

**Symptoms and Concerns**  
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**27 July 2005: Surgery + 9 months**

**Older Symptoms and Status**

*Overall:* Given sleep (see below), I seem to do rather well; there are occasions (not so many that they are still “special”) that I wake up and feel so good that all this must have just been a bad dream

*Collar:* no longer worn, except occasionally while passenger in car (and bus, if I ever were to ride one!)

*Horner’s syndrome:* unchanged, but also unnoticed

*Dysphagia:* unchanged; still occasionally have to cough sticky bits of food into my mouth for further processing

*Nerve pain in right thumb/forefinger:* reduced, but still omni-present; capsaicin cream (0.35%) helps hypersensitivity – apply 1-4 times per day PRN, with the need decreasing over time ; exacerbated by typing and driving; generally a “livable” syndrome at this point

*Neck ROM:* rotation left OK (but poorer than pre-surgery); rotation right very limited; vertical motion (flexion/extension) OK downward (but certainly poorer than pre-surgery) and extremely limited backward; sideways motion (yaw, ear-to-shoulder) very limited; I continually bump into things I used to be able to duck to avoid

*Driving:* OK; adjustment of mirrors helps in backing up; have not tried to parallel-park yet; bumpy roads seem to exacerbate right hand symptoms; livable situation in that I need to drive given my rural living situation

*Right arm strength and ROM:* ROM improving, except for behind back; strength improving in most muscle groups with biceps most noticeably lagging; right arm still considerably weaker than left in most areas; PT work limited by pain in jaw/neck/shoulder (see below) and renewed back pain (see below); but overall improvement over the last 4 months has

been dramatic; I now “just do things” and am surprised if I cannot rather than thinking from the start that I will not be able to do them

*Energy level:* rather good, but may have plateaued since June; depends on ability to sleep (see below); still cannot work really full days, but I am up to 7 hours at the office or so most days; my mind is sharp but tires somewhat easily; trying to become full-time by September; others seem very impressed at my overall energy level

*Medications:* 500 micrograms of B-12 daily to help possible deficiency; 0-400 mg of (generic) Neurontin in the evening to help with nerve disorders (see below) – not sure this is helpful

*Mood:* varied; varies from guarded optimistic to occasionally pessimistic and depressed; my mood is also tied to sleep

*Upcoming medical visits:* x-rays, scans and consultations at MGH in mid-August; consultations in NYC to follow, but not yet scheduled; Ithaca-based neurologist in early September (11 week lead time to see one!); acupuncture for general strengthening and specific right arm work 2-3 times a month; PT visits about every six weeks

*Short term plans:* decided not to sell house and move into Ithaca, but will stay in our rural environment; Candace to start last year of seminary in NYC in late August – we will move belongings in late August; hope to resume full-time faculty and research obligations starting in late August

## Newer Symptoms, Problems and Concerns

### *New nerve issues:*

This is by far the newest issue that is of most import. I had a singular incidence of this in August 2004, which I did report to my local oncologist. Episodes resumed in April 2005 and have steadily become more frequent, more extensive and more discomforting. At my mid-April meeting with Dr. Bilsky he felt these were neuropathies; I have an appointment with a neurologist in September. At Dr. Mead's suggestion I have been taking a B-12 supplement, without apparent effect.

The symptoms are dominantly (but not exclusively) in my feet, dominantly (but not exclusively) lying supine, and dominantly (but not exclusively) at night.

The most common foot symptoms are burning in the outer toes (2,3,4,5) on both feet, not necessarily simultaneously. There are also more jab-like pains in the big toes and tingling occasionally in the heels, insteps and shins, again bilaterally.

Second in frequency and annoyance are tingling in the outer digits (3,4,5) of both hands, jabbing pains at the base of the thumbs and/or forefingers, and extension of the normal tingling in the right thumb and forefinger into the wrist and forearm. There is also occasional tingling in the base of the trunk – groin, rectum, and genitals.

Medication may or may not help. There are days I take no Neurontin and sleep well and days on which I have been regularly been taking 400 mg in the late evening and the symptoms affect my sleep.

*Sleep:* Can be interrupted or delayed by nerve issues (see above); these poor nights of sleep have become more frequent, being perhaps once every two weeks in April to now being perhaps twice a week; even on nights that I do sleep well, I seem to need an hour or so more sleep per night than pre-surgery

*Conditioning:* It seems I breath harder after hills and work that I found easier in the past; hopefully this is just a matter of conditioning; at some point I assume there will be additional follow-up on the small anomalies in my chest scan

*Pains in jaw, head, neck, shoulder:*

Upon leaving RT I had a “click” in my left jaw; after starting weights with PT I now have even more frequent clicks and “looseness” on both sides of my jaw.

At some point in doing PT exercises I incurred soft-tissue strains to the left side of my head (from jaw under and behind ear), neck (posterior) and shoulder; this has taken several weeks to resolve and still represents a weakness in my recovery efforts.

Also seeming associated with PT exercises are occasional slight headaches over the left eye

*Tightness in neck:* my anterior neck muscles occasionally get so tight I feel choked; usually very temporary and after PT exercises

*Pains in back:* some years ago (4? 5?) I injured my lower back (sacral ... below waist) by shifting my weight while sleeping; while this recovered nicely there has been a lingering weakness there and I periodically re-injure it; the rate seems to have increased a bit, with two such episodes while in Cambridge (Jan and Feb) and one in early July; the most recent took rather long to normalize and stabilize (about a week), limiting my ability to do PT exercises; ice helps the pain; stretches help too