

My story: Colin Salter – laryngectomy since November 2006. (16th January 2008).

In a clinic at Barncoose hospital, Redruth, I asked the consultant for the bottom line of what he had just said.

“In two months this cancer will kill you if we don’t take it out”, he replied.

It was days before my youngest son’s 30th birthday, and exactly two weeks before my 36th wedding anniversary.

I thought about the implications. As a Christian I was ready to die and stand before God’s judgement, confident in the forgiving grace and mercy of Jesus. My daughter had once told me I was selfish to think like that – and I guess she was partly right.

I also thought about our family. They were well set up in their own homes and careers. One grandson was months old so the next generation was emerging. My wife Brenda would be worried, given that her nature is very different from mine.

Finally there was my work. I had already had to return from Sudan because of ill health, cutting short ten planned years of service after just four. Now I was starting to consider writing projects for publishing in Sudan, teaching what I would have done if I had still been there. Would all this be terminated now?

We shared this news, first with our two grown up children, then our three brothers, and lastly with our friends locally and around the world. (When I say “We” I really mean Brenda, because I could barely speak). We were open with

everyone. We know from experience that rumours quickly fill empty spaces where information is suppressed and so we told it as it was. We received back immense support and encouragement from everyone.

There were lots of different medical appointments squeezed in between diagnosis and operation:

- The Multi-Disciplinary team meeting, to be introduced to the people who would be responsible for our care.
- A C.T. scan, to check if the cancer had spread anywhere else, with the results phoned through to us after a few days. As a patient you have to deal with uncertainty as you await these results. I think knowing even bad news, is easier to handle than the speculations of uncertainty.
- A Pre-Operation Assessment of my fitness for the major surgery.
- A visit to meet a laryngectomee with my Speech and Language Therapist.
- And at my own G.P.'s surgery, a diabetic review.

I remember the often repeated phrase at these events, "Have you got any questions?" Looking back I reckon I did not understand enough to be able to ask intelligent questions! If I had known the right questions to ask I may have got some answers! My mind was a befuddled blur.

There were some good leaflets given to us which we devoured eagerly, in our own time, at home. One of the best was "Understanding Cancer of the Larynx" from the charity CancerBACUP.

We were aware that life changes would happen, but it was all so new. And everything was happening so quickly I think we “heard a lot” but “took in little”. Our daughter and family arrived from Southampton to stay with Brenda during my operation. The morning of the afternoon I entered Wheal Coates ward at Treliske, we had a family walk in the blustery cold of Portreath beach.

I took my laptop with me into hospital. I submitted it to the necessary safety test and it was awarded a green sticker! Doubts were expressed by some staff that I would use it during the 2-3 week stay. It turned out to be a God-send, enabling me to do a bit of work on my website, giving me daily purpose, a focus outside of my own condition, and some contact with other people. Using headphones I could also listen to my chosen music.

The anaesthetist and surgeon both visited me on the ward and explained the procedures for tomorrow. The “patient-controlled morphine drip” fascinated me. I was told I could self-administer 1ml. morphine every time I pressed a button. I wondered how much I would use. I had never really thought of the pain after the 3-4 hour operation.

I was told that every tube I discovered attached to me when I woke up would have its own purpose – and I was not to be alarmed. There would be at least two tubes in my new stoma (a hole in the neck to breathe through at the top of the windpipe). One would be a feeding tube as I would not be able to eat usual food until hemlines stitched inside my throat had healed. Another would

be for a mixture of oxygen and moist warm air to help me breathe safely. I would also have two drainage tubes from my neck removing unwanted fluids like blood and serum. There would be more tubes in my arms and the back of my hands. These would be for intravenous infusions (drips), for my insulin, and for taking blood samples. And there would be a catheter for measuring urine output. I made that nine in all!

I was warned of discomfort, frustration and depression in the days ahead. These were apparently normal responses to the laryngectomy, and the staff were ready to help me through.

After I had been back on the ward a few hours I requested a mirror and looked at myself. I saw plenty of attachments, but basically the same ugly old me underneath. That first night was very long. Every hour my blood sugar and other things were monitored. Considerate as all the nurses were, sleep was elusive and punctuated.

