

Milestones

Keith Thomson

After major surgery in January 2005 (partial glossectomy + radial free flap) and six weeks of introral, neck and superior mediastinal radiotherapy in April-May, I was left feeling somewhat bruised and battered by my medical colleagues but now at last the road to 'normality' could begin. It was not as easy as I had thought.

This article documents some of the milestones that I painfully passed. I had to learn that improvement could only be measured on a monthly rather than a daily basis otherwise I risked becoming very despondent.

The whole process made me realise that just how fit one has to be to live a 'normal' life. To be able to work, study, exercise and to go out in the evening and socialise can seem an unattainable goal when you have come through such treatment.

I was used to running half marathons six or seven times a week and completed the London Marathon twice with placing in the top 20,000. I was therefore fit for a man in his late fifties.

This is a diary of events for the six months after treatment ended.

May

On the 17th, after 30 awful sessions of radiotherapy I was left with ulcerated oral mucosa (mucositis), almost perpetually drooling due to a highly inflammatory hyper-secretion. In addition to a painful pharyngotomy syndrome, I had no saliva or taste.

I was reliant on regular analgesia (co-codamol and diclofenac) and various different mouthwashes (preparations (Gelclair, Aluclair etc) to enable me to swallow sufficient high calorie liquids (Fortisip and Sca drink) to maintain weight and thus avoid the ever present hovering spectre of a PEG (percutaneous endoscopic gastrostomy).

Regular courses of fluconazole for oral thrush, omeprazole for indigestion and anti-emetics (metoclopramide from my oncologist or domperidone preferred by my GP) were needed to decrease frequent nausea. Often even these could not prevent me vomiting most evenings when I attempted to brush my rear molars with an electric toothbrush, which had been recommended during radiotherapy. I found zopiclone 7.5mg to be an effective sleeping tablet, but how addictive time will tell.

June

On the 10th I drove with my wife to Scotland for the annual fishing trip with the lads on the River Avo at Ballinallacloy. Speyside staying at my mother's house for two days en route. The highlight of this visit was sitting motionless outside with five red squirrels running around as they gathered nuts from a nearby bird table (fig 1).

I still needed at least two hours rest every afternoon - Radiotherapy induced fatigue is very debilitating. Initially I was unable to sit down to a meal even with good friends because I was in pain and unable to eat anything particularly in the evenings when my symptoms were worse.



Fig 1. Red squirrel in Scotland

By the 19th, the end of the week I could manage a lightly boiled egg at breakfast in company while listening to the fisherman's tales of success and loss from the night before.

I was only capable of, before exhaustion set in, about 20mins casting a 14ft salmon rod twice a day. The last night at about 5pm I hooked a 10lb salmon which was subsequently landed by my fishing friend Marty who went to the river in his shoes armed with my net saying 'there is no way this one is going to get away!' It didn't (fig 2) but I'm not sure who was more exhausted, me, the fish or Marty!



Fig 2. The one that did not get away

Unfortunately celebrations were cut short by the news that my father-in-law was in hospital in Tybridge Wells with a serious head injury after falling down while shopping.

My wife and I had to return home early; sadly, four days later she died from his injuries. Two weeks later on the 1st of July I attended his funeral, a challenge given because I felt so unwell and was reminded acutely of my own mortality.

After returning home a pain management consultant colleague diagnosed the postoperative status of the grafted area of my tongue as a form of autoimmune dystrophy and I was started on pregabalin (so of gabapentin) in addition to the orotracheal already prescribed by a maxillofacial surgeon friend during the fishing trip. This combination of drugs gradually began to control the triad of symptoms I had, nicknamed my 'pilates', namely oral hypersecretion, tetanic spasms at the operative site in my neck and pain in the grafted area of my tongue particularly initiated by cold.

The post radiotherapy tiredness is always lurking just around the corner, you awake feeling fine but after morning ablutions you suddenly feel knocked. I tried to walk a short distance each day spurred on by my enthusiastic friend David who is himself a general practitioner. My own excellent and caring GP, whom I visit on a monthly basis, is not so enthusiastic about exercise but as David rather unkindly said maybe that is related to his size!

I have learned that it is very important for a ill doctor to have a other medic co-ordinating the various treatments and that must be your own GP. It is very important not to go down the road of self-prescribing, tempting though that may be. On one occasion in desperation I did obtain some cocaine spray for my postoperative tongue which was totally inappropriate.

July

This was a idle moment and I took the opportunity to watch major sporting events on our plasma screen television. Wimbledon (with Andy Murray),

Test Matches (the amazingly exciting Ashes) and the British Open Golf at St Andrews won again by Tiger Woods.

For exercise my wife and I continued to walk in the Valley Gardens in Windsor Great Park to see magnificent blooms like the azaleas in the 'Punchbowl.' (fig 3).



Fig 3. Valley Gardens

Unfortunately I also had time to watch on screen the unfolding atrocities in London on July 7th.

Therapeutic during this month was sitting on the floor with a total of ten kittens born to two of our cats probably via the same black and white tom (fig 4).



Fig 4. Kittens

August

The turning point for me came during a week with friends in the Cotswolds I started to try and eat the food on offer rather than just survive on high calorie drinks. I managed, with some bearable discomfort, to eat a reasonable amount of chicken with vegetables and since then there has been no turning back.

I travelled on my own to Scotland by train to Dundee owing to the shutdown at Heathrow caused by the Gate Gourmet dispute.

The weight to a timeshare near Aviemore with my mother who was suffering from chronic diarrhoea (? cause) and my younger sister who had had her mitral valve repaired at the Brompton only 5 weeks before.

She only spent five days in hospital and was rapidly improving, a way I was rather jealous. What a trio we made!

