



**Five years on, November 2012,
and still
living with the consequences.**

It is exactly five years since my laryngectomy operation. To remove an aggressive carcinoma sarcoma my surgeon took the whole of my voice-box. Before the operation I asked what the alternatives were. Another surgeon told me, “You have at the most two months to live”.

Now five years on **I am cured of cancer, but I am living 24/7 with the life-changing consequences of the treatment.** My reader will notice there are two distinct parts to that statement which sum up how I feel. I have had one further cancer removed from my throat in April 2009. I am on three-monthly checkups at the oncology clinic. As far as it is possible to say, I am cured of cancer. The threatening alternative “two months to live” has been removed. For that I am largely thankful. But I admit to frequently struggling with the second part of my statement: the fallout – the collateral damage – the side-effects – the discomfort and frequent pain caused by the necessary treatment.

1. **I cannot use my voice to preach and teach as I used to.** I especially miss my involvement with Arabs and Africans in Khartoum, Sudan. That one country has recently become two. There are difficulties foreseen for the congregation I used to pastor, in what is now a stricter Islamic state. How I long to be there to try and help them see God’s hand in all the necessary changes. But I am not able.

2. I cannot converse easily with other people in a noisy room. My new artificial voice prosthesis makes me sore quite quickly as I try to let people hear me above the background hubbub. My lack of vocal cords means other parts of my inner throat do the rubbing and vibrating. It is well worth this soreness in order to keep communicating with people, but at church, in concert intervals, at the rugby ground, in bowls club meetings, after funerals, and even with just six around the dinner table, it is hard to get a word in unless folk are very, very aware and considerate. But enough of my new quiet voice!

3. I cannot get enough breath to walk unhindered as I used to.

Redruth, the town where I live, has some steep hills within its boundaries. Brenda and I live towards the top of the town. Walking down to the shops or the church is very little problem. Walking back up the hill is a very different story! I have now worked out several good stopping places to perch my bottom while I regain breath. A bag of shopping in each hand means it is impossible to do anything except mouth, smile and nod to greet friends. I have tried various types of HME cassettes (Humidity & Moisture Exchangers – my changeable noses!) but to little avail. The Hi-flow ones are best for me walking uphill, but I still find I have to take whichever one I am wearing out completely before I arrive home. I do regularly try the Hands-Free device, but find it takes more breath to use it well. I am not up to that yet. While on the subject of HME cassettes:

4. I must be very careful bending forward because the cassette easily gets blocked. This applies when walking, lifting up heavy bags

in the shops, bowling, gardening, even picking up something I, or someone else, has dropped on the floor. Mucous normally secreted by blowing your nose, together with collated moisture from the oesophagus, collects to ooze and smother the breathing holes in the HME. This requires a very quick removal, coughs to clear more, and ultimate replacement of the useful – but now offending (by attempted murder!) – cassette.

5. **I get violent neck and throat cramps.** These have developed in the last two years and I take tablets to try and control them, so far with limited success. These cramps are painful and frightening. Stretching the throat seems to be the best way of stopping the cramp but I am aware how strange this can appear in a shop, in a church service or in a home group. The tablets appear to have made them less violent and sudden. I am still taken unawares by them, notably when I come in from a cold outdoors and drink a lovely hot cup of coffee. One day I think I will drop the hot drink over myself, but to date Brenda has been on hand to take it from me. All in a carer's duty! I also often get cramps in the shower, cleaning my teeth and cleaning my stoma. All times when I hold my head at a particular angle.

6. **I have precious little of my own saliva and so my teeth and gums go largely unprotected.** My dentist, who is very aware of my condition and the effects of the operation and radiotherapy, prescribed a special toothpaste right from the beginning. Now she has just told me that she sees the first signs of a softening of my front teeth. I am to have one of them filled next week. Colgate have just brought out a stronger version

of the toothpaste which my dentist has immediately prescribed for me. I have just brought eight tubes home from the chemist, enough to last until my next four-monthly check up. I am aware of an often dry mouth for which I usually carry an artificial saliva spray. I regularly get painful blood blisters in my mouth although neither the GP or dentist have linked these with any of my past or present treatment. I did not suffer from them before my laryngectomy although that proves nothing.

7. **I have some difficulty in swallowing food.** Some seems to get caught on the back of my voice prosthesis. The surgeon has said that there is a little shelf there and *it* could be holding things up. Anything up to three hours after eating I can suddenly have an undigested mouthful of food or drink brought back. This can be very awkward if I am out from home. My speech therapist gave me some exercises to do several years ago. The more time passes the less effective these seem to be. I am due a valve change (I have had this valve six months) so I will ask her then if she has any other ideas.

