

The Fibrofog Mystery

by Tamara Liller

Talk to any person with fibromyalgia (FM), or the medical professionals who treat or study them, and it won't be long before you learn about one of the more mysterious aspects of FM—fibrofog. As its name implies, it is a phenomenon not yet completely understood, but it is capable of interfering significantly with everyday activities and with brain function.

In her bestselling book, *Fibromyalgia & Chronic Myofascial Pain: A Survival Manual*, Devin Starlanyl, who also has FM, refers to fibrofog as “the wheel is turning, but the hamster left town.” She offers several examples of the havoc it wreaks:

“When you are in fibrofog, steam irons are stored in the refrigerator. Freshly made milk drinks go on the shelf where they silently turn into a dismal green mold. You transpose letters when you write, and you do the same with the numbers when you try to balance your checkbook. Some days, you can't even put a coherent sentence together. The words rattle around in your mouth and don't seem to connect coherently to the ideas in your head.”¹

FM researchers I. Jon Russell, M.D., Ph.D., and Alice Larson, Ph.D., describe another common aspect of fibrofog in their article on the neurophysiopathogenesis of fibromyalgia:

“Patients report that it is not satisfying to read a book or to watch a program on television because they lose track of what is happening. For example, they must repeatedly return to previously read pages in their book to understand later events. They find themselves easily distracted by anything or nothing and then must reread again and again.”²

As humorous as individual incidents of fibrofog can be, there is no question that this group of symptoms is not only very challenging to deal with when in severe form but also destructive and hurtful, sometimes even terminating careers when mental acuity and a quick response time are required—being an emer-

gency room physician, the driver of a school bus, a police officer, or a math teacher. It can just be plain embarrassing as well. Devin Starlanyl explains:

“Fibrofog frustration is compounded when you're experiencing it because you can't express yourself well. However eloquent you are at other times, you may be incapable of putting together a coherent sentence when you are in a fog. You may even stutter as you vainly grasp for the right words. You are left vulnerable by your scrambled psyche, and the slings and arrows of an uncaring world zip right through your crumbling defenses. You have lost control, and you can't explain why.”³

Physician/author Mark Pellegrino, M.D., who also has FM, reassures us that fibrofog “is not a dementia or early Alzheimer's.” In his book, *Fibromyalgia: Up Close and Personal*, he offers quite a comprehensive list of common characteristics of fibrofog:⁴

- Forgetfulness
- Absentmindedness
- Concentration problems
- Confusion
- Disorientation (get lost easily)
- Difficulty finding or saying words
- Short-term memory loss
- Difficulty understanding what you've read
- Difficulty calculating simple math problems
- Mixing up words
- Right-left confusion
- Poor ability to give directions

He also includes emotionally-oriented symptoms of depression, irritability, anxiety, and panic attacks.

As we will see later in this article, these symptoms are not just limited to fibromyalgia alone.

What Causes Fibrofog ?

Thinking back on what we already know about fibromyalgia and how it affects the body, we might recall right away the famous 1998 study by Mountz, Bradley, and Alarcon showing decreased blood flow in specific areas of the brain in women with fibromyalgia⁵ and wonder if there is a link between that state of affairs and the various manifestations of fibrofog. Alternatively, we might recall the well-established studies demonstrating abnormal levels of various neurochemicals in the brains of people with FM and ask similar questions. The role of whiplash or traumatic brain injury is another obvious line of inquiry for fibrofog, as is the research on the abnormal functioning of the autonomic nervous system in FM.

These examples and others not mentioned are likely to be fertile avenues for future research. Functional imaging studies performed on FM patients engaged in cognitive tasks will provide important data, too.

It is also important to consider the various forms that fibrofog can take, translate them into research constructs that they can be evaluated in quantitative terms, tabulated, and measured in different ways. So far, the term *cognitive dysfunction* appears to be the most useful overarching term for the phenomenon known as fibrofog since it encompasses abnormal functioning in areas such as memory, facility with language, word choice, concentration, focus of attention, etc. The good news is that there are already established tests that have been designed and validated in the fields of psychology and neurology which can be recruited for research studies on fibrofog in FM patients. Of course, for more complex studies of fibrofog, researchers will need to develop and test new measures.

The component of fibrofog receiving some of the earliest attention, research-wise, was memory. Psychologists Jennifer Glass, Ph.D.; Denise Park, Ph.D.; and their colleagues at the Institute for Social Research at the University of Michigan at Ann Arbor were able to construct quite ingenious research studies to better understand memory and related issues in FM. Those studies and their results have been covered in earlier issues of *Fibromyalgia Frontiers*.

