

My second year as a laryngectomee.

19th January 2009.

It is 2 years and two months since my laryngectomy as I write this.

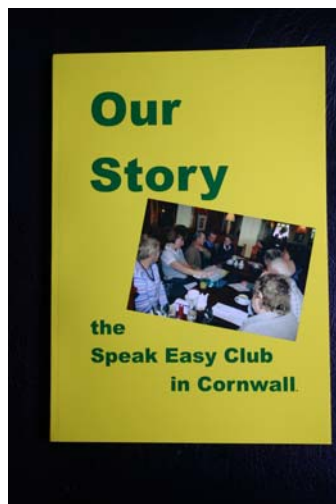
I remain so thankful to God for His goodness and grace in my life.

I am NOT saying it has all been easy.

I think this year has been the toughest of my life without doubt.

God-willing I'll be 60 years old in just ten days time!

One highlight has been **the publication of a book** of the real human stories from our "Speak Easy in Cornwall", a club for people like me. I was privileged to interview all the members, both patients and carers, and then write their part of "Our Story". There are fourteen accounts in addition to mine and Brenda's. *I will be pleased to send you a copy at UK£7.50, plus £2.50 post & packing (plus any overseas postage). Contact me to place an order.*



Our **Speak Easy Club** meets once a month in various places around Cornwall. Since April 2008 I have served as the secretary.

Two years on and I am still adjusting to my new and different life post laryngectomy. Let's consider five areas.

1. Life at Work. I am self-employed and work from home as a writer and publisher. My previous life as a Christian minister travelling to preach and teach at public meetings around the UK and Sudan has stopped. I have had to let that go. It was as much as I could do to lead the congregation of my home church in a public prayer at one Sunday morning service in September last year.

I reckon to work at half to two-thirds pace now. I do not have the stamina I once did. I set myself little goals, like being at my desk by 08.45 to 12.45 for five mornings a week. I walk for an hour most afternoons to keep fit. It is uphill from Redruth town centre to our home, so that can be a challenge carrying our daily shopping. I usually have to stop once or twice due to breathlessness.

Then I try to work again from 4-6pm, dealing with various things which arise, emails, phone calls, Speak Easy business etc.

I have started some voluntary work too. Every month I count birds at the Hayle estuary for the RSPB. This takes me on a 5 hour walk, stopping and spotting en route.

For the past two seasons I have been a deputy green warden at the bowls club which is just along our road. This involves setting up the green at the start of the day and collecting the gear and storing it overnight.

Plus I have been on a two day course beginning the process of becoming a hospital visitor (or befriender) to fellow patients and their carers at Royal

Cornwall Hospital, Treliske. The application forms go in this week. Who knows what will happen? During the last year I have done quite a bit of unofficial visiting without all this, sadly necessary, paraphernalia.

2. Hobbies and the Friendships of life. These are certainly different from before. Perhaps most of my friends were work colleagues whom I saw regularly when I was out and about here, there and everywhere. Now I am home based I see very few of them. A handful call on a regular basis and I am always pleased to stop and fellowship with them.

April to September I am an active member of Redruth Bowling Club (lawn bowls) and enjoy playing. People have been very kind towards me, understanding the problems I may have leaning forward – possibly blocking the stoma filter – and also keeping the rain out of my stoma when playing a league match during sweeping rain! I cannot speak loudly enough to give directions to the other end of the rink, so I appreciate it when people look at me “for my hands to speak”.

My HME back-plates are a problem to keep sticking in sometimes humid conditions. When they slide a bit they can be dangerous, the sticky part even blocking the stoma. I have yet to find the best way of wearing a raincoat to keep dry yet not having my neck area so moist as to remove the adhesives. *Any ideas gladly received.*

At church all year round, and at the Redruth rugby club from September to April, I find myself getting frustrated at not being able to be heard in a crowd – even chatting to the person sitting or standing beside me is difficult because of the background hubbub. The other people are mostly really understanding. They are as helpful as they can be. It is me who is frustrated, and I must learn to accept my new life as it is, with its limitations.

I am sometimes moved to tears in church when I cannot sing the hymns and songs. Last Truro Cathedral carol service was one such time. It is perhaps a good thing that I cannot shout at the rugby referees! At least when I am bird watching the birds don't mind if I am quiet 😊. And I usually bird watch on my own.

3. Travelling. Basically, I don't travel! It is probably not that I can't, but I don't. Eighteen months ago I was quite ill during and after the one journey we made, up to north Wales for a week including a Bryn Terfyl concert. So I have not risked it since.

