

And so it was that.....pain.....

My husband had his cancerous voice box removed in November 2006. In April 2009 he had a related cancer removed under his jaw and the site was then treated with radiotherapy. Between the surgery and the start of radiotherapy we were linked with a Macmillan District Nurse who was a liaison with our GP and had many practical ideas which she had the experience and ability to instigate. She started Colin on Amitriptylene to add to the MST and Oramorph he was already taking..

There are many sensitive structures in the neck and jaw, so the radio therapists come at the problem area from different angles to minimize collateral damage.

Either from the surgery or the radio therapy Colin was left with pain - nagging, constant pain inside a circle about 2 inches from his ear, inside the ear, and intermittent pain with heat in the ear that we can see!

It was hoped that the pain would settle - but it was not at all willing to do so.

Our G.P. prescribed painkillers. The pain was still ascendant.

At follow up oncology clinics – various suggestions were made - all to no avail.

After several months, the ENT and oncology consultants referred Colin to the hospital's Pain Clinic in October 2009. These specialists listened. They understood. They explained - quite graphically - about the damaged nerve moving around, trying to find another nerve end to link with, but so far not managing to do so. The longer the situation went on the less likely the nerve was to find a partner, but it was still possible! However to reduce the pain in the interim - add Gabapentin to the mix and continue to reduce the Oramorph.

In October 2010 another referral to the Pain Clinic, by which time Tramadol was in the mix and Carbamazepine was added. At the six week evaluation the Carbamazepine was stopped - Tramadol had already disappeared!! - and Oxycontin and Oxynorm introduced. The possibility of a Stellate Ganglion injection was mentioned but put on the back burner because it did not work for everyone, might not be possible with Colin's amended throat and neck anatomy, and would be very uncomfortable to do because of the existing sensitivity and pain.

Somewhere in this time I made something that I probably ought to patent - take one knee high - fill smoothly with two old socks -tie to right size - use to take pressure off the ear when laying down!!

Oxycontin reduced the pain level but never took it away. The dose kept having to be increased and, as it was increased, so Colin became less able to concentrate and more needing to sleep, having more sweats and being more confused. Each time it was raised I felt confused - this drug is compounding the problems and here we are taking more!!.

God was then (and is) sovereign - I asked Him why this was all happening - I knew His strength and care - that was sufficient answer to me.

When Colin was taking 80 mg Oxycontin twice a day plus top up 20ml Oxynorm we had another visit to the Pain Clinic to discuss the Stellate Ganglion injection. No guarantees it would work - works on some people and not on others - because of Colin's rearranged

neck anatomy from the laryngectomy operation there was a possibility the consultant would not be able to complete the injection - would we like to go ahead?

Yes! There and then the consultant placed the injection where he wanted it - by a spur of bone on a vertebra next to a nerve junction - Colin's whole left side was numb for a few hours but after an hour of checks we left - I was so glad a friend had taken us because the bus would have been very difficult to manage!

No pain since!

BUT bringing the Oxycontin down 10 mg every 4 days, and when we reached 50mg then 5 mg every 4 days, has given more headaches, more sweats, more confusion and more sleeping than ever before. I never knew what shape the next day would have - should I cook lunch - would I have to freeze yet another meal - should I not bother and could we have yet another meal of cereal and fruit? - would Colin be awake to talk with visiting friends? - would he be alert enough to update his website?
(I know two 'yet another' in two lines is not good English – but it just shows how I felt!!)

We have spent 2 years plus of Colin having a 'half life'. We are looking forward to two months' time when he will be 2 weeks clear of the opiate Oxycontin and we can see what level of reality he comes to. Then to reduce more of the drugs cocktail and wait for his body to settle again.

I have written as I felt - there is no implied criticism of anyone - everyone mentioned, and the staff at our GP surgery, have been wonderful - thoughtful and kind. I have written to give others in similar positions a 'someone else has been there' history. Each journey is different but we probably all deserve a degree in applied caring, with medical terminology!!!

P.S. the pain came back after nine and a half weeks - the second injection has not been as effective yet - 8 days on!!! (But is now – 18 days on!).

Brenda Salter. 4/9/11 (Only the final bracket added by Colin).