

**My story: Brenda Salter** – carer since November 2006. (10<sup>th</sup> January 2008).

In the ENT clinic at Barncoose hospital I realised that this diagnosis was our answer seven months of uncertainty. We had not known what was wrong with Colin's voice and throat. We did not know why he could not preach and teach in his job as usual. Suddenly we did. The consultant said they had found a carcinoma sarcoma – a potentially lethal and vigorously growing cancer. The whole voice-box would have to be removed, and quickly. I felt numb. I did not seem to be panicking, yet somehow I felt I should be! It was all rather surreal. I functioned without feelings.

What followed was a whirl of activity for twenty-three days. We went to oncology at Treliske hospital and were introduced to the multi-disciplinary team who would be looking after us. There was the consultant surgeon, the speech language therapist, the pathologist, the dietician, a general nurse and the MacMillan nurse. An operation date was fixed there and then. It was five days later than the date first selected due to the surgeon's other commitments.

We emailed many friends when we arrived home. We phoned particular family members. I chased around to buy Colin tie up pyjamas for hospital as he doesn't normally wear them!

Back at the hospital we had a pre-operation assessment. This was exactly the same as for two previous micro-laryngoscopies with biopsies. They had been in July and October. Nothing at all to be alarmed about in this.

But after the P.O.A. we were invited by the Speech Language Therapist to meet a laryngectomee in her office. I really think it would have been better if I had never seen and heard this man. The encouraging assurances from the team about the new voice Colin would have post operation did not ring true with what I saw or heard. This meeting definitely made me much more apprehensive.

Two days before Colin had to check in to the ward we celebrated our 36<sup>th</sup> wedding anniversary. We had a steak lunch at our favourite hotel in Redruth. We were both aware that we did not know if we would ever do this again, but we did not really talk about it.

We were very fortunate that a student nurse, who was a friend with common interests, was appointed to study Colin's case as part of his course. He would be with Colin through the entire hospital process. He was even able to phone me at home, directly from the operating theatre. He put the consultant on the phone, who said he was very pleased with the operation and felt he had removed the complete cancer, sound and intact. Tests would later confirm this.

When I first visited Colin the evening of the operation I was not unduly put off by what I saw. I knew where and what they would be cutting. I expected all the tubes, though not necessarily the noises. I remember being impressed by the

warmed, humidified oxygen puffing and gurgling to help the bronchia cope with no longer being attached to Colin's nose!

I chuckle when I remember calmly sitting in one corner of the ward while the duty staff went into overdrive because Colin had blacked out. I had a strong advantage over them. I'd seen this many times before. I knew that, if left alone, he would come round after a short while, usually with a bright smile on his face.

I was reluctant to go home that evening and to leave Colin in hospital. I had nursed him through many things before and I really wanted to be with him now. The staff kindly said, "Come in any time".

Later on, this made it harder when I was asked to leave the room while staff removed one of two drainage tubes from Colin's neck. I cried and cried as I walk up and down the corridor – it seemed forever – before I was called back in. I recognise that this is a clash between open visiting hours and the needs of patient treatment. I also recognise that I had been on an emotional roller coaster ride. It was good that the tears had the chance to flow.

On a lighter note, during the two week stay in hospital a physiotherapist was asked to help Colin breathe in better oxygen levels (they were checked on the regular blood pressure and temperature rounds). She decided Colin needed to exercise, but this was rather difficult when attached to the wall and bed by a variety of drips, feeds, monitors and drains. So we developed our own form of

the American Stroll – forward, 2,3,4, backward, 2,3,4, etc. and brought much apparent amusement to the staff by counting and walking miles hand-in-hand yet never being more than four steps from his bed!

Of course, normal communication between us had been taken away. Colin could not talk. The Speech Language Therapist provided a magnetic pad with stylus for writing. Colin also kept copious notes of the daily round of hospital activities along with all the important information he was told by the medics on their rounds. When I first came in every day I sat and read these to catch up to date.

We could still hold hands.

Our family were naturally very concerned for both of us. Every evening on returning home I sent some emails and made some phone calls. People said I must take care not to become overtired. Colin wrote some emails from his laptop which he was able to have with him in hospital after it was electrically checked and stamped. I think writing was a great therapy for him.

Our son lives locally, but our daughter and family visited from Southampton on a couple of occasions. The welcome visits caused extra disruption to their usual lives as well as to mine! Plenty of people were offering help to me in the time of crisis. Normal life outside of hospital was suspended. Only what had to be done was done.

For me the crunch came when Colin left hospital after fifteen days. We were given lots of equipment – a portable suction machine (which we never used), cleaning brushes, back plates, Heat and Moisture Exchange cassettes, pipettes, etc. But at home there was no immediate back up with medical knowledge and encouragement. Suddenly there was only the two of us! The first two nights I did not sleep but lay awake wondering what every single noise coming from Colin was. Coughing, spluttering, gurgles and crackles. Was he still breathing? I checked – remembering *where* to check as now his nose and mouth were not involved in that activity! Those first nights I nervously checked many, many times.

Perhaps a home visit from a professional would have been confirming and encouraging after two or three days, just so I could know we were doing OK.

