From the other side of the fence (1) –
A personal experience of Hell on Earth

Keith D Thomson

(*The title of this article does not reflect the excellent care I received as an NHS patient at the Royal Surrey County Hospital in Guildford.*)

Introduction
Life is a personal journey from beginning to end and as we all know not only pleasant things happen in between these two major events. I was 57-years-old, a Consultant Obstetric Anaesthetist at the North Hampshire Hospital in Basingstoke who enjoyed good health (or so I thought), happily married to Fiona for the past 25 years. We had two delightful children, Rebecca and Duncan, both at University. I enjoyed fly fishing, shooting (shotgun and rifle) and running half marathons (even completing the London Marathon in 1999 and 2000) as well as organising conferences on 'Medical aspects of childbirth' in capital cities of former Soviet countries like Riga , Moscow and Vilnius. I also spent a significant time and effort promoting Mercy Ships an international Christian Charity of which I am a UK director. I not only have organised five floats in the Lord Mayor of London's Show, and the Mercy Ships runners in the 4,500 mile round Britain 'Island Race' in 2000 but have worked for a few weeks every year since 1991 on the Mercy Ship *Anastasis* in West Africa.

On the 20th Dec 2004 everything almost fell apart or at least radically changed when my maxillofacial surgeon (also friend and colleague) Mr Cyrus Kerawala told me – 'The biopsy of your tongue shows definite squamous carcinoma with ca in situ round the edges. I advise that you need an operation, a partial hemiglossectomy: staging neck dissection and radial free flap to rebuild your tongue.' Christmas and New Year were a difficult time with the impending op hanging over me like the sword of Damocles.

The date was scheduled for the 14th Jan. Three days before I went to the Royal Surrey County Hospital to have a load of routine pre-op tests done including ECG, Bloods, Doppler of both arms, chest X-ray was not performed because I had already had a CT. I had a very reassuring meeting with Girish Dohn, my anaesthetist, who explained how routine the anaesthesia would be (for him!). I managed to persuade the surgical team to let me arrive at 6am on the day of surgery – sleeping with one's wife in one's own bed was definitely a better pre-op experience.

The day of surgery
I arrived in the hospital with an aura of calm, a sort of warm feeling surrounding me, apparently about 400 people on the Mercy Ship Anastasis were praying for me. Two or three names even came to mind at specific times – I need to check with them and confirm this. Arrived in the anaesthetic room with only my prayerful premed! Girish apparently got all my required lines in first go, but rumour had it that he was very slick. The next thing I was aware of after 10½ hours of surgery and about 18 hours ventilation in ITU was a nearby male voice saying 'he still has too much fentanyl on board for extubation we will leave him for another 30mins.' That was quite tough when I could not speak or see and was lying on my right side but did realise where I was. I guess I was on SIMV as I certainly was not fighting the ventilator but my chest seemed to move in a dissociated but controlled fashion. I have no visual memories but it was agony around the nasal turbinate bones when they eventually pulled the tracheal tube out.

I then spent two more days and nights in ITU, memories are very hazy and probably unreliable although I do think I remember a particularly attractive nurse called Vicky asking whether she could wash my 'front piece' during a rather pleasant bed bath! I have vague memories of a dispute during the last night as to whether I went to the ward or stayed in the ITU as they needed my space for another patient. Anyway, I remember being pleased that I stayed. I also remember having absolutely no sleep for two successive nights, looking at the clock every hour probably due to the high ambient noise light and general bustle. Even back on the ward, sleep was still a problem as it was very noisy at night with new admissions, regular monitoring of us patients and in my case frequent checking of the vascularity of my tongue flap. I remember being visited by my wife and children on both days and also by Pippa, an SpR who used to be an anaesthetic SHO in my department. Also being sat out of bed by the physiotherapists on the first post op day – this was a real struggle.

