radiotherapy. I had confidence in Mr Homer but 'working out for the best' felt like it was stretching it.

Mr Homer's colleague, Mr Bhalla an ENT surgeon, was earmarked to perform the operation. I would continue on the oral antibiotics until then, however, I could only stay on this variety of tablets for four more weeks, after which I would need an alternative drug. No one knew if another combination would work for me. The operation would be as soon as possible.

I'd been off work for five months and there was no immediate prospect of a return. I had no op date and the potential consequences of what I might be like if the op didn't go well were unappealing. Several people had offered me financial support, but I didn't want to get into debt any more than necessary. I decided I'd have to put my lovely home up for sale. I discussed it with the boys who were in agreement with the sale if we were to survive financially. Our home had everything we needed. Over the period of living there we had made it into 'boy haven' with a basketball net, outside table tennis, gym room with weights, punch bag, rowing machine and indoor bike. I might never be able to recreate 'home' again. Within ten days of being on the market I had a buyer willing to pay the asking price. The selling process was underway, and I was still without a date for

the op. The prospect of having to move when I felt so ill was awful and unappealing, but I had no choice. I didn't look for a house because I intended moving in with Lesley for a few months. It would have been awkward in her smaller property for my boys to stay. Three weeks had passed and there was still no sign of an op date despite meeting Mr Bhalla for a pre-op assessment. I was feeling so ill and depressed that Lesley rang Sarah and explained my current state. Within an hour Sarah replied that Mr Homer would do the op himself on Friday 20 April. Without wishing to offend Mr Bhalla, I knew Mr Homer and trusted him. More than anything, this was Mr Homer's original handiwork, and he knew my history better than anyone.

In the meantime, I had an MR scan with contrast at The Christie via the familiar cannula. This was to check for any re-emergence of the Alien. The day before my op I saw Mr Homer. The news from the scan was good. No signs of trouble.

# Chapter 9 Relief

Lesley drove me to MRI for 7.00 am and stayed there all day. I was readied by 10.00am, consent forms signed. I finished up being second last on the list and went down to theatre at 4.30pm, back in the recovery suite for eight-ish. On coming round from the anaesthetic, I was immediately pain-free, my eye felt under less pressure and I could see more easily as my eyeball was no longer constrained by the plate's pressure. There were no scars as the whole procedure was performed through my nostril which wasn't even sore and my eye was sitting in a much more natural position. Mr Homer and his team had worked another miracle. The following day I felt so much better, although I still had the HSP rash. Those symptoms subsided over the ensuing days and weeks. The sweaty feet smell emanating from my nose was gone for the first time, which I considered a significant change, a feeling perhaps not shared by Mr Homer. The transformation was incredible. I returned to work ten days later having already had a spin on my indoor bike. I could sense the roller coaster slowing right down. I started both work and sport gradually, tentatively building up week by week.

By the second week I was regretting ever putting my house up for sale. I really didn't need the stress of a house move. What I did need to do was put my back into work and get PhysioSport back up to speed. Cheryl had done a great job for me in my absence but there is a limit to what one person can do. I arranged a visit to the estate agents, explained the situation and called off the house sale. A decision I would not regret. The agents understood my plight and were very good about the whole affair. I never asked about the purchaser's reaction. As far as I was concerned, it was something I would never have normally reneged on, but this was a special circumstance done for the right reasons. My boys were pleased. The additional upheaval at this time of uncertainty over my health might have been negative. As long as I could earn enough to afford the mortgage repayments, I was happy too.

I returned for a review at The Christie, four weeks post-op, Mr Mani was pleased with my progress on the ENT front. However, my right eye was still watering which caused me similar symptoms to the original onset and I had blurring of my vision with repeated redness and pain. He arranged a referral back to Miss Cook at the Eye Hospital in Manchester.

I kept Dr Revell and Dr Rao informed by letter and thanked them for their input and kind attention during the HSP episodes.

I needed to commit to the holiday I'd planned with Lesley and family for July. Having had so much trouble and many hospital visits I didn't want to leave the country, get into difficulty abroad then mess up their holiday too. I hadn't tested my eye when swimming in chlorinated water and I already found bright sunlight irritating. Regrettably, I decided I'd have to give it a miss, losing my deposit in the process.

My double vision had improved following the removal of the plate. I found playing squash helped to improve my eye movement despite the added disadvantage of wearing protective eyewear which had become mandatory for me. The desire to seek out the fast-moving ball made my eye work harder than it might have otherwise.

# Chapter 10 Tidying Up

Five weeks after the operation I attended an appointment with Miss Cook. Initially, I was seen by her registrar who performed a saline test for my right tear duct, similar to the procedure over a year ago when the fluid welled up before shooting through. The result appeared to be a temporary blockage of the tear duct as per the previous year. Miss Cook repeated the test thirty minutes later when the saline ran through unimpeded. Interesting. I would need a dacrocystogram (tear-duct-o-gram) to further assess my tear duct system.

A month later, neuroradiologist Dr Laitt performed the test by inserting a small tube, linked with a pump containing dye, into the tear duct. As the dye was released, serial X-rays were taken. After that test Dr Laitt decided a CT scan would also be beneficial. He took me the short journey down the corridor to make the arrangements while the dye was still 'active'.

Another month later and I was back to see Miss Cook. I'd already mulled over the various alternatives of how to deal with my possibly non-functioning tear duct. The scan results might influence the decision one way or another. Today I would discover if my eye, which had taken such a hammering for nearly two years, would return to full function or not. Needless to say, it was an important day for me.

Lesley and I arrived at 9.00 am for my appointment, scheduled fifteen minutes later. I had noticed Mr Qureshi and a few other staff, but not Miss Cook. Perhaps she was away? No one had told me so. I was confident Mr Qureshi could deal with my case, as he knew my recent history. A nurse called me through for the obligatory routine eye test. Time was ticking on, however, I was unconcerned as we'd both taken the whole day off, anticipating from experience that I could get shuffled to another clinic for tests, then back again to review the findings.

There were other patients also waiting to be seen in the clinic. Several patients wore frosted lenses or sunglasses to obscure eye problems. Would that be me someday? My visual estimations suggested there were some patients who needed more help than me.

At midday, three hours after my scheduled appointment, I was seen by Ms Tan, a doctor I'd not met previously. I knew from my own job that grasping the essence of a case by reading the notes alone is difficult. My hospital notes were now two inches thick and expanding rapidly while Ms Tan was short of time. We didn't get far before Mr Leatherbarrow, consultant ophthalmologist walked in. I'd never seen him before either, but from his demeanour I knew instantly that he was senior and experienced. I gave both doctors a résumé of my case. He recalled having had discussions with Miss Cook about me previously. Unfortunately, the computer system was playing up so it wasn't possible to review the findings of the tear-duct-o-gram. I had discussed the scan results with Dr Laitt at the time they were taken so relayed the information. Mr Leatherbarrow outlined the various options available.

A dacryocystorhinostomy could be performed, creating a new passage to bypass the old. A silicon rod would be put in place to maintain the channel as it healed then removed at a later date, leaving a patent duct. However, the radiotherapy I'd had could prohibit this as the tissues would have been scarred and maintaining the duct afterwards might be difficult.

In a second option, a permanent Pyrex glass tube known as a Lester Jones Tube (LJT) would be added. This would effectively create a drainpipe which would need careful maintenance for life. In my case, because of the loss of bone and my new eyelid arrangement, this was technically more difficult to fit, and they often need revising as they can easily dislodge. In my case there was no bone to anchor the device.

The third option, Botox injections into the tear gland located just above and to the outer side of the eye, would reduce the flow of tears but would need repeating every few months.

In an adjacent room, arrangements were made to view the inside of my nose with a nasoscope. Mr Leatherbarrow declared it was a 'bomb site'. That was no surprise to me. The larger than normal cavity would make fitting a LJT slightly easier in that respect.

I liked Mr Leatherbarrow and had confidence in him. He informed me that Miss Cook would contact me by letter to take the matter further. In some respects, it had been a positive morning and in others disappointing. I'd arrived with expectations. My preference at this stage was to explore and enhance the existing duct then maintain the channel using a silicon rod as in the first option.

We called by the ENT department to speak to Sarah. She offered to contact Miss Cook. Sarah had been such a great help to me, as had Philip my nurse. Their contribution had not been hands-on, but they helped orchestrate my care. Their willingness to help in any way lifted my spirits so many times and meant so much to me. At a future date I would go on to nominate them both for national excellence awards.

# Chapter 11 Challenges

Feeling improved and more confident in my health following a few months respite from tests and interventions, I was thinking of putting something back into the system that had supported me. When I was diagnosed in August 2011, I was very grateful for the facilities and resources available at The Christie. Fortunately, the hospital was local to me. Over the past 100 years, people had raised money so everyone could benefit, and I was extremely thankful for their efforts. What could I do to make a difference? How could I help those people who would take 'my' appointments in the future?

Furthermore, I was appreciative of the support from Philip my nurse. Everyone in hospital should have a Philip. Macmillan provides information about most types of cancer through the internet and leaflets. It's a scary time when you're in the process of being diagnosed. Having information to hand or an advisor to talk with, on Macmillan's helpline or in hospital, can make a huge difference. Macmillan advisors and nurse are there for patients, relatives and carers. In different ways, both charities had been instrumental in my care.

One day Elliot, my older son came in announcing that he'd like to cycle from Paris to Manchester and row the English Channel en route. What a great idea! This was exciting. Sam and I were on board as were two of Elliot's friends, Jake Shackleford, who I already knew, and George Francke, a fellow medical student. On further delving it was not possible to row from France to England, though we could row in the opposite direction, land for only ten minutes, then row back, which seemed pointless.

Elliot turned his sights to rowing the Irish Sea twice, plus a circular cycle route through England, Wales, Ireland, Northern Ireland and Scotland, returning to England. An unpredictable rough crossing of epic distance would be difficult to schedule if we were tight on time and, moreover, dangerous. It would be costly to secure a support boat and we had no experience of rowing in sea conditions and were unlikely to be able to practise or train other than on an indoor rowing machine.

Discounting the highly ambitious rowing theme, the idea evolved into climbing the Three Peaks – Ben Nevis, Scafell Pike and Snowdon – and cycling between. That idea led on to the Four Peaks, which included Slieve Donard in Northern Ireland. We were back to a circular route, this time including ferry crossings: From the Christie in Manchester to Snowdon, Holyhead, Dublin, Slieve Donard, Belfast, Stranraer, Glasgow, Fort William, Ben Nevis, Dumfries, Scafell Pike and back to The Christie. 850 miles (1370 km) with 4260m hill climbing. We calculated it could take us eleven days. That would be eight days of cycling 105 miles per day, two days climbing and one day crossing the Irish Sea. Providing we started on Thursday 11 July 2013 at The Christie, my usual head and neck clinic day, maybe Mr Homer and Philip could wave us off. The trip was planned to coincide with the Tour de France that was also taking place and scheduled to finish 21 July. We anticipated that watching the Tour highlights each evening would be an inspiration for us and, to add spice to the challenge would try to reach The Christie before the Tour reached the Champs Élysées. That would become our challenge. It was different and I liked that.

Only Jake had experience of 'proper' cycling. Otherwise, none of us were regular cyclists or walkers, we were just five athletic guys. The training would bring us all together on a regular basis and the fitness benefits would help get me back to where I was prior to my diagnosis, if not beyond that level. The challenge mirrored my own trials of the past eighteen months with its ups and down. 'Facing Challenges Together' (FCT) was born.

The two charities, The Christie and Macmillan Cancer Support would benefit in a 50:50 split. People donate for different reasons. We had one local and one national charity. We wanted to appeal to as many people as possible.

This was a once in a lifetime event, for me at least. Our target was to raise  $\pounds 50,000 - a$  tall order during the present austere times. To get anywhere near our target we would require as much publicity as possible. That's when I started writing my story. It was only meant to be a few pages long!! It would describe my journey and its effect on those closest to me. We were all on the roller coaster together. Additionally, by telling my story, perhaps I could provide hope and inspiration to those suffering with me with cancer or similar life-threatening diseases. It might raise awareness of a condition that I and many other people had never been aware of before.

Elliot passed all his medical exams and Sam performed really well in his Alevels to take his place at Manchester Medical School. Under the circumstances it was a fantastic effort by both of them.

### Chapter 12 Coasting Along

Early in September, I saw Mr Homer for my six-week review at The Christie. He performed a decrusting and examination of my sinuses by nasoscope. Everything looked fine. My next review would be in October when we would fix up an MR scan. It sent a chill down my spine. The previous occasion I'd had a scan I felt too ill to really care about the results. Now I did. The following day I saw Miss Cook at the eye hospital.

Miss Cook clarified the options that were available to me regarding the tear duct replacement. Her preference appeared to be the Botox, an opinion shared by Mr Homer the previous day. Following a prolonged discussion over the mechanics of the tear duct and the likely adverse effects of the tumour and radiotherapy it was decided that a silicon rod be inserted along the full length of the existing duct (12mm), left in place for two months then removed. During the same period I would trial the Botox. Hopefully, the tear duct would maintain its lumen when the silicon rod was removed and, meanwhile, I could assess the effect of the Botox. That seemed a reasonable plan and I still had the Lester Jones Tube to fall back on. The procedure could be performed under a local anaesthetic in 4-6 weeks' time.

After only two weeks waiting I was contacted by telephone asking if I could attend for the procedure on Monday 24 September. It was short notice, perhaps because another patient cancelled. I accepted the offer and rearranged the patients I had booked in for that Monday. We arrived at the first floor reception at Manchester Royal Eye Hospital for 7.30am. Following some brief questions and a blood pressure check from the nurse admitting me, I was ready to go. I said my goodbyes to Lesley then walked the short distance with the theatre nurse who was clutching my increasingly large bundle of hospital notes. The mood was relaxed as I lay down on the theatre plinth, the calm atmosphere not reflected in my own increased blood pressure reading. I was slightly apprehensive.

Miss Cook and Neena Peter, an ophthalmologist, performed the procedure. The Botox injection into the lacrimal (tear) gland was first on the agenda and came with a scratch and a sting. Not nice, but over. Two local anaesthetic injections into the nose side of each eyelid followed with similarly unpleasant sensations. Any imminent pain was extinguished as the chemicals took hold. Some mild probing and what I understood to be a fine piece of wire had entered into my nasal cavity. The Mono-Crawford lacrimal stent was threaded through the tunnel, clipped, and delicately restrained in position. The stent would effectively block the tear duct for the next three months while the surrounding tissue healed and when removed, would hopefully leave the channel intact. Let's hope so.

The week before, I had visited my GP over something trivial. Almost as an afterthought he asked how I was doing. This was the first time I'd seen him in nearly two years. I kept it brief as I knew I was on the clock. He offered no questions about the technical or interesting aspects of my unique case, missing what might have been a learning opportunity. His parting comment was that I'd 'had my money's worth' out of the NHS! It struck me what an unnecessary and insensitive comment to make. By leading a healthy lifestyle, I had hoped to avoid cancers and other major diseases, so had in no way contributed to its occurrence. Furthermore, I'd made the most of the opportunities presented to me by the surgical team and returned to work with haste. To be spoken to like some free-rider or malingerer I felt was uncalled for. I was growing tired of their practice.

We'd had a few months to contemplate the logistics and organisation of our bike and climb challenge. We each needed to acquire road bikes, obtain a van for eleven days and select a van driver to support us, work out the best route, look at alternatives for accommodation and create ways to raise funds. The whole task was really quite daunting and potentially quite costly for us, however, we liked a challenge, particularly Elliot and me. Very quickly we could see why people would join an organised fundraising event rather than plan their own as we were.

Within a week of our decision, I had started design of our logo and discussed the creation of our own website with designer Paul Claire from That Skinny Dog design, who I'd met previously but had never done any business with. He very generously produced a fantastic website without charge which would ultimately become integral to our fundraising and communications hub. My logo was converted into computer-compatible language by Elliot's girlfriend, and we were soon to go 'live'. I'd also had useful discussions with representatives from both The Christie and Macmillan regarding fundraising and online donations.

I purchased our first bike, second-hand through eBay, keeping things as economical as possible. I placed a speculative low bid and got it! The bike, which was practically unused, arrived from London via a friend who was travelling up to Manchester. As I was a novice, not knowing quite what frame size was most suitable, it proved to be slightly on the large side for me, but I could ride it for now. We were gradually becoming more acquainted with bike knowledge through reading magazines, the internet and consulting fellow cyclists. There was much more to understand than we'd first appreciated regarding bikes, bike kit and how expensive it all was. Despite not having all the correct kit, we set about training and cycling as efficiently as possible which, for us, meant riding in single file and as close as possible to the rider in front. Sam borrowed a bike from Jake, while Elliot used 'the green machine', my old straight-handlebar stalwart and trustworthy bike I'd had for twenty years. One month later Paul had our website up and running. One of my patients, John, wanted to kick start our campaign and be our first donor, very generously donating £500!

On 30 October, I was back at the eye clinic for a review. Sam, my younger son, was able to come too, so I picked him up on the way to Manchester Eye Hospital. It was an opportunity to chat now he was studying at university and for him to experience hospital 'life'. We were sitting in the waiting room when a lady arrived. Despite there being twenty other available seats in the waiting room she sat next to me. I recognised her. We had spoken in January at The Christie when I was coming to the end of my radiotherapy, and she was about to start hers. At the time I gave her the benefit of my limited knowledge and experience regarding radiotherapy treatment, and some reassurance, wished her well and gave her a hug. Her nose and upper teeth had been removed and a skin flap put in their place. I thought she needed a hug at that time, to know that being disfigured wasn't offputting. After a few minutes of sitting next to each other I asked if she remembered me. She did. It was good to catch up.

Alison's experiences made my operation look like a baby. Listening in to the conversation, Sam had been privy to real patient experiences. I saw Mr Qureshi who was happy with my progress and arranged a review in early January to remove the stent. As we left via the waiting room I once again gave Alison, my fellow sufferer, a hug.

### Chapter 13 Scan Troubles

Later that week, I had my biannual MR scan at The Christie. The cannula went in with no trouble and within an hour I was done. Five days later I had a phone call from Philip, my nurse, to inform me there was something abnormal on the scan and Mr Homer would like to see me the following morning. It was disappointing that it wasn't clear but at least they were quickly onto whatever it was. The roller coaster had just started creeping that bit faster.

The following day, 8 November, Lesley drove me to The Christie. As I checked in at reception my notes were not in the pile but in with the MDT meeting. That meant my case would be discussed by all the disciplines. My heart sank slightly as I recalled that same process a year ago.

Sitting in the waiting area were three other people – a guy, a girl and, perhaps, her mother. It was not immediately obvious who, of the three of them, the patient was. The girl was perhaps early thirties, attractive and slim. Anyone sat there at 9.00 am may well have been an urgent case. As the time approached 10.0 am, when the MDT meeting finished and the consultants, doctors and nurses emerged, I could see her anxiety rise before she started sobbing. Having been in that very same position I was empathic. I knew that fear and trepidation. I too was pondering my future, hoping I'd not be returning to those bad days, further ops and time off work.

Mr Homer, Dr Natalie Lowe – a new face to me – and nurses Debbie Elliot and Philip saw me. Following an inspection of my nose with a nasoscope it was decided that a biopsy was required. The area highlighted on the scan could be either scar tissue or the return of the Alien. The biopsy procedure was relatively pain free once the local anaesthetic took hold, just unpleasant and bloody. With packs of cotton wool stuffed up my nose I left content in the knowledge that all that could be done, had been done. I would learn the results the following Thursday. We just had to keep our fingers crossed.

I had been getting back to normal with regard to work and sport. I could now endure, on occasions, twelve-hour days at my practice. I felt much the same as my former self. On the squash front I was playing for the same club, in the same team and in the same league as I always had. I was still not quite as fit or as sharp as I had been, but I was confident that once the stent was removed it would improve my overall vision. I was sure that by New Year I would be competing normally. I received a call up for the county squash team (over-45s), away at Cambridge, in two weeks' time. This would be a milestone in my recovery and an enjoyable trip with the guys that I don't see on a regular basis.

Elliot acquired his road bike, again via eBay. He was delighted with his beautiful red and black Specialised Allez machine. We were gradually getting kitted out via internet websites, usually when items were on special offer. Elliot, Sam and I were working well as a team doing 30-mile rides, sometimes joined by Jake who was, for now, far too good for us.

I worked the morning of Thursday 15, then met with Lesley at The Christie, where we would always sit in the green chairs. There were four different-coloured chairs in each quarter of the outpatient department enabling the staff to locate patients more easily. Sitting in as much isolation as possible to limit cross-infection, I saw from a short distance, Philip, and Debbie Elliot. They would know by now. I knew it was bad news as neither of them came over, not wishing to be compromised. When the time came, Mr Homer and Philip greeted Lesley and me. In the privacy of the side consulting room, Mr Homer embarked on that difficult task of letting me down gently, which he did kindly while Philip sat with his arm around Lesley who had tears in her eyes. The Alien was indeed back. Not in the same site as before but close by: a satellite of the original. My adversary had fled the initial destruction and ensuing radiotherapy, cleverly evading elimination, and detection until now. I was ready, 'prepared for the worst, hoping for the best'. In truth, you're never prepared. It is beyond normal contemplation.

The Alien was hiding to the right side of my nose. The plan was for a further operation under general anaesthetic in one week's time to investigate the whole area, take further biopsies and commence treatment with a chemotherapy cream. On a positive front, at least the tumour wasn't in the region of my eye and we had seemingly caught it early. Furthermore, I felt I had the best medical team to deal with any eventuality. The previous six months had also allowed me to recover both mentally and physically. I would be in and out on the same day as the op and should require no time off work or sport apart from the county weekend – perhaps? The roller coaster was gathering speed and the track ahead was out of vision for now. I sent a group text to my bunch of well-wishers keeping them informed.

# Chapter 14 Rearranging

7.00 am, Friday 23 November. I arrived at the Elective Treatment Centre on the second floor at the MRI with my unwavering supporter, Lesley. She had been there for all my operations. It certainly took the potential strain off both Elliot and Sam and my friends. The lads were able to continue their studies in the knowledge someone was with me. They knew she would be in touch as soon as there was any news and when I came round from the anaesthetic. When the boys came to visit she would immediately move to allow them to be by my side. Through my own adversity the boys and Lesley had become closer in their shared experiences and feelings, and I knew if anything happened to me, Lesley would continue to support them in my absence.

By 8.30am, I had changed into my operation gown and had the usual health checks. My blood pressure was a bit high perhaps, an adrenaline response that would increase as I got closer to the theatre doors. Unusually, it took the anaesthetist four attempts to get a cannula in my cold and clammy hand. I was out just before 9.00am. Mr Homer took biopsies from inside my sinus, around my right eye and from outside my nose. By 11.30am I was back on the day ward. In recovery I'd woken to blood being wiped from my face and feeling cold. Mr Homer came to see me mid-afternoon, as did Philip. Mr Homer had changed his mind about the chemotherapy cream and was in favour of removing the tumour.

I decided not to travel with the squash team to the Cambridge County match the following day as the op had depleted me. I'd had a sore throat all week and needed to recover for the next stage of my treatment. They had narrow wins and were through to the national finals. Well done guys!

It was a long wait until the following Thursday when I would get the biopsy results. With each day the tension grew, the roller coaster roaring inside me. Would I live or die? How would I die? What if there were multiple tumour sites? Could I continue to work and pay my mortgage? Would I have to contemplate selling my home again? I know it sounds trivial but to compound the whole affair my boiler at home was playing up. Small things become magnified when the mind is already at melting point. It took a fortnight and three engineers to fix that fault.

During the week I called in to see Roz and Brian, the Trojan. Brian was having battles of his own. We were, as they say, a 'right pair'. The people who helped me through those previous trials and traumas were there for me once again.

Thursday morning, 29 November, at The Christie's head and neck clinic would be another defining day. The clinic was unusually quiet. In what had become 'our' side room, Lesley and I waited for the posse of Mr Homer, Dr Natalie Lowe and Philip to arrive. Mr Homer began in his professional, calm and reassuring manner.

'The good news is that there are no other known areas affected by the tumour as far as could be detected'.

The only affected area in the right nose region would require removal from the inside out, breaking through the skin on the right side while taking frozen samples for pathology testing as the area undergoes resection. As a second dose of radiotherapy to the same area was contraindicated, there was no chance of mopping up afterwards. To ensure every tumour cell was removed, a slightly larger clear margin was indicated. There could be no half measures. The operation, scheduled for Monday, 10 December, would take between two and three hours. I would need a couple of weeks off work and sport if it all went well and, more importantly, I'd be rid of the Alien. Nose reconstruction could be as early as January with Mr Blackburn, maxillofacial surgeon. The precise technique for reconstruction would not be decided upon until the first operation had taken place but the various options sounded plausible. Unfortunately, the tear duct stent for which I had so much hope had been dislodged during the procedure. When we'd concluded the details, I started to fill up with tears as the emotions of the last three weeks spilled out. Lesley was there with a hug. She knew more than anyone the impact the Alien had on my life.

I felt I could sustain two more operations. Could it be any worse than a rugby stud injury or a dog bite to the nose? Yes, it could. I was confident Mr Homer and his team would pull me through two more hurdles. I required photographs, courtesy of medical illustration, prior to the surgery so a temporary prosthetic device could be created that matched my tissues, to disguise the hole. That way, I could more comfortably return to work. The bike ride was still on!

We saw a nice chap at medical illustration who took no time in obtaining the desired photos with twelve simultaneous camera shots from different angles. The impressive result was a 3D computer screen image that could be rotated and viewed from any angle. The clarity was a bit too good for my own liking! Measurements could be taken between any two points on screen.

At this stage I would try and make light of the situation by suggesting I could choose to have my nose recreated like Daniel Craig's. In reality, I'd always been happy with my nose until my big operation and radiotherapy over a year ago. As it had lost some of its sharpness, people frequently remarked that it looked like a boxer's nose. It was a shame but in the whole scheme of things I could cope with that. Perhaps the reconstruction would be an opportunity for redress.

I called round to see Brian the Trojan. Following a lobectomy of his right lung he had developed an infection and a new tumour site in his pelvis. He would later go on to be admitted to The Christie to clear the lung infection and start a new course of twenty radiotherapy sessions that would conclude between Christmas and New Year. The perspective and knowledge Brian and Roz offered was always reassuring. Brian was the Trojan and I was his protégé.

I carried on my life as normal up to the operation day. Lesley and I took the familiar trip to MRI, registering at 7.00am on 10 December, at the Elective Treatment Centre. The registrar, Dr Jonathan Beinstein, explained the procedure and obtained my signed consent. He had examined and treated me previously when conducting routine ENT checks at The Christie and MRI. His was a very pleasant and reassuring presence, perhaps contributing to more calmness for this operation than the previous five but, despite that, I felt the roller coaster was gathering speed on some tricky track.

Mr Homer also came to reassure me, prior to going down. By midday, I was anaesthetised once more, returning to the short stay ward at 5.30ish. The procedure that took four and half hours had included some time spent analysing cells for the clear margin. I had moderate pain on coming round from the anaesthetic, which settled quickly to the point that I could manage with paracetamol alone. I had a plastic moulded T-shaped splint taped to my face, the horizontal bit of the 'T' above my eyes, with the vertical bit covering my nose obscuring the full extent of the operation. A small plastic 'trumpet' stitched to my nasal septum maintained the shape of my right nostril. I had a peaceful night and was discharged the following day pretty much pain free. I had a visit from Philip and Sarah, my two guardian angels, before leaving. Despite feeling pretty good, I took full advantage of resting at home that week. Arrangements were made for review in clinic the following Friday.

# Chapter 15 'Get In The Hole!'

Bob, my neighbour, took me to the review appointment at the MRI ENT clinic where Philip greeted me and proceeded to carefully remove my T-splint. Concerned about any possible adverse reaction to my new appearance he offered to cover the room mirror. My thoughts were that the damage had already been done so I'd have to get used to it sooner or later. Lee, the registrar, removed the latticework of stitches retaining the dressing and the trumpet. I chose not to have strong pain relief. There were three really painful episodes and a few choice words before it was all over. I went to the mirror. The hole was much bigger than I'd anticipated or prepared for. The whole triangle forming the right side of my nose from the nostril to my eye had gone. The void was hideous. Looking into the inside of my head was grotesque: a slimy cave with lots of small pockets. It was a view I would never have harmony with or become accustomed to.

The following day, both my eyes and face were noticeably very swollen. It was the sort of reaction I had expected immediately following the op but not necessarily now. Mr Homer and Philip saw me in clinic the following Monday, four days later. Everything was looking fine. We were waiting on bone biopsy results that would be available in two weeks. It took longer to test bone than soft tissue samples as the bone had to be dissolved before a test could commence. Mr Homer surveyed the scene with the reconstruction in mind. As the hole was too large to be covered with skin alone it would require a supporting structure for strength: cartilage. That tissue could be donated from my own ribs, which would be a painful process or harvested from a cadaver (dead person). Frankly, I'd had enough of operations and pain so the chance of avoiding that and recycling someone else's cartilage was more appealing. The only downside to having radiated cadaver cartilage was that it would be more brittle than my own. It was proposed that the cartilage would be inserted into my forearm to allow my tissues to mesh with it, then three to four weeks later to transplant the whole lot, skin, cartilage, and blood vessels to my face. In the meantime, I would have a prosthetic made which would sit in the hole and be of similar appearance and skin tone to my surrounding tissue.

Disregarding medical advice, one week following my op, I returned to work with a dressing over the area. If I could work, I would do, provided it was safe for my patients and me. Cheryl would act as my safety net if I couldn't cope. It was important to me that I got back to work and sport as quickly as possible. Previously I had climbed a mountain to get back after a six-month lay-off. I couldn't bear the thought of that again. Bizarrely, the HSP skin reaction had returned to my lower legs since the biopsy operation. I was monitoring the situation closely as I always associated the HSP symptoms with an infection or irritation in my sinus while Mr Homer preferred to link it to stress. Without being arrogant, I knew my own body. If it were stress, I would have had it permanently for the last eighteen months! We arranged to meet again at Christies in three days' time when I would see Mr Homer and meet Mr Blackburn the maxillofacial surgeon regarding the reconstruction.

Unfortunately, Mr Blackburn got held up with an operation the day of our proposed meeting and news of the prosthesis wasn't good either. The prosthetist that had been earmarked for me had gone off work for some unknown reason. In clinic I had the hideous void decrusted using long-nosed forceps. The sense of vulnerability on passing a piece of sharp cold metal through a sensitive healing aperture made my palms sweat. Like the scene from 'Marathon Man' when the interrogator has a sharp instrument in Dustin Hoffman's mouth ready to create excruciating pain with the slightest prod. Lesley couldn't watch as my body tensed in anticipation.

With his attention on the reconstruction, Mr Homer further described how they would remove some bone from the back of my skull to replenish some of the nasal bone that had gone. Furthermore, I would need a 3D CT scan.

Prior to October 2010, I'd had few medical issues so I'd never had much interaction with my GPs. I never thought that procuring a flu jab for Mum while she was looking after me the previous year or obtaining repeat dressings for my nose would have been so difficult. Throughout the past fifteen months there had been no contact from that practice to check my progress or to see if I needed any help or advice. I felt there were too many episodes at my GP surgery when there was a culture of 'can't do' rather than 'can do'. When you're in need of help and feeling fatigued the last thing you need is hassle over trivial issues, so I took the decision to transfer to a new practice.

The following week during the Christmas and New Year period, Philip and Mr Loughran, a colleague of Mr Homer who clearly knew my history, saw me at

The Christie. Unfortunately, there was still no meeting with Mr Blackburn, no movement on the prosthetic side, no results from the bone biopsies or date for the CT scan. The delays were frustrating. My next two operations would now be running into February, which conflicted with my commitment over physiotherapy coverage of the National Squash Championships and my ability to be fit and ready to represent Cheshire in the County Finals in March. Whilst they might seem trivial in the whole scheme of things, keeping to my normal structure was my own way of not giving in. I couldn't allow the Alien to sense a chink in my armour.

I emailed Sarah who was straight on the case. Hopefully, I would see some progress before my next clinic appointment on 3 January 2013.

Christmas and New Year were once again muted affairs and their significance had diminished in the light of my health issues. I needed to rest following the previous operation as it had taken it out of me physically. In the main I was mentally strong, however, even I would fall into the occasional low. I could recognise the gradual change in mood. I rationalised it as being like a spring – I would have to go down before I could come up. It would last for several days then it would be over. On occasions I could be on the border mentally. By talking up my situation when asked I could convince myself things were better than perhaps they were. Reflecting off people in this way generated a more positive response from those around me, similar to 'if you smile the world smiles with you'.

Sarah and Philip had pressed for the 3D CT scan, from which, the images were used to create an acrylic life size model of my skull. The scan date was now only a few days ahead. The following day I was at The Christie to see Mr Blackburn and his colleague Mr Musgrove, a fellow maxillofacial surgeon. Though it was our first face-to-face meeting they knew my history from previous MDT meetings.

