

ANA/NJ Newsletter
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**Meeting at Princeton Medical Center,
April 13, 2008**



Suzanne Milani introduced our speaker, Nancy Conn-Levin, who is a health educator and the author of *Brain Tumors and Fatigue*, a patient education guide sponsored by The Brain Science Foundation. Nancy is herself a 12-year brain tumor survivor and has been personally affected by fatigue for twenty years. In her experience, she observed, fatigue is the kind of serious health problem that can actually go unrecognized by the people around you. You're like the little duck that people perceive as swimming effortlessly on the pond, whereas in reality underneath the surface there's furious paddling taking place to maintain

course and momentum.

Fatigue, which is a common complaint among brain tumor patients, is "more than being tired." What is at issue here is "a debilitating, persistent loss of energy that is not relieved or improved by sleep." It may last for years, and it can involve cognitive changes such as difficulty concentrating, short term memory loss or sensory overload. For brain tumor related symptoms, neuropsychological testing is advisable to help clarify cognitive changes and identify possible coping techniques. This testing can be done even years after surgery or other treatment. Nancy cautioned that since fatigue can actually be caused by a variety of medical or other conditions (e.g., anemia, depression, chronic pain, insomnia, poor nutrition, etc.), a thorough medical evaluation is always an important first step for anyone with fatigue.

Nancy recommended that learning to ask for help is one of the best coping techniques. This was #12 on her handout list entitled "Fourteen Healthy Suggestions for Coping with Fatigue": "Asking friends and family to help (and being willing to accept their help) can free up energy to use for other tasks. Be as specific as possible when making a request for help. People who care will want to do something to make things easier for you." Among her other suggestions for coping are:

- Pay attention to your diet.
- Get adequate sleep & rest.
- Drink enough water.
- Avoid inactivity.
- Keep humor in your life.
- Smile about something every day.

Nancy Conn-Levin is co-facilitator for the Monmouth & Ocean County Brain Tumor Support Group, Inc. (www.njbt.org). She can be reached at mngioma634@aol.com. The text of her booklet, *Brain Tumors and Fatigue*, can be found at www.brainsciencefoundation.org.

Notices

- The planning committee for the upcoming ANA/NJ Mini-Conference (see below) hopes that everyone received the August announcement of the conference and the mail-in registration materials. Just in case, Jane Huck has enclosed a copy of the Registration Form with this newsletter. Call Jane if you have any question or need assistance for attending the conference.
- The online “Acoustic Neuroma Survey 2008,” sponsored by ANA/NJ, the University of Pittsburgh and University of Virginia, is now ready for AN patients to take at www.ansurvey.com. The survey will be made available until the end of 2008. Please take a few minutes to complete the survey. Your participation is very important and will be greatly appreciated. A paper copy of the survey may be downloaded and returned by mail.
- Congratulations to the Acoustic Neuroma Association of Canada now celebrating its 25th Anniversary! For information, including details for the association’s revised Message Board, go to www.anac.ca.
- We were sorry to learn of the death of Dr. Judah Folkman, age 74. Dr. Folkman will be remembered for the seminal idea that tumor growth can be checked by blocking the tumor’s supply of blood. See the review of Robert Cooke’s book, *Dr.Folkman’s War:Angiogenesis and the Struggle to Defeat Cancer*, in the September 2001 issue of the newsletter.
- Karger Publishers (Basel, Switzerland) has announced the forthcoming *Modern Management of Acoustic Neuromas*, edited by Jean Régis and Pierre-Hughes Roche. Forward by L.Dade Lunsford, University of Pittsburgh.

The ANA/NJ Newsletter may on occasion refer to particular physicians, medical procedures, health institutions or commercial products. All such references are informational only and should not be viewed as recommendations or endorsements.

Chronic Fatigue Syndrome

Anyone having continuing problems with fatigue is likely to begin to ask questions about what is called “chronic fatigue syndrome” (CFS), a disorder characterized by profound and persistent fatigue. As yet, no one in our ANA/NJ group has reported being diagnosed with CFS. Still, there have been accounts of long-lasting, debilitating fatigue that has sounded a lot like instances of CFS. The article “Acoustic Neuroma and Fatigue” in our newsletter for June 2004 referred to these accounts but made no connection with CFS.