The Ward
Clandon ward was a remarkable experience a sort of microcosm of human life with three main sub groups: nurses, patients and the doctors. The nurses, including HCAs (healthcare assistants), were from many different countries including Nigeria, India, the Phillipines, and Britain. There were rigid protocols for drug administration, etc. I'm not sure whether PRN analgesia could work because there were very definitely only four fixed times during the 24 hour day not on a 'when needed' basis.

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With large incisions in my neck, left forearm and abdomen my analgesic requirements were surprisingly low; fentanyl patches for the first two days followed by regular co-codamol and diclophenac given via the naso-gastric tube. I decided not to have a prescribed morphine PCA as I was worried about the risk of vomiting and possible damage to my tongue flap. The early morning drug round varied between 5am and 6.30am, a jab of Clexane(low molecular weight heparin) certainly woke one up!
So by lunch time one had already done an 8 hour day, not surprising one felt exhausted and by bedtime at about 10pm even more so.

One's concentration seemed limited, I used to read a little, listen to taped music and use my laptop to start this article and watch DVDs.
I usually spent the morning observing medical ward rounds, waiting for the next tube to be removed (femoral line, drains, catheter etc), various tests to be performed, either elsewhere in the hospital (eg x ray department) or at the bedside, usually blood – one only hoped one would be on the schedule for the phlebotomists who were excellent, rather than a mishmash of PRHO, SHO and eventually SpR who once descended on the poor man on my left, whose veins were particularly difficult. All the staff, doctors and nurses seemed to be able to have a go at inserting Venflon IV cannulae – I never saw a drop of lignocaine (local anaesthetic) used – luckily my only re-siting was performed by an anaesthetic SHO who had once worked at my hospital and did a very efficient job at midnight – I did keep my promise to give a charming Romanian female maxillofacial SHO a box of chocolates for getting blood from me at the first attempt!

Post-Op delusions

Interestingly I was totally deluded and paranoid for the first four days on the ward. I am not sure whether this was a combination of prolonged anaesthesia, the stress of surgery or having no sleep for the previous two nights. My main delusions were that I could hear the Junior Docs somewhere in the background discussing and plotting about me, particularly with regards to restricting my fluid input, which I felt was always inadequate – they did not seem to have heard of insensible losses in spite of the heating in the ward and were determined that my positive balance should be no more than 500ml. I had to demand extra IV fluids at about 2pm for three successive days as by then I felt so dry, headachy and generally awful! For a patient with a normal heart and kidneys, fluid overload is quite difficult.

My other delusion was that an acquaintance with whom I used to enjoy a rather strained relationship was trying to get into the ward to see me without permission. She had some fantastic rows with the South African maxillofacial senior registrar. She never actually came, but my wife did discover a woman in a nearby bay, who had an identical shrill voice. On more than one occasion I remember hiding my face behind a newspaper when I thought she was passing the entrance to my bay because I felt I looked so ugly; unshaven, unwashed hair and tubes coming from every orifice.

My perception of the five bedded bay I was in each day was very different to the extent that I thought I was being moved about the ward but this apparently was not the case. The bay seemed to vary in size, it was not until one week post surgery that I seemed to settle down, the voices stopped and the ward space around me remained constant. Interestingly when playing *Scrabble* with my wife on day 5 I seemed unable to cope with putting down more than three letters at a time but by 7 days I could play normally and win!

The afternoon from 3pm was for visitors. The nursing staff seemed to be able to relax the departure time as they deemed suitable, for individual patients, for this I will be externally grateful as on the first three evenings when I was in such a deluded state that I was convinced, among other things that I would not make it through the night, my dear wife (what an amazing support she was, and continues to be – I wonder how people cope after major surgery who have no close family) stayed to comfort and control me until 11 pm with no thought of supper, and until after the night staff had taken over.

Other patients

At one time in the opposite side of the bay was a challenging 17-year- old with appendicitis who had been released from police custody for treatment. His father, in my books a real and very patient hero, was called in at 2am because his son had become very agitated and was allowed to stay the rest of the night. Sadly there were all sorts of family problems with an alcoholic mum and the patient himself on various illicit substances.

