

Three years and three months after becoming a laryngectomee.

It was November 17th 2006 when I lost my natural speaking voice to cancer. Then, just when I had graduated to three-monthly checks at the oncology clinic, another cancer was found in my neck. April 6th 2009 this was surgically removed. From May 26th I was treated by radiotherapy over 33 sessions until July 9th. Now I have just been told by my surgeon that I can graduate again, from being seen monthly at the oncology clinic to being seen bimonthly. Last year, 2009, was another roller coaster of a year!

It seems to me that as a laryngectomee life largely revolves around being careful for myself and my voice prosthesis. Almost every decision Brenda and I make includes thinking of how we are going to cope with my health needs. Even little things like, "Have you got your spare HME cassettes?" when we are going out. "Are there enough pocket tissues for several coughs?" if we are going to be out, or in someone else's home, for a while.

We have ventured further away from home just once recently. My nephew was getting married right across the country, in Suffolk. We were pleased that I have my driving licence again. I got it back after I had been without a blackout for more than a year. We were able to share the 325 miles driving each way. **I do feel nervous when I am behind the wheel in case I have a bad cough with no warning.** Thankfully, to date I have always been able to sense a cough coming and stop the car safely.

We planned our travel carefully. We stopped overnight at a bed and breakfast west of London. We spent four nights at an Inn midway between the wedding venue and Brenda's family. (We opted for this central base so I could set up a place and system for the once or twice daily valve cleaning). We enjoyed the magically picturesque wedding. We distributed Christmas presents to all the family. Several friends came to visit us for meals in a nearby pub. **I proved to myself that I could be away from home and from our local hospital.** I managed eating the food I chose from the menus. My "voice" did become sore with so much talking, but it was worth it. As an added bonus we called in for lunch with our daughter's family, and visited a recently bereaved friend of ours, and met up again with the groom's parents, all on the two day journey back home.

Brenda and I reckon it took me three or four days to get over the trip, but we were glad to have done it. **Valve and stoma cleaning "on the road" are not as easy as at home.** Seeing properly is the most difficult. Hotel rooms don't usually offer angle lamps with well placed mirrors! Speaking in a lobby with two or three others is comfortable for me, but trying to talk in a wedding marquee with 200 other guests was just about impossible. Chatting with Brenda while driving is a challenge too, since I need one hand to press the cassette.

In general, three plus years on, I would make the following observations about laryngectomy life for me:

1. I have had to get used to **doing less than I want to** in a day. My energy levels definitely are lower. I manage to work at writing for Sudan four mornings most weeks. The highlight for me in 2009 was the publishing in Khartoum of “Issues Facing Christians in Sudan Today”. The book is out there in three languages, English, Arabic and Dinka Padang. I wrote half of the chapters and edited the writings of Sudanese church leaders for the other half. I am now working on discussion questions for my Christian Discipleship book “Raising the Standard”(1987). We hope to republish this, including the discussion guide, in Sudan later this year.
2. When I walk after lunch most days I do notice **a lack of breath**, especially coming up the hill from the shops to our home. If I wear a normal HME cassette I notice I am breathing hard. If I wear my hands free HME cassette I usually have to stop and open it for more breath. If I wear the Hi-Flow HME cassette it seems better, but it seems a waste for me to change cassettes for just one hour’s walk and shopping!
3. **Bending forwards** still poses many problems, with phlegm immediately **blocking the HME cassette** – of whichever type. Setting the log fire, picking up something dropped on the floor, plugging in or unplugging any appliance, gardening, filing in the bottom drawer, looking at books on the bottom shelf, are among the trouble spots. I try to remember and take the cassette out first (using a tissue as a mop) or I sit on the floor which means I can keep my upper body upright. I

cannot kneel because I have two artificial knees. I always carry at least two spare HME cassettes with me at all times.

4. After trialling different types of **adhesive base plates** to hold the HME cassettes, I have settled on Optiderm for general use and Xtra base for use with the Hands free speaking system. I used the Optiderm during and after radiotherapy when my throat skin was exceptionally tender. I found it suited my skin well and remained firmly stuck on, so I have kept using it in preference to the Regular base plate.
5. I still am working at the **Hands free** because I find it much more stressful to speak using it – due, I think, to breathing difficulties. The **white spot “tongue”** can close when I’m breathing not speaking! The green spot “tongue” I have to exhale hard to close in order to speak. I am going to order the medium “blue spot” with my next order from Countrywide supplies. I find the Xtra base plate sticks on well for Hands free without the need for any more glue, as long as I clean my skin off properly beforehand. I still wait to see how it works in the warmer summer weather and when there is perspiration around!
6. I am still **unable to smell** anything at all and my taste is very limited as a result. I have tried the “polite yawn” technique unsuccessfully. Very occasionally I catch a whiff of something, but it is accidental. I do not know how I do it! I certainly cannot smell something on demand. I eat food because I have to, not because I want to. I have recently stopped losing weight much to the glee of my cancer-care team. (How my diabetic-care team will view it remains to be seen!).

Finally let me just share with you all one moment of delight at the recent Christmas. Our family were all staying with us. My eldest grandson – who was at one time scared of me and my stoma – actually played with me, pushing in my cassette with his fingers to enable me to speak! It was a delightful change in his response to me. Fortunately he didn't press the cassette for too long and cause me to pass out through lack of breath.

Thank you for letting me share these thoughts with you. I believe that I am learning to live within the limitations my body sets. Finding the right balance of going/not going to places where I cannot comfortably converse is an ongoing challenge. Even our Speak Easy club can be noisy with 12-16 people there. Working when I can and resting when I have to is another matter of balance. Brenda and I enjoy it when friends come to visit and our front door is usually open.

We thank God for the new laryngectomee friends we have made (about 35 on our Club's mailing list). We also thank God that through email and post we can keep up with friends and students in Sudan.

Perhaps I can say along with the apostle Paul in the New Testament: **“As you know, it was because of an illness that I first preached the gospel to you”**, Galatians 4:13. Everything that comes my way – and the things that don't – I believe firmly, is God's doing. I try to accept everything as from His hand.

Colin Salter. 5th February 2010.