Without my primary carer wife at my side I was forced to be more self-reliant. The most difficult time was one evening when my mum developed severe muscular spasm in her left buttock. It is very stressful being a unwell doctor when a close member of the family is suffering. However I managed to persuade a local GP to come and see her via theurse-led NHS 24. He gave her some codeine phosphate which helped both her Gluteus Maximus and her bowels!

September

A flight to Faro, driving a hire car, eating 'al fresco' in a Portuguese restaurant were all new experiences on my journey to 'normality.' A few months ago it had been hard to imagine whether I would ever be doing such things again.

The warm weather promoted walking, attempting to jog and swimming but it was still hard to think that I was running sub two hour half marathons as a supervet a less than a year ago.

After returning home I had a video laryngoscopy performed which showed I still had a paralysed left vocal cord. My speech therapist has been doing a good job as my voice sounds normal to most friends.

October

First of stopping point of beer on the 1st, back to work on the 3rd - on a 'morning only' basis. Once the first few vertebrograms, LMAs, tubes, spinals and epidurals had been inserted with no difficulty I felt much more confident.

My major problems were firstly concentration, particularly scary anaesthetic monitors at frequent enough intervals and secondly becoming increasingly tired as the day progressed. I was able to eat most things if not dry (still no saliva) or spicy (sadly stimulating the taste buds with chilli or curry just causes pain). I attended a Windsor Medical Society dinner where the guest speaker was Lloyd Scott, who has achieved many remarkable feats since recovery from Chronic Myeloid Leuk-aemia, including the London and New York Marathons in a diving suit!

On the 15th I gave a 20 minute presentation about Mercy Ships in front of approximately 900 rotarians in the Riviera Centre in Torquay.

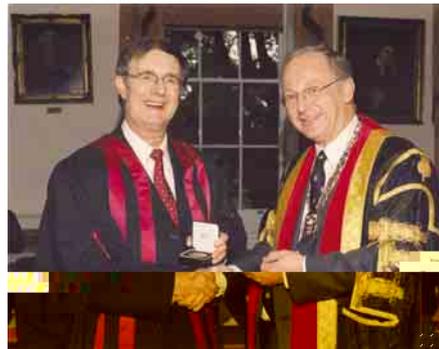


Fig 5 Presentation of the Jubilee Medal by the President of the RCA

On the 19th I was honoured by the Royal College of Anaesthetists where I was presented (fig 5) with a Jubilee medal for my work in Africa over the past 15 years. All these events were confidence inspiring on my road to recovery.

November



Fig 6. Villa in the Algarve

Sitting with friends, once more in our Portuguese villa, surveying the

beautiful scenery (fig 6) I think about ongoing milestones and what challenges the future holds: gradually returning to work fulltime, (on the 11th I did my first unsupervised list) the award of a Paul Harris Fellowship at the Rotary Club of Newbury on the 21st, a presentation at the first Baltic Anaesthesia conference (Riga, 8-10 Dec 2005) and the commissioning of the Africa Mercy in London in April 2006.

Hopefully I will travel to Monrovia, Liberia, for the last week of the final outreach of the Mercy Ship Anastasis in May of next year.

The unanswered questions still remain, will my taste and saliva return, will I have grandchildren, will I outlive my mum, will the 'Big C' return and get me?

Acknowledgements

The major stay of support during these six difficult months, apart from my wife, family and many friends, has been the caring staff of Paul Bevan House, a day hospice situated in the grounds of Heatherwood Hospital in Ascot. The weekly visits, initiated by my attentive vicar Sebastian, started two weeks before the end of radiotherapy and still continue as I write.

This 80% privately financed set up provided a fantastic supportive environment and it was a privilege for me to spend five hours there every Wednesday.

I had my feet massaged, hair cut, yoga sessions, an excellent lunch (where the oral ulcers healed and I was eventually able to eat) and pottery lessons from John, a charming retired architect. I enjoyed making things from clay starting with a red squirrel for my mother, which actually looked like a squirrel, this was followed by various mugs, pots, a crocodile eating a black child ('the scream') and also a large caricature of my own mouth which I donated to my surgeon (fig 7). These latter two gave the art therapist much food for thought.

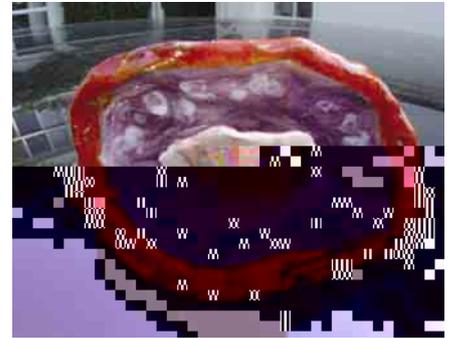


Fig 7. Caricature of my mouth

Other patients at this day centre ('hospice' has more sinister connotations) seemed far worse than me but we were all united by being members of a club to which one of us was tied to belong: Charles has metastatic prostate cancer and describes returning from a tunnel of light during major surgery during which he almost died. Steve has an inoperable brain stem tumour. Brian has pulmonary mesothelioma. David is only 24 and has had a left hand amputation for sarcoma in the sacrum. Liz suffers from Hodgkin's lymphoma and has a 15-month-old baby as well as two older children. For the birth of the eldest I may have performed her epidural 10 years before.

I listed to familiar but very real complaints: late diagnosis, long time waiting clinics, off and on caring doctors, many attempts at tests and vein punctures, packed hospital wards with inadequate number of nursing staff. I tried to pretend I was only a fellow patient. Other support included home visits by a MacMillan nurse, an occupational therapist and also acupuncture sessions with a consultant at the Thames Valley Hospice Windsor.

www.thameshospicecare.org.uk

None of this vital care was suggested by any of the medical staff looking after me. It all stemmed from the nurses at Paul Bevan House.

□ □ □