They viewed the aperture in my nose and assessed the various possibilities, which they discussed openly in front of me. Transplanting rib and cartilage to wrist then to nose with skin from my forehead seemed their favoured choice. After a good meeting, lasting 30 minutes, we decided to come back in two weeks when we would all have had chance to mull over the options and, furthermore, the acrylic model would be available. The other good news was that, as far as they could detect, I was clear of cancer cells on all clear margin biopsy samples

taken during the op on 10 December. I was obviously pleased to hear that news, but it had to be taken in the context of being told as much twice before when it was ultimately proven otherwise. Only the passage of time would truly convince me I was clear.

I was looking at three or four more ops over the next six months. Additionally, I'd lost substantial training time for the bike ride the previous month, recovering from my op. There was a realisation by me that I wouldn't be prepared sufficiently for the bike ride scheduled for July. It was an easy decision to make to postpone the ride but not easy to admit defeat, however, this was the new me, making sensible realistic decisions. Following discussions with my boys, we postponed the ride until the following year when we would all be stronger. Disappointing, but it had to be taken in the whole context of what was happening.

Sarah and Philip had succeeded in making all the recent arrangements for me. The roller coaster was travelling quickly but on straight smooth track.

The following week I attended Whiston Hospital, near Liverpool, for my prosthetic assessment. As Lesley and I walked the link bridge from the car park to the entrance we joked about this being a real day out for us, visiting a new hospital! I met prosthetist Jane McPhail and her younger colleague Nina, who took a mould of my right nasal region from which a wax prototype would be formed. Following a short discussion, we viewed the pre and post-prosthetic photos of several patients who'd had had similar issues to my own. The transformations with the prosthetics were impressive.

Sam bought his road bike during the post-Christmas sales. Similar to Elliot's, a Specialised Roubaix in red and white. We were starting to look vaguely like proper cyclists! We had converted from using normal pedals to using cleats. The cleat allows special cycling shoes to fix to the pedal, which is more efficient while riding, but when you stop, you do have to remember to disengage from the pedal with a flick of the foot before being able to put a foot to the floor. In those early days, we all had minor falls through not disengaging early enough! During the winter months I conducted most of my cycle training indoors. It was safer, more comfortable and cleaner. The reality of the enormous effort required to cycle 105 miles per day had really sunk in.

I had been treating a patient whose father raced and built bikes. He was looking to offload one he'd been using that he built himself. He was approximately my height so I knew more or less that it would suit my stature. I bought this smaller frame bike then sold on eBay, the larger framed cycle I had been using.

A fortnight on from our initial meeting, I returned to see Mr Blackburn and Mr Musgrove plus Mr Homer, Mr Barclay and two registrars. A new procedure was proposed to insert donor cartilage and skin under my forehead skin above my left eyebrow. This would be left to take for four weeks. A strip including cartilage, additional skin and forehead skin would then be formed and dangled from my forehead to the right side of my nose, leaving one end of the pedicle flap still attached to my forehead to provide a sufficient blood supply.

A further four weeks after the creation of the pedicle, providing the graft had taken, the nasal area would be severed from the pedicle blood supply like a baby's umbilical cord at birth, and the remaining skin flap returned to my forehead. Any shortfall of skin returning to my forehead would be taken via skin graft from elsewhere on my body. For me this seemed like a better, more logical solution. The sensation in my forehead had not returned to normal following my big operation a year earlier and it spared my ribs and wrist from surgery. We arranged to meet again in three weeks. That same day I was back at Whiston, where Nina and Gina tested the wax prototype and prepared the colour match.

The prosthetic was ready to collect by 24 January. It was a relief to have something bespoke rather than the white-coloured dressings I'd used daily for the previous six weeks. As it was more solid and a closer fit, it helped in the formation of vocal resonance and prevented jets of air across the surface of my eye, which had been both irritating and drying. It even appeared to help with my vision, by perhaps providing support for my eye orbit and, in turn, the muscles attached to it. The girls at Whiston were not quite as happy with the colour and fit so I needed to return the following week for the final fitting.

The completed version of the prosthesis was both a better colour match and a better seal against my skin. I was happy and I knew this was to be only a temporary measure. The mould was so realistic. From a few metres away people didn't detect a problem.

I was back at The Christie to meet with Mr Homer on 7 February to discuss the proposed nasal reconstruction. This time there was no new variation to the scheme, which pleased me. As my case was no longer urgent I would have to slip into a slot on the operation theatre list when one became available and Mr Homer had several big cases coming up which didn't bode well. The following day I had a call from Sarah. They had scheduled me for the following Friday. The procedure to insert the three donor cartilage pieces in pockets between the skin and underlying tissues above my left eye would take approximately one hour.

I'd not felt well all week but managed to hold off whatever was bugging me. It was the usual procedure at 7.00am, mid-February, in the Elective Treatment Centre. By 8.30am I was in the anaesthetic room and back on the ward by 11.00am. The procedure had taken two hours and felt no more than sore. The incisions formed a letterbox shape of three sides excluding one short side that provided the blood supply. Its borders, retained by approximately twenty stitches, were covered and protected with bandaging. I'd been informed previously that the cartilage came from death row in America. I felt no ethical or moral objections to taking it. To honour my newly acquired cartilage, I would use a few Americanisms like 'it's a mighty fine day', 'have a nice day' and 'get in the hole!' – I liked Americans I'd met, so I felt pleased with the association. The district nurses removed the stitches the following week.

Mr Homer reviewed the situation shortly afterwards and set a new date, 15 March for the next stage. During the interval between operations, I returned to playing squash and cycling, which kept me physically fit, strong and sane. Furthermore, any natural increase in blood flow to my forehead skin caused by sweating would benefit the healing process. I did unfortunately acquire a small skin infection covering the tip of the cartilage but it was not sufficiently problematic to stall the next operation taking place.

I was second down to the theatre on 15 March for the two-and-a-half-hour next phase operation. The forehead skin flap was left in contact over my right eye via a short side, while the other three sides of the 'letterbox' were dropped down to be attached to the lower half of the hole margin in the right side of my nose. The flap would continue to have a blood supply from my forehead but would begin meshing with the circulation from my nose region. The long sides of skin in between my nose and forehead were rolled until their edges were opposed then sewn forming a sausage shape, the pedicle, while the opposite short side was sewn to the rim margin. This overlapped the inside corner of my right eye, mildly restricting my vision. The open area of skin on my forehead needed cover and protection. A full thickness skin graft was taken from my abdomen, leaving a nine-inch incision across my tummy. Some people may have been happy with the bonus tummy tuck but for me it wasn't really helpful other than to protect my forehead. I returned to the ward, my face covered in fresh blood. As I was wheeled past the visitors waiting area I caught a glimpse of Lesley.

'I'm here babe', I shouted.

It was reassuring to have that person who really cares by my side, to say a few words and squeeze my hand. I could detect from Lesley's voice that she was shocked. I knew I would look weird and I did. Surprisingly I had little pain. As Lesley left to go home Elliot and his girlfriend Debora joined me. Mr Homer checked over me at the end of his operation schedule, allowing me home that night, which I always found preferable. Elliot drove me the short distance south to Lesley's home. Having had eight operations at this stage I was familiar with the discharge routine. Any medication would always take a minimum of five hours to appear. On this occasion I agreed to call back the following morning to collect some prescribed antibiotics. I always felt that if that delay, however long, could be speeded up for each patient's discharge from hospital, how much 'bed time' that alone could save the NHS.

Four days later, Mr Homer was happy that the graft had taken, setting up the date for the next stage for 26 April, when the pedicle would be severed. The skin nearest my nose would be used to cover and attach to the remaining upper rim of the hole while the rest of the flap would be returned to my forehead, wasting some of the stomach graft.

I returned to work on the Monday following the Friday op. I deliberately took fewer appointments that whole week to allow me to recover and Lesley ferried me around to avoid the need to drive and generally took care of me. I looked very strange with my skin sausage extending from my forehead to my nose. Some, females in particular, took amusement in that it looked similar to a penis while several people remarked that I looked like elephant man or would be fine for a Star Wars or Dr Who scene. Fortunately, I wasn't unduly offended, especially as I knew this was to be only a temporary feature. The roller coaster was running smoothly at this stage.

Elliot and Sam cycled together with George in a University of Manchester 85-mile cycle event. It helped give them a hold on the distance and nutritional needs, and a glimpse of inner city cycling punctuated by multiple red traffic lights and heavy traffic. These were essential tests if we were to prepare and ultimately negotiate our challenge with success.

## Chapter 16 2013. Snakes And Ladders

I felt well enough to go to Stourbridge with the 'lads' who had made it through to the Inter-Counties National Squash Finals. There was no way I could play, even if selected. Robbie had always said he would take me either way which left me free to perform physio duties, not just for Cheshire but for the other county players too if needed. I looked a right state with my head bandaging wrapped and taped around my head, worn like a turban with the 'penis' poking out from below. The squash-playing guys and girls were either kind, discreet or took no notice, carrying on as normal. It was exactly as I would want it. Unfortunately, having won through in the semi-finals on Saturday, we went on to lose narrowly in the final but it was nonetheless a great weekend with lots of laughter. I didn't feel at all envious that they were playing while I was not. I simply hoped my time would come again and it gave me renewed determination to recover my fitness.

Ten days post-op and my sixty or so stitches and staples were due to come out. Removal of the staples from my stomach incision, which was sore from rubbing against my trouser belt line, was absolute agony. Otherwise, the grafts were looking fine, and Mr Homer seemed happy. The area would need a cleanup, redressing and review in two weeks. I could return to sport but because of the potential contact of my grafts with protective glasses or i-Mask (visor for eye protection) I wasn't able to play squash or tolerate a helmet for cycling outside. I was content with cycling on the indoor bike and solo squash practice for a few weeks to avoid any complications.

We had 26 April pencilled in for my next operation, to divide the pedicle, finish off my nose and return to my forehead the remainder of the 'sausage' when unwrapped.

My life was like a game of snakes and ladders. The malignant diagnosis at Wythenshawe Hospital in August 2011, then again following my first anniversary scans at The Christie in November 2012, were representative of the longest snakes. The ladders were the operations and a single square equated to about a month of my life. I felt as if I was closing in on the top line of the board, treading carefully in an attempt to reach the ultimate destination, the final square beyond the setbacks. Home and dry. Safe. The winner.

#### Chapter 17 Fighting Chance

In mid-April, I heard news that Mr Homer was off work indefinitely. I wasn't told the reason and I didn't ask as it was not my privilege. Having seen him on so many occasions, we had developed a good relationship which was relaxed and jovial – so much so, when he learned of our bike challenge, being a fit man, he had volunteered to cycle a leg with us.

The 'sausage' situation was by now really grinding me down. The extra stimulation of my face caused me to lose sleep and exposure of my right eye to bright sunlight and cold winds was painful and discomforting. On 21 April, I sent an email to Sarah.

'Morning Sarah. I don't know why Mr H is away indefinitely but if he (or any member of his family) is ill or injured I do wish him/them a speedy recovery.

'With regard to my next operation, Mr Homer did think this could be my final operation involving the attachment of the cartilage forming the bridge of my nose to my skull bone. He said he could do this by screw but because the bone had thinned through radiotherapy, he could more simply use a stitch. I'm sure he suggested the operation would take about one hour and I'm guessing I would be able to go home that evening.

'At the outset, this operation was going to be between 3-5 weeks following my 15 March operation. Having reviewed me in clinic, Mr Homer was in favour of four weeks, which would imply 12 April. Only because of lack of operating space has it been delayed until now.

'Over the past two weeks I am noticing that my nostrils, which were level, are being pulled up on the right-hand side either from tension via the pedicle or scar tissue contracture.

'From the outset, we knew my right eye would be irritated by exhaled moist air passing across my eyeball. My eye has endured a huge insult over the last two and half years and is once again complaining, more so this past ten days. I have a constant pain at the back of my eyeball. I require painkillers now that I didn't two weeks ago and I find waking through the night the most dreadful part of the whole day. It reminds me of the same pain during my 'bad old days' prior to waking with full-blown orbital cellulitis. During the day I find comfort in keeping my eyes closed and application of a heat pack.

'Whereas I was keen to cycle on my indoor bike I now don't feel I have enough energy.

'I am degenerating very quickly. Even Friday's potential operation date feels too far away. Please, please, please could someone help me otherwise I am about to lose some ground or require another operation to counter the effects of leaving this one too long.

'Unfortunately, Lesley's son has had a stomach and sickness bug, followed by Lesley herself. Consequently, I have had no contact with them and have little assistance outside of work. I'm continuing to work because I have to. Fortunately, I can do some of it with my eyes closed.

'Please let Philip have sight of this email. I didn't want to bother him while he was off on leave. I know you will both try very hard to get things sorted for me and I do thank you very much for all your help. You've both been pillars of support to me. Let's hope Mr H is back in the nick of time, otherwise, I have seen Mr Blackburn on several occasions or I'm happy to go with whoever wants to take me on. I can't be that complex!!

'Thanks Sarah as always. Graeme.'

The roller coaster was gearing up once more. I was holding my breath in anticipation of a torrid week ahead.

On 23 April, news broke in the Daily Mail that Mr Homer and an anaesthetist had been in a scuffle outside the operating theatres at MRI and both had been asked to stay away from the hospital until further notice. This was definitely not the news I wanted to hear. Mr Homer had saved my life and my eye and whilst I trusted his judgement and would prefer him to complete the job I was desperately uncomfortable, enough to need someone else to complete the task. I telephoned both Philip and Sarah asking if 'Prince Naseem' (the ex-professional boxer) was in. The reality was not quite as funny when I was told Mr Homer and the anaesthetist were both suspended until further notice. Philip and Sarah worked hard that day to get my operation rescheduled with another consultant for two days hence, one who I had met previously and had assisted with my operations. I was disappointed that Mr Homer would not be the one to finish my reconstruction, however, I knew Sateesh. Who would have believed it? What else was there to go wrong? The roller coaster twisted down the track. Thursday, 25 April: my ninth operation. As I wasn't being admitted until lunch time I ate some breakfast at 6.00 am then travelled to work to see several of my own patients before meeting Sateesh at The Christie by 10.00am. He conducted a short examination and went through the pros and cons of this next operation. Not that I had much choice in the matter, I had a sausage on my face.

On my visit to The Christie, I saw several people I'd not seen in a while. Lynne on reception always made a point of conversing. Debbie Elliot, Dr Natalie Lowe and Lolita – one of the nurses from MRI who was working on ward 9 at the time of my second operation – couldn't believe I'd remembered her name. I always made it my business to remember people's names. It made people feel important because they were important. It didn't matter to me if they were a nurse, a porter or consultant. They were all important to me.

By 12.30 pm, I had been admitted to the MRI in the usual fashion, greeted by the anaesthetist, Dr Wadsworth and a student doctor. I was ready to go down to theatre, always Theatre Suite 9. This was a 'David Beckham Day', when everything went well, and I was made to feel like a superstar. I was back on the day ward by 5.00 pm. The operation had gone well. Despite feeling sore and painful immediately afterwards, which lessened quickly with some morphine medication, I was allowed home by 8.00pm. I just made it home before throwing up, possibly the effect of the morphine or having had some breakfast, a deviation from my usual routine. We had the familiar problem of getting discharge medications – this time twenty-four hours later!

The following day, though the surrounds of my eyes and nose were predictably swollen, I had no pain and felt much more comfortable without the tension and restriction of the pedicle. A turban-style bandage covered my forehead, applying pressure where the remainder of the pedicle skin had been returned. Over several months the operation sites would settle down though there remained the possibility of some tidying-up work in the future. Was this the start of my new life?

# Chapter 18 Hope

I woke the next morning, my eyes barely able to open through swollen eyelids. Despite that I felt almost euphoric at the prospects ahead. The threat to my life, my eye, my livelihood, my family, and my sport had been lifted. This was the start of my new life, and I would go out and make the most of it. The bike challenge was back on track and the roller coaster the calmest mode it had been in for the past eighteen months.

The following week, Sateesh reviewed me in the plastics department. I had noticed a small jet of air starting to escape from the skin union close to the corner of my eye. I didn't share Sateesh's confidence when he suggested this would unite in time. Within a few days the gap was noticeably wider when Philip removed the remaining stitches.

I had a couple of sessions on the squash court and a 70-mile bike ride the following weekend. My boys cut me no slack on the bike ride apart from allowing me to ride at the back of the threesome peloton, protected from the wind. Despite my thighs enduring four and a half hours cycling, I was surprised how they held up and how normal they felt the next day! To get my body accustomed to daily cycling, I began cycling the 32-mile return journey to work.

My new GP practice was really looking after me. Three separate GPs had telephoned me to discuss results of tests and progress and they wanted to see me in surgery. The philosophy of proactive care and communication and cooperation with MRI and The Christie was a welcome change.

I was reviewed at Mr Homer's clinic at The Christie, on 9 May. At this point I was unsure whether he had been reinstated following his hearing at MRI earlier in the week. Thankfully, he had. Prior to this latest operation Mr Homer had intimated this could be my last operation so I was very disappointed that he began by saying that it might not be possible to close the gap at all owing to the narrowness of a bridge of skin between my eye and the transplanted tissues. After all the preparation and hope, leaving a gap would be unthinkable for me. The finishing line had gone from January to April and now over the horizon

altogether. It was decided I should meet with Mr Homer and Miss Cook to decide the way forward.

Lesley and I met the two consultants and Philip the following Tuesday. Despite being overrun with patients, Miss Cook gave my eye and surrounding orbit a thorough examination as she discussed with Mr Homer the merits of this and that. As mine was a unique case, she wanted to put it out to all eminent oculoplastic and orbital surgeons throughout the country for their views. That morning, in the Medical Illustration department, I had photos taken for later distribution. There was no immediate urgency to close the gap.

In the meantime, I was able to work, keep fit and enjoy occasional evenings out despite my slightly unusual nasal carbuncle. I felt the roller coaster had ground to a crawl. I had been battling for over two and a half years and I hadn't taken a day off work other than for operations. I had been waiting to cross that finishing line so that I could arrange a nice trip away with Lesley and a celebratory meal out with my pals, Mark and Jim, and their partners. That evening date had been proposed so many times then dashed.

My neighbour, Brian the Trojan had been admitted to MRI himself. He had been struggling to get over pneumonia. Roz kept me updated with his progress, which had been encouraging. Another long-standing friend, Belinda, had also been visiting The Christie with skin cancer. This was one of those defining weeks for her when she would learn the results of recent scans. In those consultations, lasting only a few minutes, a person's expectations about their life and those close to them can change so cruelly and dramatically. During my own consultations I would sometimes struggle to decipher the information as my brain seemingly wanted to block out what it didn't want to hear. Too much to comprehend. A few days allows the information to sink in and to assess the effect it will have, coming to terms with a new life and likely diminished expectations. Despite it all, I continued to believe in fate. Destiny is slightly different. I felt I could have an effect on that.

Over the next month, I was drifting into a depression over thoughts of never being able to close this gap. Several times a day I would wind up some cotton wool coated with Vaseline, wedging it in the ever-increasing gap to prevent air passing across my eye thousands of times a day causing it to become sore. The cotton wool also prevented a person in close proximity to me being able to see directly into the cavity inside my head. My next appointment with Miss Cook was 25 June before which she was attending an international conference in Bristol allowing her the opportunity to discuss my case with eminent professional colleagues.

I was already feeling low when I received a letter from the eye hospital cancelling the appointed date with Miss Cook in favour of mid-July. Frankly, I could have jumped off the nearest road bridge. That was the depth of despair I had slumped to, all because of a stupid fight preventing Mr Homer finishing off the job in April. Was it easier to blame someone else than look at myself? Wasn't it hard enough? What about fate? Where did fate fit in now? Was I a medical hot potato?

I emailed Miss Cook directly explaining how I felt. She responded in the most kind and empathetic manner asking me to attend the original date.

On 25 June, Lesley, Philip and I met with Miss Cook. She had good news from her conference. There were no promises, but she felt confident there was a way to recover the reconstruction and seal the gap without compromising the function of my eye. The plan was to do the operation jointly with Mr Homer in four weeks. The following day, Philip telephoned me to say the proposed date was not feasible, but he had secured an alternative new date of Tuesday 9 July, even sooner, which was a bonus.

I worked the morning of my op, taking the rest of the week off to recover, as advised by Miss Cook. That evening, following the five-hour operation, Lesley sat squeezing my hand. I was too sedated for much conversation but had no pain whatsoever. I stayed in overnight and left the next morning looking like Mr Bump. Miss Cook and her colleague, oculoplastic surgeon Mr Dharmasena, had reviewed me prior to leaving hospital. He described the delicacy of peeling my skin, like removing the intact skin from a kiwi fruit. I understood his analogy. It was a technique similar to how I communicated with my own patients. The bandaging post-operatively was extensive, covering one eye and preventing me from driving, working or playing sport for the following week. By my standards, a minor inconvenience.

The stitches were removed in two phases the following week. Miss Cook was really pleased with the outcome, as was I. She and Mr Dharmasena had recovered the situation and the gap was virtually closed. The narrow slit that remained could be closed in a future operation, perhaps combined with Mr Homer lengthening my contracted nose to return my nostrils to horizontal. That was my hope.

Before considering a further op, I wanted to get through my annual cancer scan successfully. I was working and playing squash virtually normally and I was also back on my bike. Miss Cook had managed to return my sense of humour and smile which had gone missing during that dark phase. My next consultation would be with Mr Homer on 22 August to discuss the next step. The roller coaster, which had had me suspended, dangling precariously, was moving once again.

Brian the Trojan was back home too, again making a remarkable comeback.

By the time of my appointment with Mr Homer – who had, meanwhile, been upgraded to Professor Homer – my forehead and nose were settling nicely. Prof Homer was not interested in any more intervention with regard to levelling my nostrils but did request a scan, principally to check the anatomical rearrangements than for any recurrence of the Alien. The scan came through for mid-September. It was a straightforward cannula in the arm, perfectly executed, and followed by a lay down for 45 minutes in the scanner.

Physiotherapists, like all professionals, need to demonstrate a certain amount of continual professional development hours per year to maintain their professional status. I'd noted a course focusing on cycling injuries by a leading physiotherapist who had worked for many years with British Cycling. I already had some useful insight from reading cycling magazines, however, the single daycourse in Bolton promised to fill more than some of the gaps as regards bike setup and adjustment. Making sure the seat, pedals and handlebars were in the correct position to prevent injury, optimise performance and make for a more comfortable ride was so important, particularly on long rides like we were contemplating.

The day after seeing Prof Homer at The Christie, I arrived at my practice in the early morning to find a letter on my desk from Howardy, a patient and friend. Since the intervention with my eyes, blurry vision was an early morning feature, making reading slightly difficult. It was a lovely letter, but I couldn't quite understand it until I noticed a beautiful Bianchi racing bike tucked away in my room. Howardy had bought the bike a year ago, ridden it a couple of times and not enjoyed the road or the actions of some car drivers. I had tears in my eyes, partially from the normal blurriness and the rest from emotion building inside.

That weekend, I took my Italian stallion for its first outing. It was a joy to ride. Elliot, Sam and I rode 90 miles on the Saturday, climbed Helvellyn in the Lakes on the Sunday and notched up a further 90 miles on the Bank Holiday Monday. We rode via Stoke on the Saturday to meet up with Martin, who I trained

with as a physio at Withington Hospital. He and his family engineered the perfect refuelling stop before heading towards Buxton then home. Helvellyn on Sunday was an enjoyable walk on a fine day and the Monday Bank Holiday ride took us to Alderley Edge, back home for lunch then towards Helsby for the final afternoon spin.

Two weeks later, I rode from Lymm to Lincoln via Macclesfield, took the Cat and Fiddle Road to Buxton, Bakewell, Chesterfield, Bolsover and Markham. It's a route with 80 miles of hills and the remaining 30 miles on flat roads. The boys couldn't make it, so it was down to just the Italian stallion and me. I'd intended to ride home the following day, but it was just too much for my legs and bum. I was happy to bank the miles and cadge a lift home.

The preparation for our challenge was going well. Since our decision to do the ride, I'd put in hundreds of hours cycle training either indoors or on road. Owing to the postponement of the challenge until 2014, disappointingly, both Jake and George would be unable to take part. Jake would be working and taking professional examinations during the proposed dates and George had university commitments. Jake would continue to support us in our training and hopefully undertake various challenges of his own in support of our fundraising.

The slit between my eye and nose was once again gradually increasing causing more air to escape, constantly irritating my eye. On 16 September, I saw Mr Dharmasena, who examined my situation carefully with Lesley and Philip in attendance. He had a very nice manner, again using lots of metaphors to get his message across. This time it was a washing line for my lower eyelid. We left content that he would discuss the situation with Miss Cook and look to close the gap sooner rather than later. Could this be my final operation? Though I didn't fancy the prospect of Botox injections into my tear gland six times per year, this was my best and only option of circumventing the dysfunctional tear duct by controlling the fluid production which ultimately passed across my eye.

#### Chapter 19 Code Words

We met Prof Homer at The Christie, Thursday 26 September, for my scan results. At this stage I'd never got through an annual scan without a problem, however, everyone seemed confident. I picked up Lesley along the way, parked locally and joined Elliot and Sam who were sitting in the green chair waiting area. Whilst both my lads were back at university, their timetables permitted them to join us. When they'd been applying for universities, I'd suggested it might be best not to be too far away in case they needed help. Little did I know it would be me that would need help and their being close by facilitated that. The university was very understanding with regard to my illness, wishing to be kept abreast of developments.

We were instructed to wait in one of the consulting rooms to be joined by Prof Homer and Philip. Our hearts sank when it was announced the scan wasn't clear. There was an area in my sinus that would require some more investigation. Prof Homer examined the inside of my nose with a nasoscope but could detect nothing unusual, suggesting that it could be just granulation tissue or scar tissue. A biopsy under general anaesthetic would be definitive. It had been prearranged for the following Monday morning, four days later. As we left, there was a huge feeling of disappointment accompanied by tears. I recognised the code words Prof Homer had used: 'Perhaps its scar tissue'. Basically, there was no bad news until we could be absolutely sure. This represented the difference between booking our first trip away in years or booking an appointment with my solicitor to vary my will. There couldn't have been a starker contrast. The roller coaster was up to its old tricks and giving us a rough ride.

The biopsy, on 30 September, went smoothly, as did the anaesthetist's cannula. The anaesthetic was fine afterwards so I was home by lunchtime. The results would be through in seven days. That's a long time to sweat. Surely after all I'd been through, I couldn't be expected to endure more?

At my follow-up appointment with Prof Homer, at the MRI ENT department, on Tuesday 8 October, Philip joined Lesley, Elliot and me. Sam had lectures to attend. Prof Homer started the letdown. It was not good news. The Alien was back. In fact, it had never gone. Lesley was already in tears while squeezing my hand. This was her lowest point. Thoughts of spending her life without me flashed through her mind. As the interview progressed, I had my arm around Lesley with Elliot close by and also in tears. I managed to stay composed throughout. I'd found I was more likely to be tearful when I had good news as a sense of relief than the situation I was currently experiencing. Maybe because I had questions to ask, and I was by now becoming familiar with the shocks. Cancer respects nobody. If it can take you, it will.

I would lose my right eye, some of my cheekbone, the reconstructed area of my nose and some brain tissue. There could be no half measures. No chemotherapy. No radiotherapy. Prof Homer answered all the questions fired by Elliot and me while Lesley broke her heart in disbelief. There would be a combined removal of the affected tissues and a reconstruction at the same sitting, using skin and muscle from my shoulder blade. There would be another opportunity to ask questions of Prof Homer the following week and firm up the details. This was as much as we could take for now. We left with Philip for a cuppa, hugs, and tears. At that moment it wasn't an instinctive response to say, 'Yes, I'll do it'. Could I take any more? Could I face up to the world with even greater facial disfigurement? Would any future grandchildren be frightened by some freak? I needed to know what Lesley and the boys wanted me to do. I needed their support more than ever to get through this.

Meantime, Prof Homer would consult with a neurosurgeon colleague and Tim Blackburn, reconstructive surgeon. We left to meet up with Sam. My whole world and existence had just exploded, again. I had just landed on the longest snake. I was back where I started. We all returned to Lesley's house for a chat. Those post-appointment group chats, with my dark humour helping to mask the stark reality, were invaluable for Elliot and Sam. The honest and open policy was preferable even allowing for the upset. Better the reality than something worse conjured up in the imagination.

Despite it all, that evening I played a prearranged game of squash while Lesley went to her usual dance evening. The boys went back to their university lives and we all carried on. I made the usual half dozen phone calls and multiple texts to the utter dismay of the recipients. I was working the following day, as was Lesley. The lads had lectures and a footie match after which they came over to share an evening meal with us. Keeping everything as constant and normal as possible was our *modus operandi*. I was truly lucky to have such fantastic support. I'd made my decision. I'd go through with it. My coping mechanism was to focus on what I would be like in three months' time rather than the immediate few weeks. With one eye I could drive, work, play squash and cycle. I'd already spoken to the DVLA and obtained clearance to drive following the loss of an eye. The disfigurement would be harder to deal with. That would be something I'd hope to get used to, as would my friends and family. I joked that at least large sunglasses were in fashion, and I did at least still have two ears to suspend any glasses. This next operation would be the squash equivalent of the fifth and final game – the end of the match. There could be only one winner.

The following week I had appointments on Tuesday and Thursday with Professor Homer to firm up the details and ask questions. Unfortunately, both were cancelled for various reasons.

With the cancer like a time bomb in my head I was hoping for an op date as early as possible. It was my life at stake! Arranging several eminent surgeons, sixteen hours of theatre time, a bed in a different hospital etcetera was a complex task, even for Sarah. My feelings were always the same. When you've made up your mind, you might as well get on with it.

On the Friday of that week, 18 October, we met with Miss Cook who answered my many questions. I had huge respect for and trust in her judgement and skill. I wanted her to be part of my team and Miss Cook wanted to be present, offering to cancel whatever was necessary to fit in with the rest of the medical team. I felt confident she would strike the right balance and perspective while I was anaesthetised on the slab, unable to answer for myself. For Elliot, who sat in, Miss Cook presented a master class in rapport and bedside manner.

The following week was school half term and Prof Homer was off which added another week to the waiting game. During that time, however, he was in discussion with Prof King, neurosurgeon at Salford Royal.

We were very happy with the progress regarding Facing Challenges Together. Elliot had done several presentations to business groups and our fundraising total had risen to £3000. We were still without a van, a van driver or much sponsorship. The economic scene was quite bleak which made procuring money from businesses and organisations so much more difficult. It was a reality check for Elliot as interest and promises very often resulted in nothing.

## Chapter 20 Killer Blow

29 October was to be another defining moment in my life as my entourage – Lesley, Elliot, Sam – and I met Prof Homer at the MRI ENT department. I sat toe to toe with the professor. I had a dozen questions to ask but they became irrelevant, for as soon as I sat down the goalposts moved. The neurosurgeons, having looked at the scans, had decided the area was inoperable. Agonising over whether to have or not have the op had been a waste of time. Basically this was tantamount to a death sentence. For Lesley and my boys, we had reached an all-time low, the point Lesley had always dreaded might happen. I began this journey never thinking I would die, I always thought we had caught it early enough.

Radiotherapy was not an option having already been exposed to it in that region of the body and chemotherapy had proved unsuccessful previously on patients with a similar diagnosis to mine. Dynamic light therapy was suggested but was only a palliative measure. In desperation, I asked if anyone had overcome this with thought of mind alone, alas not. The Alien was more difficult to eradicate than Japanese Knotweed.

Prof Homer had respectfully asked a colleague, Peter Clarke at the Royal Marsden Hospital in London, to review my case and scans at their next multidisciplinary team meeting in two days time. The boys had been treated to a lesson in how to deliver the most devastating news possible in as kind a possible manner. We left the meeting, unified in our grief and defiance. My demise was not going to happen without a fight. Lesley, Elliot and Sam departed with tears rolling down their cheeks.

Several days later, Sarah told me that there wasn't a dry eye in the whole ENT department that morning. The roller coaster was climbing slowly up to its highest peak. It couldn't get higher, could it?

That weekend, in desperation, the boys and I set about looking for alternative treatments. I looked at High Intensity Focused Ultrasound (HIFU) while the boys looked at genetics and immunotherapy. We each sent emails all over the world. The HIFU, mainly originating from China, was an exciting and emerging concept of cauterising the cancer cells. Unfortunately, after much delving, the technique

was inappropriate for head and neck cancers as the skull has thick bone and air pockets, which renders that area particularly hard to treat. The boys had good feedback from their investigations, however. My cancer cells would need more analysis before any conclusions could be drawn.

The reality was that, if nothing changed, I would be departing this earth very soon. I felt relieved not to have to go through another major op and the consequential disfigurement, but the thought of not being here for my boys, not seeing them progress in life and cycling the challenge, not with me but in my memory, seemed inconceivable. Lesley found it utterly distressing, cheated out of a life together. Having found someone to share her life with, I would soon be taken away. Sometimes she would just sit looking at me in disbelief. Being strong helped Lesley and the boys to be strong too. Lesley always said she'd never known anyone stronger than me. The boys didn't need to discuss it outside our group. We were there for each other. Lesley had a few close friends to confide in and I had my pals and patients. There was little point in me becoming morose. If these were to be my final days, I wanted to enjoy what remaining time I had. I was quite open to talking about the eventuality.

