

A SUBMISSION

by Victor Smith

Prologue

The writer is in his late seventies. After an illustrious Naval career which covered a quarter of a century he became a Chef and Restaurateur, gaining a local reputation for first class food. Twenty years passed and later in life, whilst working in the pharmacy of the local hospital he developed the symptoms of cancer. It was not a surprise as whilst in the Navy he had always drunk his rum neat and had been extremely fond of a good cigar. Eventually it resulted in a Total Laryngectomy, 16 hours of surgery and almost five months in hospital.

Due to extensive surgery neither oesophageal speech nor an artificial valve to replace his larynx was a possibility so he became an exponent of that splendid piece of German engineering, the *Servox* artificial larynx.

Eating had also become a problem, with the top of his oesophagus constantly trying to heal itself up. This entailed regular visits to his surgeon to have it dilated. After some years he was presented with his own *Maloney Bougie* allowing him to carry out the procedure at home, improving his Quality of Life greatly.

Becoming a Trustee for two Cancer Charities he gives numerous talks on cancer at various Universities and Conferences. Probably his most notable was at 10 Downing Street in 1999.

What follows presents a short insight into his life as a speechless survivor of cancer and the NHS.

Diagnosis

With the benefit of advancing years I see that time certainly does fly, often taking with it both long and short-term memory. Nevertheless there is one ill-starred occasion, almost two decades ago, which never leaves my mind entirely. Much has happened since that day, some good, some bad, always it has been connected and relevant to that sinister occurrence 20 years ago.

It began with a normal visit to my GP. Nothing to worry about, I had a sore throat, but I knew why. It wasn't a medical mystery, nothing more than my constant snoring in bed at night. It didn't keep me awake, but it did disturb my wife. Many times I'd been woken up and informed that it was the spare bedroom for me for the rest of the night.

I would duly shift my bones, often to a cold bed and resume my sleep. However it did cause a minor rift in the household, my wife was a working girl and entitled to her sleep too.

At that time I was working in an environment which contained practically every drug known to man. Potions and elixirs, some from the Middle Ages, surrounded me. I tried every one that seemed compatible with the problem of mild soreness which was interfering with my domestic life and my baritone rendering of various operatic arias whilst at work.

I'd read in a woman's magazine that snoring could be easily cured, "*Thread a cotton reel onto a length of string and tie it around the waist with the bobbin at the back prior to going to bed*" was their prescription. This invariably stopped you lying on your back and, QED, prevented the snoring '*which everyone knows*' is aggravated by sleeping in that position.

I went to the local medical centre to see our family Doctor. He'd served us well over the years, ever since joining General Practice after caring for a Brigade of Gurkhas. Eventually we had tried everything which could have eased the soreness of my vocal chords. As a last resort we agreed that he'd write the regulation letter to the local ENT specialist who, by happy coincidence had his consulting rooms at the hospital where I worked.

Some weeks later a brown envelope arrived on my hall carpet, well fielded by my Border Collie the letter advised me of an appointment with the expert.

The ENT Department was part of the newly built complex in the heart of the Hospital, a £10m addition which had taken three years to complete. The consulting rooms were just around the corner from where my friend Ivan spent his days distributing surgical stockings, various prosthetics and plastering the occasional arm or leg. As a sideline he collected used postage stamps on behalf of a Donkey Sanctuary. He was a firm believer that enough time and money was spent on human beings, his postal harvest helped in a small way towards the care of donkeys and retired pit-ponies.

Strolling in as nonchalant manner as I could muster I entered the brightly coloured corridor of the new complex. An odour still remained of drying paint and plaster. The closing of the automatic doors behind me cut off the sounds of outside

activity completely, it was like walking into an empty church. I presented myself to the auburn haired nurse, who, smiling, invited me to take a seat.

I settled down amid a pile of old magazines. The waiting room was open-plan and shared with the Eye Department. Boring grey plastic chairs colonised the area. On the walls were various notices, one implied that out-patient appointments were broken only on pain of death.

I studied an enlarged print of a Turner seascape, a force 8 gale in the English Channel. I remember them. My worst experience in 25 years of storms at sea had been in the Mediterranean. That azure sea with light breezes and constant sunshine so often depicted in travel brochures. Our submarine had been on the surface off the Greek Islands. On its open bridge with the water rising waist high, we watched bolts of lightning smash into the surrounding sea. I really did believe that Zeus was on Mount Olympus throwing his javelins at us. After about four hours and some accurate navigation it was calculated that we were going backwards. We dived and went to the comfort of a 100 feet to enjoy our rum and dinner, then sleep until morning, a new day and hopefully improved weather.