Could there be a causal relationship between the acoustic neuroma experience and CFS? This is something that’s not going to be investigated soon, but we should at least be aware of the wide-openness of the “Possible Causes” of CFS according to the Centers for Disease Control and Prevention (CDC). The CDC website states: “The cause or causes of CFS remain unknown,

despite a vigorous search. While a single cause for CFS may yet be identified, another possibility is that CFS represents a common endpoint of disease resulting from multiple precipitating causes. . . Conditions that have been proposed to trigger the development of CFS include virus infection or other transient traumatic conditions, stress, and toxins.” (See www.cdc.gov/cfs/cfscauses)

A computer check on the popular health site WebMD discloses a similar openness about CFS causation. The site statement reads: “Doctors don’t know what causes CFS. Sometimes it begins after an illness like the flu, but there is no proof of any connection. It’s likely that a number of factors or triggers come together to cause CFS.” Actually, WebMD raises doubts about the very idea of CFS: “Most experts [the site says] now believe that it is a separate illness with its own set of symptoms. But some doctors do not believe this. There are no tests for CFS. Because of this, many people have trouble accepting their disease or getting their friends and family to do so.” (See www.webmd.com)

What are the primary symptoms of CFS? First is medically unexplained fatigue lasting at least six months and severe enough to cause a substantial reduction in daily activities. In addition, to qualify as CFS, the fatigue must be accompanied by at least four out of eight other primary symptoms, namely, headache, sore throat, swollen lymph glands, unrefreshing sleep, memory/concentration impairment, achy joints, achy muscles, and dramatic worsening of fatigue after minimal exertion. The list of symptoms (1988, rev.1994) is in the process of being refined and upgraded. CFS is still at present a set of symptoms (a syndrome) that has been agreed upon to help diagnose and aid in the research of a medically unexplained illness, in hopes that ultimately a biologically distinct disease may be identified. It’s a lot like talking about tinnitus, which is a symptom for a medical problem that is still to a large degree unexplained.

An article in *Science News* a couple of years ago reported on the particularly acute case of a patient diagnosed with CFS who was treated at a Fatigue Consultation Clinic in Salt Lake City. This was a woman 52 years old who “began to feel inexplicably tired, day after day. . . She developed debilitating exhaustion, severe insomnia, muscle aches, and what she [called] ‘brain fog.’ Whenever she overexerted herself, aches and pains would spread throughout her body, sending her to bed or the couch for several days at a stretch. [She] tried ducking out from her job during the day to go home and nap. Later, she cut her hours to halftime, and then went on sick leave. . . She never returned to work.” (See “A Vexing Enigma: New Insights Confront Chronic Fatigue Syndrome,” *Science News*, Vol. 170, July 1, 2006)

The woman from Salt Lake City was fortunate in being diagnosed with CFS very early in her illness. Usually the diagnosis, if it is made at all, is complicated and time-consuming. The “Diagnostic Challenges” for CFS reported by the CDC, include: 1) no diagnostic laboratory test or biomarker, 2) fatigue and other symptoms of CFS are common to many illnesses, 3) CFS is an invisible illness and many patients don’t look sick, 4) the illness has a pattern of remission and relapse, 5) symptoms vary from person to person in type, number and severity, and 6) no two patients have exactly the same symptom set. Given challenges such as these, doctors might easily become frustrated and patients depressed as the search drags on for an explanation of complaints. (www.cdc.gov/cfsdiagnosis)

A new book that should prove helpful for anyone suspecting CFS (both patients and doctors) is Dr. Benjamin H. Natelson’s *Your Symptoms Are Real: What to Do When Your Doctor Says Nothing is Wrong* (Wiley, 2008). Dr. Natelson is a Professor of Neurosciences at New Jersey Medical School in Newark specializing in helping patients with complicated illnesses such as CFS and fibromyalgia. He is Co-Director of the UMDNJ Pain and Fatigue Study Center and the author of *Facing and Fighting Fatigue: A Practical Approach* (1998). For the most part, the patients he treats have already seen numerous doctors where the diagnosis has too often been “It’s all in your head.” Too many diagnoses of “nothing is wrong,” writes Dr. Natelson, are a consequence of doctors not listening to their patients. There is too much emphasis on fast results,

high-tech procedures and medical insurance. The “art of medicine” – “an entire way of thinking about and relating to patients and their wellness – is falling by the wayside.” Dr. Natelson goes on to recommend that patients with serious but unexplained health problems should seek out doctors at medical schools (in general they have more time to listen) and/or female physicians (in general they listen better than men). In any case, he warns, beware of doctors who exhibit the “three Bs – brash, boorish and overbearing.”