I contemplated my immediate future, my work, my practice, my home. With respect to work, Colette and Caroline, who I'd trained with at Withington Hospital, would come to my rescue once more by covering my period of absence along with Cheryl.

I spared my Mum the truth. Until we'd heard back from the Royal Marsden and the work my boys were doing, there was still a chance. I wondered if she could survive the severe sentence being imposed.

I met with my friends Jim and Mark to discuss my thoughts. I needed to know that I was still capable of rational decision-making. Mark would revise my will. I made sure all my papers and documents were in place with details of account numbers and such. I was mildly disappointed to see my life's assets easily fitted on just a half A4 sheet with room to spare.

The thought of not being here seemed at odds with how I was feeling. I was cycling better than ever. I would represent my county at squash again. Apart from some facial swelling and a mild headache no one would suspect anything for now. I'd imagine my boys cycling together, having children, talking over day-to-day issues of medicine and general things without me. We still had times to share and challenges to meet. I wasn't ready to go. I still had lots to offer.

I told Lesley I would expect her to meet someone else to share her life. I hated the thought, but I also wanted someone to look after her. Although Lesley

was about to turn fifty, she would easily pass for forty as she was and is a slim and beautiful woman.

We dined out at one of our favourite restaurants, Damson in Heaton Moor, to celebrate Lesley's fiftieth birthday. Several years ago, we'd talked about visiting New York for this special event but that was beyond me in my present state. The food was fabulous as usual. As we faced each other, tears rolled down our cheeks. Perhaps this would be the last birthday I'd be here to celebrate with my special girl. Owners, Alison and Steve, called in specially to meet us. Lesley filled Steve in on the latest as I was choked for words. There's not much anyone can say in those circumstances but Steve, who is usually overflowing with words, said the right thing: nothing. Instead, we had a hug which said it all. Steve was like a brother to me; someone I had a real affinity with.

# Chapter 21 Odds

We met Prof Homer nine days later at The Christie. The Royal Marsden had reviewed my case and thought an operation was feasible after all. The roller coaster was showing some forgiveness. The Salford neurosurgeons were now happy to proceed to an operation. Philip made some hasty arrangements for MR and CT scans later that day as it was necessary to check there had been no significant change since the scans five weeks previously. There was a glimmer of hope. My chances of ultimately surviving cancer, assuming I recovered from the operation, were in the order of 10%. That figure had fallen from 50/50 in just two weeks.

Lesley and I decided to take the following week off work. We deserved that. On the Monday we met a church minister and friend of Lesley's, Nick Bundock. What a nice ordinary guy. It was reassuring to know that if I were to depart this world there would be people like Nick to support my family. We chatted for a good while then finished by praying together. Later that day, Lesley and I went looking for wedding rings, not that I'd even asked her to marry me yet. We each knew the symbolic gesture we were making to each other. The rings we would buy later that day would carry personal inscriptions. On our journey into town that day we talked about my church funeral, music, where my cremation might be and possible venues for a wake afterwards. What a bizarre situation, but these things are better discussed than left to an unsuspecting soul to second-guess what I would have liked. We talked about individual items in my house. I told Lesley I would leave her my wall clock. She happened to hate it chiming at night. She looked over as I smiled, and we both burst out laughing.

The following morning, my entourage met again with Prof Homer and Philip. The mood was a bit more upbeat. Prof Homer needed to check that I was prepared to go ahead with the proposed surgery. The scans were unchanged from those taken previously and the neurosurgeons were also willing to go ahead. The donor site was not now to be my shoulder blade but either my abdominal or thigh muscles plus overlaying skin. A titanium plate would be pre-formed using previous CT images to replace the planned removal and loss of forehead bone. I was informed that, as I was to undergo brain surgery, I would be restricted from driving for twelve months owing to a possibility of epileptic fits. Instinctively, my mind was racing for a solution. Perhaps this could be a blessing in disguise for my cycle training? Unfortunately, cycling too would be out of the question for my own safety. This restriction would make life very difficult for me living fifteen miles from my workplace though I understood the need for caution. There was no way I would put other people's lives at risk. Effectively being banned from driving was harsh punishment. Following my op, when I would most need assistance, I would be denied even that freedom and comfort. I didn't relish spending my few remaining months hanging around Altrincham bus station. Life could be a real bitch sometimes. Prof Homer would contact me once a date had been fixed while arrangements were made for consultations with both Prof King at Salford Royal, and Mr Blackburn, reconstructive surgeon, plus pre-op tests.

Two days later, I heard from Sarah that 10 December was the proposed op date which would at least give me more time to sort my practice before going off work for up to two months.

Recently I'd heard the story of a female motor racing driver, Maria de Villota Combo. Maria lost an eye in a motor racing accident. She was under thirty years old and a beautiful looking girl. Despite those difficulties she carried on her life with a smile. She wore different coloured eye patches to match whatever she was wearing that somehow didn't look at all out of place. Tragically, she died of natural causes one evening, perhaps as a consequence of brain trauma suffered in her original motor accident. She'd married less than a year earlier. I felt saddened but inspired by her story and spirit. I decided that if I felt low, I would think of Maria and try to smile through it.

The next weekend I was picked up by the lads on the way to our over-45s county squash match at Rochdale. I took my medical bag as I always like to feel useful, plus my squash kit, just in case. There were two injuries in the morning match, which meant strapping the skipper's calf muscle so he could play again, and I filled in for the afternoon's match. Though I didn't win, I didn't disgrace myself either. I was 95% back to my former standard. The missing 5% accounted for my difficulty finishing off tight games. Cheshire once again qualified for the national finals, set for the following March.

Running my physio practice with constant setbacks to my health was proving very tough. Each occasion I had a significant time off work it would take me many months and enormous amounts of energy to recover to the normal level of patient activity. Furthermore, I had to keep my practice administration ticking over while I was off. Additionally, Cheryl had taken another part-time job which prevented her from undertaking any extra hours for PhysioSport. Perhaps now was the right time to sell up? I discussed it with a few pals in business who concurred. I could no longer afford to shoulder that responsibility. I was happy to return to work if I could leave the running of the practice to someone else. There was no time to make any plans before my op other than make a few phone calls to prospective suitors.

Perhaps not surprisingly, I'd had a headache for some weeks. The cancer was up against a very sensitive structure. My forehead was swollen and, with neck aching and upper spine tension, long days at work were additionally hard. These symptoms were possible indications of meningeal irritation (meningitis). I spoke to Philip at MRI. Prof Homer was out, as were all the registrars. I could try A&E or see my GP.

I was able to see Dr Baxter at my new GP practice that afternoon and he couldn't have been more helpful or friendly. I left with a prescription for antibiotics knowing I would see Prof Homer at The Christie in two days' time to reassess the situation. I couldn't afford for anything to get in the way of the operation scheduled for three weeks' time. I cancelled my prearranged squash match and the planned evening out to watch the Bowdon first team play as I really didn't feel well. I knew about meningitis from my previous encounter though, for now, this wasn't in the same league.

I met with Prof Homer at The Christie on Thursday 21 November, along with Elliot and Sam. He checked over the recent facial swelling and was reassured that I was feeling somewhat improved. There were no changes or further revelations to the proposed op as had happened so many times before. I was to have an MR scan the day before my op to be absolutely sure of the current state of cancer growth. There was a piece of good news. Following the boys' investigations, we had asked for a special pathology test on the cancer cells. There is an element to the cell called KRAS. If this had mutated, then my prognosis may well have been worse. As it was, it hadn't, which meant that following the surgery I could take an oral drug called Cetuximab that would help my body recognise and prime the cancer cells for destruction. The only side effect was a rash. Unfortunately, I was good at having unusual rashes!

Prof Homer took us through to meet Mr Tim Blackburn, reconstructive and maxillofacial surgeon. As we walked, it was an opportunity to ask about his own

training and running as he was a keen fell runner. I liked those short conversations, when people like Prof Homer became ordinary people like us. For him, I hoped it might be a break in the ritual conversations about cancer.

I had met Tim Blackburn previously over my nose reconstruction, but he'd not needed to become surgically involved then. I introduced him to my sons. Barbara Farimond, specialist maxillofacial Macmillan nurse and colleague of Philip, two nurses and a registrar were also in the small, modern consulting room. Tim was incredibly reassuring. He started explaining why he should use my outside thigh muscle for the flap graft rather than my abdominals, based primarily on reduced operating time and the success rate of this type of graft. I was happy to go with his recommendation, especially when he reported that other sports people had made complete recoveries. Though I would have preferred to use my left thigh, now was not the time for those details. This was about saving my life. The flap would cover the area of my right eye, right nose and cheek.

He described the procedure that would connect the blood supply of the flap with the vessels in my neck. There was a 95% chance of it taking first time and, if I had to go back to theatre because it was failing, a 75% chance of recovering the situation. The muscle would be plump initially but would eventually revert to concave, which was more 'normal'. There was the possibility of a primitive static prosthetic eye eventually. Our thoughts at this time were to get rid of the cancer, cover the hole, then deal with any issues after I'd recovered.

Tim asked me how I thought I would cope psychologically. I'd got this far without too many problems, but this would be a massive alteration. I was feeling pretty confident I could cope, suspecting it would most likely affect me in the early days after the operation when I might look in the mirror and realise that this was me now. That would be the hardest time. As long as I could continue to feel well, I'd hope to reframe my thoughts and get on with it as best I could. 'Getting on with getting on' was an expression of mine. My boys, Lesley and my friends would pick me up and carry me when I needed help.

During all these conversations with such eminent consultants, my boys were privy to their unique skills of delivery, rapport and communication. This was a harsh learning experience, but one which they might look back on in their careers when dealing with their own patients. They were coping with my desperate situation so well.

Sandra, an optometrist, was a recent patient of mine. She was shocked and astounded when we talked about the onset of my problems because she saw several people a day with similar eye watering symptoms to mine. She felt sufficiently moved by my story to write a short piece about my history which was published in *Optometry Today* magazine. I was grateful to her for taking the trouble to make her fellow colleagues more aware. If one patient gets spotted earlier as a result of that article it will all have been worthwhile.

My appointment with Scott Rutherford, neurosurgeon at Salford Royal was set for Thursday 28 November. A colleague of Professor King, he would be the last member of the operating team I would consult, the twenty-seventh consultant to see me. I was looking forward to meeting him.

## Chapter 22 To Be Or Not To Be

I played squash on the Tuesday evening although the headache I felt on head movements was much worse following that particular match. Irritating the sensitive brain structures was counterproductive to my enjoyment of playing and best avoided prior to my operation so I decided to forego playing squash for the time being. That still left me with indoor cycling and rowing to maintain my fitness and keep me sane. As I exercised, it was as though I had spent a lifetime conditioning my thigh muscles to be in peak condition for this vital donation.

Elliot, Lesley and I met Scott Rutherford two days later. Despite the letter of instruction giving directions, we still had to ask twice for directions before navigating successfully through the Salford Royal maze of corridors. We sat in his office while he explained the complexities of the op – approximately fifteen hours of surgery, followed by a short stay in intensive care, stepped down to high dependency, then a normal ward, before discharge in seven to ten days if all went well. There were the usual complications of stroke, infection and death during any operation, plus a real concern over leakage of the cerebral spinal fluid that surrounds the brain, which could lead to meningitis. There was little point asking Mr Rutherford hypothetical questions at this stage – I would leave those until several weeks after the operation when tissue cells had been analysed, my recovery assessed, and he had all the facts at his fingertips.

I would have a last-minute MR scan on the Friday before this, my tenth operation. If there was a significant change from the previous scan, taken three weeks earlier, the whole operation could be called off. The operation was a daunting prospect for us all as it carried huge risks and would certainly divert the course of my life. As we returned to the car park, the enormity of the situation hit home. Originally, I had thought my Mum should travel over the weekend following my op, that way, the drains, drips and gore would be subsiding. I thought it would spare her that upset. Now I thought it might be sensible to see her before the operation, to spend a few days with that special person. Just in case.

The boys had been with me to all the recent appointments. They realised the seriousness and still found it preferable to being in the dark.

A hastily arranged pre-op meeting with the skull-based specialist nurse, on Monday 2 December, played havoc with my work diary. I allowed four hours to be sure of getting back to work by mid-to-late afternoon. Again, the Salford Royal corridors and signage tormented us. The meeting with the nurse, Andrea, was short, but useful then we moved through to pre-op. The process of asking twenty questions of my past medical history, taking a blood sample, blood pressure, pulse rate and ECG took an incredible four hours, involving three practitioners and three long waits between each interview. This extended process necessitated us calling four of my patients to cancel, as I wouldn't be back in time for their appointments - a simple enough task if it wasn't that in most hospitals there is frequently no mobile phone signal. I never asked what my blood pressure reading was! But I did nearly lose the will to live, there and then. There appeared to be a total disregard for a patient's time or any desire to get people back to work. My introduction to Salford Royal had been underwhelming and uninspiring. With so many appointments now 'under my belt', I felt in a reasonable position to comment. Yet my confidence in Salford Royal and my consultants was undiminished. The hospital had a fine reputation, and my consultants were handpicked and keen resolve this case. I just needed to be patient whilst making my way through the system. The roller coaster continued to thunder along the track.

As I arrived back at my practice, I bumped into Roz. Brian was again having difficulties.

The Friday before the Tuesday operation, not wishing to be panicking about being held up in unfamiliar heavy morning traffic, I arrived at Salford Royal an hour early for my 08.15 scan appointment. The neuroscanner had a smaller tunnel than the usual scanners, which would presumably give better definition to the images although, for anyone with claustrophobic tendencies, it could have been scary. Fortunately, I was fine in that respect. No cannula this time but an injection of dye halfway through the scanning process. The radiographer allowed some dye from the intravenous injection to leak into my tissues causing a nasty sting for the remaining ten minutes. I was just hoping enough dye had entered my vein to produce the required image.

Scott Rutherford telephoned me later that day with news of the scan. There was no change from the previous scan. The operation was still on. We wished each other a good weekend in anticipation of the week ahead. That message would signal my final day at PhysioSport for several months.

## Chapter 23 To Be

Apart from some bike maintenance, the usual training session and a couple of walks, the weekend was quite restful with my lads and Mum over. To all my friends and family on the Sunday I sent a text so they knew what was happening.

'Hi fellow riders. The roller coaster reaches a crescendo this Tuesday with the ride of my life. It's an all day ride with new forehead titanium plate and muscle transfer from my thigh to where my eye has been. I'm having synthetic tissue to replace the lining of some of my brain. We'll be pausing in intensive care before coming round on Wednesday then if all goes well, a gentle glide home by Xmas. El & Sam will be in touch as soon as there's news. Thanks for sharing the ride with me and being there for me and my family. XXX'

In response I had some fantastic messages of support and encouragement from the people that underpinned my spirit and belief.

I had a final hour-long training session on my indoor bike the Monday before my Tuesday op. I was tempted to cycle outdoors as the weather was conducive; however, being so close I didn't want to endanger the chance of the operation not going ahead at this stage because of an avoidable cycling accident. Lesley prepared a lovely meal of my choice and we settled down for an early night.

The following morning, 10 December, we rose at 5.45 am having slept well. I was able to take my last drink prior to 6.00 am but no food. A quick shower and shave then Lesley, Elliot, Sam and I left for Salford Royal Hospital. I was pleased Lesley had company for her return journey home because I knew she would be upset leaving me at the theatre doors.

The roads were quiet. Arriving shortly before 7.00am, we checked in at the Elective Treatment Centre having identified the location among the maze on a previous visit. Following a short wait, we were called through to prepare. My thoughts, as always, were that I was having the operation anyway so might as well stop worrying and focus on remaining calm. Lesley, Elliot and Sam watched as the nurse took my details and a blood sample from my left arm. I remarked to her what an expert job she had made of it but, half an hour later, another nurse

came by asking to take more blood. The first sample had been dispatched with a misspelling of my name!

The second nurse took blood from my right arm, this time not as successfully in terms of volume or comfort.

Ten minutes later the same nurse announced I would need yet another sample as there was insufficient blood in the second attempt! Elliot suggested that the first nurse take the sample, which she did, once more without pain from my left arm, while the second nurse would check the details. On a day when I would have umpteen punctures this was an unnecessary and avoidable issue.

Scott Rutherford and Prof Homer spoke with me on their way to get gowned up. There were no last minute changes. By 9.00 am I was being led through to the anaesthetics room annexed to the theatre. There were last-minute words and hugs with Lesley and my boys, my closest of allies, as we went in different directions for very different days. Elliot, Sam and Lesley would remain in my thoughts until the anaesthetic took hold. They each knew it was my only route to survival. Theirs would be a torturous day of waiting for the phone to ring with any news, while I would recall little else than the short time with the anaesthetists, some small talk, the cannula in the back of the hand then off I went into a deep sleep until the following day.

Andrea and Scott contacted Lesley and the boys throughout the day then finally, at half past midnight, news came through that the operation was coming to a close. Elliot had found the day difficult. He was more apprehensive over this one and had deviated from his usual university routine. Having my Mum at home, prone to tears, perhaps increased that anxiety.

Up to now I had always stood firmly defiant, sticking two fingers up at the Alien. My strategy had changed. My life would need to take a different tack now, acknowledge the tough duel, step to one side and let my world class surgeon accomplices give the Alien their full broadside in an all-conquering blitz while suffering any collateral damage.

I came round twenty-four hours later in the state-of-the-art Intensive Care Unit. The operation had taken sixteen hours and had seemingly gone as well as possible. As I awoke from the induced sleep, I sensed the airway in my throat being slowly extracted to the dismay of my gag reflex. There were very bright lights and people talking to me. I was in an unfamiliar environment, still heavily sedated, drifting in and out of consciousness. I seemed to be in a central openplan area which was part of a walkway. In my dreamy, chemical stupor I recall Scott speaking to me briefly then, as he turned away, I started vomiting what tasted like swallowed blood. Later on that day I would repeat the same unpleasant event. Was it the morphine that seemed to have a nauseating effect on me?

My throat was still sore and dry from the intubation tube combined with dehydration. Painkillers and antibiotics were administered via lines into both arm and groin veins. Additionally, there was a drain from the thigh donation site and I had been catheterised, creating a tangle of tubes and bags. An anastamosis (join) had been formed with my existing circulation in my neck region supplying the newly created skin flap with blood. Over that junction was attached a mini-Doppler ultrasound transducer, continuously monitoring the pulsing of blood and providing an audible 'bub...bub...bub'. When my blood pressure fell it raised concerns over the viability of the graft, whereupon noradrenaline was pumped into my body to get me back 'up to steam'.

It was an altogether unusual experience. If I hadn't known better, under the bright light and feeling disorientated, it could have been a scene where I was captured, sedated and about to face interrogation. Fortunately, it was only my wayward dreaming, perhaps attributed to the morphine. Steve and Kelly, my nurses, looked after me extremely well.

Lesley and my boys visited me in intensive care the following day carefully primed by Andrea about my appearance, ahead of seeing me. A forest of approximately 150 stitches bordered the flap graft and my head was swollen but not as badly as they'd expected. Lesley was fearful what I might look like and wondered if she would be able to cope. As she surveyed me she wondered if I'd ever work or play sport again. The trauma I had endured had left me looking in a bad way, pale, ill-looking and unable to communicate. I had earned my place on the intensive care unit. The medical staff were receptive to Elliot and Sam's questions. Concerned over how Lesley and Sam might react, Elliot's fears had been allayed by my appearance being not as bad as had been portrayed.

My Mum, visiting me the second day, was just relieved to see me alive and tried not to cry in front of me this time. Having spent thirty-six hours on the intensive care bay, my nursing was ready to be stepped down by moving the short distance to ward H7 where it was possible for my consultants to have easier access to me. I continued in my bed for another two days still attached by a spaghetti of tubes. I could eat only a small amount, as I had no appetite. My throat was still painful and dry, my lips swollen and numb. There were clear industrial-looking, plastic pipes up each nostril maintaining the nasal airways, though each pipe seemed to be blocked. To keep the tubes in position, they had been stitched to each nostril and I had an incision the length of my now very sensitive right thigh.

To straighten or change my sheets several nurses would log roll me with considerable care and consideration given to the level of pain induced by moving me.

The operation had been brutal and mutilating, much as I expected. I felt beaten up by a dozen men. Along with that destruction I had lost my right eye and my life had changed forever. By all accounts the operation had gone very much to plan, if not better. The forehead titanium plate had not been used but could be inserted at a later date. At the time, I couldn't care why not as I was too weak to ask. Afterwards, I was told it was to reduce complications and that seemed perfectly reasonable to me. My skull had felt bruised and sensitive to the lightest pressure having been clamped for hours during the operation. Once again, I spent day and night at an uncomfortable 30-degree angle to reduce the cerebral swelling, unable to find any relief that a three pillow-combination could possibly provide. The gravitational drainage worked as my swollen head gradually returned to normal size.

I felt well cared for by the nurses and staff on H7. Branching off the modern ward, my ample side room, with its own en suite facilities, provided an ideal location to give my body the rest and sleep it was craving.

Scott was very pleased with my progress on each of several occasions I saw him. Tim Blackburn reviewed my facial work, which was taking nicely. He removed the stitches retaining the nasal tubes. Given my previous experience of stitches in the nasal septum, I was expecting more pain so it was a nice relief that it was pain free. Next to come out were the nasal tubes, which were approximately ten centimetres long and the sort of thickness you might see on the back of your everyday washing machine! Not painful but it felt as if he was lifting my nose off my face completely, then I saw the size of the tubes and knew why. For several days it was great to be able to breathe more easily, especially at night, only for my nostrils to once again become blocked by the muscle flap and mucus.

Tim was chuffed with the thigh graft, 'the best bit of thigh he had ever extracted'. Not that it was easy. I had blood vessels that passed through the muscle tissue rather than over its surface. It took him several hours extra to divide those tissue away. I still hadn't had sight of my thigh incision which was covered with a dressing. With the drain still in-situ any attempt to contract my right thigh was extremely painful. The following day, Lawra removed the thigh drain. Despite her best efforts to make it a pain-free affair, the drain was stuck. I tried to subdue the pain with an audible 'Ahhhhhh!' The bladder catheter was much easier to remove. When one of my lines into my wrist dislodged, a nurse practitioner came specifically to reinsert a new one and freshen up the other as I was still requiring intravenous antibiotics. At midnight, as each was inserted, I shrieked out loud. Several nurses came running to my rescue. It had never previously been so painful inserting a cannula. You really can't compromise on the quality of needles. What I had just experienced will stay in my memory forever.

It always makes me smile that, with all the high-tech state-of-the-art medicine, the age-old question of 'Have you been for a number two?' is as important as ever. As with my previous long operations, the anaesthetic and limited food intake following a big op seems to slow the bowels to a stop. I was a regular daily sort of guy, so to go seven days without was a concern. When my boys came to visit, I talked about this constant question.

'Have you been?' they would ask.

Rather than the daily shake of the head, I so wanted to reply, 'It's knee deep in s\*\*t in that toilet'.

For my lads, that signalled the return of my sense of humour which had been notably absent for a few days. After that, any question could feasibly be answered by, 'It's knee deep in s\*\*t.' Perhaps that was the disinhibition, the inappropriate behaviour Prof Homer had warned about when we original talked about possible complications?

Without some of my tubes I was now standing and walking around unaided, although my balance and coordination were way off. I was still acclimatising to one-eyed vision while my thigh muscle, which had lost twelve centimetres in circumference, was painfully inhibited. My facial stitches were carefully removed in two stints on consecutive days without a hint of pain. To Scott's amazement, I was down to only a few paracetamols per day. I knew I was doing really well. Andrea, my skull base nurse specialist, continued to answer any questions, give reassurance and liaise with my various consultants. I had a chat with the nutritionist who felt I was getting back to normal, and the clinical psychologist, Russell, felt I was coping with the physical and emotional changes. By Thursday, only nine days following my operation, I was on my way home.

Elliot and Sam had only come to visit but ended up taking me home there and then. My visitors throughout had only been my boys, Lesley and my Mum. I really couldn't cope with more. The major concern on my discharge was to monitor for cerebral spinal fluid leakage, clear, perhaps slightly salty tasting, perhaps blood-stained, fluid coming from an incision, the ears, nostrils or felt at the back of my throat. That would signify a break in the brain barrier, which could lead to meningitis. I had strict instructions to rest and not to over-exert myself. The loss of five kilograms and several centimetres off each thigh circumference didn't unduly concern me.

On the ride home from Salford Royal I was the front seat passenger, imagining what it would be like to drive with my new single-eye arrangement. Pretty difficult I thought, but other people do it so I guessed I would adapt in time. Any cycling restriction discussed preoperatively had been lifted while driving was now in the hands of the DVLA to decide. Meanwhile, I was happy to be chauffeured for the next few months.

#### Chapter 24 No Place Like Home

It was blissful to get back in my own bed, which had a horizontal mattress with my own pillows. I walked twice a day with Mum, who was staying over indefinitely to look after me and report back to the troops if I was doing too much. With each day, the walks became longer and easier. In the cold weather I had to safeguard against my skin flap becoming too cold leading to shutting down of the circulation. There were sporadic visitors, which allowed for a nap on the sofa in the afternoon most days.

On Christmas Eve, I met with Prof Homer at Manchester Royal Infirmary. I'd not seen him since the morning of my operation. My lads and I arrived for the early morning appointment and were immediately shown through to seats outside Prof Homer's consulting room. The ENT staff knew us all well by now. They were experienced and professional and always struck the right tone.

Prof Homer was in a slightly more relaxed mood than normal. He told me the op had gone better than expected. He was pleased with my appearance and my responses to various questions. The pathology results over the cells taken at the time of my operation were not yet available. I knew from previous tests that dissolving the bone tissue took some time before they could start testing for cancer cells. As we left, with an air of optimism, we met Sarah who was pleasantly surprised by how well I was looking. This was her first sight of my new appearance which, at first glance, looked as though I had a plastic dressing where the skin flap covered where my right eye had been, extending up, across and above my left eye. It was 13cm long and 5.5cms at its widest point. As the days progressed, the forehead part of the graft became sunken while the eye part became more distended. I had my optimum look when I first got up in a morning before gravity took hold. I needed to shave the hair from it too, though an application had already been made for funding for hair removal. I joked with my visitors that I only shaved for certain special guests.

Christmas Day was a slightly muted affair. I was still very tired, not sleeping too well as my nose was half blocked by the flap graft. Any pain was under control with paracetamol alone. I was regularly lying in bed until late morning, which was just not like me, although I'd been advised to rest and my body was confirming that. Lacking in energy, I kept visitors to a minimum which allowed me to do as little or as much as I could cope with. People who knew the extent of my operation were very kind and respectful, offering help if I needed it.

Wrapped up to resist the cold weather I would walk at least twice a day, supplemented by practising walking up and down stairs. Descending stairs with complete control was particularly challenging and painful for my thigh muscle but better to remodel the tissues now than to wait until it became adhered and contracted. With an eye on the summer challenge, I had an easy indoor bike ride just before New Year. Only ten minutes on the easiest level but it was a start. I'd recovered no weight yet as my appetite was still poor.

By the time of my next review with Miss Cook, on 7 January, I had more consistency to my days. I was getting over the op and returning to normality but by no means anywhere close to my former self. Miss Cook was amazed at my progress. As mine was a rare case there were few previous cases to compare with. My eye was watering, and I was having some difficulty reading. The watering was perhaps a result of post-op swelling or scar tissue blocking my tear duct. Miss Cook proposed to do nothing at present, let the area settle, then deal with any potential tear duct issues at a later date. The internal bony eye orbit had been removed as close to my left eye as possible without compromising the tear duct whose exit channel leads into the nasal cavity. The lacrimal sac, which protects the exit point, had also been spared. A normal eye vision test was arranged for the following week to determine if I would benefit from the use of reading glasses.

Two days later I would meet with the remainder of 'my team'. Unfortunately, like buses they all came at the same time but in separate hospitals. Following some shuffling of times, we did fit it all in. First up was Mr Scott Rutherford, neurosurgeon at Salford Royal. Elliot drove Sam and me to the early morning appointment with both nurse Andrea and Scott. They were both pleased but conveyed a cautious note not to overly strain myself. The pathology results were back. There was no detection of cancer cells against my brain, which was a huge relief, and the clear margins were absent of cancer cells as far as could be detected. This was indeed good news and vindicated the decision to undergo extensive surgery when there had been such initial apprehension. Only time will prove that assumption. For now, at least I had a reprieve. It was a short thirty-minute hop across Manchester to reach The Christie for my next appointment with Prof Homer and Tim Blackburn. In the waiting area I had a conversation with nurse Debbie Elliot then moved through to a side consulting room with another nurse. Prof Homer joined us, with his registrar, along with nurse Philip and a colleague, nurse Barbara Farimond with two student nurses, then Tim Blackburn with fellow consultant, Mr Massimo Maranzano, the maxillofacial surgeon who had plumbed in the circulation for my neck during the big op. This was a record congregation, even by my standards!

Prof Homer reiterated the good news regarding the pathology results and examined up my nostrils with a nasoscope after which he announced there was little if any crusting. My blocked nose was the result of the muscle flap obstruction which he felt would diminish over the next year as the muscle atrophied (wasted away), if not, then it could be resolved surgically. Mere mention of another op filled me with dread. Meanwhile he could arrange a small plastic splint to keep my left nasal passage open for sleeping. There had been mention previously about taking a drug, Cetuximab, following the surgery to mop up any remaining cancer cells. Prof H thought it best to keep me 'unchemotherapyfied' for now, keeping the option open for a later date if needed. Prior to my operation there was a 10% chance of ultimately surviving the Alien assault. On questioning that figure post-op was now nearer 50%, a five-fold increase in my odds! I'm guessing having had so many black days this was an opportunity for everyone to join in with some good news and my lads and I were very happy to share some of the joy.

The roller coaster was in a more forgiving mood right now. That week alone had seen me make tremendous strides forward. Previously, I had wondered whether I would ever get back to work or complete my bike ride. I felt so weak at times but now, within only a few days, my strength seemed to be returning. The bike ride was a gruelling prospect. Not only that but I needed to put in some hard and long training rides to prepare for the event. I kept the intensity low as I gradually increased my time on the indoor bike, mindful not to damage my healing right thigh. I was walking up and down stairs, gradually stretching my thigh and hip regions, pushing through the discomfort. That's where my physio and rehabilitation skills were so useful, knowing when you could push and when to hold back. My right upper lip was still numb, and I still lacked full facial control, not dissimilar to a stroke victim. I'd practice smiling and pulling different expressions. I'd make Lesley laugh by attempting to whistle at sometimes inappropriate occasions. Lesley knew what it was about. Eventually I would master that simple but symbolic act. I was always working on something. That was one of my secrets to rehabilitation: lots of small packages of exercise add up to something larger.

The following morning, 10 January came some news I had been dreading. Gordon, my old friend, was eighty-five years old and like a dad to me. We went on annual family holidays together, spoke regularly on the phone, cooked meals for each other and shared a cruel sense of humour. He was better than a dad. He was also godfather to Sam, Elliot and ten others, a title he took seriously. Seven years ago, he had been very ill, lost a lot of weight he could ill afford to lose and finished up having a pacemaker fitted. Following eight weeks of hospitalisation he recovered fantastically well until ten months ago when he began with similar chest symptoms.

Leading up to my operation he was struggling somewhat but was receiving medical care. So as not to exhaust him, and to help limit my exposure to infection, I didn't visit but kept in close contact by phone. As I emerged from hospital, Gordon was being admitted to North Manchester General where he had been cared for previously. I was hopeful this would see his condition improve but, gradually, he deteriorated.

I was too weak and vulnerable to visit him, so his visitors gave me daily updates. During the early morning of 10 January 2014 Gordon passed away. Despite the warning signs it was still a shock, upsetting and sad. His spirit, generosity, warmth and humour will live on in my boys and me. My twentyseven-year relationship with a unique person and thinker had helped mould my life and would continue to shape me and my boys for years to come. Being off work for a further four weeks would, by chance, enable me to help sort through Gordon's house and belonging with the other executors when it might otherwise have been difficult.

On Monday morning, 13 January, I was back at the Eye Hospital for an eye test. Formerly, I'd had one eye that was slightly long-sighted and one that was slightly short-sighted, so somehow, I never needed spectacles. Now I was left with just the long-sighted eye, which required a mild lens prescription for reading. Much to Lesley's amusement this was regarded as an age-related phenomenon. Despite having a difficult balancing situation for glasses on my rearranged nose, we did find a suitable pair. I'd finally succumbed, aged fifty-two.

By the time I saw Miss Cook again, on 28 January, I'd averaged forty minutes of indoor cycling per day, numerous walks and two sessions of ball hitting only on the squash court. The thought of moving at speed or lunging to reach a ball was beyond my thigh flexibility and strength for now. I found having only a single eye challenging on court. Sitting still in a static environment like watching TV was much the same as with two eyes. Moving around on court with a fast-moving ball and my opponent moving next to me was another dimension, but one I was determined to master if I was to get back to playing with my mates.