In the waiting room my companions were few, an elderly lady on my right was an obvious candidate for the eye clinic, whilst the small boy sitting close to his anxious Mum was a likely applicant for a grommet in his ear. I never saw either again as the nurse appeared from her cubicle and called "*Mr Smith please*".

Inside the consulting room a deeper voice came from the background, from the region of a washbowl in the corner

"*Take a seat will you*". There was an obviously placed armchair adjacent to a large desk. The whole image was of glass, chrome and black pvc, circa late twentieth century. I listened intently to the sound of a scrubbing brush working its way over fingernails. The previous patient must have been a mucky one.

The voice materialised as a slight figure in a starched white coat. "*I believe you work in the hospital?*" Lunchtime's cold beef and salad lay heavy in the pit of my stomach, was it indigestion or fear? "*Yes sir*" I replied.

"*I'm Mike Frampton, one of the Consultants, I understand you have a throat problem*" I nodded in agreement, my mouth had gone dry and I was aware that a chill had entered my veins, the air conditioning must be set too low. I related the facts and reason why I was there, Mike nodded from time to time encouraging me to go on, he even smiled at my attempts at a joke.

"*Let's take a look shall we? Pop up into the chair*" There was a vague resemblance to Mastermind, but this was no light-hearted quiz programme. In a well practiced manner he deftly adjusted his headband and reflector. Selecting a long stemmed mirror he warmed it over a spirit lamp,

"*Not hot, just warm. Open your mouth and stick out your tongue*" Hesitantly I obeyed. With a piece of gauze he caught hold of my tongue, pulling it forward he inserted

his mirror to the back of my throat. "*Mmm, I see*", a moment later "*Okay*". With that my tongue was released. I swear he'd held it down under his foot. I swallowed and rearranged my jaw.

"*Something very nasty down there Victor*". Again I nodded.

"*I could tell you that it might be benign, but I don't think you'd believe me.*" I had a feeling that this was one of the key moments in my personal history. I tried to breathe slower and deeper. Looking over Mike's shoulder I saw a large picture of one of the latest nuclear submarines.

"*You a submariner?*" I questioned, changing the subject whilst my over-heated brain caught up.

"*I was a few years ago, that was my last boat.*"

"*My last boat was Ambush, that seems a lifetime ago now*".

"*Just a bit before my time,*" replied Mike.

This was the moment when I tossed a coin mentally and decided that this was a man I could trust. If the crew of a nuclear submarine could put their faith in him, that had to be good enough for an ancient diesel-electric sailor.

Two days later a laryngoscopy confirmed his diagnosis. I had a cancer in my throat which appeared to be wrapped around my larynx affecting my thyroid, and goodness knows what else. I was pleased when a phone call to the Radiological Unit in a nearby town produced the information that a vacancy existed for treatment commencing the following Monday.

Treatment

Having Radiotherapy every day for several weeks was no joke. On my first visit to the Unit instead of being shown into an X-ray suite as expected, I found myself in what seemed a very similar setting to the Plaster Room at my own workplace.

A chap in a white jacket invited me in a very nonchalant manner to lie down on a bench and rest my head on a wooden pillow. Very Japanese, remarkable to say the least as there were no plates of sushi or flasks of saki evident, but like a well trained patient I obeyed without question. It was a most uncomfortable position, made worse by his continued silence and the sheet of warm plastic which, to my surprise, he laid over my face.

I must have flinched in alarm because white coat decided to break his vow of silence and take me into his confidence. He explained that it was his job to make a mould of my face and neck to provide a mask which was necessary before treatment could commence. It was a painful half hour. Nobody's neck, filled with

squamous carcinoma takes kindly to being bent at an angle of 45 degrees and pressed down onto a wooden pillow whilst heated plastic is shaped around his facial contours. All this was carried out by a character who most assuredly subscribed to the theory that *'Silence is golden'*.

When treatment got underway in earnest, it was a lonely business. Strapped to a table semi-naked I was lined up with immaculate precision in the jaws of a giant Microwave. With my new face mask firmly in place all was ready for bombardment with extremely high frequency impulses. It all created an overwhelming sense of vulnerability and isolation, but it was going to make me better!