The marriage of a former occupant of the same bed had broken up and his 23-year-old daughter and her boyfriend arrived to give him and his new partner quite a hard time. Another inmate of our bay was an architect who had designed the new Basingstoke town centre shopping complex. As I said before the ward was a real microcosm of life!

Nursing care

The standard of care from nurses and HCAs was not only very professional but humane and caring. I remember particularly incidences which somehow encouraged me: Indian staff nurse Mary told me that her dad was a consultant anaesthetist in Wales, the same age as me and had recently had a severe stroke (i.e. was far worse off than me).

Secondly a student nurse originally from Nigeria told me she had once lived in Paris so I tried out my French and discovered that my speech in that language was far more intelligible than English – this gave me quite a boost at the end of a difficult day.

No one on the ward could forget Darwin, a staff nurse from the Philippines who was always very cheerful, polite, patient and skilled at all he did. I feel a definition of a nurse or HCA in Clandon ward, many of whom have been there for years, could be '*someone who works for relatively low rates of pay for the privilege of caring for people at the level of their most basic need*.'

Mercy Ships

As is my wont, I did attempt to publicise the charity Mercy Ships (**www.mercyships.org**), of which I am a UK Director. My wife brought a suitable supply of literature and copies of the video of last year's BBC documentary, *African ER*, about the organisation's work in Sierra Leone. Surgically this consisted of maxillofacial, ortho-paedic, ophthalmic and surgery for vesico-vaginal fistula repair. Ironically one of the last patients I personally anaesthetised on board the Anastasis in Benin at the begin-ning of December was for a radial free flap to his face!

Post-Op progress

The progress of a patient in a hospital after major surgery is punctuated by a sequence of various 'firsts' including first flatus, first bowel opening, first passing of urine after catheter removal, first shower, with, and then without, assistance, and not forgetting the first walk. I think I was a pretty compliant patient, although at times, I am sure, a challenge to the staff.

I expect I am not the first doctor who found it difficult to let go and put oneself totally under the care of other medical professionals. The only 'crime' I committed was at 04.50 am, one week post surgery when my extremely aggravating naso-gastric tube somehow fell out and I turned the 'Nil by Mouth'' sign above my bed round to 'Light Diet' – so I was able to order, two hours later, some apple juice and plain yoghurt for breakfast!

Prior to this I had managed to drink two litres of water, the only risk was that I would not be able to swallow the oral high calorie Fortisip which was required rather than 2,000 Kcals daily in a volume of two litres via the naso-gastric tube. Luckily my plan succeeded and the tube did not have to be replaced.

My problem was and still is difficulty with swallowing, I tended to aspirate what I was swallowing if I breathed in or talked at the same time. The speech therapist was very helpful in trying to help me to overcome this not insignificant problem. Other vital professionals involved in my care were the dietician,the physiothera-pists and the pharmacists.

Looking back

It is an experience that I hope and pray I will only have to undergo once, the only really painful memories were the removal of the 'B' drain, the nasal extubation and surprisingly, an intravenous injection of the antiemetic cyclizine.

The nursing staff were all excellent, some of the junior docs I observed did at times seem rather arrogant and did not necessarily give much explanation to patients about why they were going to have certain tests.

Little human touches do matter to patients – I remember one of the maxillofacial SHOs holding my hand and saying 'don't worry I will look after you' – that made quite a difference to me at that time.

In getting used to my new situation I found the following quote from 'The Word for Today' (UCB – Jan 19th 2005) helpful:

'*When we get stuck in the past, it is always at the expense of the future. After the initial shock is over and the anger has dissipated, step over your depression and start making plans.*

Announce to your heart that you are going to live again. Do not get stuck in a stage that was just meant to be part of a process. This too shall pass. Let it.'

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