Each squash session became progressively easier though my eye watering didn't help that task. Miss Cook concluded that the tear duct was most probably blocked by the weight of muscle graft, which would hopefully relieve in time. If not, a stent could be used to keep the channel open.

That morning, by chance, I bumped into Alison, my friend from The Christie who had cancer of her upper palette and nose. She had featured on daytime TV and in some magazines since we last met. Although she was a complete stranger it seemed natural to give her a hug. We had a degree of empathy. Alison knew nothing of my latest exploits. She herself was waiting for another operation to imbed magnets in her cheek bones in preparation for a prosthetic nose. I was really hopeful she might find it a good solution and one she could live with.

Originally Prof Homer had signed me off work for two months. In the early days post-op, I felt I would more likely need six months off but with just less than two weeks remaining I did feel up to returning to work. I would attempt to start with mornings and early afternoon sessions three days a week, building it up, as I felt able. I was still waiting for a DVLA decision regarding revoking my licence. Getting to work and back via, lifts, cycle or walking three days a week would be time-intensive and a logistical nightmare. Something I would have preferred not to endure.

# Chapter 25 2014. Give Me Strength

The week before going back to work, Lesley and I managed to get away to the Lakes for three nights, courtesy of some friends at the squash club. Although it was snowy and wet, the rest and relaxation were very welcome for both of us.

On arriving home, there was a letter from the DVLA. We opened it with trepidation. They had not yet completed their investigations but would contact me within the next three months! I couldn't wait that long for an answer. I'd had no epilepsy and I felt capable of driving by now. In the meantime, so long as my consultants were happy, I could resume driving. I contacted my three main consultants who responded in the affirmative allowing me to start driving again in time for my return to work. Thankfully, with the use of door mirrors, it wasn't as difficult as I'd anticipated. Freedom at last! I could get to the squash club to practise too.

Some of my patients were amazed to see me back so early. By working only three days for several weeks I hoped not to fall into the trap of exhausting myself. Greeting each patient with my facial disfigurement was a small test of my ability to handle the situation. With the patients I had known previously I briefly explained why I was looking different. Some, not surprisingly, thought it was a plastic dressing covering my eye. If only it was. With new patients I didn't talk about my disfigurement. I felt I didn't need or want to unless they asked me. They had come to sort out their problems, not necessarily to listen to mine.

This was the new me. A different me. When I was out and about, if I could I'd wear a baseball cap, something I'd done frequently even before my rearrangements. I just didn't want to attract attention. When that was not possible, I might wear sunglasses, if they were appropriate – though getting them close enough to my face, obstructed by the bulky flap, was difficult. If there was no option for either camouflage, I would just walk around like any other person. I felt that if I behaved normally then people would treat me normally and generally that is what they did.

I was adapting to monocular vision too though judging distance was my greatest challenge so far. I could pour water from a kettle onto a work surface

when I thought it was flowing into a mug. For now I had to make sure the spout was in contact with the mug before pouring. These were simple modifications. As the weeks went by, my memory of having two eyes would fade as my new normal established itself. I had been warned by Prof Homer of disinhibition following my surgery but as far as I was aware I was okay on this front and I never abused the licence for it.

In February, I heard that a friend had died of breast cancer. She was only my age. I felt angry with the world for taking away this person from her two sons and numerous friends. There seemed no justice. I had missed her funeral service in November, though I would have liked to have been there had I known.

Next came the news that my ninety-three-year old uncle had died. Again, this was a shock as I had no idea he had been ill. He had been admitted to hospital with breathing difficulties and died a few days later. Attending his funeral was an opportunity to see relatives I'd not seen since the start of my own troubles.

My Trojan friend Brian died on 28 February. It was a huge blow to his lovely family, his friends and me. His fight with the dreaded disease had been epic and courageous. His funeral was a heartfelt service at the United Reform Church in Heaton Moor near my practice. In the light and friendly building, Simon, Brian's son, gave a tribute to his father, each word a true reflection of the Brian I knew. Aside from his words Simon's delivery and tone gave such a feeling of love and respect for a great and gentle family man and father. Afterwards I was privileged to mingle with Brian's family and friends. As I sat alone at the church, I had the chance to think about my friend and me. Brian's death from cancer had special significance to me. It could have easily been me in that coffin with Brian in attendance.

Life was like a roulette table. In the normal world the table was huge with the ball very unlikely to land on your number. As a cancer victim the table seemed much smaller, thus the probability of your number coming up was much greater. It felt, prior to Christmas, that the ball had rolled into a square next to mine. Death was close. Unfortunately, it had rolled on Brian and Sally's numbers which made me feel very sad. I could remain on the small roulette wheel for at least another five years. Does it ever end, I wonder?

Furthermore, one of the first team guys at Bowdon squash club had been having abdominal problems. I knew he was to have investigations. The result, he had bowel cancer, which was another shock. It appeared to me that cancer is very difficult to spot. Nobody really wants to think 'cancer' first. Apart from skin cancer which can be visible, most are difficult to spot early. The presenting signs can be minor changes only in organ function. Being sensitive to minor, perhaps unusual changes, seemed key to being diagnosed as quickly as possible, enabling treatment at an earlier date, hopefully leading to a better outcome. Spotting change in the face of multiple existing problems presented an even greater challenge.

Gordon's was the next service I attended. A thanksgiving service at Stand Church in North Manchester. This was my third service, on consecutive Fridays, marking a very sad period. Again, it was a lovely service which was in keeping with Gordon's musical and religious connections. We had a nice get-together afterwards, where I could meet up with some of his friends and family. Not a day had gone by without me thinking about Gordon, my surrogate dad.

Between all these deaths my Mum's husband, Dave, was diagnosed with pancreatic cancer. Some cancers are easier to treat than others. Pancreatic cancer carries a particularly poor prognosis. It seemed as though the Alien cancer was pervading and prevailing, a feeling that I detested. That feeling would drive me on in my own contest with the killer and spur on our charity efforts. This was the only plausible and real way for me to undermine the Alien's existence.

Despite all my upheaval and Gordon's passing, my boys achieved good results in their exams. I was really proud of them. Good doctors have to function with all sorts of stress and distress. This was a true test of their resolve. We continued with our cycle training, Elliot supporting me on my first long bike ride, managing the Cat and Fiddle road climb in a 53- mile round trip. What's more, I didn't suffer muscle aching the next day.

Both Sam and Elliot had news of a bursary award from the university for innovative projects involving travel. The Zochonis Award was a welcome boost to their sponsorship.

Following my telephone calls after Sally's death, her ex-husband Bryan volunteered to be our van driver for the challenge and his sons, Will – who I knew well – and Tim would perhaps join us along the way.

My neighbours at home offered to buy a van for us, livery it up, insure and tax it, then, when we were done with it, sell the van and donate any profit to our cause. There are fabulous people in this world.

On 10 March, I had appointments at the MRI with both Prof Homer and Miss Cook. It seemed I was progressing well apart from my nasal breathing being restricted, watering of my left eye caused by a blocked tear duct and the aesthetic appearance of my skin flap.

There was a dip in my forehead where skull bone the size of a tennis ball had been removed. Originally the plan had been to insert a titanium sheet during the operation but that didn't happen. This would be something to think about at a later date perhaps but could be a tricky procedure being so close to my brain. Prof Homer would arrange an MR scan to look at the anatomical changes, assess healing and check for Alien activity. Also there might be merit in trying to support the collapsed left side of my nose to aid my breathing. An arrangement would be made for me to discuss a potential small op with a rhinoplasty surgeon to resolve some of my breathing restriction.

Regarding the eye watering, Miss Cook proposed an examination of the tear duct under local anaesthetic. There was a chance she may be able to resolve the problem at that sitting or plan some future intervention.

Hair growth on my skin flap, donated from my thigh, required regular shaving to keep it close. Arrangements were in place to have my initial assessment and test patch at a Manchester skin clinic within two weeks.

The response to advertising my physiotherapy practice for sale in January in our professional magazine had been favourable. Of the dozen that enquired, three were seriously interested. Each made visits to meet me and view the premises, some returning for second viewings and questioning. I was in the nice position of being able to choose my future boss assuming that I would be continuing to work. Ideally I could continue to do three days work per week. The sale of my practice might be enough to bring my mortgage at home to an end and relieve me of the administrative, practice promotion and marketing aspects, lightening the load on my shoulders. At one point I used to refer to my hospital bed as my satellite office. My new partners would provide better continuity if I was off for any time or had to terminate working full stop. The discussions so far had been encouraging.

With sixteen weekends of training left before the start of our conquest – and despite a bitter cold wind – we were once again on the Cat and Fiddle route from Lymm to the Peak District. After the thirty minutes of climbing from Macclesfield to the top we would always call in at the Park View Café. The staff were always very friendly and the portions ample. We rode with Jake to

Macclesfield and arranged to meet George at the bottom of the Cat and Fiddle Road but George didn't make it as he lost his way from Manchester.

The ideal group size seemed to be three riders, me at the back with Sam and Elliot alternating at the front. The lead rider has the hardest task of cutting through the wind which can equate to as much as 40% extra effort. At the back I have the easiest ride in the slipstream of the other two. It required a fair degree of concentration to ride close enough to the back wheel of the rider in front to achieve maximum relief from the wind without colliding with the cyclist in front, leading to a nasty accident. Potholes were also a constant hazard, particularly for the rider at the back who couldn't easily see the tarmac ahead. If the tyre caught the edge of a hole it would more than likely cause an immediate puncture, buckle the wheel or throw you from the bike. Jake had such an accident several months previously on an early morning ride close to Manchester ending up in casualty and a couple of days off work. His bike was a write-off. And Elliot had a similar episode, with a car, on the notorious Wilmslow Road into Manchester. He hit the nearside of a car turning right across the traffic, landing on the bonnet, smashing the windscreen and finishing on the road surface on the far side of the car. He escaped with bruising and several days feeling stiff. His bike was also a writeoff.

My birthday was looming. Prior to the Alien I'd never been too excited about celebrating my birthdays, but this annual event had new significance. It signified another year of existence against the odds. I'd been intending to invite both Sarah and Philip to join Lesley and my boys for a bite to eat somewhere for some time so this would present the ideal opportunity. Unfortunately, Sarah couldn't make it but it was nice to see Philip.

Sarah had been off for a few weeks, and it would be several more weeks before she returned. I'd lost my girl on the inside who was brilliant at chasing up and organising appointments and tests for me. I'd joke that, on the bottom of her letters where she would write 'Secretary to' Professor Homer, Mr Loughran and Miss Penny she should add my name. I was looking forward to her return to work. My boys who were hoping to go on to become consultants themselves one day, recognised the importance of a good secretary and the difference a 'Sarah' can make.

The last week in March was busy for us all. Elliot and Sam had an eighthour bike ride in the 100-mile Cheshire Cat sportive cycle ride which developed into 110 miles having followed some other riders off route. That was a good lesson for our challenge. We couldn't afford wasted miles. At the same time, I was away with the Cheshire over-45s squash team at the national finals. Once again, we made it through the semis on Saturday only to be beaten 3-2 in the final itself – same result as the previous year. I didn't play, other than going on court with our reserve player to practise on the Saturday.

After some persuasion from Lesley, later in the week, I arranged to see Prof Homer about the nosebleeds I was having. With cancer, sometimes that can be a sign of problems. He was happy following a thorough investigation with a nasoscope and discussed once again surgery to improve my breathing. I was happy to leave this until a later date when I'd got through scans and the whole area had settled.

After what seemed an eternity to arrange, I finally had my assessment for hair removal at a private clinic in central Manchester. The whole process was explained, and a small area of the graft subjected to the laser for skin testing. The laser light would destroy the skin root. In my case I had the ideal combination of darker hair over the lighter coloured skin graft. My probability of a successful outcome was 75% and the whole process would take eight months at monthly treatment intervals. The same day, I met a couple of guys who were interested in acquiring my practice. Our discussions were going well, and I really hoped we could get a deal which would be good for them, Cheryl, my patients and me.

With fourteen weekends to go to our ride, my focus was on getting back-toback rides. The weekend forecast was for fine warmish weather. On the Saturday, I was on my own riding a new route that had been suggested to me. Lymm, Macclesfield, Whaley Bridge, Buxton, Cat and Fiddle then home. It was a hard ride with lots of hill climbs. Fortunately, I had the wind behind me on the return leg to complete the 66-mile journey. On some of the steep climbs and the long climb up Long Hill to Buxton I wanted to get off and rest. My pride wouldn't let me. At those times I was thinking of Sally, Brian and Dave. My suffering was incomparable, so push on and get over it I thought. Being on a solo ride gave me thinking time for Dave who had been admitted to hospital the previous day, vomiting blood. Later that night, he died peacefully with his son Paul at his side. Mum, who had been with him most of that day, didn't quite make it back to the hospital in time. The following day was an easy flat twenty-five miles with Elliot. My thighs, aching from the previous day, gave up complaining after an hour of riding. I arrived back, changed, checked my emails and there was an offer from the guys interested in my practice. Not enough to persuade me to sell but perhaps a start. Each week at work was getting progressively busier with patients. Appointments with my GP, the skin clinic for my first hair removal session, a meal out for my birthday and a squash session completed the hectic week. In heavy rain Elliot and I rode the Cat and Fiddle route on the Saturday morning strengthening our resolve in the difficult weather conditions.

The following week, Elliot and Sam completed a two-hour hill ride while I had to make do with two hard sessions on the indoor bike and a knock at squash. I was slightly limited following my eye operation on Monday 7 April. Miss Cook was in charge for the hour long morning operation to investigate the tear duct in my left eye which had become non-functioning. As I lay face up on the theatre bed, my head in a special head rest to maintain a static position, Miss Cook started with the anaesthetic. Needles into upper and lower eyelids while we chatted and my toes curled. Once the numbness had taken over a fine rod broke whatever was causing the obstruction. The tear duct was now open and widened by inserting a balloon catheter.

The final act was to insert a solid stent into the tear duct, which would maintain the lumen as it healed to be removed in two months' time. As my eye became progressively more swollen, I sensed Miss Cook having more difficulty locating the stent. The anaesthetic was wearing off and soreness became the new sensation. By the time I had walked back to the reception area, my eye was really swollen and painful. Only now did I feel the stress created by the bright lights and prodding in a delicate place. I wanted to sit down, close my eye and shut out all sensation. My body felt overloaded.

Lesley who had come with me was acting as my secretary, taking calls diverted from my practice. As I walked back, not realising the state I was in, she gave me the phone announcing that a patient of mine would like to speak to me. I put on my bravest of conversations. The nurses were really kind. On asking me what my pain scale was they returned with two paracetamol tablets. Over the course of the next forty-five minutes, I recovered from 7/10 to 1/10. By coincidence I had an MR scan arranged at MRI, approximately the same location at 2.30 pm. I had time to return home, have a sleep and get back for part two of my day. The hour-long scan of my head, neck and jaw was a welcome lie down.

The cannula in the median cubital vein at the front of the elbow was pretty painless but bloody.

As for Facing Challenges Together, that week I was busy speaking to Victoria Pendleton's agent to enquire if she could ride us out from The Christie at the start of our challenge. It was a big ask. I also spoke to our Manchester Macmillan representative, Becky, who could perhaps help link us with Travelodge on our journey around Wales, Ireland, Scotland and England. Travelodge were also contributors to the Macmillan charity so perhaps we could link up well. In response to press releases by the lads, ITV was in touch to arrange a day's filming with us. We weren't sure of the exact plan, but it would become clear. The make-up department would surely have their work cut out with me!

The roller coaster had been in a calm mode for a few weeks now. I wasn't anxious over my upcoming scan results, but it was in the back of my mind. What if it shows something? What if the Alien has survived?

That weekend, Elliot was away with Jake, competing for Great Britain in a duathlon. The event was a five-kilometre run followed by twenty-five kilometre cycle ride, culminating in a further five kilometre run in Horst, The Netherlands. With Sam otherwise engaged I was contemplating another solo ride. The wind was light and the forecast cloudy with no rain until later. I headed off towards Stoke-on-Trent to meet up with my pal Martin again. I completed the whole 71-mile hilly trip in four hours forty minutes, averaging 15 mph, part fuelled by Martin's hospitality and omelette. As I arrived home the rain started. Perfect timing. I followed that up on the Sunday with a gentle ninety-minute ride around flat lanes close to home.

# Chapter 26 Stress Free For A While

The week started well. Philip telephoned me late on Monday afternoon with news relating to my recent MR scan. As I picked up my mobile phone, I could see Philip's name, so I knew the nature of his call. This was a point where my life could conceivably be turned upside down in an instant. Though Prof Homer was on holiday he had reviewed the scans, and so too had Dr Gill Potter, an expert radiologist. Both were of the opinion there was nothing of concern.

When a gap appeared between patients, I was able to ring Lesley and Mum. Both shed tears of relief and I too had teary eyes. What a huge relief for all of us. For Mum, who had had a tough time of it recently, it was especially nice to give her good news. I also spoke to Sam and texted Elliot who was still abroad. It was only several days later on driving into work that I could really feel that sense of relief. I'd forgotten what it was like to lead a normal life without constant clinic appointments and the need to fight for mere existence. Planning anything more than a few weeks ahead had been almost impossible. The only thing I did plan was the bike ride and that had been derailed once. I couldn't afford to drop my guard; however, the Alien had previously proven a formidable opponent. For now, the roller coaster was on favourable track. I sent the usual textees a happy message for a change.

Two days later, Lesley, Sam and I were heading over to Lincoln for Dave's cremation ceremony and an overdue reunion with Mum, who I'd not seen for several months. I offered to stand up at the service and read a poem she had chosen. Fortunately, I managed it comfortably. As a fellow cancer victim, I had a certain empathy with Dave and felt honoured to be able to stand up there for him and our families. The thought of standing in front of so many strangers with my unusual facial appearance never entered my head. It was only when Lesley passed on a comment from a relative suggesting this was a turning point for me that I even thought about it. As far as we were concerned, I'd already turned that corner. Dave's cremation marked an end of an unwelcome stream of services.

Over the Easter weekend Elliot and Sam were keen to cycle the route I had done solo two weeks previously – Lymm, Macclesfield, Whaley Bridge, Buxton, The Cat and Fiddle, Macclesfield, home. The five-hour ride was colder than we had anticipated. The seventy miles at their pace really took its toll on me. The previous day I'd fiddled about with my slightly noisy gears. Reading instructions from an A-Z bike manual, then adjusting this screw and that, had taken me two hours but it had been a good learning experience as the gears moved smoothly. I was exhausted by the end but not enough to prevent us going out that evening to celebrate my scan results and Elliot's good performance for GB in the duathlon. Both my thighs ached for several days.

With the temperature warming up outside, eye watering from my tear duct deficiency became less pronounced. I was waiting, hoping that the small stent occupying the tear duct channel would ultimately produce a trouble-free eye.

Cycle rides to work and back and on the indoor bike kept my legs ticking over until the weekend. We decided to take it a little easier as Elliot had a cold, and I was feeling tired from work and physical training. We did a short thirtythree-mile trip to Alderley Edge. It's largely a flat route though we couldn't resist taking on Swiss Hill, a steep climb on cobble road in the village itself.

Following a press release instigated by Sam, the next Tuesday, 29 April, we met with ITV Granada presenter Paul Crone. On a beautiful sunny morning, while riding our bikes in different combinations and doing interviews, we experienced what it takes to create a few minutes of television footage. It was a surreal day, all of us mildly out of our comfort zones and in the spotlight. The film clip which went out several weeks later was well received. Our challenge was gaining momentum.

By the end of the week, Phil, my generous neighbour, had purchased a threeyear-old transit van for use on the challenge. He was also planning the preferred arrangement of seats, bike space and livery. The enthusiasm surrounding our challenge was palpable as more and more ambassadors came on board, friends and relatives who felt sufficiently moved to collect money from their own friends during the period of our challenge. Each had a bespoke FCT water bottle to collect money in which proved a fantastic support to our own fundraising efforts. If the trip went well, I had ideas of offering to organise it again the following year, this time opening it up to any riders/climbers wishing to raise money for The Christie and Macmillan. On Thursday lunchtime, I took the trip into Manchester by tram. The newly constructed track extending to Parrs Wood, Didsbury offered a very short trip from work where I could park my car and ride virtually to the door of the SK:N clinic. This would be my second session of laser light, hair removal. Ironic really, that me, a follicle-challenged gentleman should be having hair removal. Within fifteen minutes, Jenny, my therapist was able to complete the laser treatment and have a little chat before heading straight back.

Miss Cook reviewed me the following day. The clinic waiting room was bulging with patients and their companions, some conversing about the long wait. I wasn't for joining in with their complaint. For me it was quite nice being greeted by the various doctors and nurses that I knew as they passed by. Miss Cook and I chatted for a while and decided the stent should be removed at the end of June, which fitted in well with our bike ride.

Through the eye clinic I'd been invited to attend a support group for people with eye problems but, already back at work and dealing with my facial issues, I didn't feel the need to attend. Miss Cook asked me again, this time, not so much for myself, more to help a couple of patients who were struggling after similar operations. I was in the unenviable position of talking from experience so the opportunity to help other people in my situation was all I needed to spur me on to attend the next scheduled get together.

The bank holiday weekend presented the chance for a few rides and a few games of squash. On the Saturday we invited our neighbour, Graham, to join us for a short thirty-two-mile trip to Jodrell Bank and back. On this nice sunny day our usual discipline of cycling efficiency was turned into a race prompted by Graham taking the lead on the return home. It was good fun to have a change and good training. Squash with Jim followed on the Sunday with a further bike ride on the Monday. As Sam was suffering with a cold it was just Elliot and me for the sixty-five-mile trip up to The Cat and Fiddle and Buxton then through the picturesque Goyt Valley via Errwood Reservoir and back where the hills were steep and unending, at one point travelling at 40 mph downhill. That speed was scary enough for me! Despite the hard ride my thighs felt fine for another game of squash the following evening. That weekend brought us to 3000 cycle training miles since we had conjured up our challenge nineteen months earlier, the equivalent of cycling from Manchester to Jerusalem. Facing Challenges Together had reached £5000 in donations.

With the dimensions of the support van determined, Phil was keen to get it ready. The boys left the job of van logo design to me! I loved that sort of creativity and liked nothing more than something original and different. Years ago, on holiday in Wales, on a rainy day, Gordon introduced me to pencil drawing. Relishing a challenge, I got to grips with pencil and paper and within a few weeks found I could draw pencil portraits reasonably well. For a short period, I went on to do portraits of famous sports people, getting them signed then giving them away to be auctioned off. Gordon – who had been an architect – and I enjoyed creating little bespoke designs and alterations around our house. Those little touches which were visible on a daily basis were a happy reminder of good times. He would have been proud of his godchildren and me. It was appropriate that his influence back then was influencing us now.

Elliot in particular was doing a great job with the FCT website. He had no formal training in IT, just YouTube and trial and error. We were averaging fifty hits a day on our site with a peak of 168 in one single day. Not bad, I thought, for novices. Though The Christie and Macmillan's fundraising departments did offer as much help as they could we were pretty self-sufficient.

I'd still not heard back from DVLA regarding my driving status. Despite having several interested parties to take over my practice, none had come to fruition. PhysioSport was busy again and I was coping well with long days and the volume of patients. I felt more inclined to get someone to help me with the workload, someone that might eventually take over from me in several years.

Elliot had recently bought a Garmin satnav to navigate our journey. Any straying off route could be costly in time and energy. It also had a heart rate monitor. The lads had the bright idea of having the device on their bike with the heart rate monitor on me. That way they could check whether I was coasting along or could push me to my maximum!!

The cycle training had slowed for a few weeks. The lads had end of year exams so long five-hour rides were out of the question. I was content with short sixty-minute indoor sessions of cycling or rowing with the odd cycle to work and back.

Paul Crone called me in the afternoon of 14 May to let me know our TV clip would be aired that evening. He and the producer were really pleased with the clip, as were we. Perhaps the only bit we could have improved was the mention of Facing Challenges Together. People may not have made the connection. But this was a learning curve and I felt sure the appearance would ultimately lead on to other opportunities.

Prof Homer confirmed he would be able to join us on 2 July for our 'grand depart' from The Christie and official send-off. Maybe this would be another chance for some public relations. There might be a new angle to take? 'Consultant saves patient's life then supports patient in bike ride for charity'?

The following week I had a call from a friend and physio who I had trained with, Dave Roberts. He knew of my illness and charity ride. He'd just been let down on arrangements for a physio to support the Dallaglio Cycle Slam and wondered if I could fill in on two weeks abroad, one week in Italy, and one in Switzerland. As it was a charity event there was no remuneration, but Dave pledged to support our challenge to the tune of £1000. Furthermore, as long as I got the physio side of it sorted, I was free to cycle some of the most scenic regions of Europe with the other riders. The cycling terrain and trip certainly appealed but I needed to think about my own practice and a trip abroad, which I'd had not done for several years but Dave needed a quick response. Yes, I'll do it!

The schedule was tough in terms of hill climbing with distances averaging eighty miles a day. Without knowing the format yet, I was hoping to cycle the mornings then rest ready to accept the riders who had done 'the full Monty'. That represented ideal training for me without being too exhausting. It would be my first time abroad since my diagnosis. Fortunately, I had checked my passport was fully up to date and the authorities were happy to accept my changed appearance without new photo ID. Getting someone to cover my practice at short notice was very difficult and ultimately fruitless.

The week concluded with a trip to a local optometrist at the request of the DVLA for an ordinary sight test and field of vision test. The former I completed with flying colours the later hopefully well enough. Resting my chin on the rest I focused on a light source in the centre of a large white coloured bowl. I had a button to press each time I spotted a light anywhere in the bowl. Of the 128 flashes I spotted 120. The eight I missed were on a tiny arc to my lower right side. If I'd had a chance of repeating the test I think I could have angled my head that bit further downwards and captured them all. Frankly, as long as I passed and could continue driving, I was happy.

It was now thirty-nine days until the start of Facing Challenges Together.

The weekend weather was poor, though the bank holiday Monday brightened up to give the three of us the chance to test out the Garmin bike satnav on a fifty-five-mile trip around Cheshire lanes and moderate hills. The following week was busy sorting a proper packaging box for taking my bike on a flight, booking the extra box onto each flight, sorting my mobile phone for European use and arranging travel insurance. I did get a reasonable quote though they would only cover me for a single trip. Having a rare form of cancer, I was rejected many times before I found a company that was specialist enough to take me. It was a very busy week at work trying to sort everything before going away. Cheryl would cover a few extra hours to see PhysioSport through until I returned. A visit to SK:N for hair removal completed the week.

That weekend I packed my bike and clothes for the early flight on 1 June.

# Chapter 27 Trip

I met up with Dave Roberts, at Manchester Airport Terminal 1 and was introduced to paramedic Rob Watson, fellow physio Jack Dixon, and Dr Simon Morris. Our flight to Venice went smoothly and as we came in to land, I had sight of Venice, which was much smaller than I'd anticipated.

There was no time for tourist trips as we were quickly shuttled Northwards towards the Dolomites, to the lovely walled city of Treviso. On arriving, Dave introduced me to Lawrence Dallaglio who was a few centimetres shorter than I'd expected but broad and powerfully built. Following a few more introductions we left for lunch at one of the traditional town squares. For me it was good to get through the flight without any unforeseen medical difficulties, something most people – including the former me – would previously have taken for granted. Having caught up with Dave over lunch we were back for an introductory meeting with the participants for the first week's cycling.

The first day of the Dallaglio Cycle Slam 2014 was to ride seventy-two miles from Treviso to Belluno heading into the Dolomites. I was keen to ride but bowed to my physio duties. I travelled in the ambulance with Rob who would also be my roommate for the duration of the trip. I noticed when putting on my socks I had the small bruises which I associated with the HSP. I felt sure it was a reaction to flying. Perhaps wishful thinking. I'd just have to keep a watchful eye on the situation.

As physios we were to support the riders before, during and after the ride which made for long days. The first day was light, with the odd requirement for assistance which was much as I expected with fresh riders. There was a lunch stop and evening meal each day. The lunch stop was organised by proper caterers. I was hoping to pick up useful tips for our own ride from the variety of fabulous easy to digest foods and snacks they produced. Everyone had their own individual nutritional preference and requirements.

Each rider had a daysack containing extra clothing for rain protection and the long cold mountain descents. Gary was charged with the task of getting the bags to the lunch stop each day and to the hotel at the end of the day. As riders were split into six groups of varying cycling prowess, getting bags there for everyone all of the time was an impossible task. Some riders were happy to saunter and have lots of coffee stops while others rode it like a race. As the distance between the front and back riders grew, supporting all riders for emergencies, both mechanical, provided by Halfords, or medical, became difficult.

As the day had been relatively uneventful – apart from a suspected heart attack brought on by a dry tuna sandwich – I asked Dave about me cycling the following morning which was met with a firm 'no'. Despite that refusal I had my bike assembled and kit on the following morning just in case he'd had a change of heart. I'd discussed with the doctor the merit of cycling close by the gentleman with the heart scare, carrying a defibrillator in my rucksack, just in case. Instead, that day I hitched a ride from Belluno to Cortina in a support vehicle with Simon the team doctor. Simon was a GP, but also contracted to Burnley Football Club and Lancashire Cricket Club. He was a great impressionist and interested to know my story. It took the whole day to give him the full history of my illness, punctuated by navigational issues along the route and attending to riders. Again, it was fairly quiet on the physio front during the day which increased my frustration at not riding, but a number of riders started to trickle in later in the day with the aches brought on by the day's intense efforts.

The third day was Cortina to Bolzano. There were two climbs of nine and six miles in the morning followed by a long descent in the afternoon. Dave allowed me to cycle the morning, which was all I had requested. I cycled perhaps too fast up the climbs with some of the fast boys, enduring cramps in both thighs, but carried on regardless. It was great to get out on the road as I needed to train for my ride. Sitting in a vehicle the past two days, seeing other people riding, had been purgatory, especially when we'd been needed only a few times.

The scenery was spectacular. Snow topped mountains all around. As it was, I could have cycled back to the hotel to set up the physio room for the early arrivals quicker than waiting for a lift in one of the cars. I was happy to have bagged my tough morning ride and hopefully get another chance on the final day. The other cyclists liked the idea of me riding with them. They knew I had complete empathy and understanding with their physical and mental strife. I'd chatted to and treated a good few riders by now. All the riders including a few celebrities, were very friendly, which included Steve and Scott who joined me for breakfast that morning. The fourth day was Bolzanno to Bormio via the famous Stelvio route including forty-eight hairpin bends to climb the towering escarpment frequently riden in the Giro D'Italia and a training ground for professional cyclists. Tough on the thighs and busy in the physio room.

Then the final day of stage one, and I was pleased to be cycling again. Lovely Bormio to St Moritz and our final stretch in Italy before crossing the border into Switzerland. Only forty-nine miles. There were two early climbs of fourteen and five miles, several smaller climbs and some long descents. Scott, Steve and Clive caught up with me by the second climb and kindly allowed me to stay with them by pausing along the route and taking photos. The views were magnificent, at one stage cycling through roads with snow two metres high on either side. The descents were long and straight, enabling me to reach 48 mph on the smooth nonpotholed tarmac. This had been the ride of my life!

For most of the riders this was their finale, the end of their week's trip, thus there was less demand for treatment that evening. We said goodbye to many of the cyclists that night following the meal. One guy who was perhaps slightly younger than me with two children gave me a huge hug. He was visibly upset. To my utter surprise, he said I'd changed his life. We had talked earlier in the week then followed it up by reading my story on our Facing Challenges Together website. The lads at the table with me were, I thought, taken aback by the strength of emotion, as was I.

The Saturday was a rest and change-over day. Despite that, there were people to treat in the morning and afternoon who were cycling several stages. I made myself available to treat people in an effort to make up for my cycling, which also allowed the rest of the team a trip up the mountain behind St Moritz for lunch with stunning views. I was also content to miss out on the nightclub the previous night in favour of watching England v The All Blacks at 9.00 am the following morning and walk around the lake and town at midday, knowing I could be available at short notice if I was called back to work. I wasn't interested in any heavy drinking sessions. My head had plenty to cope with without a hangover.

Each evening, following the meal, Lawrence was invited to dish out 'fines' for the day's indiscretions, in the form of shots of Grappa. He was naturally gifted with the microphone, handling the audience with great humour and wit.

Before approaching Dave regarding my week's cycle training, I had looked at the schedule for stage two. There were two short runs the first and last days with a suitable morning ride the third day. I didn't think I'd be letting either my colleagues, who knew of my challenge, or any rider down. Using the previous week as a guide I thought there would be no problem asking Dave – wrong! Following a discussion over what was agreed, and a little charm, we settled on me riding the following day and to review the situation on a daily basis.

On Sunday 8 June, we rode 50 miles from St Moritz to Chur, which had been used as a stage in the Tour of Switzerland, a nice easy training run for me.

The following day, I was alternating lifts with Rob and the doctor, supporting from Chur to Altdorf. The temperature had soared to 40 degrees Celsius. Dehydration was more an issue now than cold. I revised my knowledge of heat stroke and exhaustion with the doctor.