This year, Dr. Glass is back with an excellent article reviewing the newer studies which have been performed on memory, distraction, and problems with focusing attention, among other things.⁶ Of special interest to FM patients is her discussion of *why* FM patients experience cognitive problems.

*See Hart RP et al. "Chronic Pain and Neuropsychological Functioning." *Neuropsychol Rev* 2000;10(3):131-49.

After evaluating research involving four different comorbid variables of fibromyalgia which have the ability to undermine cognitive function: depressed mood, anxiety, poor sleep, and pain, she found good evidence showing that while psychologic variables like depression and anxiety can be partly to blame for cognitive dysfunction in FM, their presence cannot totally explain it. Similarly, while sleep problems can contribute to cognitive dysfunction in FM, they cannot entirely account for it, either.⁷ However, pain, the cardinal symptom required for a FM diagnosis is another story.

In her article, Glass notes that "pain, both chronic and acute, can have a negative impact on cognitive function. Neuropsychologic performance is lower in chronic pain states [as noted in a review by R.P. Hart*]. Indeed there is a growing body of research about the effects of chronic pain (including many different pain conditions) on brain morphology, physiology, and function in both animal and human models."⁸

Although existing studies cover a variety of chronic pain conditions which may only occasionally include FM, Glass writes that "stronger evidence exists for the role of pain, both in its ability to disrupt attention and from central nervous system reorganization in the face of chronic pain."⁹

The jury is still out on whether it is possible to improve cognitive symptoms (fibrofog) by treating pain. More work needs to be done in this area. So far, we know that in a Canadian study directed by Dr. Bruce Dick, short-term, local analgesia did not improve cognitive function,¹⁰ while studies by Munguia-Izquierdo in Spain (warm water exercise)¹¹ and by Etnier in the U.S. (physical activity program)¹² suggest that cognitive improvement *is* possible.



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The Vestibular Connection

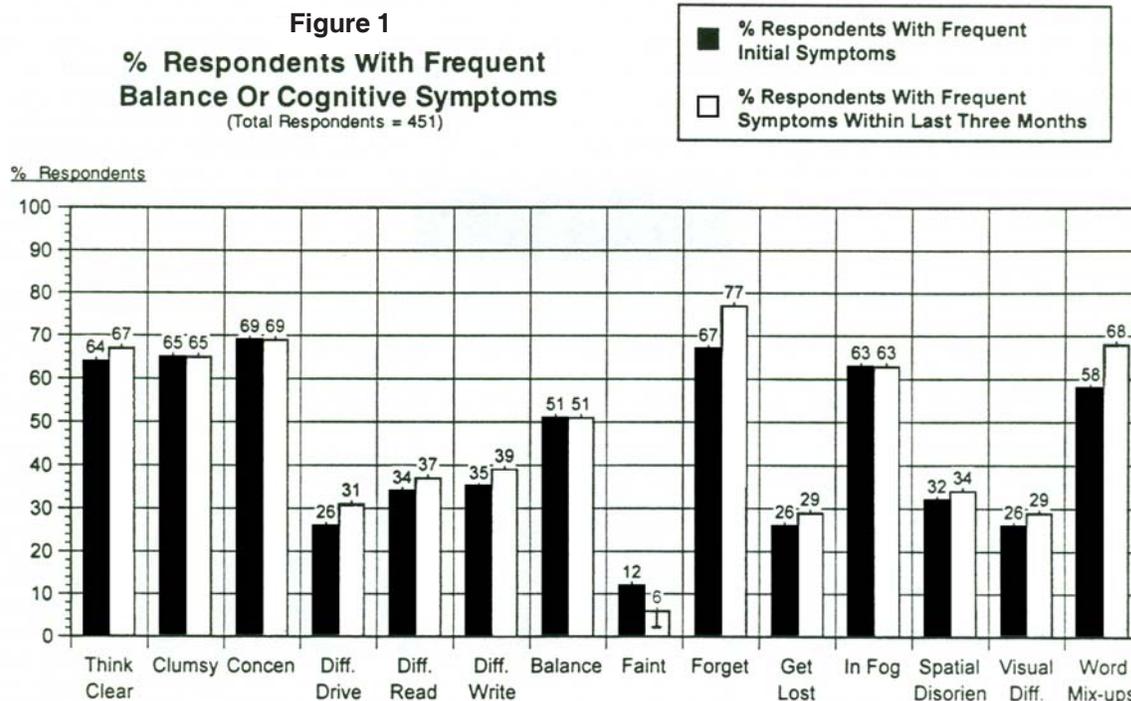
While the widespread existence of cognitive dysfunction (e.g., fibrofog) in FM is well-known among most patients and medical professionals, there has been relatively little awareness of the widespread nature of vestibular dysfunction and/or problems with balance within the FM community. Back in the mid-1990's, Ulf Rosenhall, M.D., Ph.D., and a particularly forward-thinking, Swedish research group in Gothenberg composed of esteemed audiologists and otolaryngologists with a special interest in fibromyalgia, published a group of articles on hearing and balance in persons with FM.¹³ In one study of 168 patients, Rosenhall found that 4/5

the study subjects with FM had balance problems, and while most had less severe problems, "one-fourth of all patients had pronounced or severely disabling symptoms."¹⁴