The vestal virgins who lured me into their temple of healing quickly melted away slamming the door behind them. Once behind their three feet of concrete and lead the fun began. The red lights came on and I was left counting the bleeps while the machine irradiated the cancerous cells within my neck.

After my prescribed amount of torture, liberation arrived. Redressed I sat quietly awaiting transport home. Once there, after a welcome cigarette I always fell asleep in the comfort of an armchair.

After weeks of radiation eating became a nightmare, almost impossible. My throat felt like a witches cauldron filled with something obnoxious which constantly bubbled away. *"Eye of newt and toe of frog"* came to mind. Most certainly the *"fire burned and cauldron bubbled"*.

Like all things it ended. A few weeks later my oncologist is optimistic, there is some evidence that the tumour is shrinking. We both cross our fingers.

At the beginning of the following year the blow fell. Ouch! Mike Frampton had completed his usual inspection, releasing my tongue he replaced his mirror on the trolley, there was a distinct look of melancholy on his face. I knew it had to be bad news.

"Sorry Victor we 're back to square one".

"Okay, so what's next?" I replied.

"We can't go back to Radiography, we've used that up", he answered.

"I'm not very keen on Chemotherapy" I put my oar in quickly.

One of my jobs in the Department where I worked had been supplying the various drugs used in chemotherapy. Essences of periwinkle as we jokingly referred to them. Vincristine, Vinblastine and Chlorambucil were in vogue at that time. I'd seen the effects of chemo on a few patients and had never been impressed. Losing my hair wouldn't have been a problem, merely helping nature along. I had the sort of 'lived in' features which only a mother could love, so vanity didn't enter the equation. Loss of hair might have been an improvement, it did a lot for Kojak and

he had a cross-hatched face like me. Chemotherapy never seemed to have a good press. To me it was a hit or miss remedy.

My reasoning was simple. Carcinoma is a growth, therefore like a weed in the garden the best way to deal with it was to chop it down. Much more effective to use the axe than mess about with dubious weed killers. Mike was a bit apprehensive at the alacrity with which I accepted surgery. Possibly in the past he'd had difficulty in retailing the 'third option'. I expect it was a hard sell to most people.

That night was one which passed slowly. I kept thinking back to the year before and my first encounter with glottal cancer. Had I made the right decision? I'd advanced one step and slipped back two. I'd turned my back on Chemo, so it really was back to Square One. The sense of Death is mostly in apprehension. Was I apprehensive in any way? I don't think so.

Once the decision had been made I received an invitation to meet with a plastic surgeon at Odstock Hospital a few miles away, renowned for its Bums Unit. I was a little surprised that a plastics man was involved, still ignorance is bliss at times like this. My son borrowed his Chairman's car and we shot off down the Motorway one lunchtime to keep a midday appointment in some style.

Mr Rossi was interested in the minor arteries of my forearms. "*Was I right or left handed, did I sing?*" I had to admit that no choir of national repute had ever required my services, but that I had once been a member of a male voice choir and that singing in the bath and when alone at work were favourite pastimes. I've always loved the sound of the human voice, when in an Italian port I could always be found in the local opera house. Even today I am more familiar with the San Carlo in Naples than my local cinema.

Mr Rossi chose my left forearm for his target, some flesh and a small artery would be used inside my neck. The date was now set for my operation, it was just a case of waiting.

On the third of February I put the cover on my ancient Remington typewriter and left the office. The words of Brutus came to mind "*If we do meet again, then we shall smile*". Taking a short cut over the frost covered grass to 'Admissions' I was still muttering Shakespeare as I checked in. Greetings were exchanged and I was wished the best of luck. I very much hoped so. I had no intention of shuffling off my mortal coil, certainly not dying at work. There were lots of things I wanted to do, but dying in harness like a worn-out old Clydesdale horse wasn't one of them. My idea of fading away was more in line with a deckchair on the beach, the sea

gently swirling over my feet, the sun on my shoulders and my stomach full of smoked trout and Guinness.

Checking into the ward I discovered I had the bed closest to the Staff Nurses desk. They obviously weren't taking any chances on me doing a runner. I'd just unpacked my bag of bits when the team from Intensive Care came to introduce themselves. Nice people, they told me not to worry about the operation and losing my voice. I quickly interjected and told them that in the past talking had cost me a couple of teeth and got me into trouble, losing my voice would probably extend my life. I'm sure they thought they had a real joker here. Perhaps they were correct, though whilst in their care I was no trouble and well behaved. A couple of hours later I met my anaesthetist. A big bloke, he introduced himself as 'Stunner'. I could see his point. If the anaesthetic failed he could always use a short jab to the chin.