The third leg was Emmenten to Interlaken. I rode the morning, starting at Lake Lucerne along the flat leading into the nine-mile climb to the top, then back into physic role at the lunch stop. Interlaken was so pristine.

The following day I was in physio-mode all the day to Montreux. We stayed in a beautiful hotel overlooking Lake Geneva with the best views from a hotel I'd ever experienced.

I cycled the remaining 55 miles from Montreux to Chamonix, with two good climbs of ten and five miles. Once again, we were not really in much demand that final evening. It was our turn to say goodbye this time as Rob, Jack, Dave and I were going home the following morning. The trip home was uneventful apart from the ambulance being stopped by police near the airport and being ordered to get back to France, a stewardess questioning me on my visual capability to operate an emergency door near to my seat and failing the e-passport entry back into the UK. Elliot collected me from the airport with Sam and Lesley greeting me at home.

The whole trip had been a massive success. I'd met lots of nice people and had a great time with Dave, the team and the riders. I'd travelled abroad for the first time in years, seeing some of Europe's most spectacular scenery. Dave really looked after me, treating me like a little brother all trip. He kept me laughing with his unique expressions and dry sense of humour. I'd completed some good training and remained well throughout. My thigh had been trouble-free and I'd avoided as much sun as I could with regard to the flap area. My eye, however, had been painful for several days and the lower leg HSP bruising was still hanging around.

I'd had the chance to assess the Slam from a distance in logistical terms, with regard to our own ride, efficiency of moving from location to location, bike storage, support vehicle and kit access while riding. Our own bespoke kit would be arriving in the next week. Only sixteen days to go. I was grateful to Dave for giving me the opportunity of a lifetime. Perhaps, more than anyone else, I took as much as I could from each day for that reason – I might not be back.

# Chapter 28 Prep

I returned to work on the Monday to a busy diary. I also had appointments that week with Prof Homer and Miss Cook.

Prof Homer had a good look up my nose with a nasoscope. As far as he could tell all was well, apart from discovering there was a MEDPOR plate up there that he was unaware of. We discussed widening of the nasal passages to improve my breathing and there was a possibility of a day case operation with splints up my nose for a few weeks, sometime after my bike ride. Originally, I'd thought of putting off any further operations until I'd had my next scan. I'd not got through an annual scan without a recurrence in the last three years, but perhaps I was feeling more optimistic now.

During my trip abroad I'd noticed the speckled bruising around both ankles that had accompanied the HSP auto-immune reaction. Prof Homer couldn't easily explain it and in fairness it wasn't his area of expertise. We would continue to monitor the situation with a view to seeing a dermatologist. Lesley had also noticed the slight sweaty feet odour from my nose that I also brought to his attention. For me, the bruising and odour had always been associated with the HSP. I'd noticed also there was a small hard node in my right neck near to the scar, resulting from connecting up the circulation to the flap in December, and a small bump in front of my right ear. Prof Homer was able to reassure me that this was no more than scar tissue and advised me to see my GP regarding the cheek bump. I was now hypersensitive to any lumps and bumps so I needed to hear that. There was no suggestion of a scan or biopsy.

Miss Cook removed the stent from my left tear duct the following morning in the hope of leaving an intact channel. I would have to monitor the situation over the next few weeks to assess any improvement. Fingers crossed! We had a nice chat despite the busy clinic and she wished us well on our forthcoming trip. More than most people she had seen me at my absolute low, clinging to life and in desperation when I first met her with the HSP reaction. She and the other consultants could take a lot of satisfaction from my rejuvenation following my huge operation only six months previously. That weekend, the van for our Facing Challenges Together journey had arrived on my drive courtesy of Phil. It was the amazing! It had six seats, air conditioning, alloy wheels and space for five bikes, and was also liveried up with all our logos – our own and our sponsors, The Christie and Macmillan – along with our website and Twitter details. It looked professional but also fun. Sam and I took it for an immediate trip to the Peak District, walking Kinder Scout via Jacob's Ladder. It was a short three-hour jaunt and a trial test of the van, walking equipment and our walking legs. We made short work of it by running some of the track to get back for a celebratory meal with Ell, Sam, Lesley and her boys, Elliot and Josh. Ell had just been awarded a first for his anatomy degree, Sam had honours in his end of year exams, Lesley's Elliot has finished his GCSEs and Josh his internal exams. We all fitted in the van together.

My lads had performed incredibly well once again. They were proving to me they could work well despite adversity and distractions – perfect training. The university had assessed and granted an application from both Elliot and Sam to transfer clinical work from Preston to Wythenshawe so they could be nearby for me.

With ten days to go some more polo shirts and our cycling jerseys had arrived. The jerseys in particular were so good, more than matching my expectations. It was like organising a wedding when there's a lot happening at the beginning, less in the middle, then increasing activity as the big day approaches. It was all coming together. Our fundraising had reached £7000. I was really looking forward to congregating at the recently constructed Oak Road main entrance of The Christie, with our bespoke van, our matching outfits with bikes, my lads and Prof H.

The following week was pretty straightforward. I had only the skin clinic to attend. Hair removal was going really well so far. I had a session on the rowing machine while the boys were able to spend more time out on the road bikes having finished their courses for the year. We were busy sorting the final logistics of our trip, tidying up the website, arranging the bike tools and parts we might require, medical kit and final list of food items and sorting the best method of stacking the bikes in the van. It was particularly important not to damage the delicate gear mechanism at the rear of each bike, so Phil had arranged for the van to have multiple anchor points for securing the bikes and bags for any eventuality.

That same weekend, a few days before our FCT ride on the forthcoming Wednesday, I noticed that the small spotted bruising on my lower legs had multiplied. That, coupled with a moderate sweaty feet odour from my nose detected by Lesley, set alarm bells ringing over an infection in my sinuses. Lesley persuaded me to go to Manchester Royal Infirmary walk in centre for a check-up that Sunday morning. I was seen by a very polite and kind nurse who admitted she knew very little of the complexities of HSP. She made the right call to get me seen by the ENT experts. Following some blood pressure, temperature, and chest auscultation checks plus a blood sample, I was off to be seen by Mr Alex Bowen, a young ENT specialist.

Having read my notes, he had a good handle on my case. Looking into the nasal cavity and given that I had a slightly raised white blood cell count, he concluded that it was an infection, which was the likely cause of the HSP reaction. I could either be admitted for intravenous antibiotics and observations or go home and be vigilant. I chose the latter. I had too much to do in preparation for our trip, at work and home for an inpatient stay. I started immediately on antibiotics, clindamycin and co-amoxiclav, advised by the histology department.

That morning just about summed up my life. Arranging something with any certainty was difficult. My life could change in an instant. The roller coaster which had been calm for a good few months had just reminded me of its potential to frighten. I'd trained for twenty months for this ride. How cruel would it be to deny me now at the eleventh hour!

I had my busiest two days at PhysioSport for two years, seeing as many patients as I could before I left, finishing at lunchtime on the Tuesday to give me sufficient time to sort any last-minute issues and pack our bags. The HSP bruising and smell had peaked. Hopefully the antibiotics would hold it off to enable me to complete our long-anticipated event. I texted my friends and followers to remind them we were starting our challenge. The biggest challenge for me had been to make it to the start line!

#### Chapter 29 Three Men And A Van Driver

Wednesday, Day 1: The boys and I left from home just after 12 noon Wednesday 2 July 2014, arriving in our bespoke van at The Christie main entrance at 12.30 right on cue. The newly constructed entrance was a fitting backdrop for photos, while the off-road drop-off area afforded a safe place for the twenty-five or so people to send us off. The thirty minutes before we left rushed by with so many photos and last-minute hugs and best wishes. Prof Homer adorning his new FCT cycling top to match ours completed a pretty professionallooking team. Literally, a last-minute interview with The Christie's communications department photographer and we were off to the tune of cheering and clapping. It was a fitting send off.

The morning had been sunny, but as lunch time approached some cloud rolled in making for a slightly cooler and more preferable temperature. There was a strong head wind of around 15 mph as we headed South then West towards Denbigh in North Wales, a distance of seventy-two miles. Our strategy was to stop each hour for a short break to take on food and water if necessary, then stop every three to four hours for a major refuel at a pub or café. We rode through Northenden, Wythenshawe and Altrincham to Ashley where we turned towards North Wales, following close to the M56 and taking in High Legh, Stretton and Preston Brook before reaching our first moderate hill beyond Frodsham: Helsby Hill. Shortly afterward we stopped for major refuelling at Dunham-on-the-Hill. Continuing on through Ellesmere Port, crossing into Wales to Shotton until Northrop, we encountered much quieter back roads through to Denbigh, our destination for day one. We packed the five bikes into the van at 7.45 pm, courtesy of some fellow's driveway, then headed back home for the evening.

I chatted to Prof Homer in the rear seats while Mark O-B, our driver who was in a hurry, tested our method of securing the bikes! We arrived back for 9.00 pm to a welcome from Lesley and family and a lovely smell of lasagne. Or so I was told (I couldn't smell it). We all had glowing wind-burned faces and my thighs felt like furnaces the whole night. The weather had been kind to us. Prof

Homer had cycled really well, though I suspect his thighs knew it the next day. I believe he had done a bit of supplementary training to fell running and triathlon to be sure of not letting us, or himself, down. He was competitive, determined and seemed pretty good at everything.

While travelling back home, he and I discussed the implications of the reemergence of the HSP. His thoughts were to continue on the antibiotics, so long as my stomach could take it, get a CT scan when I got back and perform an operation to widen my nasal cavity at the same time as looking at the MEDPOR plate, which could perhaps then be removed.

In other news, Murray was out of Wimbledon going down 3-0 to Dimitrov – a shock.

The Garmin satnav system for Elliot's bike helped us navigate our way each day. It proved brilliant at finding small narrow roads where the traffic was light or non-existent. Each evening Elliot would work on 'Map My Ride', a website, updating the Garmin with the following day's itinerary. That first evening, he tipped water over his laptop keyboard rendering it useless. Fortunately, Sam's laptop came to the rescue.

Thursday, Day 2: Continuation of our cycle from Denbigh to Snowdon, forty-one miles, climb Snowdon (3560ft) then cycle onto Bangor thirteen miles further.

Bob Sabberton (driver number two), arrived at 7.45 am and helped us complete the loading of the van. We had my spare road bike in case any of us had real mechanical trouble, cakes, flapjack, nutritional bars and gels, cool bag, The Christie's shirts and FCT water bottles, medical kit, cycling and climbing gear, some clothes for leisure wear and bike maintenance/repair box. Fortunately, there had been no damage to the bikes from the return journey home the previous evening, but we modified our means of securing them by packing bags between each wheel to increase stability. As we travelled back to Denbigh I spoke to Dean Kirby, a reporter from the *Manchester Evening News*. Sarah had been in contact with him the previous day. Would this be a breakthrough for our publicity?

The dry conditions turned to rain as we prepared to cycle the morning's forty-one-mile run to Llanberis. We were on quiet back roads with heavy rain and strengthening headwinds. Soaked to the skin, we repeatedly clawed our way up short but steep 25% hills, zigzagging across the road to lessen the steepness. Coming on top of a moderate ride the previous day, the energy was soon sucked

from my thighs. Cold and wet, I sat sheltering in the van footwell, head bowed, muttering, 'Bloody hell, Bob'.

On one of the steep wet descents, Sam, who wasn't the most confident of descenders to start with, locked up his brakes. Following behind I could see his bike snake uncontrollably until he hit the tarmac and then the grass verge – a less desirable stopping mechanism. I was able to stop reasonably close by and run back up the hill. Fortunately, he had landed well. Only a few grazes and tears in his jacket. We had started riding at 9.30 am. By lunchtime we'd reached the base of Snowdon at Llanberis via Capel Curig and the Llanberis Pass – a welcome downhill run for all our hard work. We changed into climbing gear, packed the bikes in the van and headed for lunch in the café close to where the mountain railway departs. The sun had appeared, thank goodness. We each consumed an Oggie, a large local meat and potato pasty. Being cold to the core, it was so good to eat something hot with a hot cup of tea. I was giving back to my body what it had lost in the morning toils.

Sixty-nine-year-old Bob had previously not been entertained by the thought of walking up Snowdon (1085m) but, at the sight of the sunshine and prospect of good views, made a swift U-turn and decided he was coming up with us. The boys strode ahead of Bob and me, up the well-defined stone track, pausing occasionally to allow us to catch up. While Bob and I were having a nice conversation, putting the world to rights, the weather was turning bleak again. Heavy rain was again accompanied by strong winds. As we climbed the 4.7 mile path to the summit we asked those coming down what it was like at the top. The familiar answer was it was far too windy and dangerous to attempt it. The railway had stopped running people to the top and the café at the peak had closed. Cold and wet, we trudged onwards and upwards in poor visibility until it became clear we too were not going to make the summit that day. The wind was fierce. Fortunately, we still had enough sense to turn around 500 metres from the peak, knowing we had tried, without putting our own and other people's lives at risk. We would also be denied the fabulous views on offer at the summit on clear days. As we descended the path the weather brightened once more.

On changing back into clean, dry cycle kit we resumed our thirteen-mile cycle trip towards Bangor on good fast roads. There, we stayed at a well-known chain where we had a decent bed and shower. We spared the bikes a trip in the van by having them in our rooms overnight as Bob returned home to allow Mark O-B (driver number one) to resume on his return to Bangor that evening. While that changeover was taking place, we had enough time for a large burger and

chips. Not my normal diet but it could provide calories and warmth - and was available at Berger King! It had been such a tough day with the disappointment of not reaching the summit. If every day was like this, I could see the schedule slipping, or not being able to complete the whole thing at all.

Friday, Day 3: 25 mile cycle to Holyhead, ferry crossing at 11.50, arrive Dublin at 2pm, 54 mile cycle to Dundalk.

Each cycle ride started with the very important ritual of applying chamois cream to those areas subjected to pressure and rubbing while on the bike saddle. I'd never done this amount of cycling previously, so I was extra keen not to be doing it with a sore ass. Following a cuppa, instant porridge and some muesli we were on our way at 8.00am. As we started riding the rain lashed down. The roads were busy as we headed towards the Menai Bridge which connects Anglesey to the mainland. Spray from the rush-hour traffic added to our soaking. Two hours of gentle undulating road completed the 25-mile journey to the ferry port at Holyhead where we changed out of our soaked gear into normal clothes for the ferry crossing, packing the bikes securely in the back.

The ferry was busy with passengers on this rough crossing but neither made a difference to the four of us as we slept most the journey having eaten lunch aboard. On arriving in Dublin, the weather seemed brighter. We made our way to the outskirts of the city to recommence our cycle route where we discreetly changed into dry cycling kit. Not dry for long, though, as the heavy rain resumed. The road surface on the fifty-four mile journey to Dundalk was poor and rough, causing us to work harder for the same speed and to attempt cycling on the ten centimetre solid but smooth white line painted on the road side. Allied to that, the spray coming up from the bike in front meant we were unable to ride in close single file and we couldn't benefit from the drafting effect of riding as a team. We rode through small villages and past isolated beautiful properties on flattish roads. The number of times I asked Elliot 'how far to go?' was a marker of how tired I was feeling. I was so wet and cold I needed to eat and drink something warm for replenishment. Fortunately, we found a Chinese 'chippy' making lifesaving hot chips before I expired completely. Having sat in the van to get warm and using up my last remaining dry garments, we continued on to our B&B in Blackrock, arriving by 7.00 pm.

We had a family room and the use of a washing machine and drier – phew! With the two machines working flat out we left for a meal out at a fantastic Chinese restaurant overlooking the sea. Our average speed had dropped from 16 mph on the first day to 13.7 mph. That was a reflection of the previous day's hilly and hard ride, poor road surface and the sapping nature of the weather. The van had been our saviour providing us with dry clothes, a place to shelter and food snacks.

Saturday, Day 4: 40 mile cycle north through The Mourne Mountains, climb Slieve Donard (850m) plus cycle 33 miles to Belfast.

A lovely, cooked breakfast was followed by the ritual packing of each of two bags. A day bag for all the items we might need that day and a larger bag containing day clothes and any remaining cycling/climbing kit. It was supposed to make it easier to find kit as and when we needed it. In practice it didn't quite work.

As some of the clothes were still not quite dry the dashboard and van front seats converted into the mobile laundrette. Thankfully we were treated to a sunny, dry forty miles of cycling. Heading North with lovely views of the Mourne Mountains we soon crossed the border with Northern Ireland. Hill after rolling hill mapped the way to Newcastle and Tollymore Forest Park, County Down, the entry to the main route up Slieve Donard (2789ft). By midday we had the bikes in the back of the van on the sea front car park readied in our climbing gear. Time to refuel at Nikki's Bar where the staff took a genuine interest in our challenge and the food was great.

It took four hours to complete the walk to the summit and back while Mark stayed with the van. The first third of the route was formed by rocks and tree roots, followed by another half of the route laid with stone alongside a beautiful stream, before a final shorter but steeper section. As we climbed higher the wind speed increased. Fortunately, the final section had been afforded a stone wall, giving protection and, with only a few spots of rain this time, we were soon at the summit. The Mourne Wall, built 1904-1922 was continuous with a tower at the peak. There were great views on this sunny afternoon over the Irish Sea only two miles away: Newcastle, Dundrum Bay and Belfast. On our ascent we had bumped into some guys who had overtaken us on the road. Recognising our shirts, they paused to question us. It was reassuring that people had taken notice. As there was also a Macmillan walk and cycle taking place over the weekend from the forest at the base, we felt in good company.

Following a quick change of clothing we were once again on our way cycling North to Belfast. The roads were good and any rain, which we'd seen

from the summit didn't cross our path though the streets of Belfast were awash, causing us to get soaked anyway.

As we entered Northern Ireland there were gates proclaiming Unionist areas with numerous Union flags. Even the kerb stones were painted in red, white and blue. I had grown up with the Northern Irish conflict, but my boys being younger had little recollection. This was quite an education.

We ate in a pleasant hotel that evening which was reasonably priced and saved us any walk. Most people at home might suspect I had been involved in a car accident. In Belfast they may have though it was more likely to have been a bomb blast.

Meanwhile, Kvitova had beaten Bouchard in a very one-sided Wimbledon ladies final for her second title that afternoon and the Tour de France had begun in Leeds before record crowds.

Sunday, Day 5: Belfast to Larne by van, ferry to Troon, cycle 40 miles to Greenock, exchange van drivers in Glasgow, cycle 35 miles from Helensburgh to the Northern tip of Lock Lomond.

Originally, we had planned to cycle the flat twenty-five miles to Larne from our hotel, however, the ferry was very early, at 7.30 am, which would have meant getting up at 4.30 am to be there in plenty of time. We were too exhausted for that and in need of a good, full night's sleep. We contemplated cycling to Larne the previous evening, but we had already had an exhausting day and reached the hotel the previous evening at 7.00 pm, too late to take it on. Following our usual homespun breakfast and with our bikes already secured in the van we set off just before 7.00 am. On reaching the ferry terminal, which was much quieter than Holyhead, we were directed on to the ferry without delay. We departed from Larne early for a very calm and sunny two and a quarter hour journey back across the Irish Sea. After the on-board cooked breakfast, which went down well, there was an opportunity for a quick kip.

Arriving just north of Troon, we found a discreet spot to change into cycle kit and unload our bikes. Passing through Kilmarnock, we headed north to Stewarton and Lugton before reaching Greenock on the Southern shore of the Firth of Clyde. The road surface was good on the undulating route. That coupled with a light following wind made it possible to travel more quickly, completing the journey in two and a half hours.

Originally, we had planned a ferry crossing to Kilcreggan, however, Mark O-B needed to swap with Bryan (driver number three) who had made his way up

to Glasgow by train. We loaded the bikes securely, then we all headed off to Glasgow Central for the exchange, me nodding off in the front seat. Catching a nap whenever possible had become a feature of mine by now. I was sleeping poorly, partly as a result of my restricted nasal breathing, the antibiotics, which were now playing havoc with my guts, and the infection I was fighting. We exchanged drivers by 2.00 pm and headed to the Northern shore of the Clyde at Helensburgh, sparing us the ferry crossing. We had a very nice lunch at Waitrose, where we also stocked up on fruit and a few necessities before resuming our cycle Northwards. Happily, the sun was still shining. The thirty-mile route took us parallel to the most spectacular scenery so far, first Loch Long then Loch Lomond from Tarbet, Northward to its tip where we completed our journey. Once again, we packed our bikes, travelling back to our pre-booked accommodation at The Tullis Inn.

Our accommodation, the meal that evening and our breakfast were all lovely. They even obliged by making a smoothie of some raspberries and strawberries that Brian had brought from his allotment. Our average speed had risen to just over 14 mph and we had passed the 300 mile mark, visiting five countries in only five days. There was an unfortunate incident with a camper van driver, who clearly didn't appreciate cyclists on 'his' roads, squeezing me into a crash barrier in a deliberate act of reckless road rage.

Earlier, Novak Djokovic had beaten Federer in a thrilling three sets to two victory to take his second Wimbledon title.

Monday, Day 6: Cycle 60 miles through Glencoe to Fort William.

Following breakfast at the inn we left in the van, dressed in cycle kit ready to resume our journey from the tip of Loch Lomond, North towards Fort William. We were riding by 9.30 am just in time for the rain to begin. Passing through Glencoe was both hilly and hard riding but made easier by the light traffic. The low cloud obscured what would surely have been some of the most fantastic views so far. By lunchtime, we were looking for a hostelry to warm up and get dry though there were none to be found apart from the Glencoe Ski Centre. A short departure from our route gave us the chance to change into clean dry clothes for some much-needed fuel at the centre. In the afternoon we continued our ride Northwards, tracking the Eastern side of Loch Linnhe on roads that had only small undulations. The rain persisted until we reached Fort William where a Morrison's store gave us some refuge from the incessant downpour. We had reached our most northerly point. Hurrah! Once again, we needed to change into dry cycling kit, restock the van with food and buy food for that evening's meal while we refuelled in their restaurant.

We had a few hours left of riding, so we chose to clip off the thirty miles we had planned in the schedule for the following day. It enabled us to stay slightly ahead in case of any unforeseen eventualities. The evening sun greeted us on our ride back Southwards towards Oban. Distracted by the spectacular scenery of Loch Linnhe and Loch Crenan on our right, my thighs stopped registering the pain of nearly 400 miles cycling. We bagged the extra miles and returned to an apartment in Fort William to prepare for our Ben Nevis climb.

Over the previous two days, Sam's bike had developed an unpleasant grating noise. As Sam and Bryan prepared the meal I set to work on Sam's bike as Elliot did his usual updates on the PC, apart from when I needed an extra pair of hands. After some diagnostic spinning of the wheel and head scratching, I suspected it might be the rear wheel bearings. On taking the wheel hub apart the bearings were greaseless. I cleaned the mechanism, regreased, and reassembled the wheel hub, hoping I had addressed the problem, if only temporarily, to get him home. Otherwise, he was on my spare bike. Fortunately, it worked.

The boys in the kitchen produced a delicious risotto to complete the day's consumption. I had eaten muesli, a full cooked breakfast, strawberry/raspberry smoothie and two cups of tea at breakfast. The usual flapjack, cake, banana, apple, Titan bars and energy bars at the four van stops, four litres of water along the way, fish, chips and veggies at lunch, cheese and onion toasty at five-ish and two plates of risotto, two bottles of beer, plus the usual skimmed milk that we drank immediately on completing every day's activity. We were burning more than 6000 calories per day.

Once again, we made use of the washing machine. That evening was the beginning of scratching at insect bites for which the West coast of Scotland is notorious at this time of year. I don't know how the locals manage. My HSP rash was disappearing, allowing me to stop the antibiotics. With a few days under our belts, we were all cycling better, feeling stronger and the weather forecast was encouraging too.

That evening we had an article published in the *Manchester Evening News*. Only when I returned home did I find out what an accurate portrayal Dean had produced.

Tuesday, Day 7: Climb Ben Nevis (1344) and cycle 30 miles East of Oban.

We were up at 7.00 am, our normal waking time each day. Bryan took us on a short van ride to Glen Nevis at the base of Ben Nevis (4409ft), Grampian Mountains, the highest peak in the British Isles, for the climb which we anticipated would take us seven hours. The Pony Track, referred to as the Tourist Route, was well prepared with rock and stone, paving the way to the summit, with a gradient more or less similar to the top. Pausing for a break each hour for something to eat, we reached the peak within three hours. The rain couldn't quite keep away with moderate showers both on the way up and down. As it was too narrow to walk three abreast on the path the boys walked ahead of me. It allowed me time to think, contemplate and appreciate having the opportunity to undertake a once in a lifetime challenge with my two sons. Our relative ages would suggest that as their fitness became greater mine would similarly decline, so there was a certain window during which we could more or less endure similar amounts of physical strain. On our way up we had fabulous views of the surrounding lochs and hills which disappeared behind clouds as we approached the peak, formed from the dome of a collapsed volcano, where it was cold enough at the top to sustain snow in hollows. We sheltered from the moderate cold wind for lunch at the summit among the ruins of an observatory last used in 1904. Another three hours descending over occasional trickling streams, and we were meeting Bryan with the van ready to take us close to Oban where we had finished the previous evening.

We had another two hours of cycling in the warm late afternoon sun by Loch Etive, clipping off some extra miles before returning to the prearranged accommodation in Oban which had great views over the harbour area. The hostel provided us with a large room suitable for all four of us. We ate locally along the harbour front area, haggis being the order of the day. Being past the halfway point in days and distance was a reassuring watershed.

In the background a TV was showing Germany hammering Brazil 7-1 in the football World Cup semi-finals.

Wednesday, Day 8: Drive from Oban to start point, cycle 75 miles to Bridge of Weir.

The sun was shining and the wind slightly behind us as we resumed our cycle from the prescribed point on the route past beautiful lochs and hills. The terrain and conditions allowed us to ride at a faster pace Southwards towards Dunoon and Hunter's Quay, our crossing point over the Clyde. Loch Awe, Loch Fyne and Loch Eck in the Argyll forest were spectacular.

We stopped after forty miles for lunch at a very nice inn along the route. I was so tired I fell asleep at the table between ordering and the main course arriving. Continuing for a further fifteen miles we reached Hunter's Quay by mid-afternoon for a serene and gentle crossing by local ferry to Gourock. Another twenty miles in the warm sunshine completed our day. Elliot had sourced a local golf and country club for the evening, where we made full use of the pool facilities to ease our aching bodies. A pleasant meal followed.

The Argentina v Holland semi-final went to extra time. I found out in the morning that Argentina were the victors. I just couldn't manage to stay awake to watch it live.

Thursday, Day 9: 100 mile cycle to Lockerbie.

Once again, we woke to sunny skies. Having refuelled on our self-prepared breakfast of porridge and muesli we were in the van going to our drop point. The hills during the morning session prohibited us from developing any rhythm over the fifty miles of moderately steep inclines, passing through Mauchline and Pathhead, before stopping for lunch in Sanquhar. Once again, I fell asleep at the table. Cycling on in the midday sun we happened upon the beautiful Drumlanrig Castle, where we paused for photos. Shortly afterwards we stopped again, this time to replace my punctured inner tube, surprisingly, the only occasion we would do so throughout the whole trip. Onwards we cycled through Thornhill, then East of Dumfries via Lockerbie to Ecclefechan and ultimately Annan. Elliot had arranged a very spacious cottage out in the sticks for that evening's refuge with the all-important washing machine. Bryan, who was proving to be the perfect butler and chauffeur, had purchased the evening's food and did the honours in the kitchen, to the hum of the washing machine. Ell did the website updates. I repaired some damage to my rear wheel rim resulting from the earlier puncture.

As the evening air cooled, we ate outside with views of open countryside and the company of a pony reaching with its neck over the dividing fence. We had passed the 600 mile marker and chalked up 100 miles riding for that day. After much deliberation, Elliot and Sam redefined the route for the following day. The forecast once again was for fine warm sunshine.

Friday, Day 10: Cycle 68 miles from Southern Scotland to Langdale, the Lake District. Cycle extra miles from the following day's schedule.

We left Bryan in the morning sunshine toiling with the clothes that still hadn't dried overnight, while we cycled through Gretna Green, and I explained to the lads the significance of eloping to Gretna to get married in the days when parental consent was more significant. We were over the Anglo-Scottish boarder in no time, riding twenty miles of relatively flat roads followed by forty-six miles of hard rolling hills. There was no wind. A lovely country pub was the venue for our lunch stop. Determined to taste all the local delicacies wherever we went, I had the Cumberland sausages.

By mid-afternoon we reached the point in the Langdales where we would be walking to the next day. In the sunshine and clear blue sky, the Lakes were an oasis of shimmering colours. Exhausted, I fell asleep once again, this time on a jagged narrow stone wall! Our first mission on recommencing our cycle was to take on an incredibly steep hill pass. The boys had deliberately taken me off course as a bit of a joke. They were ahead as I struggled with the heat and incline. As they came down past me, they said it wasn't part of the route anyway! I was distinctly unimpressed to be wasting valuable energy and fluids.

We had twenty-seven miles of cycling remaining heading Southward, plus a van ride to our accommodation in Eskdale on the west side of Scafell Pike. The van bonnet became the support over which I slumped my depleted body during several essential breaks.

'How much further Elliot?'

'Just another six miles or so', Elliot replied.

We finally reached Newby Bridge where there was a convenient spot at a fork in the road to stop. We carefully packed the bikes for the winding road trip and headed off to Eskdale, picking up Elliot's pal, George Francké, who had made his way up from Manchester by train. That evening we stayed at the Eskdale YHA hostel. Once again, Bryan did us proud in the communal kitchen preparations and cooking. We had nearly 700 miles on the clock.

Saturday, Day 11: Climb Scafell Pike (978m) and cycle on to Earby in Lancashire.

The plan was to ascend Scafell via Wasdale Head at the north end of Wastwater then walk over the summit plateau fringed by crags, descending into Langdale Valley on the opposite side. By taking this route we could avoid cycling the notoriously hard and steep Wrynose and Hardknott passes. The ascent of Scafell Pike (3209) was steep, with loose stones close to the summit making footholds difficult, while the return involved negotiating over large boulders until the path became more defined. I was able to chat with George who was now on map reading duties, teaching Sam and Elliot the finer points of navigation. It took us two hours to reach the summit and four hours to descend the gentler sloping Langdale side until we reached the meeting point with Bryan who had retraced his road journey from the previous day. Bryan took us through bustling Windermere and Bowness to our cycling start point at Newby Bridge.

There were another thirty-five miles left in the day. The first five were hard hills giving way to faster, flatter downhill runs where we indulged in some fun racing. While holding a GoPro camera in one hand, Elliot hit a pothole causing him to be the second faller of the trip. Fortunately, he was travelling slowly, toppled over and was unharmed apart from his pride. Jake, (Elliot's mate) who had cycled from mid-Cheshire for the final hour of cycling until 8.00 pm, accompanied us in the moderate rain and fading light to the YHA accommodation. For the second night running, we slept in bunkbeds in a cramped room. The plan was to start cycling at 8.00 am the following morning to give us time to complete the forty-two-mile run home.

Sunday, Day 12: 42 mile trip directly south to Christie Hospital, South Manchester.

You would be right in thinking that an eleven-day challenge shouldn't take twelve days but, because we started at 1.00 pm on the first day, we had until 12.59 am today to complete our challenge within our prescribed time frame. I'd let people know the previous evening that we would be at The Christie at approximately 12.30 pm if they wanted to greet us. Howard, The Christie's representative, was also keen to know the timings.

We started cycling twenty-five minutes later than we'd agreed which put us under immediate pressure. There was moderate rainfall, it was cold, and we had harder than anticipated hills. To miss our target by minutes after all the effort would have been crazy. Not everyone shared my punctuality, desire, or tired feeling in their legs. Perhaps racing the previous day had sucked out some of my energy reserves? Jake and Elliot repeatedly came back to offer me some moral support and shelter from the wind. The one thing I really disliked was being wet and cold. It seemed to sap my strength more than anything else.

We skirted Burnley and Bury on our way into Manchester, passing the end of the road where Gordon had lived, in Whitefield. It was poignant, as if we were paying homage to a great friend, like the Tour cyclists do for their cycling heroes. Unfortunately, though the sun had appeared, and it was warmer, there was no time for photos amidst iconic Manchester landmarks. We headed straight through to Fallowfield where we paused, unloaded any unwanted jackets, food etc ready to make our entrance at Christies, sending Bryan ahead in the van to signal our imminent arrival.

Five minutes later, to a lovely reception and applause from our adoring fans we reached our final destination on time. The assembled group was large enough to make a noise but small enough to thank everyone personally for coming. We had loads of photos and Howard, the representative, gave a short explanation of how grateful The Christie was for our fundraising efforts – now at over £10,000. I also stepped up to publicly congratulate my boys on completing the challenge, for all those who had come along to greet us and to recognise all those people collectively who had helped us achieve something very special.