The concurrent occurrence of both cognitive and vestibular symptoms in persons with fibromyalgia was evident in another research project during that same time. In an exploratory study undertaken by the National Fibromyalgia Partnership in 1993, members of 14 FM self-help and support groups across the United States (451 respondents in all) filled out a carefully designed, 14-page questionnaire about the medical condition, fibromyalgia. One of the findings from that study was that a sig-



Reprinted from: *Fibromyalgia: A Multi-Dimensional Profile [Final Data Results Of A 14-Group Questionnaire Project]*



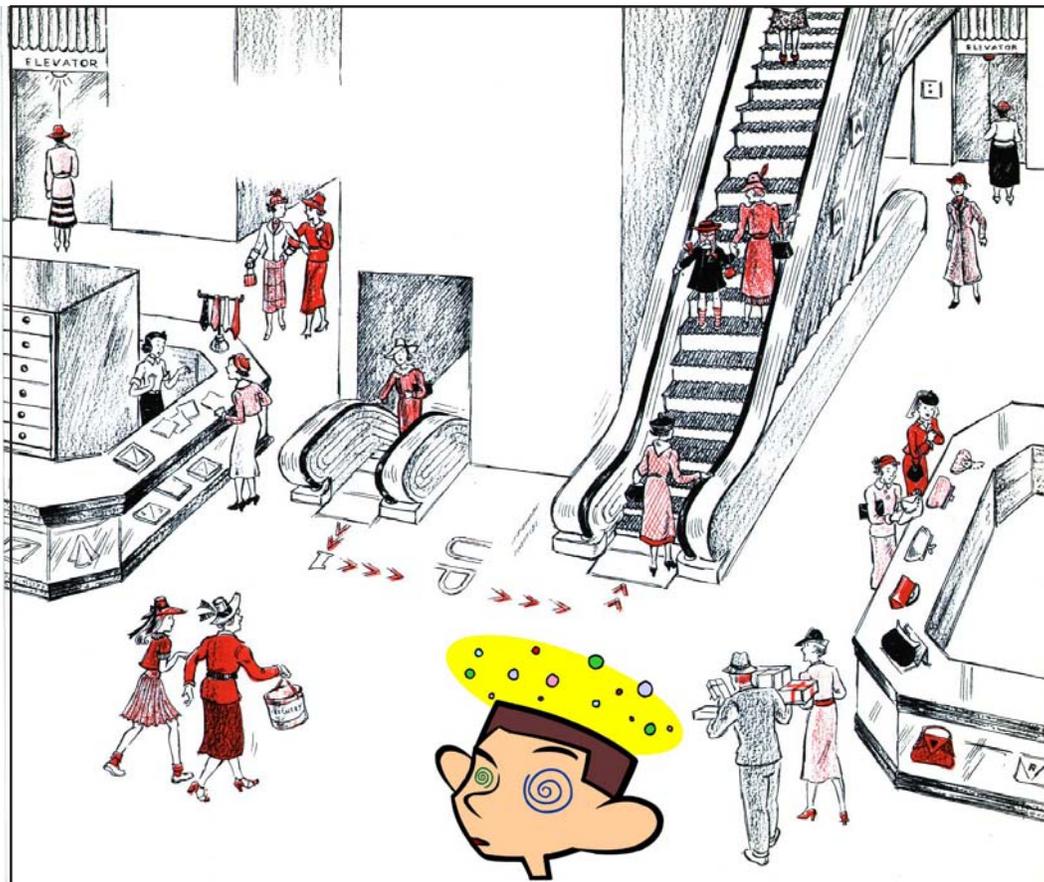
Questionnaire respondents were asked to look at a list of 96 symptoms covering a wide range of complaints and concerned with all areas of the body. They were to respond "yes" or "no" as to whether they frequently had the listed symptom (1) when they first developed fibromyalgia, and (2) within the last three months of answering the questionnaire. The graph above includes symptoms related to cognitive and vestibular dysfunction. The full names of the symptoms are listed in order below.