I remember being offered suction – a machine vacuum to clear phlegm etc. from my insides. As the nurse brought the tube towards me I opened my mouth to take it, and was surprised when she did not put it into my mouth but below and unseen by me, into my stoma. The breathing role of my new stoma was an important lesson to learn. Without the suction early on breathing becomes difficult. I recall once waking up feeling unable to breathe because of a clogged up valve. The requested suction soon brought relief.

I soon got used to being flushed out and medicated through six inch long Plastipak tubes. The cool flowing liquids refreshed my inside. There was pain in my throat and from the various needle attachments, though it subsided quickly over the first few days. More than once I confused the morphine pump with the “nurse call” button, but it was nice to see the nurses anyway! I saw no shame in taking all the pain-killers I was offered.

By mid-afternoon 24 hours post operation, I felt well enough to do an hour’s work on my laptop, editing one of my books to go on our Sudanese website.

When Brenda and other visitors or staff came I remember being embarrassed by burps and gurgles coming from my stoma. I had (and still have) no control over them. When they come they come! It seems I worried over them more than anyone else.

I knew from my work as a pastor that being in hospital is tough on the entire family. They have all their usual things to do as well as fit in time for visits. As a patient I looked forward to family visits, but I was also aware how demanding it was for them. I tried to reciprocate their love in visiting me by being considerate of their own needs too, and not expecting too much.

I had ten days of only “Jevity” meals. These came via a tube from an inverted bottle of yellowish “squelch”, and would take 12-16 hours each. A dietician regulates the formula of this feed and suggests the quantity plus delivery speed. It was fed through the tube into my stoma, my oesophagus and then

my stomach. I never once felt really hungry, even when others on the ward were tucking into their breakfasts or lunches.

There were nuisance moments on the ward. Foremost for me was the palaver of bowel movements while being attached to so many immovable things. I found having to call the nurses for this embarrassing. Little things like being able to go to the loo and washing by yourself become big moments of great achievement. I recommend trying for this independence as early as it is safe to do so.

One day, instead of the assisted washing I had been having on the bed, I decided I was free enough to have a wash in my room on my own. I did everything to do with it for myself, during which I discovered two things. Firstly, that a pull-over-the-head T-shirt top was not as useful as a front button opening shirt. (To wear the former means disconnecting several tubes in order to get it on). Secondly, when you are naked and you don't have a voice, and someone the other side of a pulled curtain calls, "May I come in?" you cannot stop them! I embarrassed at least one therapist, one nurse and one cleaner by being less than dressed when they called out and then just came on in!

It was always fun trying to communicate with the staff. They were all very encouraging. I felt I made some friends. I had no voice so resorted to mouthing the words with my lips, gesticulating with my hands, and—at the last resort—using pen and paper or the donated "magic" scribble board. I last remembered playing with one of those as a child some fifty years ago.

The “swallow test” was a big moment. This coloured x-ray would see if the inside wounds had healed enough for swallowing drink and food. They only happen once a week, so would make a big difference to being released to go home. I had to pass, or wait another week. I remember crying when I came back to the ward and telling Brenda, “I’ve passed”. Again the staff had been encouraging in the run up. The result almost caused them as much joy as it did me. Perhaps they wanted to get rid of me from the ward? Did I cause that much trouble?

I spent a little while thinking, “How did I get this cancer?” I have never smoked and I do not drink more than a dozen glasses of wine a year. I hardly fit the “heavy smoker plus heavy drinker” image in the books and pamphlets, though I own up to being a bit overweight. The ultimate answer has to be, “God gave it to me” - otherwise he is not the Sovereign God I believe him to be. I also wondered why God was helping me heal so quickly when he chose not give me healing from the cancer? (At least, not without the intervention of a major operation). My response must be to accept the cancer, the operation and other treatment, plus all the consequences, as from God’s fatherly hand— and still worship and praise him. He knows and does what is best, always.

I think it was more difficult for Brenda than for me during this hospitalisation. I had all the activity, she had the space to worry. Several times a day I heard first hand from doctors and specialists, while she had only my “memory” notes

to read. I communicated as best I could when she visited, but it was not like it used to be. It would never be, ever again.

On a practical note, Brenda found the £40 monthly car park ticket to be of good value, rather than paying at least £2.70 every visit.