One by one, people disappeared off home while we loaded our trusty van for its last trip with us. It would shortly be sold with any profit going to our charities – such was Phil's generosity. My boys and I returned home and immediately unloaded everything. There was no clenching of fists or popping of corks in celebration. It was more of a relief that we'd done it. It wasn't a trip to luxuriate in, it was meant to be physically hard and inexpensive. We had cycled 800 miles in just under 56 hours, at an average speed of 14.15 mph at a maximum speed of 39.7mph. We had only one puncture in the whole trip. Our combined walking/climbing time was twenty hours.

Later that day Germany was victorious over Argentina in the 16th World Cup Final in Brazil.

To view the Facing Challenges Together video, return to the Home page and click the video.

# Chapter 30 Reflection

It had been a huge experience setting up Facing Challenges Together, training and ultimately seeing it through while putting other aspects of our lives on hold. I had no sense of anti-climax on completing our challenge. My energy was immediately rekindled with existing and new ideas including the finalisation and publication of this book.

The credit for organising the routes and the accommodation must go to Elliot. The routes avoided busy main roads as much as possible, bypassed super steep hills and balanced each day's efforts to be more or less equal in magnitude.

The budget for accommodation was approximately £30 per person per evening. Over several weeks, Elliot trawled the internet for bargains and discounts at a variety of different standard venues in suitable locations.

With the schedule so full we had no time for visiting any of the places we stayed in or passed through. We had neither time to watch The Tour de France in the evenings, nor, quite frankly did we have any desire to see another bike.

We never compromised on food. We were each burning at least 6000 calories per day. Without constantly topping up our muscle glycogen stores we would have ground to a halt. Viki and Cheryl had supplied us with a good variety of flapjack and cakes and Roz with jelly babies. We all finished the same weight as we started.

Sam organised the walking routes and printed maps and, consequently, there were no mess-ups getting lost on any of the climbs.

Each evening, Elliot updated the FCT website with photos and a short script for each day. He programmed the Garmin satnav with a route for the following day, which most often required modification from those that we had planned from the outset as we were generally ahead of schedule. At times, owing to patchy internet connections at our accommodation, updating them was difficult.

With the satnav on his bike, Elliot barked out the directions en route. Forever the motivator, he would tell me it was only just another ten miles, around the next corner, over this hill or nearly there. It worked! Despite all the training my legs ached and felt sore for the whole of the first week until they grew tired of sending messages that were being ignored. I wasn't stiff, though I did stretch each day. I was never really aware that my 'operated' right thigh muscle was any different from before. The infection I started with seemed to have declined by the first course of antibiotics and the HSP rash was disappearing. The antibiotics which I took until Fort William did have an undesirable effect on the number of occasions I would need the loo each day and possibly interfered with food absorption. Fortunately, I never needed to stop en route!

Insect bites were a problem in Scotland, primarily to the lower legs, and they could also bite through lycra! Okay through the day but they itched at bedtime.

The van was just brilliant. It carried us, our bikes, and our clothes, giving us shelter from the rain and wind, a place to change clothing, a refuelling point, dry laundry and for me to slump onto when I was so exhausted. We became more proficient at loading and packing the bikes safely as time went by. With its bespoke design it was a great backdrop for photos, a display of our sponsors and a means of warning drivers that there were slow moving individuals up ahead! In traffic we always cycled in single file. Most drivers were fine, some peeped in support while there were a few who didn't respect cyclists at all. In Scotland, road cyclists were as rare as golden eagles, as were cycle lanes. We counted only two short sections of road with a cycle lane on the whole of our Scotland route.

People approached us during our walks and climbs, or while paused by the van, often with a story of a relative or personal experience with which we had struck a chord, even making a donation.

Within a few weeks of our return, we were once again reported in the *Manchester Evening News* and *Warrington World Wide*, and appeared on *Granada Reports* with presenters Lucy Meacock and Tony Morris. I've never had so many people say they were so proud of us, respected us and were inspired by our endeavours.

Facing Challenges Together will be my only charity event. There is only so much you can expect your personal friends to give. In fairness, I never asked for donations. Every offer of help or donation was given because people asked us how or where they could donate. Some people have been hugely and unbelievably generous. The very good newspaper articles and two appearances on ITV *Granada Reports* stimulated not one direct donation. I always said I would be doing the challenge for £50 or £50k. We were a vehicle for people to think about donating, no more than that. We were content with our input to the whole event.

Facing Challenges Together has helped me regain my fitness, given me a psychological boost, provided me with a focus to claw my way back and through The Christie and Macmillan, will hopefully help other people in difficult times. Fortunately, I am still fit enough to embark on a challenge like this. It has been great to share the feat with my two sons, something we will talk about for many years to come. Raising money for the two charities and doing something positive had been a heart-warming experience for us all.

For the past twenty years, I've had a picture on my wall at work with a motivational statement, 'What lies behind us and what lies before us are tiny matters compared to what lies within us'. I believed that on some of the tougher days.

My new challenge is not to accept challenges! I need to get back to my simple life, sort out some medical issues still arising from the loose metal plate and my restricted breathing, focus a little more on work and spend some quality time with my biggest fan, Lesley.

We decided to offer Macmillan the details and logistical arrangements of our ride. They have a specific cycle fundraising team that could perhaps promote the ride in the future. It would be an appropriate legacy.

My own expression for how I deal with it all is 'I'm getting on with getting on'. That's all I do.

## Chapter 31 What's It All About?

I've not felt tearful, sad, or emotional writing this. It's been an enjoyable and perhaps a therapeutic experience. Previously when I read stories of people, I might think, that's an interesting read. I might not imagine myself in their shoes. When I see items on the news, a bomb blast or an airplane crash I think how awful without comprehending necessarily the number of hearts and lives that have been broken and will never be the same. It seems a fairly natural instinct to shut out the bad and to imagine oneself in pleasant surroundings and circumstances believing that something dreadful will never happen to me. But it did.

For Peter my friend in the next bed in ward 9, my father who died following bowel cancer on the night of my third op, Brian my lovely Trojan friend, my Mum's husband Dave and Sally I'm sad to say, their race is over. I'm not alone, as I'm fighting at the same time as some of my close friends and my brother who was recently diagnosed with CLL. Robbie who visited me in Warrington Hospital admitted to me following a game of squash that he really didn't think I would make it. People didn't think I'd make the FCT ride either. That's when I know how lucky I am to be here. Without the fantastic support of my family, Lesley, friends, my patients, skilled surgeons, doctors, nurses, friendly porters, I too would not be here. The NHS might have its failings, but it remains a phenomenal institution, particularly in desperate situations like mine. I do believe, however, that in the NHS as in life you have to champion your own cause or have someone to do it for you. If I lived elsewhere else in the world I might not be here now.

Elliot and Sam had been exposed to medical interviews, before their time. The gradually increasing severity and gravity of the subject allowed them to slowly acclimatise and cope. They had learnt to be sympathetic when you can't be empathic. Never say you understand when you have no personal experience. Deal with what you know rather than hypothetical thoughts. They'd understood how simple changes, like a cancelled appointment, could alter a patient's psyche, and how keeping to appointment times was important and professional. Treating any patient in the future should be as important as treating a favourite family member and being aware that it is important to see the patient's whole life in the context of their treatment. Communication is paramount and small things do make a difference. Patients hang on every word. Their experiences have made them think more about life, lives and families. It had been a tough learning experience.

I refer to my tumour as the 'The Alien'. Of course, this is in fact my own cells that have changed and started replicating uncontrollably. I have been criticised by the odd person for referring to it like this. I never felt as if I could embrace the Alien in any way. This was just my way of gearing up my mind and staying in the fight. Everyone has to find their own best coping mechanism.

Fortunately, I'd had good health prior to my cancer. I exercised regularly, had a good diet, normal weight, didn't smoke and drank in moderation. Those factors helped me maintain a good circulation. Without a good circulation there is less blood to heal the body. Being healthy hasn't stopped me getting cancer but it has given me the best opportunity to recover from operations and radiotherapy. Using my physiotherapy rehabilitation and medical knowledge has enabled me to return to work and sport very quickly. Sometimes, it's a case of knowing when to listen to pain and stop what you're doing or recognise the pain and continue in the knowledge it will subside. Graded exercise has helped me to regain my strength and offset depression by supplying uplifting endorphins (the body's natural opiates). Sport has helped bind me with my boys and maintained communication with my squash buddies. The skills I have learned through sport I have been able to apply to my contest with a most tenacious adversary. At times I've felt under siege, hardly able to make progress before the next onslaught has begun.

Physically I am much the same as before. My thigh is recovering strength and my abdominal donor site is completely recovered. I've lost all sense of smell. I have a much reduced sense of taste, limited sensation over my forehead, right cheek, lip and some upper right teeth. My face has an obvious skin graft. My appearance is as though I've been in a car accident. The inside of my nose and mouth is tight. I use sunglasses whenever I'm out for protection from the breeze and sunlight, to offset temperature changes and sometimes to hide my appearance. I squirt salted water through my nose twice a day, clean my eyelid daily and require no medication. Looking from the outside in, is very different to me looking from the inside out. With time, I'm sure that will improve. I'm not keen when people take a step back and say, 'Now let's have a look at you', then start commenting. It's like having a critical appraisal. I've had occasional incidences with strangers who launch in with both feet. If everyone did that to me I'd never want to come out of my house so I shrug it off politely by changing the subject. I've seen more than thirty consultants, had twenty-two CT scans, ten MR scans, one PET scan, one ultrasound scan and thirteen operations. I'll continue to have regular checks and scans at The Christie for the next five years. Only if I reach old age will I know I've defeated the Alien. Until then I'll be on my guard.

I live my life on a precipice. I was nearly denied the chance of making my bike ride by an infection against a plate just days before. Within weeks of returning from my bike ride I've had another CT scan and biopsy of a lump that has appeared just forward of my right ear about the size of a ten pence piece and I'm due another operation very soon. I'll be sweating it out until I get those results. You can't imagine how that feels unless you've been there.

I'm still waiting for a definitive answer from the DVLA regarding being unfit to drive.

The experiences of the last three years haven't all been negative. I've met fantastic people. Small irritations are nothing to worry about anymore, more something to laugh about. Perhaps I'm more chilled. After all, what's the worst that could happen? I've had to contemplate my death, yet I've survived. I appreciate more, those simple things in life, the sort of things we take for granted like the smell of cut grass or the perfume worn by my gorgeous girl, which I really miss. I savour each occasion or meeting with someone special. I don't know if I'll be doing that again or for how long. I enjoyed my life before and I'd change very little. I've worked very hard in the past and I wouldn't want to do those hours now. I don't look much farther in the future than twelve months ahead. As the roller coaster negotiates the track, I try to enjoy each day, make a difference and live each day one at a time. I love my boys, my mum, my family, Lesley, my friends, my job, my patients, my sport, my life. What more do I need? Perhaps a hug now and again. Yep.

# Chapter 32 July 2014. In Keeping

I knew nothing about publishing until this point. I hear Lesley saying, 'that's something else you didn't know'. Until now. As always, my friends and patients prove themselves to be a fountain of knowledge and ideas. It has been largely their prompting that encouraged me to write this book. In a similar manner to my tussle with the Alien and completing the challenge, human spirit, that commodity you can't buy was in abundance.

Would I use a publisher or self-publish? What do you think? You know me pretty well by now.

I wanted to see how my little rag tag bunch and me would fair. I wanted to do it my way with my very passionate and enthusiastic friends. That promised to be so much more fun. The pleasure of shared success or failure, knowing it had been our collective efforts. Where would it lead? The destiny of *Riding with the Alien* would at least be in our own hands.

I apologise for any spelling mistakes, grammatical errors, rubbish writing style and anything else. These were my own words and thoughts as I saw it, raw, uncut, and unadulterated. I'm an author by default only. I'm really just an ordinary guy facing extraordinary problems with some outstanding friends.

#### Epilogue

#### **Facing Challenges Together Update**

So far we'd raised over £21,500 jointly for The Christie, Manchester, and Macmillan Cancer Support.

#### **Tuesday 5 August 2014**

Review of neck scan and biopsy results with Prof Homer. Unfortunately, the Alien was back (never quite gone), this time in my parotid (saliva secreting) gland in my right cheek and in a lymph gland in my right neck. Boy, that Alien must love me!!

I'll be having a neck dissection operation to remove those glands entirely as soon as possible plus radiotherapy/chemotherapy. They can't keep removing bits of me, if they do, I'll soon be just a pair of feet in sports shoes! That operation can't come soon enough when you want to live. After a relatively calm period, the roller coaster was back to some of its old tricks!

Facing Challenges Together climb/bike ride reflected the ups and down of my medical battle, never attributing any significance to the actual number of ups and downs – there were four major obstacles en route: Snowdon, Slieve Donard, Ben Nevis and Scafell Pike. At the point we started riding I'd had my initial diagnosis and two recurrences. This latest development would be my fourth and hopefully my smallest hurdle, my Slieve Donard, and hopefully the last! How ironic.

# Part 2: No Capitulation

#### 2014

As we were about to publish Riding With The Alien, I remember someone saying, 'But it's not the end of the story'.

Unfortunately, that person was only too right as my ride continued for another 9 years. I did publish part one of this book, 'Riding With The Alien' never thinking that I'd ever be writing another; however, in 2023 I felt I should bring my 'ride' up to date. Will I ever reach 'The End'?

Hang on tight, get another G&T and another box of tissues...

#### Chapter 1 Smile

The tear duct stent which Miss Cook inserted in April was intended to create a lumen to allow fluid to drain from the surface of my eye. That small tunnel closed up, so it was either keep trying to get a functioning tear duct via other means (LJT) or limit the tear flow with regular botox injections into my tear gland. Both options were on the back burner for now as I had a bigger fish to fry.

Very soon after completing the Facing Challenges bike ride I was back in clinic with Prof Homer to examine a noticeable ten pence piece size lump in front of my right ear. As it was quite superficial, Prof Homer was able to accurately insert a biopsy needle to take a totally pain free sample then and there. Arrangements were also made for an MR scan.

By August 2014, it was confirmed, the Alien had found its way to my parotid gland and at least one lymph node in my right neck. My old adversary was proving extremely difficult to shake off. It was the fourth time it had returned. The plan was to perform a parotidectomy and neck dissection in one operation. As the facial nerve, which supplies the right side of the face, ran directly through the parotid gland it could be tricky, compromised by either the Alien or the surgery.

Within a few weeks I had notification that my surgery would take place on 1<sup>st</sup> September.

It was the usual procession to Manchester Royal for a 7am admission with Lesley, who dropped me at the front entrance and left for an anxious day of waiting to hear when I'd come out of surgery. I had the usual pre-op checks, then a short wait while some other poor subject had an operation of short duration, akin to a warm-up for the main event of the day. It turned out to be a five-hour procedure including removal of that main salivary gland, the parotid, plus the stripping out of 30 lymph glands in and around the known affected lymph gland in my neck, in a scattergun approach. Prof Homer also took the opportunity to remove the MEDPOR plate from my nose which was possibly harbouring an infection.

As neck dissection operations were apparently fairly routine, I'd taken that to mean it would be something of a breeze. As I came round from the anaesthetic I soon realised it had been anything but. I was in a fair amount of discomfort.

It was immediately apparent from the first day post op that I had weakness and loss of sensation of the right side of my face. It was devastating to have the facial appearance and function associated with a stroke. The facial nerve has five branches supplying the area from the eyebrow to my chin. Prof Homer told me he had deliberately severed the upper two branches which were basically of little use to me anyway, as I had no right eye. Of the remaining three branches it was hoped the lack of signals through the nerve were the result of temporary bruising or disturbance of the nerve during the operation, a condition known as neuropraxia. Any other type of nerve injury and I might never recover the function.

After three days, I was more than usually pleased to get home to the comfortable surroundings of my home, a soft pillow and Lesley.

It took a few more days than I'd anticipated to return to work. My patients, and my colleague Cheryl, were obviously understanding about my absence, but that patience can only last for so long. It didn't help that I'd be off again with radiotherapy looming.

I had had a lovely smile up to that point. which had always been an important communication feature in all aspects of my life. Having already lost one eye, it would have been a hammer blow were it not to return.

## Chapter 2 Eggs, Eggs, and more Eggs

My whole right cheek, chin and neck needed mopping up with radiotherapy post-operation in the hope of catching any Alien cells that might possibly remain. I followed the same radiotherapy procedure I'd experienced back in 2011 with creation of another immobilising mask that would pin me to the table and routine blood tests.

I was bracing myself for the six-week onslaught beginning in Oct. I'd be combining radiotherapy with Capecitabine oral chemotherapy for added effectiveness. I had been prewarned that radiotherapy through the neck area was tough, and that most patients don't get to the finishing post without a feeding tube and possibly hospital admission.

I managed to work through the first two weeks before throwing in the towel. It was basically six weeks of hell – nausea, vomiting, skin burn, oral and throat blistering, tiredness, listlessness, dry mouth, weight loss, poor sleep and immense difficulty eating despite the strongest painkillers, mouth care and steroids.

My Mum, bless her, came over to help out. She probably had thoughts of building me up with some home cooking; however, in the latter stages the only diet I could manage was mushroom soup, eggs, eggs and more eggs, which I ate for breakfast, lunch and dinner in as many different combinations as possible. Anything else had me hopping around the house in throat burning agony.

Halfway through, I had to abandon the chemotherapy. I just couldn't swallow the tablets; my brain wouldn't allow it.

Burning my tissues with radiation, didn't strike me as likely to help recovery of my facial nerve either. The function in my face remained poor and the skin around my right chin was like a Christmas turkey, red and flaccid.

The Alien had certainly gnawed away another portion of my functionality. Smiling, eating, tasting, drinking, dry mouth, dry throat, stiff neck. The list went on. All were compromised to some extent. There wasn't a lot left!

I finished radiotherapy on 19 November, a stone lighter.

Despite still feeling ill I returned to my practice 10 days later working only a few hours three days a week. I knew I'd get some additional respite with the Christmas break and slowdown approaching.

Though it was of less significance it was another Christmas period ruined.

The roller coaster had been twisting and turning at top speed for a few months now. It was the toughest period since encountering the Alien and I needed a respite.

Exercise, even light, was still out of the question, as was any socialising. I'd be needing all my strength for the 'work basket'.

I renewed efforts to sell my practice or reach a suitable arrangement where I could amalgamate with someone else. Running my practice effectively while being away from work was proving difficult, draining and increasingly stressful.

As the roller coaster slowed and the track twisted and turned I had no idea what would be ahead, but it felt foreboding.

## Chapter 3 2015 Snigger

At this stage everything was coming thick and fast. The roller coaster was all over the place. I regularly had three or four hospital appointments per week which was good in respect of keeping an eye on me but was screwing with my work diary.

Somewhere around this time Lesley moved in with me. That immediately made things easier for both of us and freed up some time. We never wanted to fuse our two families but as the lads were older now that didn't present a problem. What precipitated the change for Lesley I didn't ask. I imagined it was because she couldn't bear to live without me! Both Lesley and her exhusband, Ian, lived in Didsbury so her lads, particularly Joshua could either continue his education in South Manchester or come with Lesley to Lymm, going to Sam and Elliot's old school. He chose South Manchester.

Lesley's ex-husband Ian still lived in Didsbury so Lesley's two sons continued their education in South Manchester.

Short periods of light resistance work on my indoor cycle were always my first port of call as I started another comeback. To venture out to the squash court was by far beyond me for now.

I was more or less back to normal working and a sale of my practice was imminent which would relieve me of the responsibility for running my practice and allow me to concentrate solely on treating patients.

There were several interested parties. Two wanted me to continue working while the other would have taken over completely. If my health allowed I wanted to continue working so I was keen to choose a nice boss. Colette and Caroline who I trained with at physio school owned a local practice a short distance away in Gatley and Colette had stood in for me more recently when I was hospitalised or too ill. The amount on the table was nowhere near my accountant's expectations but I had my 'back up against the wall'. It allowed me to continue working at a less intense level and took away the responsibility, which at this point was running away with me. I talked it over with Peter McSorley, a businessman and friend who led me to the right decision. Sell to survive.

It transpired that the radiotherapy and surgery had 'glued' my Eustachian tube, preventing equalisation of the pressure in my right ear, leading to deafness on that side. This short tube linking my middle ear to my nasal cavity could be unstuck with a wire threaded though the small canal, which is difficult, or siting a grommet in the ear drum which is a much easier means of restoring the ear pressure but can come with repeat infections.

I chose the latter option. In February, I had scar tissue released in my nose once again accompanied by a grommet placed in my ear drum.

Knowing the Alien had been on the move I had a PET scan in March, looking for activity anywhere in my body, particularly in my liver. The scan showed an area of concern in my sinus region somewhere behind where my right eye orbit was, but nowhere else. To clear up any doubt, I had an MR scan in May which also confirmed the suspect area in that same region.

It was too painful to biopsy under local anaesthetic. So in June samples were collected through my nostrils under general anaesthetic. Waiting for those results was always stress inducing, but to everyone's surprise, clear. Whoopee!

That glimmer of hope was just the fillip I needed and before long I was pretty much back to a good level of fitness, cycling and on court.

By July PhysioSport was sold to Colette and Caroline. It was sad that it had been forced upon me but gave me the best chance of survival. I could sense a snigger from the Alien as another aspect of my life was stripped away.

### Chapter 4 Impact

Lots of other people do it, so I felt confident I could too. Adapting to monocular vision was a challenge and perhaps more successful when you're younger than me. Pouring water from a kettle into a cup, or wine from a bottle, reaching for a washing line in mid-air or shaking someone's hand required much more forethought. Some adaptions were going on automatically in my brain while others I had to make a conscious decision to perform differently. I soon forgot what it was like having two eyes. This was my new norm.

In an effort to claw back use of my right facial muscles, I made an appointment at the Lindens Clinic in Sale to assess my facial palsy. The clinic was original opened by an ex-tutor of mine, Di Farragher OBE, who had been honoured for her pioneering research into trophic stimulation, a means of 'feeding' the muscles with specific programmed signals generated from a small hand sized unit. Her work originally centred around a condition called Bell's palsy which caused a similar pattern of weakness to mine.

Di was taking a back seat now so I was seen by a very competent, knowledgeable and well-connected physio, Wendy Walker, who had a lovely very engaging personality. Di's daughter, Jenny, who I'd known as a child when I was a student was helping run the admin side.

From my assessment, EMG studies showed that the right side of my face was working at between 6-20% of the left side. I would be suitable for treatment once CCG fund had been approved.

Meanwhile, a blemish by my Mum's eye that she'd had since her 30s had slowly progressed. She had surgery in her 40s and some topical treatments and though it didn't look like it would be terminal she was eventually diagnosed with skin cancer. It did cause a beautiful lady to feel self-conscious, a feeling I could have empathy with. That was mother, father, brother and me to complete a 'full house'.

Removal of hair from the flap graft concluded in April.

Another annual MR scan had been arranged to check for Alien activity, again including my liver. Having never got past this annual hurdle in four years I can't say I was overly optimistic for the results; however, Philip telephoned with the best news possible. The scan was once again clear. Next scan would be in 6-9 months.

Being less committed at work this was perhaps an opportunity in my life to get a dog, before it might be too late. Up to this point Lesley and Elliot, understandably, wouldn't allow me to get a dog as neither wanted to be left with the responsibility if I expired. We agreed that if I was clear on my most recent scan then we could go ahead.

I started searching for a whippet before either Elliot or Lesley changed their minds. Their elegant shape, calm temperament and athleticism appealed. We were initially looking for a rescue but were offered three greyhounds as a package – too much for a novice owner.

Trophic stimulation with The Lindens Clinic was approved and gave the best chance for the right side of my face to recover muscle tone and function. Though Prof Homer was not an advocate my thoughts were nothing ventured, nothing gained, and we were too late now for nerve transposition. I'd attach six electrode leads from a small stimulation unit over exact sites for one hour each day. Programmed intermittent pulses stimulated the junctions where the nerve enters the muscle, maintaining the muscle while the nerve slowly regrows hopefully.

The year concluded with a trouble-free Christmas and New Year for our first Christmas living together.

### Chapter 6 2016 : Cheese Gromit?

The year began with a hearing test. The grommet had led to recurrent ear infections and was now blocked, causing a return to almost complete deafness in that ear. The hearing test confirmed the deficit and a referral was made for a hearing aid and a bespoke watertight earplug for showering. More appointments. Arrrh. That was swiftly followed by another short op to reopen the nasal airways and replace the right ear grommet.

To overcome the constant problem of nasal scarring, conversations were taking place regarding reconstruction of my nose which had become very distorted by surgery and radiotherapy. Balancing glasses for reading and wearing protective sunglasses for cycling and driving was 'a balancing act'. If something could be done perhaps my breathing would be improved and the whole look and symmetry of my face redressed.

Regular eight-week botox injections into the tear gland helped temper watering of my eye watering for now. Thankfully, Miss Cook was an expert at delivering the delicate jab under the upper outer eyelid.

Early Feb, Lesley and I drove over to Harrogate to pick up a black whippet puppy. He was one of a litter of twelve to Gypsy and Roger (breeder had a sense of humour).

He was due to be collected by another couple who unfortunately had just had a cancer diagnosis of their own and decided it would be too much, so ironically, we stepped in. Lesley cradled him all the way home wrapped in a blanket. By the time we were halfway home she declared she loved that little black puppy to the extent she was sure she must have given birth to him! We named him Gromit so that I could talk to him in that Peter Sallis voice, 'What shall we do today lad'?

Having never owned a dog it was a quick learning experience with toileting, socialising, diet, training, toys and bedtime. He was great at regulating my days. I could no longer hang on at work when I knew he was crossing his legs waiting for me to get home. Despite Lesley's initial reservations, Gromit had converted her to dog lover.

In the respite from Alien intrusion, I joined in the regular circuits classes that had sprung up at Bowdon squash club.

Results from head and neck MR scans were once again clear. This was a record. Eighteen months clear for the first time! Facial stimulation was helping

diminish my turkey neck appearance and there were visible flickers of muscle activity.

Dave once again contacted me for physio duties re the biennial Dallaglio Cycle Slam, this time starting in northwest Spain, up into the Pyrenees heading into France, down to Barcelona, then over to the Balearic Islands late May until mid-June. It would be a longer trip for me than the previous ride. I didn't have the same necessity or desire to cycle like before when I was training for my own FCT ride. The same guys, Simon, Paul and Jack would be involved. Lesley didn't particularly care for being on her own, especially for that length of time, but at least she had Gromit for company.

Elliot had his medical graduation that summer in Whitworth Hall at Manchester University. He'd already landed a run through registrar post in ENT in the northwest deanery. The run through part meant he wouldn't have to apply for a training post midway through and he was guaranteed to stay locally for another eight years.

#### Chapter 7 Taking Flight

Maggie's, a new cancer support centre, opened during mid-summer. It was advertised in the Christie itself which was thankful as it was across the road from the clinical site, tucked behind a large research building. I was already familiar with MacMillan but I thought I'd take a look when I was next visiting Christies. It was a beautiful low rise architectural masterpiece both outside and in, with a garden which was yet to flourish and a greenhouse to die for. I walked through the open glass door into the contemporary open plan fover with kitchen and large table where I'm sure someone greeted me. As no one wears a name badge, I perhaps thought they were just being kind. I sat in one of the several rooms to relax and take in the tranquillity. Someone offered me a cuppa, but I didn't accept, stayed for a while, then left. Next time, I did the same walk around, discovered a few more rooms and had a cuppa. That epitomised Maggie's soft approach. Before long, I'd met a few of the staff like Annie, a volunteer and Angela, a support worker who like most the staff, had previous experience working in a cancer treatment roll and environment. Before long they knew my name and I was 'in'. This was a great place. Nonclinical, and it fitted what I instinctively felt I needed. Maggie's conjured up the best features of home, cathedral, greenhouse, and art gallery all rolled into one.

Sir Norman Foster, architect of the Gherkin in London also designed this innovative new Centre. Having grown up close by in Levenshulme, he had a special association with Manchester. Created with a light aeroplane appearance, the cockpit represented by the greenhouse, the wings forming the roof and the cross-braced trusses resembling the structure of early flying machines, it cut an appearance capable of taking flight perhaps. An escape?

## Chapter 8 Zen Master

In late May we flew to San Sebastian, a beautiful City on the Spanish West coast, in preparation for the Dallaglio Cycle Slam where we were reunited with some of the staff and riders I'd met two years previously. There was an additional massage therapist, Jess, an Australian who worked from a clinic in London. Dave was none too happy that he'd not had chance to appoint his own or vet her first. Her connection was that she was known to one of the main riders.

The first day took us through the San Sebastian streets lined with tall grand buildings. I was twinned with Paul, expert paramedic, and my roommate from our last trip. Callsign, 'Hinge and Bracket', we were in the ambulance. Dave (Rooster) and Jack were together and Simon (The Doc) with Jess, only Jess was feeling rather sick and hungover. The treatment sessions start early before the riders depart then afterward when they return. Jess was nowhere to be seen on that first morning and not contactable. Dave was fuming, and that can be a scarry sight!

The route took us to Bilbao, another beautiful City close to the French boarder, up into the Pyrenees with its scattered villages where the views were stunning, through Andorra, into Foix, Montpellier, Carcassonne, Perpignan and Girona.

I rode the stage down the Northeast Spanish coast from Girona to Barcelona. It was an exhausting run in the heat with fabulous views of the Mediterranean Sea to our left. Navigating through the bustling Barcelona streets with two eyes would be hard enough but especially challenging for me!

The next day Paul, Jack, me, and some staff, were crossing by ferry to Mallorca while Rooster and The Doc joined the riders on a flight. It was an overnight crossing, so we naturally imagined, a cabin would be provided, alas not, or, we could bunk up in a ten man room with a load of unknown foreign lorry drivers. It was a long night. We arrived in Palma looking like we'd had a night on the town, and the hotel couldn't provide breakfast so we found a café nearby to moan about our journey and refuel. It was like the snickers advert as Paul turned from Ozzy Osbourne to Zen Master over a bacon and egg sandwich.

We had a couple of cycle tours around Mallorca, taking in the Northern mountainous region then back to Palma through the centre where I joined in. I asked to be in with Austin Healy's group who were a bunch of fit lads - mistake. After about ten miles, the pace was proving too much for me as my lactic acid threshold was breached.

The following day we were off to Ibiza, party Island. We were not looking forward to the ferry, however, Rooster had negotiated a trip on a fabulous motor launch owned by one of the riders, which was moored in the harbour ready to transport us and other Dallaglio staff. Unfortunately, someone had to drive the ambulance which fell to Paul, while Jack joined me in taking control of the cruiser's powerful engines skipping us across the ocean (under supervision of the skipper). We even managed to catch and overtake the ferry, 'waving' to Paul, bless him. We anchored in a beautiful Ibiza cove, rode to shore, then up some steep steps to a lovely restaurant. The owner of the motor launch bought both Jack and me lunch, to cap off a memorable day.

The riders were always very generous. We hardly bought a drink the whole trip. Each evening everyone sat together for a meal. The riders would receive some 'awards' then Laurence would hand out fines in the form of shots for any indiscretion. If you'd been 'clean' that was a good enough reason for a fine! As this was a charity event there was sometimes an auction. I had a couple of copies of my book sent over for the purpose. Obviously signed copies are more desirable, as two riders exceeded £3000, eventually taking a copy each!!

I don't really recall the Ibiza rides. Not because I was out of it through alcohol, but I don't think there were any. Everyone apart from me was in party mode – my 'head' wouldn't cope with strobe lighting and a hangover. One of the riders paid for everyone to go to one of the iconic nightclubs plus drinks for the night. The bill was more than my annual earnings! Rooster had returned straight home from Mallorca to be with his wife Kim, whose much loved dog, Arnie, had died while he was away, and take care of some issues at Lancashire Cricket where he was head physio.

We returned home 18 June. It was good to be back home to be with my special girl Lesley and special boy, Gromit.

### Chapter 9 Blow

On the Dallaglio trip I noticed some increased neck stiffness and cramping pain on turning my head. Nothing physio-wise seemed to touch it.

Four months later, head and neck MR scans showed the Alien had returned in an inoperable lymph node next to the Vertebral Artery in my right neck close to my skull. Would this thing ever go? This was the fifth time!!! Back down that snakes and ladder board. Perhaps this was what had been picked up on the PET scan in March, three months ago?

Preparations were made for radiotherapy and chemotherapy starting November for three months.

'OMG, I'm not sure I can go through that again'?

Reconstruction of my forehead, nose and tear gland planned for the New Year were now on hold. This was a swift, out of the blue, loop the loop from the roller coaster.

I'd returned to a pretty good level of fitness, sufficient to return to represent my club and I'd recently performed my first inspirational speech. I was due to speak at an Ophthalmology conference the following month, but I had to cancel. I didn't feel inspirational with this hanging over me.

Following another scan, in November, it was decided that it was too dangerous to contemplate radiotherapy as the Alien was so close to that major blood vessel, the Vertebral Artery, which forms a major blood supply to the brain. If left, it would either occlude the vessel causing a stroke or rupture leading to a mammoth bleed. If I had a preference I'd go for the later as it would be over within minutes.

David Thompson, oncologist, who had recently taken over from Prof Slevin, delivered the blow. I was offered NON-CURATIVE palliative chemotherapy, which would have diminished effectiveness over time. We'd reached a new low! Lesley and the lads were in tears during the interview, however I was defiant as ever. I must have inherited that from my Mum.