Mike came to check that I was still willing, the time was finalised as "*About eight thirty if I get my breakfast on time*". It was good to know that one of us would start the day on a full stomach.

I watched some television and had an early supper of fishcakes and peas. After reading the first chapter of a jumbo sized paperback I'd brought in with me I ambled off to the bathroom. Once inside I lit up a panatela. My last I supposed. To mark the occasion it was a good one, not my usual brand but something a bit special. If perchance it had been rolled on the thigh of a Cuban maiden I wasn't going to complain. I lay back in the hot water, luxuriating in a mass of bubble bath, savouring each and every lungful. Enveloped in a cloud of steam I heard the Ward Sister knocking on the door and enquiring if I was smoking. I remembered the immortal words of Kipling "*A woman is only a woman but a good cigar is a smoke.*" Sister departed, no doubt I'd hear more later.

Well soaked with my fingers crinkly I reached the final inch. That's it. Finally I'd given up smoking. Easy, I don't know why I hadn't done it years ago.

Later on looking out of the tall windows, I could just make out a row of nearby trees bending in the offshore wind. It was a dark night, dry and moonless, cold and as black as the Earl of Hell's riding boots. A pity I couldn't tell from the night stars what tomorrow would bring.

The ward began to settle down for the night. I guess it would have been appropriate to talk for ages into the small hours. I was losing my larynx in the morning. My voice would be a thing of the past, never again would I shout for England at Twickenham nor sing "*Abide with Me*" at Wembley.

I'd been told about oesophageal speech by a visiting Speech Therapist, but I'd never met any exponent of it. Jack Hawkins was the only role model at the time. Future communications seemed a bit 'iffy. Still there was no point in letting my fancy run rife. I wonder if there exists a brave man with a good imagination?

The operation was a 'Total Laryngectomy' it took over eight hours and involved two surgical teams. My last thoughts as Stunner pressed home the plunger of the hypodermic in my left hand were solely about the feeling of tremendous ecstasy produced in the seconds before oblivion. Like having five star cognac injected intravenously.

Perhaps you're a Laryngectomee too? You're a member of a most exclusive club, the only association that requires you to have your throat cut in order to join. It makes the Freemasons look like small beer indeed. Rejoining the planet hours later I was first aware of fans blowing cool air over me. Propped up at an angle of 45 degrees I became aware of plastic tubes from a ventilator criss- crossing my neck and of bags of blood and saline suspended from stainless steel hangers. My left wrist and forearm weighed a ton, they were encased in plaster. It was from here that some ten square inches of flesh and a small artery had been removed for use somewhere in my neck.

At the foot of my bed a small group of indistinct figures were assembled.

"Hi! We thought you were going to sleep for another day". It was Mike surrounded by the ENT team. Carefully I brought them into focus, *"Don't try to speak, just nod or shake"*. How many times was I to hear that phrase over the years. Even today it is in regular use.

"Any pain?" he asked. Cautiously I moved my head from side to side. Mike moved closer

"Everything went well, have another sleep, I'll see you again later." Always the obedient patient, I drifted away on a cloud of opium alkaloids.

I was in Intensive Care for three days. I had two companions and a succession of pretty nurses who kept me under regular close observation.

I was monitored constantly, every detail being noted on a large chart. A young man in the bed on my left was the victim of a motor cycle accident, it was touch and go for 24 hours but sadly he died. The third occupant of the unit was directly opposite, like myself he was propped up at the regulation 45 degrees. His wound was obvious, running like a zip fastener from his chin to below his navel. No keyhole surgery here, he'd been well and truly excavated. He was relaxed and cheerful, our one sided conversations broke the monotony of the long semi comatose hours.

My last night in ICU was without doubt the worst in my life, the 'Black Dog' of despair and desolation was snapping at my heels. What had gone wrong? My brain performed somersaults, it must have been about dawn when the truth hit my little grey cells. My morphine had been switched off, no longer was the pump whirring. My visit to Cloud Nine was over.

Returning to the main ward marked the beginning of an almost five month stay. I progressed from open ward to private cell. Strange, already the patterns of my life were changing. I didn't read newspapers and my jumbo sized paperback remained unopened. From being an avid reader, a professional communicator whose life had been built on codes and ciphers, on words and sentences, I now had no interest in reading. It remained so for many years.

