

Richard S. Galik
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This update comes **9 1/2 weeks** after my surgery of 27 October 2004. I apologize if it is a bit rambling, but several aspects are interlocking and a bulleted, outline style was hard to manage.

My trips to NYC (8/9 Dec) and (especially) to Boston (13-16 Dec) **were exhausting**. For about three days (17-19 Dec) I had sharp headaches, minimal appetite, and extreme lethargy, sleeping up to 12 hours a day. For several additional days I had a bloated feeling and some difficulty taking deep breathes, as well as very minimal energy or desire to do anything. While this has improved, I still do not think my **energy level** is back to where it was before these trips.

The CT/MR studies done in Boston indicate **tumor presence** along the right vertebral artery, either residual or recurrent. It has been decided to nonetheless proceed with radiation therapy.

Overall the extensive surgery has left me “**remarkably intact**”, in one doctor’s words. Many have expressed marvel at the skill of the four surgeons.

As to **pain in my right hand and arm**, one benefit of the period of illness was that these pains were essentially non-existent, despite my sleep and lethargy meaning I missed many of my routine times for taking **Neurotin**. This indicated to me that sleep was more effective than the medication! I have also been asked whether I find the medication to be effective and realized that I could not give a solid answer backed by personal observations. So, I have been paring back my dosage to **200-300 mg/day** from a high (just before the Boston trip) of 800 mg/day, without any marked increase in the severity of the symptoms.

Now that I have somewhat recovered from the travels and again am more active, symptoms in the hand and arm **have** returned, not at high severity, but more varied:

- The tips of the right thumb and forefinger can vary from tingly to burning to numb over the course of an hour or so; this continues to be the most persistent symptom.
- The longer shafts of these two digits and their extension to the wrist are sometimes hypersensitive to touch and can have burning

or jabbing pains, especially at the joints; this symptom seems to be declining in frequency and intensity.

- There is some jabbing or burning in the wrist itself, both sides; this is not very frequent.
- I have burning or aching in the right forearm and upper arm at the elbow, and in the right upper arm, both mid-arm and where it joins the shoulder; while not (yet?) very intense, these are similar to pains I had prior to surgery that were linked to tumor pressure.

These hand/arm pains seem worst at night, just at bedtime, so I still do take 200 mg of Neurontin (or its generic) then ... although it is hard to judge its efficacy.

The **muscles on the right** (base of thumb, forearm, upper arm) continue to lag behind the left.

Sleep has not been consistent. Most nights I sleep well, but there are still times that I will spend 10 or more hours in bed for 4-5 hours of sleep. It has been at least two weeks, however, since I have had any morning “fuzzy” feeling.

The ptosis and changed pupil diameter of my **right eye** seem unchanged and are now assumed permanent.

Throat issues remain largely unchanged. My voice seems fine, both speaking and singing, and does not seem to get hoarse or unduly tired. I still occasionally catch “last item eaten” in the back of my throat, especially if the food item is sticky; but this is not “new” and I see no danger of my gagging or choking.

I still wear the **Miami** hard collar during the day, except for showering, when I use the stiffer **Philadelphia** collar. The fit of the Miami is getting a bit “sloppy” – the padding is getting thin and my neck has noticeably shrunk in circumference since the collar was fitted in late October. I change to the **soft collar** at bedtime. In the evening I have noticed that the structures (bones and hardware?) of the base of my neck in the rear are quite pronounced; they seem smoother when getting up in the morning; this may be a question of posture?

I have resumed taking an **herbal tea** once or twice daily to strengthen my constitution for the upcoming weeks of radiation therapy.

The news that the CT/MR studies from Boston show residual/recurrent tumor and the recurrence of arm symptoms that were dominant pre-surgery have made me take a perhaps more realistic look at my **long term prognosis**.

Upcoming medical events? dental work 3 Jan; Xrays 3 Jan; travel to Boston 5/6 Jan; start radiation therapy 10 Jan.