'It's not over'.

I'd relied on conventional medicine to this point, now I needed to look elsewhere, to alternatives, otherwise I was surely out of this world.

The roller coaster, white knuckle ride was roaring along in an uncontrollable fashion.

## Chapter 10 Researching

If I was to have any chance of survival, we need to act quickly. My boys and me were straight on it. We looked at websites, the internet, medical journals and books.

I was interested in an author's educational background, profession, and motivation in writing their books. In most cases it was because they or a family member had been personally affected by cancer.

Where a topic was repeated by several authors, I thought there must be some credibility to their writing.

The books I read-

Healing Tonics by Adriana Ayales

Super Immunity by Joel Fuhrman

Heal Your Gut, Heal Your Body by Chris Woollams

The China Study by T Colin Campbell & Thomas M Campbell

The Rainbow Diet by Chris Woollams

Cultured Food for Health by Donna Schwenk

Living well with Cancer Cook Book by Fran Warde & Catherine Zabilowicz Nourish, The Cancer Care Cookbook by Christine Bailey

Nourish. The Cancer Care Cookbook by Christine Bailey

Everything You Need To Know To Help You Beat Cancer by Chris Woollams Eat Dirt by Dr Josh Axe

Anti Cancer - A New Way Of Life by David Servan-Schreiber

The Gerson Therapy by Charlotte Gerson

www.canceractive.com edited by Chris Woollams

There were three areas of focus if we were to defeat the Alien.

i.Creating a stronger immune system

- ii. Creating an unfavourable environment for the Alien to exist
- iii. Preventing proliferation.

Elliot and Sam conducted their own research. We met at Elliot's flat in South Manchester where Sam and Elliot gave presentations to Lesley and me. In short, Elliot was keen for me to travel to Mexico to pursue the Gerson approach while Sam was sticking by anything proven only by solid research. They were quite diverse viewpoints but helped steer my decision and pathway somewhere between the two.

While the medical profession was looking for a cure in tablet form or infusion, I didn't have time to wait. I was looking back to a time when we had

low cancer rates, less processed foods, less stress, and small corner shops selling local organic produce.

I noted down the changes I wanted to make. My theory was that if each change contributed only a few percent and I could find sufficient changes to top 100 percent then I might have a chance. I needed to be the Dave Brailsford of the cancer world.

I instituted the changes as quickly as possible as the chemotherapy was looming and I knew also, that once I was into the chemo cycles, I might be feeling too ill to read or concentrate sufficiently.

### Chapter 11 Hangover From Hell

Early November I arrived at Christies for my first intravenous cycle. It was a surreal experience, with people around me sat in large comfy reclining chairs all linked to an intravenous bag. The cannula in the back of my hand offered a route for the chemical to infuse for a couple of hours. My infusion was Cisplatin which had a host of side effects. Short term, the effect on bone marrow might leave me vulnerable to infection for many months while long term side effects were alteration to peripheral sensation, being disastrous for any physiotherapist, hearing loss and damage to the lining of my veins. The addition of oral Capecitabine for the first three weeks followed by a week off, completed the concoction.

The hangover from hell was upon me in no time and continued each and every day. Again, I really struggled swallowing the Capecitebine tablets.

The next cycle was late November. Same situation.

I was struggling so much that the team reduced my next intravenous dose in December to Carboplatin, which was apparently more easily tolerated but still had me on my knees. If the Alien was suffering a little more than me, I felt sure it couldn't survive.

The Christmas period was another complete write off.

Mid treatment scans taken in December were almost unbelievable, at least to me. The tumour had been blown away. I was stunned. David, the oncologist took it in his stride, as if this was what he was expecting, which was contrary to a conversation we had prior to starting the treatment, when I asked David what outcome I could expect from the chemotherapy. 'Perhaps we could keep the cancer where it is for now, but over time, chemotherapy would have diminished effectiveness'.

David proposed a further three cycles which I turned down. I felt the toxicity was killing me, whilst all my lifestyle changes felt positive and logical in my layman's world.

Perhaps I could fall back on those cycles if I needed to?

Despite our differences of opinion, I did like David and respected his knowledge and position. He appeared to know little about the sort of things I was doing though.

My own research indicated some foods enhance radiotherapy or chemotherapy while others are best avoided.

Whenever I discussed my lifestyle changes with medical staff, I was very careful to refer to them as complementary changes not alternative treatments. I hoped to take the best from both worlds and combine them into a force the Alien couldn't handle.

I had no intention of offending the medics by pursuing an unconventional line, but this was my life at stake and traditional treatments hadn't completely 'cut it' to this point

#### Chapter 12 Change Is Never Easy

I'm detailing all the things I did and the changes I made. I didn't want to leave a stone unturned, go into the next scan, feeling I could have done better. Everything was on the table (Pardon the pun).

When I researched for changes, I had me in mind. Every cancer case and patient are different, so if you are researching yourself for yourself or a friend then you should have those circumstances in mind. Some of my changes are universal, some specific to my cancer.

Consult your doctor before pursuing any change of course.

Lesley had to be in on this just as much as me. We went through every kitchen cupboard discarding anything we considered unhelpful to securing the 'perfect' diet. The cleaning cupboard also had an overhaul.

Some changes were easier to make than others as we picked off the low hanging fruit first.

Previously I said about the three focus areas, immunity, proliferation and environment. Taking this holistic approach, each change could affect one or perhaps all three focus areas.

The changes I introduced. INITIAL PLAN Daily Supplements Vitamin D3/K2 Probiotic max **B** Complex Parafree Loratadine Astraglus Co Enzyme Q10 Aswagandha x1 Berernine Zinc Artemisonin Grapeseed extract Cod liver oil Cats claw, reshi mushroom and chlorella combined in juices Diet

Five smaller meals and two juices per day. Fruit only at first meal of day. Avoid glutens, salt, sugar, pasta, dairy products. Consume only organic fruit, veg, nuts and oats. Soya milk instead of dairy. Lemon tea x 3. Organic cider vinegar x 1 mornings. Kefir. Apricot kernels x5 per day. Unpasteurised cheese. Chicken broth prepared for 5 hours + Raw honey. Fermented vegetables.

<u>Liver cleanse</u> -Every fortnight. Rainbow salad with lots of olive oil followed by tablespoon of Epsom Salts 45 mins later.

I arranged with my very obliging GPs, blood test for triglycerides, cortisol, and blood sugar. They prescribed melatonin to help me sleep, and Metformin (the diabetic drug) as observations had shown those cancer patients on Metformin benefitted.

There was so much to learn and absorb. It was mind blowing!

We bought a juicer, but even they weren't equal and needed researching. Too fast and it destroys the nutrients, as did those that created heat. I plumbed for one of the more expensive juicers at £500 with a powerful motor that turned two metal milling spindles slowly and without heat, and it also controlled the fibre juice ratio. The juices had any, and all veg, garlic, greens, reds, yellows as we could find, sometimes with apple or carrot for sweetness plus cats claw, reishi mushroom and chlorella in powder form. It was a powerful concoction which tasted grim at times but packed a huge nutritious punch. My lack of taste came in handy at times.

Obtaining organic food was a challenge, but we did our best. Those fruit and veg with thicker inedible skin were perhaps less of an issue. Nutrients can be concentrated in the skins of some veg like carrots so unpeeled is best but not if it's been exposed to chemicals in the field or cleaning agents in preparation for shop sale.

I did look at intravenous vitamin C, though this wasn't available in this country (put it on the backburner). Instead, I had Atrovent vitamin C in a gel which gets past the stomach enzymes that would otherwise diminish the absorption to 8%.

I also looked at CDB oil but again I didn't think it appropriate at that particular point (on the backburner).

I took honociol, dandelion thistle, milk thistle and aswaganda for short periods.

I volunteered to help a patient of mine on their allotment who had a shoulder issue. Sharing some of the organic produce, digging exercise and vitamin D from being outside made for the perfect symbiotic relationship.

Cancer cells don't like oxygen, so moderate exercise is recommended, though I was already happy with my level of physicality. Preferable to exercise in the morning, gets the lymph (waste clearance fluid) moving, increases oxygenation, helps against depression, and encourages relaxation post exercise.

As cooking food alters the state of molecules, eating raw food is preferrable.

Turmeric in powder form. Olive oil at high heat in a pan, add turmeric then immediately, a third black pepper. Turn the heat down straight away. The black pepper helps release the active properties of turmeric.

Soya or oat milk. Avoids oestrogen in cow's milk, a driver for cancer. Exceptions are for making kefir, and raw milk which has natural bacteria.

Organic cider vinegar helps with stomach acidity. Nice in hot water drink in a morning. Brush teeth afterwards.

Honey. Manuka is best but expensive.

Lots of varieties of nuts and seeds.

Apricot kernels (contain cyanide and B vitamin). Limit to 5 per day.

The trilogy for good gut health: kefir, komboucha and fermented

veg. Best made at home. Creates billions of bacteria our guts need to keep us healthy. The microbiome is responsible for 85% of our immunity.

Raw cheese contains good bacteria.

Sourdough bread. Created with bacteria abundant yoghurt.

Green and organic tea

Glass of red wine with a meal containing resveratrols. Organic Cabinet Sauvignon is best.

Square of dark chocolate in the evening containing melatonin to aid sleep.

Onions and garlic have antiseptic and antibacterial qualities.

Many varieties of mushroom.

Avoid stress as much as possible as it causes release of cortisol leading to inflammation. I felt this was very important.

Many herbs are very strong against cancer.

Sleep in a darkened room. Getting a full night's sleep helps the gut bacteria to be active while we are sleeping

Whim Hoff methods. Fasting for periods can help boost the body's immune system as can cold water immersion and breathing control.

Meditation

#### THINGS TO AVOID

Dairy contains oestrogen. Added salt. Smoked and pickled foods. Sugar is the energy source for cancer cells and they crave it. Avoid burnt food. Forms acrylamides which are cancer forming. Over refined foods like some rice and pastas.

The microbiome gut pH is affected by smoking, salt, sugar, pickled products, alcohol, (especially binge drinking) and STRESS. Exercise increases biodiversity of the gut. Gut bacteria decreases at age 50 becoming less acidic and melatonin decreases. Yeast cells can colonise scar tissue and areas of inflamed tissues creating dire consequences. Fish oils calm inflammation as does vitamin D.

Liver flushes. I tried a few of these (Method in Chris Woollam's book How To Beat Cancer). Rids the liver of dead cancer cells.

Coffee enemas. I tried this too which was fine, though I dropped it a good while ago. Helps liver function.

Plastic water bottles leech phthalates and BPA which mimic oestrogen. Avoid exposure of plastic bottle to sun and heat. I use a reusable metal container.

Limit exposure to garden and home chemical cleaners.

Minimise the use of microwaving.

No prepared/processed meals

No air freshener aerosols.

Avoid beer and spirits- lots of sugar and salt.

Cancer, being such a divisive multi-level organism, had to be cut off at many and every avenue. I introduced as broad a range of changes as feasible. Lesley was totally onboard, shopping here and there for organic stuff and creating fabulous meals from new recipes.

If it's not in the house, you can't eat it.

Sticking around for a beer (or fruit juice) with the lads after a racketball game was out of the question, and eating out was limited so I could keep control of what I ate. The odd exceptions were fine but not enough to get on the slippery slope.

So many people said they couldn't do what I do but you don't really know until your back is truly against the wall.

Lifestyle change somewhat goes against the grain society is perpetually offering up.

## Chapter 13 2017: Unlucky No 6

In January, instead of being the consumer of chemotherapy, I was back playing for Bowdon teams.

I asked David if I could be referred to the endocrine unit within Christies. My first dose of radiotherapy in 2015 was through or close to my Pituitary gland which concerned me. The gland is responsible for production of several really important hormones. Under Dr Higham I had blood tests and an ultrasound scan of my Thyroid gland. The radiotherapy treatment had indeed diminished the right side of the Thyroid leaving me deficient in thyroxin, though I was unaware of any symptoms. I was immediately placed on levothyroxine to stave off hypothyroidism and would be for the remainder of my life.

Since the New Year the only 'treatment' I was on were my own lifestyle changes, no chemotherapy (against advice). Deciding, contrary to medical advice was brave and could have cost me dearly. I'd toed the line up to 'palliative treatment', but now it was up to me to find and make the difference if I could.

The recent MR scan was clear. Not a sign of where the Alien had been, though David was sure there would still be cancer cells around.

The 'clear' scan would pave the way for me to have facial reconstruction of my forehead, nose, and tear duct hopefully in June.

In mid-summer, I had an Emergency admission to MRI, for facial swelling, pain and feeling unwell. There was always something pulling me back! Following CT scans an upper right molar was removed and infection in my cheek cleared out. It was thought the tooth's root may have been damaged during my big op December 2013, leaving it vulnerable all this time. Sadly, that episode happened the weekend of Robbie's wedding to Maggie, which we missed. I'm sure they weren't overly happy but there was nothing I could do. That was my life – unpredictable and unreliable.

Christies have a renowned Clinic trials unit. David wanted me to be assessed, and at the chance of avoiding that dreadful chemotherapy, I was keen to keep my options open.

Sam & Miriam had joint graduations at Manchester Uni when I had the opportunity to meet Miriam's Mum, Dina, for the first time. It was another of those milestone moments for me. That I thought I might never be here to witness.

Another scan and there were three sites of concern. David was right. The Alien was back for a sixth time!!

An op to release the contracted scar tissues in my nose was hastily arranged for July along with biopsies of two of the three sites which had been identified, while planning continued with a surgeon from MaxFax to reconstruct parts of my face using titanium and peek plates to be inserted under my forehead and nose skin, sometime in September.

Unfortunately, those biopsies proved positive – the Alien was back in my palette and throat. I was offered chemotherapy as before but chose not to. I'd discussed it with Lesley.

'I just couldn't tolerate it again, even if my life depended upon it'.

For now, my facial reconstruction was on the 'back burner' while I battled it out with the Alien. MR scans in Sept would reveal all.

As I approached the meeting with David, post scans, I had no intuition over the results. The three areas of cancer were virtually unchanged from the scans three months previously – effectively a good result from my perspective and chemotherapy was no longer indicated so my facial reconstruction was back on, and I could continue working and playing squash at least until my next scan in the Dec.

I had a slight change of tack at that time. Previously I'd always thought of it as a contest - me v The Alien. There could only be one winner. It was turning to a position where we could exist together as long as The Alien didn't kill me. It actually felt less anxiety and pressure with this thought.

In July, I had the honour of delivering, a eulogy for Mrs Oldham, former Principal of Withington School of Physiotherapy.

'Call me Betty', she said after I'd graduated. I had so much respect for her I'd always slip back to her more formal title. I was so grateful for her decision to give me a place which proved a turning point in my life.

Following referral by David, to the trials unit, it was decided my cancer cell's DNA should be tested to see if I would be suitable for a trial drug. Testing would take 6-12 weeks.

While all this was going on, Lucy Burscough, a renowned local artist, had created an open studio at Maggie's, where people were encouraged to chat about her work and her subjects. She'd read my book and contacted me through Maggie's. I met Lucy, who was leading an arts and science project around facial disfigurement. She asked me if I'd like to be a subject. I wasn't immediately enthralled by being exposed to the public as I was no longer that handsome man, ha ha. I avoided photos and still do if I can. As there was a social purpose to the project, I agreed.

As time went on, I really enjoyed being part of the group, the art experience, and conversations with Lucy. There were five others who had had portraits painted when I came on the scene. Initially, it was one portrait each but when my facial reconstruction was proposed it presented an opportunity for a timeline of five portraits through the reconstruction process. The portraits were part of a wider exhibition called 'Facing Out', the pinnacle being a three-month exhibition at The Whitworth Art Gallery, Manchester.

# Chapter 14 Maggie's

Maggie's was spawned by Maggie Keswick Jencks a landscape architect writer and artist from Scotland. In 1993 when Maggie was 52, she was told that, breast cancer, that was initially diagnosed in 1988 and treated with surgery and radiotherapy, had returned in her liver and lungs. Not dissimilar to myself, she had a short consultation with the doctor who delivered those fateful words followed by a period sitting in the hospital corridor. That episode stuck with her as she knew there was a better way and gave her the idea for the first Maggie's at The Western General in Edinburgh, a conversion of an unused stable block within the hospital grounds. A non-clinical place to absorb difficult news, discuss options, seek practical and emotional support from professionals such as cancer support specialists, psychologists and benefit advisors. A place of beauty, colour, healing, and inspirational design. She worked on the project for 18 months with her clinical nurse specialist Laura Lee and architect Richard Murphy. Though she looked at alternative cancer therapies, Maggie died July 1995 with the plans on her bed. The following year the first Maggie's opened with her nurse Laura, in charge.

There are now 24 UK centres and several abroad. They are all bold dramatic structures with a warm welcome inside and a familiar genetic code. An approach, comfortable within its surroundings, offers an experience, responds to patients needs with inspiring architecture – inspiring hope. So unique are the designs, it has become a prestigious honour and mark to be offered the chance of designing a new centre.

Inside, each centre has a welcoming entrance, space to pause beyond the doors, office space, 12 place kitchen table, comfy chairs to rest on, rooms for group support and activities and an outdoor space or garden.

Three notable quotes by Maggie-

'People are amazing, and never so much as when they are feeling at their most vulnerable'.

'I mean to keep on marching.... Into the sunset and when eventually I must die, to die as well as possible'.

'Above all what matters is not to lose the joy of living in the fear of dying'.

Practical Emotional and Social support is provided free to people with cancer, their friends and family.

Courses include eating well, coping with hair loss, benefits, managing stress, exercise, meditation, return to work, cancer information post cancer, bereavement

support and talking to children about cancer. Expressive art, creative writing, garden, and kitchen groups provide emotional support.

Maggie's work closely with MacMillan too.

At the time of writing, each Maggie's centre costs roughly  $\pounds 2400$  per day to run and the whole organisation  $\pounds 24$  million per year. The construction of the Centres is funded by philanthropists.

Who would have thought 80% of people are £600 worse off per month as a result of a cancer diagnosis. There are approx 70,000 new visitors to Maggie's each year and 285,000 visitors in total. There are plans for new centres in Coventry, Northampton, North Stafford, Liverpool, Dumfries, Kent, Birmingham and Portsmouth. There are 60 cancer treatment hospitals in the UK.

That whole thing so resonates with me. Maggie and Dame Laura are my true real heroines of this world. I hadn't realised until I started looking into the history of Maggie's, that so many aspects of my journey mirrored those of Maggie herself. I'd like to think I share her positive outlook and perhaps explains my affinity to the Maggie's ethos?

For more information about Maggie's visit maggies.org

### Chapter 15 Sadness

The course of the year had been punctuated by many trips over to see my Mum in Lincoln. Though, she existed at a good level, with little daily support other than someone dispensing her medication, her vascular dementia was very slowly progressing. She lived in a lovely one bed apartment in a complex specifically for older, vulnerable people.

Caring for her from a distance became increasingly difficult as my efforts were undermined by my brother, with whom I'd had issues. Social services and the police were aware but unable to act.

In the second half of the year, she had another stroke, this time in her brain stem, affecting, balance, coordination, swallowing and toileting. She couldn't continue at home, even with carers, so, as I was sole power of attorney, it was my duty to find her a nice care home. She was there only a few months when she went into kidney failure and was admitted to Lincoln General.

Back in Manchester, after a long wait, I finally had the five and a half hour nose reconstruction in late November, using a PEEK implant to form my forehead and nose that slid under my skin and was secured with tiny titanium screws. Peek is a strong, light material used in the aviation industry. I'd been told the operation would be a straightforward affair, then, over a period, my tissues would grow through small perforations in the plate to eventually mesh with my tissues. I had a Lester Jones tube (LJT) inserted to form a tear duct during that op.

There was no talk of alternatives, particularly regarding prosthetics of which I knew little other than my trip to arrange a small plug at Whiston.

There was an immediate transformation of my face shape, improved breathing and vision, though the tip of my nose was already looking bluish. Whilst this was pointed out at the first opportunity, there was little concern from the consultant. It later transpired that the PEEK implant had to be trimmed because the fit was too tight. Despite that, the plate was still too tight, and the tip of my nose became black over the coming days and lost forever. There had been no attempt prior to the op to stretch my skin to accommodate the implant.

I entered into the procedure in the knowledge and agreement of the surgeon that my fallback position would be, that, if necessary, the plate would come out and I could return to my original preop state.

Within a couple of weeks, it was apparent the LJT had become dislodged. Despite going back to theatre early December, the tube could not be

relocated so had to be removed. Another attempt with a slightly different tube shape would be possible at my next operation scheduled in a month's time.

While I was at the hospital with my Mum in December, I noticed a little leakage of fluid from the incision edge. This was not good news. It was a paleyellow fluid, just a little thicker than water. There was no chance of me returning home as I wanted to be near my Mum, plus we had entered the hospital Christmas slowdown. The next few days the discharge increased to the point I needed to cover it, soaking up any discharge, and, as I was in a hospital, not exposing it to anyone.

My Mum was slowly deteriorating. She was competent but hardly eating. I made sure she had water by spooning it to her mouth. It was intolerable being there with my brother. The hospital staff knew this but were powerless to intervene. I'd been in Lincoln five days, sleeping on the floor of my Mum's apartment which was now up for sale. I needed to return home, so I left for Manchester at lunchtime on the understanding the hospital would contact me if her situation changed dramatically. It's almost like my mum hung on for me to get home safely. She died at 6pm, 31<sup>st</sup> December. It was extremely sad and upsetting to lose her, but I knew she was at least out of pain and discomfort. She could finally be reunited in heaven with her Mum and siblings which was her wish.

# Chapter 16 2018: Brutal

There were several more oozing areas of concern developing around the implant. The consultant didn't share my concern, describing it as fat breakdown, which wasn't shared by all the staff. I was seen subsequently by two specialist infection control nurses along with Philip.

It was eventually decided another operation was required to recover the situation.

Early January, in Lincoln, my brother collected my mum's death certificate from the hospital. As she was no longer with us, I was no longer power of attorney, and the hospital were powerless to resist giving it.

A few weeks later, Lesley and I travelled over to Lincoln to meet the vicar who would take my Mum's service. He had no personal knowledge of my Mum. A good while ago when my Mum was coherent, I'd discussed what she'd like for her service. Sounds a bit morbid but better that she had the hymns and prayers she liked. The vicar was taking instructions from my brother and the funeral directors only. We intended visiting my Mum in the chapel of rest. In an act of spite, my brother blocked Lesley, who had only ever been kind and loving to her. The solicitors acting for both my brother and me in respect of my Mum's will, couldn't persuade him or the funeral director otherwise. As Lesley was prevented from going, neither would I. We were a unit. We stood together.

At my Mum's funeral on 30 Jan 2017, I had half a dozen dressings on my face, just to make it look semi-respectable. My Sam and Lesley's Elliot joined us in the car ride over 'the tops' on a brilliant sunny cold morning.

I delivered a eulogy for my mum as did my brother. Ladies from my mum's home, which was on the same road as the church, some of my old friends, and relatives on my Mum's side were really kind with their words to me afterwards. Following the church ceremony, we left for the crematorium then onto separate wakes. 'My' wake was a chance to catch up with cousins on my Mum's side and her best friends.

Following the cremation, and in front of the vicar I gave the female funeral director, who looked like she was about to attend the rocky horror show, a real piece of my mind, which was pretty unlike me, but I might not have got the chance again. I saw my brother once more at the solicitors and never since.

By the end of that week, I had a four-hour op, to recover the situation, harvesting viable skin from my left cheek and the top of my skull to provide

coverage and blood supply to the grafted region. It was another hellishly painful few two days and it looked like I'd been totally butchered.

Still struggling, I was admitted to Manchester Royal Eye Hospital in March for several days intravenous antibiotics, in a ward all of my own, having blood tests, observations etc. It was around this time tests came back MRSA positive.

In the same month I had a routine MR & CT head, neck, thorax and abdomen scans at Christies. Nothing to do with my recent ops. I was asked to wait in the radiology waiting room while the scans were assessed which was unusual at the time. They'd detected multiple small segmental lower lobe pulmonary emboli. Basically, blood clots. The radiologist explained the situation and I was rushed in a wheelchair to the anticoagulant treatment centre, as I was no longer allowed to walk. I'd been on the squash court the previous day! An immediate injection of Dalteparin anticoagulant, a cuppa, instructed in self-administered injections and supplied with syringes to be going on with, then I was off home. Up to ten days post op people are vulnerable to DVTs as are cancer and chemotherapy patients generally.

On a visit to the consultant, I commented how brutal the ops had been. He responded,

'You've had worse', which might have been true but not an excuse to pour more on me.

'I feel more likely to die of your surgery than cancer itself', which was a pretty damming statement which he managed to shrug off. I was between a rock and a hard place, unable to go back but not relishing going forwards either.

Also in March I had a further two-hour op to get the implant to settle. Tough times.

# Chapter 17 Leaping Like Lemmings

I'd been 'tipped off' that my other consultants were watching from the sidelines with some dismay. A meeting was arranged with half a dozen consultants known to me and my current surgeon when we had some frank discussions. There's always professional etiquette to be considered in medicine, no one wanting to stick their necks out even though they might like to.

April brought me to the Dental hospital in preparations for a bonded bridge with Dr Carley Taylor to replace the molar tooth removed last summer.

The same month, once again there was a breakdown of the nasal and forehead skin exposing the implant. When would it end?

My next meeting with the consultant was also attended by Prof Homer. Once again there were holes in my face, the plate was exposed and I was leaking fluid. As the consultant started talking about moving skin from here to there, Prof Homer pulled rank and came to my rescue. Not that I particular wanted to hear it, but, he said,

'There will be no more skin grafts, instead, your remaining nose', which was pretty much destroyed by now anyway, 'would be better removed, with the plate'.

That would pave the way for a prosthetic nose and at least get me out of this awful situation for now.

Carly completed the bonded bridge to replace the molar tooth in May and the endocrine unit checked on my bloods.

More CT and MR head, sinuses and thorax scans confirmed the three cancer sites were still unchanged from one year ago.

In mid-June in a five-hour operation the plate was eventually removed along with the remainder of my nose and two cancerous nodes, while attempting another go at inserting a Lester Jones tube. Three abutments (anchors) were embedded in my left cheek bone for attachment of magnets that would ultimately hold a prosthetic face in place.

Stitched in place for now, there was a dressing pack where my nose had been and towards my forehead. The pack was visibly bloody, and open to the environment. A week or so later at night in bed, I'd felt this slight tickle in that region. The following night, Lesley and I were about to go to sleep. I felt the same tickle and then there was a sensation on my face. Was it blood or fluid? I put the light on so Lesley could see.

'OMG, you've got maggots coming out your face'.

They were on the bed clothes, the carpet and continuing to leap out like lemmings from the dressing. My boys came over and took me to Manchester Royal A&E. Maggots can be used in medicine to clear up infected wounds, but these weren't meant to be in my face. About 50 had emerged by the time I was seen, most probably freaking out most of the A&E waiting room. I was seen by the medics, but they didn't want to disturb the dressing, so I'd have to wait until I could be followed up in MaxFax the following day. On the way home we stopped to pick up some bacon. Not for a bacon butty as you might think. The lads had been on the internet and discovered the best thing for luring maggots was bacon. I spent the whole night laid on our cold kitchen floor with a slice of bacon on my forehead. I was able to see and collect from the solid floor the wiggly little things. I've had better nights.

With my maggot jar in hand, off Lesley and I went to MaxFax. Maggotgate was brushed off, as all the maggots had already departed. The dressing was off, and it was my first chance to see the devastation: and it was devastating. I had a red vertical letter box shape in the centre of my face. Lesley was horrified for a second consecutive day. It was shocking. We were so underprepared.

The tissues healed and lost their redness apart from a central strip. Arrangements were made to be admitted under Miss Cook at the eye hospital for an amniotic membrane to be placed over the exposed tissue, in the hope it would rejuvenate the healing process. The Stem cells and chemicals in the amniotic tissue really worked and the area was covered in viable skin within a couple of weeks.

At stages Lucy, the artist, had visited my physio practice to take serial photos of my reconstruction, or rather destruction. I sat in the same position, in the same light for each sitting.

To finish that whole period, we had Sam's medical graduation, me with a white dressing to cover the hole where my nose once was. I wasn't so bothered how I looked as it was Sam day, but these are photos that remain on the wall or sideboard forever.

I was always surprised how few people knew of Maggie's, what they were about, and who could benefit. Back in February I appeared with Sinead Collins, Maggie's Centre manager, on Mike Sweeney's BBC Manchester Radio breakfast show to promote Maggie's work. Charities struggle to get out there with their message unless they pay for hefty advertising which Maggie's didn't, so I was happy to 'piggyback' them into the studio. That appearance set the seed for another project.

It really had been a tough last seven months.

### Chapter 18 Walking Two Ferraris

By mid-August I had my first consultation at Aintree Hospital MaxFax department on Merseyside, a 45 minute drive away and the closest centre to Manchester. It was a good consultation, as I went away hopeful for a good likeness and possibly an eye too.

Despite the unusual appearance with my white dressing in the centre of my face, I carried on at work and racketball. I'd finally ditched squash as the ball was too small and fast moving, with my limited vision. Racketball, played on the same court as squash with a similar but larger rubber ball, more tennis ball sized, moved slower in the air and was easier to pick up visually. It's a skilful game and presented a new challenge. As I was making a fresh start it was good to feel I was improving rather than the disappointment of losing at squash when I might well have been victorious with two eyes.

With no nose to keep water out, swimming, and water sports, that I enjoyed on holidays was a no no. Another thing the Alien had managed to whittle away from my life.

The facial prosthetic at Aintree Hospital continued to take shape with regular trips to the MaxFax dept for fitting and wax moulds.

Yes Yes Yes!!! Review of scan results in October showed no sign of the two cancerous areas and a noticeable reduction in the enlarged left neck lymph node. This was the first time the cancer has shrunk without medical intervention. Were stress reduction and lifestyle changes beginning to undermine the progress and even the existence of the Alien?

In October we had the first part of the Facing Out program, with 'Talking Heads' presentation at Maggie's, a panel discussion exploring facial cancers and disfigurement from the point of view of the patient, surgeon, social scientist, cancer support specialist and artist. I was introduced for the first time ever as physiotherapist and author. That made me smile.

That little seed from the radio interview had grown into an idea. Why not cycle around England and Scotland visiting all 22 Maggie's Centres, view the bespoke buildings, meet the staff, get fit and perhaps get Maggie's some additional spotlight? The fund raisers at Maggie's leaped on it, and suggested I should also fundraise at the same time. My friends had already contributed so much to my FCT ride so I was a bit reluctant but eventually agreed.

I was struggling mentally with the trauma of the nose reconstruction. I'm sure the surgeon was proficient at what he did, and was perhaps at the cutting edge, but the decision making was hard to rationalise. I mentioned it to Angela, one of Maggie's support workers who sat down with me.

I got my hearing aid which wasn't the best look, but I did try it.

Results from a liver scan showed two areas of uncertain significance. Does it ever end?

I finally got a working silicon prosthetic to wear. Eureka! This was like a phoenix rising from the ashes of my failed reconstruction. My face was transformed, and I had an eye. Formerly with the graft it was possible to see I had disfigurement from 60 metres away, now it was 6 metres. The stares continued but they were more inquisitive, trying to work it out. Lesley had said to Sarah to include lots of furrowed brow lines which she had taken quite literally! Either way it was a big step up in appearance for me and as the silicon deteriorates and loses colour, it needs replacing annually, offering an opportunity for incremental improvements and to lose those furrows.

I had another op to locate the LJT but failed within a few weeks. The loss of bone was a challenge. At the time, I was offered another try but declined. I'd had enough surgery for now and needed a break from it all.

I was under ENT, MaxFax, occuloplastics, audiology, prosthetics and The Lindens Clinic. It was a lot, and I was growing tired of three, four, five hospital visits a week. I was literally sick of going to hospital, so I made a conscious effort to slim them down when I could.

I dispensed with the hearing aid. I didn't like the tinny sound and the look was not good. I had lots of other issues to contend with and thankfully, had one fully functioning ear.

I'd had a private consultation via zoom with Chris Woollams, renowned author of several books I referred to in Chapter 4, when I started my lifestyle changes. It was extremely useful, refining my approach and concentrating my focus on the things that really mattered. I started on iron medication as I was now low on a recent blood test. Why? Perhaps the surgeries or cancer cells were grabbing it.

Enzo, named after Enzo Ferrari, our second whippet, arrived just before the year end. We wanted a pal for Gromit to chase around and went back to the same breeder. He'd just had a litter of one – Enzo. Gromit was distinctly unimpressed with this annoying bundle of energy shattering the peace but has since grown to love him. They share the same dad, but are totally different in colour, temperament and stature.

## Chapter 19 2019 Respite

The year started well with results from MR scans taken in December, my liver now dismissed as a possible problem. My only remaining cancer was in a lymph gland in my left neck, only 1mm larger than the previous scan. I was offered a biopsy and removal, but I declined for now. Biopsies can sometimes stir things up and this was my chance to see if I could eliminate it by myself. I'd be rescanned in 6 months, so could fall back on an excision if the lump was progressing.