The day after I returned home Brenda was very, very tearful. She was coming to terms with the last three weeks of trauma as well as having to look after me at home, alone. A great deal of responsibility for my wellbeing now rested on her shoulders. She was having to cope with the real results of my laryngectomy:

- Where was the best place we could set up as my permanent “cleaning corner”? Did we need to buy a table and any lights or mirrors?
- I had an always visible hole and scars in my throat.
- There was my coughing, wheezing, sneezing and sometimes runny nose.
- I made a strange cacophony of noises during and after our eating together. Meals took longer.
- There was the worry of sleeping next to me. What if I lost my breath while I was sleeping? Could she unintentionally (I presume!) block my stoma while she was asleep?
- What would happen when people came to see us?
- There was the underlying fear of not knowing what to expect.
- How should she make decisions about travelling, working, going out to church, all leaving me alone in the home, etc.

They say that communication is the key to a good marriage. Our problem was that now I could not speak and Brenda could not easily grasp what I was meaning to say amid all the gesticulations! The magic slate got some use and so did paper and pencil or pen.

Without doubt for me the hardest part of living as a laryngectomee is to realise the impact this is having on my wife. My change of workplace from being largely out to being largely in. My reliance upon her for a lot of “first line” conversation with our friends, at the front door and on the phone. My intermittent coughing, occasionally causing me to fall through lack of breath. These and other ongoing health concerns still worry her with uncertainty. Brenda can see the stoma every time she sees me. I can't!

We wrote a detailed explanatory letter four days after returning home to three immediate neighbours, to our son and to our daughter. They all willingly received it and became involved with us as “emergency standbys”. I could jingle a little bell over the phone to them if I desperately needed help while Brenda was out. They knew how to get to me and how to get me to Wheal Coates ward, Treliske, as soon as possible. We are very grateful for their support, understanding and help. We've never had to use them yet.

In general people have reacted thoughtfully to the new me. Some work colleagues and other friends I do not see as much as I used to, which I find disappointing. Shopkeepers, hairdresser, bank cashiers and the like have been very good at listening to my quietly spoken requests – some even

coming out from behind their counters to put their ears to my mouth! In church, at the bowling club and at rugby most people do their best to make me comfortable. If my silence is seen as rude it is not meant to be. That may be a problem I am more self-conscious about than anything else.

From time to time a fellow bus passenger will say, "I do hope you soon get over your bad throat". I have given up trying to explain! A few have become most apologetic when I have explained my lack of voice-box. I did not mean to reprove them, but it has almost been taken that way.

My biggest disappointments have been fourfold.

- The lack of breath I experience when walking, especially uphill. This is restrictive. I use Hi-Flow cassettes where possible, but they still do not give me unrestricted freedom.
- The H.M.E. cassettes easily block with saliva and phlegm when bending forward, say in the garden or when setting a wood fire, etc.
- The back plates come unstuck all too quickly, either when I get hot, or simply when the air pressure involved in speaking blows them off.
- Having to have a new prosthesis (speech valve) about every 42 days has been a pain. The day it starts to leak is terrible with coughing and the exchange on the ward – while considerably performed – is often uncomfortable.

Brenda has been an immense help and constant encouragement to me. Her support makes all the efforts worth making.

The staff at Treliske: from surgeons and nurses to cleaners on Wheal Coates, the Speech Language Therapists and the MacMillan nurse, have all been superb.

The Speak Easy club members have all helped with practical tips given during casual conversation around meetings. The voice of experience is more practical than printed manuals. I am currently trying to learn to smell again. I have found it encouraging to know my snatches of wafted fragrance are happening several years before another fellow laryngectomee. Now I want to learn to smell a rose when I choose, and not only catch burnt toast when it happens!

I do think living without a voice-box gets easier as time passes by, (fourteen months at present). For me it is a question of learning to accept permanent limitations and experimenting with ways of overcoming the others. The biggest help is a change of mind set. I have settled the fact that life as I previously enjoyed it will never return. I now have opportunities to establish a new and different life.

I have gained new friends at the hospital and the Speak Easy network. I have a better understanding of people with disabilities. There is no point in going over things I have lost because moping will never bring them back.