Late one afternoon three of the team were at the foot of my bed, there was subdued muttering. Mike bent over my neck. I thought my luck had changed and he was about to kiss me, alas, he took a deep sniff around my stoma and announced to his companions *"I'm afraid it's all gone pear-shaped, see if we can have a theatre will you?"*

Back we went to OR. Another five hours of cut and thrust when all the previous good work was taken out and thrown away. Those parts of my neck which had been rebuilt using the flesh and artery from my wrist had been rejected. Unfortunately my original neck, which had been well and truly irradiated the previous year refused to join forces with the pristine flesh of my arm. The new lump of muscle needed this time was taken from the right hand side of my chest, a form of male mastectomy known as a Pectoralis Major.

My stay in Intensive Care this time was brief, then back to the privacy of my own room and thoughts, visits from the physio kept my lungs in good order and the nurses kept my stoma neat and natty. Days passed into weeks.

Feeding was via a nasal -gastro tube and consisted of a low residue milk. It was insufficient as was indicated by my loss of weight. Various drugs were constantly dripped into me. Life was becoming a gamble and I wasn't impressed with the odds.

On the occasions when I wasn't connected up to anything I began an exercise routine, the physio had mentioned getting mobile and breathing exercises. From my room to the end of the ward was fifty paces, how fortunate! I began with the hundred yards and over the weeks I regularly walked a mile or two each day. A smile or a wave in passing kept me in touch with the other patients.

Day to day communications were difficult, there's a limit to what you can achieve with amateur sign language without being rude. My notebook and a fistful of HB pencils had to suffice.

All was not lost though, one of my sons, a user of the latest technologies arrived one evening bearing a small plastic case. Opening it up, like a magician producing a rabbit from a hat, he introduced me to a piece of kit designed to produce graphs. It had a liquid crystal display which held twenty letters, as each new letter was added one fell off from the other end. Terrific, now I could hold conversations. Not the perfect answer to my dilemma but it was an improvement on paper and pencil. Once loaded with batteries I embarked on a monologue with anyone who had time to spare. Occasionally, due to personnel shortages and holidays I had the pleasure of chatting with senior nursing staff, even the Matron. Once I met a lady who'd marched to Aldermaston in protest at the same time as me.

Overall I showed no improvement, my weight loss continued. I spent hours absorbing numerous bottles of the milk like fluid. Had I been able to get a penny back on the empties I'd have been in business! So it was almost five months later that, underweight and only just able to communicate, with my diet confined to soups and liquidised meals. I was cast out into the highways and byways of humanity to compete with other men. Handicapped but not officially disabled.

Prognosis

With the benefit of hindsight, that 20-20 vision which makes everything so clear, the picture changes. Spending two decades in the cheerless shadow of cancer; in the beginning living from day to day, then annually, I found that regrets were replacing dreams. Time was finite. My ambition to join the Open University was shelved. My desire to paint went into abeyance. Health in retirement became the sole purpose of living. Being unable to speak makes you vulnerable and life can become a lonely affair. The '*Black Dog*' of despair can begin to bite.

However not all is gloom. Over the last few years my colon has been closely inspected. My prostate has been declared clear by a pair of Consultants who I'm sure were disappointed that another septuagenarian had escaped their well gloved index fingers. I think that my cancer can now be assumed to have run its' course, or if not, at my age any metastasis will not be taken seriously.

With the help of a gastroenterologist I discovered that my diaphragm has gone into remission due to lack of use and that I am now the owner of a '*Cup and Spill*' stomach. In addition I'm diabetic, and to cap it all in the Spring of '03 I had a mini stroke.

One sunny morning, en route to the Cancer Drop-in Centre, I felt my right arm becoming progressively numb. On arrival I knew that something was very wrong.

Falling into the nearest armchair I became the focus of the two ladies on duty who quickly took charge. It was agreed that an ambulance should be called, so off I went to Casualty with my blood pressure up in the sky.

Thus began another interesting phase, no longer a cancer statistic but another tick in the Coronary Heart Disease column. After some 12 hours in A & E it was plain to me that the Health Service is not only short of Doctors and Nurses, beds and drugs but still suffering from an acute lack of communication. Do you ever get that feeling that fate is once more kicking you into touch? No longer does life need you to play any real part in the overall scheme of things! Still it's just another chapter in this thing we call Life and we must never forget:

"When you dine at the Restaurant of Last Resort, accept what's on the Menu"

Victor Smith 2004