I happened to mention I was contemplating another bike ride to Polly, a friend and squash player. She had just sold her business, had time on her hands, and she was a great organiser that I could trust. She had a sponsor in days! Sharon Owen who ran her own business '2's Company' and lives locally very generously offered to fund the trip. She wasn't looking for advertising or anything. It was a totally philanthropic gesture. I had met Sharon previously but only briefly at a BBQ party at Polly's.

I was already on my indoor bike, concentrating on short, high intensity rides. I just needed the roller coaster to be forgiving, at least until my ride was over.

We had a few hours filming for a section of Facing Out at Maggie's, before the full opening at the Whitworth art gallery a few days later.

Finally, the opening of the exhibition, I felt like James Bond in my black tux, attending a film premiere. It was a great night with lots of friends, the other portrait subjects, and a celebration of Lucy's work. The exhibition formed the centre piece of the project with fringe projects which I'd also be involved in.

Each portrait subject had associated paintings that reflected their lives in some way. Mine had Attempted Healing by John Davies, Cyclist by Damien Le Bas and Dog and Scribe by Bob Scott, chosen from the Whitworth private collection which is kept in cold storage.

Before the summer got started, Lesley and I took a cruise to Norway, sailing through the fjords. It was difficult for me to drive with a single eye, on the 'wrong' side of the road, in an unfamiliar car and surroundings, so this presented the perfect solution. Lesley loved the whole ambiance of the cruise, dancing in the evening, conversing at the dinner table, lovely meals, dressing up while I could just take it all in, see the girl of my dreams enjoying herself, while I visited the gym each day to keep up my cycle training. Lesley deserved that. On my return I started working, one afternoon and evening at a local practice in Stockton Heath run by a physio I knew from our student days who was also struggling with health issues of her own, but bravely carrying on.

In May, I had two Facing Out engagements. Along with a local professional poet and the Maggie's creative writing group reading their poems, I read a passage from my book, Riding With The Alien. The audience was a nice cluster of people in the main Whitworth Gallery. I was quite happy getting up to read or speak. I was half-way through my ten-minute slot reading about the impact it had on my family and Lesley when I started to fill-up. I'd never previously listened to my own story out loud. I needed to pause and collect myself before continuing through quivering lips.

Later that month, Lucy Burscough's paintings of 'Graeme' reached the final selection for the John Ruskin prize. I met Lucy at the award ceremony at The Holden Gallery, Manchester with her family, but she didn't win. She would have also liked to enter her painting for a competition run by the National Portrait Gallery, but the size of the paintings were a fraction too large.

Racketball took a backseat while I increased my rides, both on and off road. We had the van, kindly arranged once more by Phil, bespoke kit and Polly had booked all the accommodation. Ready to rumble.

I'd planned the route to include all the Maggie's Centres in as time efficient fashion as I could. The Centres were only open 9-5 weekdays and I wanted to spend an hour at each. Working out the logistics wasn't at all straightforward and meant sticking very much to the tight schedule, despite any weather conditions or mechanical failure that might come our way. The route started in Swansea, snaking its way Northwards to finish in Inverness.

On two-thirds of the stages I had arranged to cycle with one or sometime multiple friends. It was a great way to include other people. They brought fresh legs and a different sense of humour each day. My son Sam, a good strong cyclist, was due to ride with me but was injured for the duration, but Elliot made it.

Each day we rode in memory or support of someone I or my fellow rider knew was affected by cancer. It was a good feeling to have that thought at the start of the day and added meaning to each stage.

Jenny from the Lindens clinic, who knew my story well, offered to run our public relations. She had contacts and set the ball rolling ultimately getting the Maggie's word into several national newspapers – our primary goal.

### Chapter 19 Maggie's Tour – Southern part

Day 1. 25<sup>th</sup> May 2019 was a beautiful sunny day as Bryan and I prepared to travel south to Swansea. Bryan drove the van for us on the FCT challenge, so he was a natural choice, if only available for the first week. We were waved off midafternoon for the 140 mile road trip down the M5, M6, M50 and M4 to a modest hotel chain on the outskirts of Swansea. As we drove South I recall thinking, this is a hell of a long way.

The following morning, we were greeted to a continuous downpour, as we made our way in the van to the start, Maggie's, Singleton Hospital, Swansea. We were meeting the Centre manager who very kindly came in specially on a Sunday to give us a tour and sendoff. Also meeting us were wives, Hilary and Julie. I met Hilary 30 or so years ago as a patient when she was an international badminton player. She was a great laugh, good cyclist and Maggie's supporter on a previous London to Paris cycle event.

The Swansea Centre was a cylindrical design having all the generic blueprint features of a Maggie's. I was interested to learn that they majored on provision for issues affecting children. After a coffee and a viewing of the Centre we were ready to head off, only it was tipping down. I looked at Hilary, she at me. Neither were ducking out for a rain delay knowing we had at least 65 miles to cover.

Unfortunately, we missed out on the prettiest part of Swansea, the Gower peninsular, instead heading for the more industrial Porthcawl. I had chosen to use the route-finding App, Kamout, providing instruction via an earphone. It wasn't a great start, as we seemed to be going around in circles. We resorted to using Hilary's iphone and we were swiftly on our way to Cardiff. We dropped a little too far South but ended up at our destination, albeit a couple of hours later than planned at The Velindre Cancer Centre, Cardiff. The recently opened Maggie's was closed, so we had to contend ourselves with a scout around the outside and off we went for a good lunch, with Paul, my Dallaglio roommate, who lives in Cardiff.

As we were behind schedule, we sped off in the direction of Chepstow, taking on some steep hills, to our stopping point for the day on the A48. The ride should have been 56 miles but was nearer 80. Hilary and Julie headed off to relatives in Cheltenham for the evening while Brian and I headed East in the van, to stay near Ross-On-Wye.

Day 2. It was a Bank Holiday the next morning, as I rejoined where we'd left the ride the previous day. I was meeting Hilary at Maggie's at Cheltenham

General Hospital. Getting the hang of the navigation app and drier weather, I made good time over 40 miles flat terrain. Once again, the Centre was closed. We had a nice lunch with Hilary's sister and family, then left on our cycles to Whitney, the destination for the afternoon's ride and Hilary's ultimate stage. It was a total contrast to the previous day with blue scattered clouds above, riding 30 miles through lovely Cotswold villages.

Day 3. The weather on Tuesday started well for the 14 miles to Churchill Hospital, Oxford, for my fourth Centre, strewn with some bespoke art works. The staff were very obliging showing me round another fabulous building. I had only another 45 miles to Ealing, for a shorter 'recovery' day. I remember going up one massive ridge, but not necessarily freewheeling down the other side. The traffic increased as expected towards London as rain resumed. I found myself on the Eastern Expressway into London. I'm not even sure I should have been on there, as it was like a motorway! I peddled like mad to get off as quick as I could. Then, on the London outskirts, I was criss-crossing the main road using subways. I made it to a nice hotel, rested up, completed my daily updates on the website, sorted the sat nav for the next day and off we went for carbohydrates at a nice Italian restaurant.

Day 4. Nick, a fellow squash player who was now working in London met me for Wednesday's ride, visiting three Maggie's Centres in London and one in Cambridge. It was a big day. 98 miles, some of it on congested streets. I was pleased I had Nick for navigating through London, and to sit behind all the way up to Cambridge. First up, a short trip to Charing Cross. Another amazing design, and brilliant staff. Swiftly onto Saint Bartholomews, for another outstanding building. Nick and I were posing for a photo by the entrance as I saw a lady I recognised.

'It's Laura isn't it', I asked,

Maggie's CEO. She asked us about the ride. Later that week it was announced she was to be made Dame and in my humble opinion, never more richly deserved. Without much break we were off to London Free Hospital via Buckingham Palace. The centre was no more than office space within the hospital, though we did see the plans and site for the new Maggie's Centre which looked spectacular. Once again, the staff were so nice. We headed once more, northwards to Cambridge, rendezvousing with Bryan who had travelled around the perimeter of London. We must have stopped for lunch, but it was so whistle stop, I can't remember anything other than Nick sheltering me from a strong headwind, and my thighs being very grateful. We made Addenbrooks Hospital, just before closing for our fourth visit of the day. Once again, they were in a temporary building but no less resourced in staff enthusiasm. Nick headed back by cycle and train to London as I cycled on past Cambridge City centre, staying that evening in Cotgrave.

Day 5. Thursday, I was joined by Peter, a friend from Lymm, heading up to Nottingham through open rolling land and fields. I was desperate to get started

on our 88 mile journey but was on the phone to reporters. I had to remember this was the whole purpose of my trip: awareness, and it was about to flourish. Jenny had done us proud. There wasn't a straight road directly to Nottingham so we were left with zigzagging until one point where we were faced with additional extra miles, or join the A1 for a hairy 10 miles. We were belting along with trucks pushing with their bow wave of air, then sucking us along. It was at least a dry day, but again a moderate head wind all the way. By late afternoon, we made the sanctuary of Nottinghamshire golf club, a very comfy abode – thanks Polly, and a nice meal that evening.

Day 6. Peter joined for the next leg too. Home to Lymm for the two of us. First, a 15 mile trip to the City Hospital for Centre number 9. A spectacular 'tree house' design with interiors by Paul Smith. My friend and physio, Dawn, surprised us with a royal greeting party. After a cuppa and chat we were off for the 70 mile homeward journey over massive hills via Buxton, the highest market town in England. It was a tough ride, made tougher by me leaving my phone (inc Sat Nav) in the van. Fortunately, Peter had his phone, but not Bryan's number, as Bryan disappeared off ahead of us. We made it to Buxton, and The High Peak Café, my favourite café on training runs up The Cat and Fiddle climb. Energised by toasted cheese sandwiches and beans, we roared home in record time, this time with me on the front. Those were two epic rides, back to back, with Peter who is ten years my senior but thankfully phenomenally fit. It was the journey's end for Bryan who had done a sterling job once again. Polly would take over driving for the remainder of the tour.

The logistics of visiting Centres only on weekdays meant I had three days off, at home, recovering. There was a chance to sort any mechanical issues, wash and dry kit, clean the van and spend time with Lesley, Gromit and Enzo. The schedule worked in perfectly for a catch up with the Dallaglio medical lads at Rooster's wife's birthday party one evening.

With multiple wrong turns, strange quirks of the SatNav and Maggie's Centres tucked away on large Hospital sites, we'd covered an additional 40 miles and 472 miles in total. The majority was still to come.

### Chapter 20 Maggie's Tour – Northern Part

Day 7. Tuesday 4<sup>th</sup> June, we set off Westwards to Clatterbridge Hospital on the Wirral. I was joined by two good cyclists Damian who I knew from Lymm and Steve a fellow squash player. The weather was dull to start, gradually deteriorating into heavy rain for our finish into Manchester, my home Maggie's.

We departed Lymm around 8am, leaving Polly to have a coffee with Lesley. Despite being slowed by the SatNav taking us on rough tracks, we covered the 30 mile distance, made our introductions, toured the semi-temporary structure and were having coffee and cake before Polly arrived in the support van! She couldn't believe how fast we'd travelled. For the 43 mile return to Manchester, we cycled north then hopped in the van to get through the Mersey Tunnel to Liverpool and headed Eastwards, North of the Mersey River to Manchester. Enroute at Warburton we picked up Peter, who joined the peloton in the pouring rain through South Manchester to Christie Hospital where staff and friends gave us a great reception. We returned home via the van for the night in Lymm ready for a return to the same spot by 8am on Wednesday morning.

Day 8. Simon, the Trojan's son, plus family met us for the early start from Maggie's Manchester for the 11 mile urban road trip through the East of Manchester to Oldham Royal. Lesley, Gromit and Enzo joined us from this point as it added no extra cost and was company for Polly and me. Simon and his dad were staunch Man United fans. I'm sure Simon sped up, to avoid a panic attack while passing The Etihad Stadium where arch-rivals, City play. The Oldham Centre was stunning, with a tree growing through the building's central glass area. I said goodbye to Simon and rode solo to The Leeds Centre that was under development. The road over the moors was cut off for road maintenance but thankfully I managed to cycle/walk through when the van had a 30 mile detour. It was still a hilly, thigh burning 40 miles for me in dry but cloudy weather. We toured the half completed building with hard hats before taking on another 15 miles to Knaresborough for the night. Enzo, not being the best traveller, had been sick several times. Riding solo was slightly harder for me and more dangerous. Having a buddy to look out at junctions and behind, plus listening for cars was reassuring. Otherwise, the time alone allowed thoughts and images to wash through my mind.

Day 9. On Thursday morning we were joined by Ian, a good club cyclist and fellow squash player. Ian being stronger, took the front affording my thighs some relief. Halfway through the pleasant sunny day, I suffered the only puncture of the whole Tour. We completed the 75 miles in good time to reach beautiful Durham in time for a quick pint then return Ian to the rail station for his trip home. Enzo conquered his travel sickness that day.

Day 10. Friday the 7<sup>th</sup> I was joined by Jeff on his trusty stead that I labelled, 'The Tank'. We had a nice catch up on our 15 miles via The Angel of The North, through Newcastle centre and onto Freeman Hospital. Another fabulous Maggie's Centre and some nice poached eggs, though it was not my intention to put them to any trouble. The following day I had a 60 miles trip planned to Jedburgh with no Maggie's visits, as it was the weekend. Tomorrow's forecast was really poor, so I decided to ride it that same day and return to our accommodation in Whitley Bay, so we could meet Jeff and his wife Dawn for a meal that evening.

The following day was now a free day, so we all got in the van and headed up to Kelso in the torrential rain.

Day 11. Sunday I was back on the 'Italian Stallion' with a solo ride to The Western General Hospital in Edinburgh on a nice summer's day. This was The Home of Maggie's, the place it all began. Whilst we couldn't enter the building until tomorrow, we could enjoy the gardens and pause by the statue of Maggie, sculptured by her sister. It was a moment for reflection and for me, spiritual unification.

Day 12. We returned the following morning to meet the staff, a tour of the beautiful, homely building, group shot and push on up the road, eastwards to Glasgow, first stop Lanarkshire. The 30 mile journey was partially completed on an offroad cycleway which was great in fine weather. At the Elizabeth Montgomarie Monklands Hospital we easily found Maggie's Lanarkshire in open grounds. Onwards, to Glasgow, along busy streets with tall buildings to Gartnaval General Hospital and Maggie's Glasgow, the seventeenth centre on my travels, where I'd arranged to meet Lesley a fellow physio who worked in the city. Great staff and Centre where we had a welcome seat at the kitchen table and a cuppa. I clipped off an additional 15 miles of the following day's schedule to complete nearly 900 miles total.

Day 13. I rode along the flat Forth Clyde canal path on the Tuesday morning to Maggie's Forth Valley, to meet both Elliot, who Polly had collected from the train station, and Jake, Elliot's pal, for whom the centre had some personal family significance. Again, the centre was hard to find, but when we did find it, was clearly in a beautiful spot close to a lake. After meeting the staff and a tour we were heading back west to Fife, but not before taking a trip onto The Prince of Wales Aircraft Carrier that was under construction in a Clyde dock yard. It was arranged by Elliot's future brother-in-law who had intentions of raising funds towards our effort. We returned to cycling after that short break to reach Maggie's Fife at Victoria Hospital just before closing. Another bespoke design and friendly staff. Elliot and I continued on for another 15 miles north, to our St Andrews overnight stop, while Jake returned home. Another 70 miles covered.

Day 14. Elliot was with me now until the finish. He was undertaking a full ironman challenge the following month, so these next few days presented some welcome training. We headed directly northwards towards Dundee, taking the Tay Bridge over the river, where we cycled in a lane above and between the two carriageways of motor vehicles, more exposed to the strengthening wind. On reaching the north bank where the new Victoria & Albert now stands, we took a left for several more miles to Ninewells Hospital. The iconic roof adorned Maggie's Dundee, a beautiful structure both inside and out. We took our time to take in Frank Geary's design, while there was sufficient space outside for Enzo and Gromit to stretch their legs on the open grassy area. The garden was slightly remote sporting a large Penguin, the subject of a fund-raising campaign. There was another 55 miles to complete the day and the 1000 milestone. Once again, we headed northwards, into gale force winds, and increasing heavy rain. 80 mile an hour winds and rain would normally have forced us to abandon but we didn't have that option. We were so battered by the gusting winds we could have never contemplated the dual carriageway for fear of been blow under a vehicle. Instead, we were safer on an adjacent cycle route. Rail transport had been suspended and a Rod Stewart concert in Aberdeen scheduled that evening had been cancelled. Late in the day we arrived at the central square in Stonehaven. Sheltering under some traditional stone buildings, both of us were soaked and visibly shaking. People smoking outside a local bar must have thought we were crazy. I've never been so pleased to see a white van when Polly appeared round a corner. When those people saw the purpose of our ride, they came over with cash donations. That was a special feature of the van. Logoed with Maggie's and our ride emblem, it became a focal point for people to come over and start talking. Some of the stories were sad, and the donations very generous. That had been the hardest ride of my life, and the same went for Elliot, who took the brunt of it on the front. We were short of our target by 5 miles, the first time we'd fallen behind on the schedule. On arriving at our hotel room, I was straight in the shower to warm up. It had been an epic day.

Day 15. We set off slightly earlier than planned to make up those 5 miles on the journey up to Aberdeen. It was still raining with strong winds as we entered the Aberdeen Royal Infirmary and Maggie's Aberdeen, a fabulous pebble like structure. Totally stunning design. We were already soaking wet, so changed as much clothing as we could. Polly had been out to buy us some more gloves, but they were also soaked through. We dried as much as we could, while I did an interview for a local paper. We waited for as long as we could for the howling gale to abate, but it didn't, so we set off anyway. We had another 50 miles straight into a westerly wind. It was a cripplingly slow pace and grind. We got in the van at one point simply to warm up. We called it a day at Huntly, 20 miles short of our target of Elgin. The forecast for the following day was better. It was 50 miles on the schedule, plus the extra 20 from today which was achievable. We carried on in the van to Elgin for the evening, returning to Huntly in the morning.

Day 16. Friday 14 June, the rain had stopped, and the wind dropped. Together we bombed it back to Elgin down some shallow slopes that were in our favour. It was a great start to the day. It was now a straight run to Inverness through wooded terrain. We reached Maggie's Inverness, the structure the shape of a fishing boat; just incredible, at Raigmore Hospital mid to late afternoon. The staff had the balloons out to celebrate at the finish, and an extra packet of biscuits. We'd done it: 22 Centres, 1180 miles (Av 74.5 miles per day) in 16 days riding. Amazingly, I felt so good, perhaps on a wave of adrenaline, that I felt I could have ridden all the way back to the start. Polly who had planned it with me said, 'It was one of the best things she'd done in her life'. For Lesley she was probably just pleased we'd all got home safely without one fall. We said our goodbyes to the staff, got the bikes and gear in the van, and headed to the airport to drop Elliot. As it was too late to drive all the way home, we stayed in Sterling for that evening.

To my surprise, Polly had fixed up with Steve, the chairman of Bowdon squash for me to appear via zoom, on the big screen, later that evening during the club's end of season do. The club had always been supportive of my endeavours and in recognition, awarded me the Chairman's trophy.

We travelled back to Lymm the following morning: job done. No anticlimax. It had been a brilliant experience. We'd achieved our goal, to raise awareness, and bagged £18k for Maggie's in the process, thanks to all those generous donors. Peter added a further donation from a local charity he was involved in, and Adam, from Bowdon club, donated the proceeds from his charity cricket match later in the year to bring the total to £24k. I gave an emotional speech to the cricket players that evening. I've never seen so many big guys in tears and happy to admit it. Several days later I was interviewed on Australia's TV Channel 9. I was hoping it would be in person but only via zoom.

The real stars of the show were 'The Boys', Enzo & Gromit who were adored everywhere we went.

It had been an incredible few weeks, and an honour to ride with my friends and family, meet fabulous staff and visit bespoke architectural masterpieces, stand by Maggie's statue and meet Dame Laura Lee. I couldn't have done it without Sharon's kind sponsorship and Phil sorting the van. In the true spirit of teamwork, I hoped we'd all done something Maggie would be proud of, and proud of each other. Unforgettable.

Once again, the Alien had ridden with me, only this time in the lymph node in my neck. The roller coaster had at least been forgiving enough to allow me this ride.

There were two post ride celebrations. One by Maggie's Manchester as a thank you and one in late summer in our own back garden with as many of the team as we could muster.

Sometime later, I received a message of congratulation from Dame Laura. That handwritten note meant a lot. Apparently, she had followed our ride from the point we met.

To view The Maggie's Tour video, return to the Home page a click the video.

## Chapter 22 Catching It's Tail

Within two weeks of finishing the ride I was in the MR scanner, followed by ultrasound guided biopsy of the only affected lymph node we thought was occupied by the Alien.

Elliot had his medical graduation in July prior to starting two years as a doctor in Warrington Hospital and then landed a plum job, a run through registrar post in ENT in the Northwest region.

There were multiple visits to Aintree prosthetics to create a second 'face' and a week away in Norfolk with Lesley and the boys.

Philip, my CNS was moving on upwards to Matron of Cancer Services for Manchester Foundation Trust. His gain was my loss as he had been so influential in my care, connecting it all together. Lesley and I congratulated him and vowed to keep in touch.

Perhaps not surprising, but one thing leads to another. I was contacted by Professor Fay Bound Alberti, from York University whose team were researching the meaning of face transplants, specifically the surgical and psychological processes, titled, 'About Face'. Fay had read my book and asked if I'd join an advisory panel of people with lived experience. Looking at the impressive array of those already involved, professors, doctors, and a dame, I wondered if I'd fit in. I was by far the least professionally qualified, but I did have a lot of lived experience, so I agreed. We only ever met by zoom perhaps three times a year, so it wasn't too enduring. Listening to these experts construct a fluid comprehensive five-minute dialogue, affirmed to me that I had a missing cog (or cogs) somewhere – I couldn't do that.

Results from a dyslexia test placed me in the moderate group. It was irrelevant now, as I'd completed my education and learned strategies to cover it. I hated reading out loud in class, spellings (but not necessarily medical words – they were logical) remembering a number sequence, getting b and ds mixed up and difficulty with the likes of though, through and thought, that all looked the same to me. The upside was I had lots of creativity, which brought lots of joy to my life and a problem-solving mind (essential as a front-line physio).

Later in the year, I had MR, CT and PET scans looking for Alien activity other than in my lymph gland and I finished working at the Stockton Heath practice that was now under new ownership. Late January, I finally had the single left neck lymph node excised. Before the surgery I said to Prof Homer,

'I feel we've finally caught its tail'.

Thankfully, my cancer was slow growing. I believe that if it had been faster, it would have been all over by now.

Theoretically, I was now detectable cancer free, and the roller coaster had been at a subdued level for some while.

Within a month of the Covid pandemic kicking off in the UK we were all in lockdown. Not surprisingly, I was on the vulnerable list, being advised to stay indoors and close the windows. How that advice changed!

I don't think I felt the changes quite as harshly as some people, because we had already slimmed our lifestyles in terms of going out, socialising etc. The worst thing for me was not being able to play racketball or go to work.

A couple of the squash lads I knew at county and international level were very badly affected by the virus despite being very fit lads. One had a significant stroke and the other very sadly succumbed to the effects in 2023. Another friend lost his mum and bother in the same week.

Whilst I'd spruced up my immune system this was obviously a devastating disease to be avoided. Lesley and I were super cautious. Lesley did the shopping, saving me that potential exposure. I had my indoor bike, a few weights, and the garden for keeping up my endorphin levels and flexibility.

I think there was a further lockdown by the end of the year which prompted me to finish working at my old practice.

### Chapter 23

### 2021

My first covid jab end January, couldn't come soon enough. When lockdown eased, I started working from home seeing just a few patients a week. This was much more controllable than in the practice setting and I knew my patients and they knew my history.

Progress on my prosthetic was frustratingly slow, partly because of covid and because the two prosthetists were alternating maternity leave. To speed things up, I started looking for a new facility.

In March I had a spontaneous infection affecting the right side of my face and ear. I did feel ill, and in the past, this had been an early sign of the Alien. ENT put me straight on antibiotics for cellulitis. At the same appointment we discussed my hearing and the eustachian tube blockage.

There was a technique, a little like blowing up a balloon, that forces air through the tube. As I'd been given the okay, I'd give it my best shot. Within a few weeks of forcing air sufficient to blow up a car tyre, there was a crackle in my jaw and suddenly my hearing was back. Wow! I persisted for a while to keep it open, and it did. Good to claw back something the Alien had taken for itself.

Sam and Miriam got engaged while in Cornwall following Elliot and Claire's engagement at Lake Windermere the previous July.

By early April I had my second covid jab and an MR scan which was clear.

Covid restriction were eased as I started with my second unexplained facial infection. Antibiotics were once again on offer which I didn't care for but I knew there was no alternative. Antibiotics can destroy some of those good bacteria in the gut I was working so hard to keep in tip top condition.

I transferred to the recently opened, North Manchester prosthetics dept in mid-summer, and it made sense to keep it within the same Trust, where I had all my treatment. Iwona, my new prosthetist was brilliant at carving my 'new face' from wax then converting it into silicon. They even 3D printed my 'nose' from my CT old scans. Oliver, another prosthetist, combined his technological skill with Iwona's creativity to produce my best prosthetic yet.

Within a couple of months, I had my third facial infection then a fourth very soon after. By now, I was starting to sense a pattern that started with the feeling of a 'boxed ear'. To my relief, I decided to daily moisturise my outer ear and that seemed to put an end to that. Perhaps a radiotherapy effect?

15 years ago, I'd played in the Squash British Open o45s. This year I played in the Racketball National Championships and British Open o60s, going out to the No 1 seed in the quarters, both times. Another box ticked on my comeback trail.

Without trying I'd become a mentor to people with cancer. Most likely a relative or friend contacted me looking for some inspiration and advice. I was always careful not to give medical advice, but to act like a signpost for gathering their own information. If it was fate that the Alien chose me then this acted as a reason.

My Covid booster was a reassurance as was a clear CT scan to complete a quiet year for the roller coaster and a good Christmas.

### Chapter 24 Magnetic Attraction

#### 2022

The year started with another Lester Jones Tube op that I'd been waiting ages for but failed within a few weeks. Prof Homer was happy with my progress so arranged my longest review yet. Eighteen months. If I felt there were issues, I could contact him.

In May I had a frosted surface LJT inserted, successful for four months, my best ever. The slightly abrasive outer surface of the tube clearly made a difference.

At Elliot and Claire's wedding in Llangollen, I was able to enjoy the day that much for being able to see clearly. The rain just about held off for the outside ceremony. Thankfully I didn't have to make a speech, particularly as there were already lots of takers. It wasn't fitting for me to wear my customary cap which left me slightly exposed. I really didn't want to spoil any photos.

Once again, I made the quarters at the Racketball National Championships but would miss The British Open in favour of Sam and Miriam's wedding in October in Southern Italy.

On a nice August weekday, Sam and I cycled over to the newly finished, Maggie's Centre on The Wirral, a beautiful building sat in the grounds of Clatterbridge Hospital that I previously cycled to on my Maggie's Tour. I looked at the distance and thought 60 miles would be fine on no cycle training. Sam, on the other hand was in training and a good cyclist, decided on an extra scenic trip on the return, forcing me out of my comfort zone and a crawl home.

I'd discussed with Sam that I felt it was the right time for Lesley and I to get married. It would be nice for her aging Mum, and we could get married before her own boys took the plunge, if she accepted? We were planning to visit Capri for a day trip while in Italy, and this represented the chance of a romantic (not my strongest suit) proposal.

My hearing continued to be improved and though slightly diminished on audiology testing was now at an acceptable normal.

Sadly, we lost my cousin Andrew in his mid-sixties late 2022. I'd had lots of long telephone calls with Andrew comparing complimentary strategies to beat the disease. He was more knowledgeable about alternative treatments than me and throughout our lives was a lovely cousin. Sam and Miriam chose to have their wedding in Italy, in October, when the temperature is more tolerable. Miriam grew up in Naples, and many of her family live there. Vico Equense on the Amalfi coast, just south, was a perfect choice for a wedding venue in a church on the cliff edge, overlooking The Bay of Naples. When Sam and Miriam got engaged, I said, 'I'll learn a word or phrase for each day until their wedding'. Both Lesley and I were able to have very broken conversations with the Italian relatives who had an equal grasp of English. We had a few days before the wedding, 14 October, in Naples then a few after in Sorrento.

Although we had a very enjoyable trip, the day for romantic proposal came and went. We didn't even go to Capri.

Early November I had four additional abutments screwed and embedded into my skull, that, once knitted with my bone, would later have magnets attached for attaching my prosthetic more securely, and the op went off without a hitch.

#### Chapter 24

#### 2023

In January, Mr Omah Gawagzeh, a colleague of Miss Cooks, took up the challenge to relocate the LJT that had slipped slightly. It was a local anaesthetic list, and I knew from previous experience, the injections would be painful. I had to stay perfectly still while Omah injected four times into my eye lids closest to my nose, top and bottom, and inside my nasal cavity. It was absolutely excruciating, not that it was Omah's fault, but because the tissues were by now scarred and didn't expand well for the fluid entering my tissues. If I had secrets to tell this was the time! The op was unsuccessful in repositioning the tube and before I'd got off the table, we were already discussing possible options for a new tube under general or maybe local. I thought, no way local.

This was no reflection on my eye operation, but it seemed to bring up a lot of painful memories from the past 13 years. My 'lifetime pain jar' felt full to overflowing. I'd had enough of pain. I don't know much about PTSD but I was suddenly in a darker place, at a time when Lesley and me were also struggling. On my walks with Gromit and Enzo I'd have time to think about those feelings and contemplate life and death. I didn't discuss how I was feeling with anyone apart from alluding to Miss Cook that I was struggling with it all, who arranged for a colleague to contact me. Within a couple of months, I'd pulled myself out of a low state of mind that I'd never experienced before and don't want to experience again. My family and friends will be reading this, thinking, why didn't you say something, and I'm sorry for no including or burdening you with it. I promise that I'll chirp up if ever I feel like it again. Now I know the trigger I'll take as much care as possible to avoid it in the future.

Tony, a lovely guy in Lymm who I'd chatted to while walking our dogs on many occasions was another friend to lose his brave battle in March.

In April we had another attempt at fixing another LJT, larger diameter, longer and angled slightly differently. Miss Cook and Omah were true to their word, having it under a general anaesthetic.

The following day Lesley, the girl I wanted to spend this life and the next life, was gone. That very special chemistry had dwindled away over the past nine months. First scan results in nineteen months. CLEAR. It was sad that Lesley wasn't here for that modest celebration with Enzo, Gromit and me.

A week later I was playing an Intercounties tournament for Cheshire, the first time I'd represented Cheshire in years. I was up against some young talented club players and pros, it didn't matter that I was beaten, so long as I played as well as I could, and I think I did that.

Attachment of magnets to the abutments completed the abutment surgery from November, ready for a new prosthetic. A magnetic personality at last!!

## Chapter 25 Die Another Day

As I wanted all the proceeds from this publication to go to Maggie's, we decided to put everything on a website, where people could read and see it for free.

What would the title be? I corrupted the title of a James Bond film Die Another Day to Cry Another Day. Either would be appropriate, but no one had used the title to publish a book and the domain name was available. It just seemed the right choice as throughout the last 13 years I'd had little time for tears because everything was coming so thick and fast.

I had a conversation several days later with Maisie Lawton, an independent reporter re a cycle event Maggie's were running. Maggie's asked me to be their 'poster boy'. (Their words not mine.) She asked me to talk about my Maggie's Tour ride and my cancer journey. I was in tears like never before, pausing several times to get through the interview. It affirmed my choice of title.

Scans in another year. Fingers crossed I can stay clear of the Alien until then and even enjoy the roller coaster at this more sedate pace with my faithful friends and family that have ridden with me throughout.

My cancer was probably caused by several things conspiring together to create the Alien. Equally it's taken surgery, radiotherapy, chemotherapy, stress reduction, elimination of negatives in my life, diet change and positivity to turn it around - to this point. Only when I die of something else will I know I've survived it.

I maintain a large proportion of the lifestyle changes I started in 2017 apart from the unusual herbs, liver flushes and enemas. The turning point for me seemed to be stress reduction surrounding selling my practice, shutting out negatives, lifestyle change and Maggie's coming into my life.

If it's one thing I learned, it's to expect the unexpected, which can be bad, but also good. Thankfully, I'm feeling much better about life right now.

To all my lovely friends and relatives who I've lost during the time I've been diagnosed. It could have so easily been me. All those thousands of people who have died of cancer that I don't know and all those cruelly affected indirectly by the covid pandemic. God bless their souls, their families and friends. Maggie's is also there for them.

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If you've found reading this site interesting enjoyable, inspiring, sad, compulsive or rubbish, please consider sharing it on social media, with your friends and relatives and donating something to Maggie's by clicking Just Giving on the Home page header.

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