Dr. Natelson’s book is remarkable for the way he explains just how he handles patients who come to him complaining of fatigue. He describes what he will think and do, the tests he will order, and the therapies he will recommend, and why. He does not promise a cure, but he never says “nothing is wrong,” and he will promise to make his patient feel better. Chapter 3, “What Doctors Know about Medically Unexplained Illnesses,” presents his evaluation of CFS, which he calls “fatigue plus.” There is a useful chart of CFS-Related Symptoms. CFS, he notes, is not a common ailment. More common (about 1% of the population) is a milder version called idiopathic chronic fatigue (ICF) with fewer than four of the primary symptoms of CFS. Depression, he emphasizes, is not a symptom of CFS but acts rather like stress to make things worse, as a “symptom multiplier.” Two things distinguish depression from CFS: 1) the onset of CFS is often quite sudden, and 2) with CFS, even minimal exertion worsens a patient’s entire set of symptoms. What is called “post-exertional malaise” is a hallmark of CFS. Dr. Natelson’s Chapter 5, “Getting beyond Depression,” discusses how doctors may often confuse CFS or ICF with depression. The chapter includes a Depression Screening Form and a discussion of how Dr. Natelson would deal with a patient who has been treated for depression. The final chapters of the book examine therapies for treating CFS, with attention called especially to “The Integrative Mind-Body Approach” (Chap.8). Dr. Natelson wants to recommend that “psychological and social factors outside the body [such as your relationship to those closest to you] play almost as important a role in influencing how a patient feels from day to day as the patient’s underlying disease.”

Acoustic Neuromas that Enlarge after Gamma Knife Radiosurgery

As Dr. Georg Norén, director of the New England Gamma Knife Center in Providence R.I. reported some years ago: “Acoustic neuromas sometimes increase in size temporarily as a reaction to Gamma Knife treatment. This is actually a favorable sign indicating a brisk response. Such swelling usually is most obvious between 6 and 18 months after the procedure. It should not be confused with increase due to lack of response in which case the tumor size will not return to the baseline but continue to increase. A definite assessment should be made two years after the treatment: was the swelling merely temporary or did the tumor fail to respond to the treatment? In any case, resection should not be considered during this two-year wait.” Based on his experience treating almost 850 acoustic neuromas, Dr. Norén then reported tumor control (shrinkage or no growth) in at least 95% of tumors. He wrote: “One year after the Gamma Knife treatment, shrinkage is confirmed in about one-third of the tumors. After four years, two-thirds of the tumors are smaller, and by 10 years, more than 90% have shrunk. Signs of lack of response to radiosurgery, in general, appear within one to three years of treatment. . . [and] failure is extremely unlikely to occur when five years or more have elapsed.” (See “Acoustic Neuroma and Radiosurgery,” in IRSA’s *Another Perspective*, vol. 5, No.3)

In a recent review of 208 radiosurgery patients treated at the Mayo Clinic College of Medicine, 1990-2001, Dr. Bruce Pollock reported that thirty (14%) of the patients had tumors that enlarged at least 2 mm after radiosurgery. The median time to enlargement was 9 months. Two patients underwent resection. “In the 28 patients who did not undergo resection at the time of initial

enlargement, 16 patients showed eventual tumor regression, and 8 had tumors that increased and remained larger but did not show progressive enlargement. Four patients showed progressive enlargement on serial imaging . . . and underwent additional treatment [resection, 3; radiosurgery, 1].” The Pollock report concluded: “Tumor expansion after [AN] radiosurgery rarely denotes a failed procedure, and the majority of patients only require further imaging. Approximately one third of tumors that enlarge will remain increased in size compared with the time of radiosurgery but will not show sequential growth. Additional tumor treatment should be reserved only for patients who demonstrate progressive tumor enlargement on serial imaging (2 % in this series).”