Having said that we were invited to the Speak Easy Club (for laryngectomees and their carers) Christmas dinner. It was just five days after leaving hospital. At the regular follow up clinics our surgeon still talks of his amazement at seeing Colin eat a full-trimmings Christmas dinner, albeit slowly, so soon after his operation.

At home I believe I was shocked – and I possibly still am – by the new situation we faced together. Communication is reduced to the bare essentials. There is a lack of incidental comments. Colin has the promised voice but I did not realise just how limited it would be. Colin gets frustrated and annoyed when I cannot understand what he is saying. I was surprised he did not keep

on writing things down like he did in the hospital. I definitely expected more from the voice. Perhaps the positive talking by the professionals built too high an expectation in me. I was told the new voice would not sound the same but it would be recognisable. I don't remember being told it would not be as instant as the natural voice, nor would it be usable in all situations.

I sometimes count myself as a carer for Colin, but at other times I don't. Of course I try to watch out for him, and to look after him as best I can. But I do not have to be beside him every moment of every day as some carers are for their loved ones. Our situation could be a whole lot worse.

The most challenging thing for me has been to take responsibility for initiating conversation and communication between us and when our friends visit. I am by nature a responder, not a starter. Now I find I have to take more of a lead because Colin cannot. It is hard.

Trying to think of things Colin would enjoy doing, while I am still coming to terms with the situation myself, is also tough. For example, going out for a meal, or having folk round for dinner is good because company is stimulating for Colin. He always used to be mixing with many people in his pastoral work at the church. But now talking while eating is difficult. And conversing where there is background hubbub is impossible.

Having Colin around all the time at home is a big challenge too. He used to be out visiting, teaching, etc. Now there is a total change of family dynamics.

There is no doubt that Colin's attitudes have changed during this fourteen months. His aggression, which led to me spending one night at our son's rather than at home, is out of character. I am sure coming off long term painkillers after two replacement knees contributed to this, but I also recognise an underlying change. The gruffness of his new voice accentuates this feeling I have, especially when I am having a bad day myself.

I have noticed that many of our friends are unsure what to do with Colin. Some do not visit because of their uncertainty, which is disappointing. When I am asked, I always say, "Please come". The stimulation of talking with other people is beneficial even if the physical effort in talking takes its toll. Talking with one or two in a quiet room is much easier than talking anywhere else. I sometimes limit the time for people when they come because I know Colin's voice wears out after a while and he easily gets overtired.

I wish more friends came to visit and to stimulate meaningful thought. Colin's role in Church and Mission leadership may have gone, but he still has all his wisdom and experience – may be even a bit more now than he had before! A lot of people visited around his time in hospital, but very few come along now.

I get disappointed when people say to me, "Is Colin back to normal yet?" The laryngectomy is a permanent operation. There is a new normal! Like me, people have to come to terms with the present, not wait for the past to return.

As a Christian I have been greatly helped by knowing that God has allowed all this to happen. We both believe God knows what He is doing. I do not claim to understand the “why?”, although the writing Colin is now doing for the Sudanese Christian church is being widely used out there. He would not be doing this writing if he was still pastor of Khartoum International church.

I would like to say that I have been helped by bingeing on Fruit and Nut chocolate bars! Many times it felt like it helped, but the reality is the opposite. It certainly did not help my figure.

It has been good to hear from other laryngectomee carers at our Speak Easy group and especially in one another’s homes. I don’t remember being warned to expect psychological impact. Sharing that we face similar battles in life: tensions at home, out of character behaviour, motivation, etc., helps me carry the load. I am relieved to realise that it is not only us who have our troubles.

I also thank God for a few close friends who have offered necessary cuddles and who have maintained an ongoing interest in us both.

Looking back I wish we had had a patient and partner talk with a professional advisor about the psychological impact of this operation. To have been forewarned of how it would affect life – the depression, the temper, the frustration and aggression, character changes and illogical thinking. A further automatically generated talk, after two to three months, for evaluating

ourselves may also have been good. I feel I need help in working out who is the real Colin now.

This is not so much helping us cope with cancer. Cancer has been no real problem to us. It is much more helping us understand the effects of the treatment on us, as two loving individuals. May be this is “clinical psychology”, I don’t know.

The Speak Easy club is of much more benefit to us now, after fourteen months, than it was to begin with. But we had to attend all the meetings, and meet fellow laryngectomees and carers in their and our homes, to get where we are now. It takes time before confidence is built and there can be genuine yet comfortable sharing. Trusting relationships take a while to build. When they are built, they offer strength and support.

I still feel very sad at the frustrating limitations that Colin has to live with. And I see them every day. But I also remember that the alternative to this operation was, “two months to live”. Not having Colin would be much worse than seeing him like he is now.

I do not think things get easier as time goes by (fourteen months post-operation for us). The operation and the stay in hospital are the easy bits. Life is ongoing and this life is rather tough.

I understand we have lost ease of communication and exchanged it for what I call economy of conversation. We have lost the ability to do what we pleased. We now have to live within fairly strict limits of speech and of breathing. I have lost a leader in my life. He is not the “go-getter” he used to be. We have lost our pipe dreams for our older years.

I hope and pray that, with God’s help, I can cope with tomorrow.