8. **My mind and head were dulled by the painkilling drugs I was taking.** Since the radiotherapy in May to August 2009 I have taken various drugs to deaden the persistent left side of face, ear and neck pain. The oncologist and the surgeon bantered with each other over who had caused it. One blamed the other's collateral damage with the radiotherapy. The other blamed the one for cutting the trigeminal nerve. I didn't mind who caused it. I was more interested in who could cure it! The hospital pain clinic put me on to more and more morphine related drugs which did take the edge from the pain, but sadly concurrently

stole the sharpness from my mind and the creativity of my brain. Three stellate ganglion injections have to date meant I have become free of my dependence on these fearsome drugs and I now take only the very minimum dose via an arm patch, changed every three days.

9. **Now I must move on to a real battle in my mind and heart.** All the previous items are practical difficulties due to my condition. This last one is a psychological challenge or a spiritual battle that I face daily. It is perhaps linked to Nos.1 & 2 above as my reader may see.

I have mentioned elsewhere that I am a practising Christian. I believe in the Sovereign Creator God who is in total control of our world and everything within and beyond it. Therefore, to quote myself from an earlier biography, I believe “God lent me a voice for 57 years before He took it back again”. I am now 62 years old.

There is no doubt in my mind that I believe this quote. However everyday I battle to accept this same truth *and its consequences*. For example just yesterday in church the congregation were singing a song with the lines, “May my voice lift your name my God” and “May my voice sing your praise for ever”. I balked when we arrived at those lines. I don’t usually sing, or read the congregational responses, as I cannot breathe quickly enough and just end up coughing disturbingly loudly. This does mean I can concentrate on the words – perhaps even more than the folk around me who are singing their hearts out! How can my “voice” lift praise to God now? If it is not in some research lab being pickled, it has long since been buried or incinerated.

I easily get to feeling very down when I allow myself to think of what might have been if I still had my “given” voice:

I wonder what would have been our role in Sudan, with all its changes.

Perhaps I would have been back travelling the country teaching and encouraging groups of pastors and church leaders as I had done between 1979 and 1999, before Brenda and I moved to live in Khartoum.

Even if we were back in England still in the preaching ministry, perhaps we would have been raising prayer support and practical support for our beloved Sudanese brethren and sisters. Or helping develop the teaching for Christian leaders I had helped begin in Cornwall during the nineties.

As mentioned above I find church is one of the hardest places for me now. Unable to sing or respond in the readings (I can usually say “Amen” at the end of those), unable to participate in open times of sharing or open prayer because people cannot hear me (and it would make an inordinate carfuffle for me to get up to the microphone or for the microphone to get down to me), unable to speak and be heard during the after-service coffee and refreshments (firstly because of the general hubbub and secondly because drinking and speaking don’t mix for a laryngectomee), I feel my loss more in church than anywhere else. This does not stop me going. It does mean I have a real struggle every Sunday.

Two churches have asked me to speak to their congregations in the last twelve months, but neither has asked since asked me back. I wonder, does

this mean I was difficult to listen to or hard to understand? Nobody tells me this. Would they be entirely honest if I directly asked them?

My own church has recently asked Brenda and I to host and to lead a home group for 16 people fortnightly, on Thursday mornings. My voice has so far been reliable during the hour and a half meetings, so much so that I have led a thirty minute Bible study discussion without too much difficulty. Mind you, I do have a very sympathetic and understanding audience in that group!

My spiritual battles with these things in and around church tell me that I have not yet fully accepted what has happened to my voice and my work, even though five years have now past. I know the theology adds up. I totally accept God has every right to do what He knows is for the best. He is *a/ways* right, even when it does not appear so to me (or to others). When I sit at my computer typing articles which will be almost immediately sent to Christian leaders in Sudan, or submitted to the American magazine Grace & Truth's editor for possible publication in a year or so's time, on a good day I can see that God has possibly widened my ministry. We certainly receive many encouraging letters or emails from readers in various unheard-of places.

But, and I am being as honest with myself and with you, my reader, as I can be, on other days I find Romans 8:28 awfully hard to accept *where my voice is concerned*. "In *all things* God works for the good of those who love Him, who have been called according to His purpose". This is a daily challenge for me,

and a challenge I don't always win. I request your prayers for me as I battle to win the victory of Jesus each and every day.

I read and reread Philippians 1:19-27, especially verse 23, "I desire to depart and be with Christ, which is better by far". When people ask me how I am and I reply with that verse, they look at me as if I am mad, even Christian people! It does seem that God has purposes in my dilly-dallying around on this earth. My daughter lovingly reminds me I can see my two grandsons beginning to grow up, and also that they can get to know me. The little bit of writing, and publishing in Sudan, God has enabled me to do, *is* being used to the building up of other Christian lives. So my own prayer is from verse 21, "So that now as always Christ will be exalted in my body, whether by life or by death, for (I hope that) to me to live is Christ and to die is gain". (bracket insertion mine).

Colin Salter 21st November 2011.