(See B.E.Pollock (abstract), “Management of Vestibular Schwannomas that Enlarge after Stereotactic Radiosurgery: Treatment Recommendations Based on a 15 year Experience,” *Neurosurgery*, vol 58, Feb 2006)

The University of Pittsburgh’s Gamma Knife Center has incorporated Dr. Pollock’s recommendations in its most recent “Future Perspectives in Acoustic Neuroma Management.” The Pittsburgh study states how there will be “occasional patients with tumors that continue to grow despite irradiation. In some the enlargement may be minimal and transient, likely related to radiation effects on the tumor and the replacement of tumor with granulation tissue. . . . Some patients will exhibit a small expansion and then no further change. These patients do not require additional procedures, but do require continued observation. In others with continued tumor growth, the possibility of a second radiosurgery may be raised. Although there is little available data after a second radiosurgery, we have used this approach in a few patients with good results (up to four years at present).

www.acousticneuroma.neurosurgery.pitt.edu/future.html.

Regarding the possibility of a having a second radiosurgery, Dr. Norén’s report stated: “I have found that Gamma Knife treatment can be repeated without increased risks if the acoustic neuroma did not respond as expected (unchanged size/shrinkage) to the first treatment. Microsurgery can also be selected, depending on the patient’s preference.”

A successful second radiosurgery would of course circumvent the debate over whether or not microsurgery is made more difficult if the patient has had a prior radiosurgery procedure. Perhaps the jury is still undecided on this issue, although difficulties with microsurgery for failed radiosurgery patients are being reported. A combined Pittsburgh-Mayo Clinic report (1998), for example, recorded that for 13 patients with prior radiosurgery, microsurgery was more difficult for 8 patients, no different for 4 patients, and easier for one patient.

(See B.E.Pollock, L.D.Lunsford et al, “Vestibular Schwannoma Management. Part II. Failed Radiosurgery and the Role of Delayed Microsurgery,” *Neurosurgery*, vol 89, Dec 1998)

More recently (2004), a report by the Department of Neurosurgery of the Hôpital Sainte-Marguerite in Marseille, France, looked at 20 failed Gamma Knife cases. “In 9 cases, the surgeon considered that he had to face unusual difficulties mainly because of adhesion of the tumor to neurovascular structures.” The report stated: “We recommend that the decision for surgical removal of growing vestibular schwannoma after Gamma Knife treatment should be done after a sufficiently long follow-up period. Our results show that the quality of removal and of facial nerve preservation might be impaired by radiosurgery in half of cases. However, these results do not support a change in our policy of radiosurgical treatment of small to medium size vestibular schwannoma.”

(See P.H.Roche et al, “Surgical Removal of Unilateral Vestibular Schwannomas after Failed Gamma Knife Radiosurgery,” *Neurochirurgie*, vol 50, June 2004)

Cyberknife at Overlook

A preliminary report on thirty-one patients treated since 2004 by CyberKnife fractionation at Overlook Hospital in Summit, NJ, shows good results. Twenty-one of the patients had follow-up of at least 6 months (mean 9.4 months). For these patients, the total radiation dose ranged from 18 to 25 Gy; most patients (94%) received 20 to 25 Gy delivered in five fractions. Serviceable hearing was maintained for 85% of patients; one patient without serviceable hearing pre-operatively progressed to full hearing loss. The tumor control rate was 95%. One tumor grew after treatment and the patient under-went translab resection. No patient developed trigeminal dysfunction. One patient experienced transient facial hemispasm. The report notes that larger follow-up is needed and is in progress. (See V.Patil, Jed Kwartler, D.Yanni, Louis Schwartz, M.Schulder, "Conservative Fractionation for Cyberknife Treatment of Acoustic Neuroma," Meeting of the American Association of Neurological Surgeons, 2007, Presentation 1519)

The success of cyberknife at Overlook compares well with the Stanford University experience reported on earlier in this newsletter. (See "CyberKnife at Stanford," Vol.X, No.2, April 2006)

We see that the friendly competition over hearing preservation rates between types of fractionated radiotherapy (multiple sessions) and Gamma Knife or Linac radiosurgery (one-session) continues to benefit AN patients. Back in 2004, the International RadioSurgery Association, IRSA, recorded much lower hearing preservation rates for fractionation. But as IRSA foretold at the time: "Researchers are constantly refining the techniques and lowering the radiation dose to allow the least amount of permanent side effects and the most preservation of useful hearing, along with a high tumor control rate."

(See "SRS and FSR: Current Radiosurgery and Fractionated Stereotactic Radiotherapy Results," *Brain Talk*, Vol.9, No.2, 2004. Comparison table with references available at www.irsa.org)

ANA/NJ Mini-Conference

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