In November 2008 Brenda and I had five days on the beautiful Isles of Scilly. However, they are still in the catchment area of Treliske hospital and the journey is 2 hours from home to hotel. Those days probably proved I could travel more if I needed to, but I am not pressing the boundaries.

I admit I do not travel well with Brenda driving 😊. I had to surrender my own licence in 2003, before laryngectomy, because of persistent blackouts.

4. Life in the Family. My family are supportive, understanding, caring and loving.

One problem we struck was when my first grandson, Cameron aged around 2 years, was disturbingly scared if I coughed nearby him. We all worked on this as a family, especially my daughter Sharon – Cameron’s mum. She and her husband Courtney prepared Cameron for his visits to our home by regularly saying things like, “It doesn’t hurt Grandpa. He’s only coughing”. And I tried desperately not to cough in Cameron’s presence!

The most successful thing however was an A4 size booklet Sharon made especially for her son. Called “My Grandpa” it tells in words and pictures what happened to me and why I am like I am. I’m told they read it together at their home several times over. It certainly seems to have helped Cameron. This Christmas just past he was much more comfortable.

(Please use this following idea to make a book of your own if you have someone with a similar problem).

My Grandpa



One day Grandpa woke up with a sore throat. A few days later he lost his voice. When his voice did not come back he went to see the doctor.



The doctor sent him to the hospital to see a consultant. The consultant did lots of tests and discovered that Grandpa's voice-box had cancer. Grandpa had to go and stay in hospital for a while and the consultant took the cancerous voice-box out of his throat and threw it away in the rubbish bin.



To finish making Grandpa better the consultant had to leave a hole, which we call a stoma, in Grandpas neck. Grandpa breathes through this hole.



He has to clean it very carefully everyday. Grandpa still takes lots of pills to help him stay better.



Grandpa speaks in a hoarse voice and makes funny noises when he breathes sometimes. He coughs a lot. Grandpa looks and sounds different to me. I know that the stoma and all the coughing does not hurt him.



I know that my Grandpa loves me very much.



Brenda and I have found the year tough, our 39th year of marriage. I am less patient and more irritable. I am interpreted as being depressed but I don't think that is true.

Brenda's hearing difficulties do not help our communication and I get exasperated at having to say things more than once.

I admit to preferring to be alone very often, to give my voice a rest!

I certainly cough less when I don't talk very much.

But that does not help Brenda, who naturally wants those little loving expressions, communications which foster deepening love and understanding. If I do speak firmly it sounds much harsher than it would have done in my old voice – and that doesn't help poor Brenda either!

We have plenty to work at! The vows we made before God almost 40 years ago we both intend to keep. With God's help, we will work our way through the difficult times and enjoy what we can.

5. Clinic and the Medical side of things. Just last week my surgeon said the healing was so good he was reducing observations to three-monthly. During 2008 I had two laser surgeries, both under general anaesthetic, to deal with patches of Barrett's Oesophagus. The symptoms were soreness and some obstruction in swallowing and breathing, plus extreme soreness after speaking a lot. One of the patches was right where the sides rub for speaking with the

prosthesis I have. If any symptoms reappear I can phone him immediately and he will look again. We are grateful to God for this progress.

My last voice prosthesis (valve) lasted six months, much longer than before. It seems my body has adjusted to having a “useful foreign body” in my throat! The prosthesis was only changed at six months as a precaution – there were no symptoms requiring the change.

I generally use the Provox HME cassettes and back-plates. I use the normal grade cassettes and the regular back-plates, sometime oval sometimes the smaller round ones. I use the Xtra back-plates, with barrier cream and silicon glue applied first, when I use the “Hands-Free” cassettes. If I do not, then the plates blow off very quickly under the pressure of speaking. Even the Xtra base ones do not work perfectly. I find myself holding them on with one finger when I do not need both hands for other things. Sales reps. from different companies have told me they are working on this known problem.

I remain unable to smell things when I want to. I have tried the olfaction technique without success. Our Speak Easy Club had an outing to the Eden Project where we tried to smell a variety of crushed leaves etc. I came bottom of the class, managing only to identify the smell of mint, out of about thirty attempts!

I do catch the odd whiff of something when I don't intend to, but I don't know how it happens.

So on to the next year, if God grants one to me. My motto text for 2009 is:

“For to be sure, Jesus was crucified in weakness, yet He lives by God’s power. Likewise, we are weak in Him, yet by God’s power we will live with Him to serve you”. 2 Corinthians 13:4.

My new and different life continues. God bless you. And thanks for reading this.



Colin Salter