- Difficulty thinking clearly
- Clumsiness (i.e., tripping, dropping things)
- Inability to concentrate
- Difficulty driving a car
- Difficulty reading
- Difficulty writing
- Disequilibrium/balance problems
- Fainting
- Forgetfulness
- Tendency to get lost easily
- Feeling "in a fog"
- Spatial disorientation
- Visual difficulties, not correctable with glasses
- Word mix-ups with speaking

nificant number of respondents reported frequent problems with a variety of cognitive symptoms, as expected, as well as frequent problems with balance and disequilibrium. According to the respondents, these symptoms were quite constant throughout their illness since they often existed both at the time they first developed fibromyalgia and were still there within three months of the time they filled out the NFP's questionnaire, which was most likely much later. (See Figure 1)

Why is this important? Because medical research is beginning to show that people in the general population with vestibular problems or poor balance are often troubled by cognitive dysfunction as well. It therefore seems reasonable to look more closely at the relationship between cognitive dysfunction and vestibular dysfunction not only in healthy people but in those with fibromyalgia as well. Even a cursory reading of books and literature on vestibular disorders makes it clear that cognitive symptoms are also a challenge for people with vestibular conditions. A sample list would likely be composed as follows:

- Problems with short-term memory
- Difficulty focusing attention
- Difficulty with multi-tasking
- Mixing up words when speaking
- Reversing the order of numbers, as in a zip code
- Trouble following a conversation or a series of concepts or events in a book or article
- Problems with reading
- Difficulties with visual and motor coordination
- Sensitivity to confusing visual stimuli: fluorescent lights or busy or bold geometric patterns on wallpaper, carpeting, linoleum floors, clothing
- Sensitivity to loud noise
- Decreased endurance or increased fatigue, especially after trying to concentrate
- Difficulty driving, especially at night
- Spatial disorientation



In cognitive and vestibular dysfunction, a visually complex location can cause disorientation and confusion.

In his article, “Cognitive-Vestibular Interactions: A Review Of Patient Difficulties And Possible Mechanisms,” Douglas Hanes of the Legacy Research Center in Portland, Oregon, writes:

“From a physiological perspective, the existence of cognitive-vestibular interactions is supported by the existence of neuronal projections between the vestibular centers in the brainstem and the cerebral cortex. It is well established that the vestibular system is critical in the execution of spatial navigation and spatial memory tasks, both of which certainly have a cognitive/cortical component. This deficit can perhaps be explained in terms of a cortical representation of external space and the body’s movement through it: deficits in the vestibular sensory system detract from the ability to accurately update this representation.”¹⁶

It would seem that we still have much to learn about the inter-relationships and interdependencies between various systems of our bodies, whether they be involved in intellectual activities like memory and our ability to communicate with others or our movement through space and our agility at handling sensory bombardment. When we learn how to read the signs, fibrofog and bouts of disequilibrium give us important clues to what is going on in our bodies. Stay tuned!

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15 Tips For Cognitive Management

- Develop a routine for important, everyday tasks, i.e., where you put your wallet or keys, when/how you take medication, etc. Do it the same way every day so as to avoid mistakes.
- Avoid distractions while doing important work. Take a step-by-step approach to projects.
- Double check numbers and spelling. On important documents have someone else proofread your work, if possible.
- Be aware that other medical conditions can affect your cognition (sinus/allergy, chronic myofascial pain, TMJ, migraines, blood sugar levels, thyroid conditions). Get help for them.
- Ask your doctor to prescribe drugs that are less likely to cause brain fog, dizziness, or confusion.
- Don’t drive if fibrofog is severe. It’s not safe, and you could get seriously lost.
- Keep notes about things. They help to reinforce your memory and organize you.
- Breathe; take regular relaxation and/or rest breaks. They help you remember things.
- Go easy on multi-tasking. According to Dr. Esther Sternberg at the NIH, your brain is not designed for it and reacts as if facing a major stressor. (*Consumer Reports On Health*, 3/08)
- Do regular, low impact, aerobic exercise (walking, aquatic exercise, etc.). It boosts blood circulation to the brain, helps reduce stress, and enhances nervous system activity.
- Interact with other people. Studies suggest doing so helps keep you cognitively fit.
- If bright lights or particular types of lighting bother you, wear sunglasses—even indoors.
- If flickering computer monitor screens are a problem, try speeding up the refresh rate on your monitor so that the M pathways in your optic nerves are less able to detect flickering. Or dim your screen. Laptops may also be easier to use.
- If balance is a problem, use your eyes to give you visual clues as to your location in space. During dizzy spells, focus on stationary, immovable objects as reference points.
- Compliment yourself for “hanging in there.”