



Bergen ME/CFS-FM Support Group Newsletter

Meeting Report

The open format of the meeting allowed those attending to discuss their experience and to ask questions. Everyone seems to develop some personal coping techniques. Sharing them with the group enriches everyone. There was some discussion of children with ME/CFS and/or FM and the challenges to their education. If some healthcare providers do not understand the illnesses, it should not be surprising to learn that people in education are no different. Despite laws created to prevent the issues, parents of children with CFS often find teachers and administrators do not accept the limitations that CFS may require and the accommodations that are needed for the child to develop both socially and educationally. These issues exist - even in some highly-rated districts.

NEED HELP? There are several resources that may be helpful to some of you.

NJ211 is a 2-1-1 creates one easy access point to the health, human services, community resources, and government assistance people need every day as well as in times of crisis. You may search our database on line, call 2-1-1 from your telephone, or chat LIVE with a 2-1-1 specialist. 211 is a national movement and is active in many states, including New York. <http://www.nj211.org>

Legal Services of New Jersey (LSNJ), an independent, non-profit organization, coordinates the statewide Legal Services system. LSNJ strives to ensure equal access to justice under law to all people of New Jersey, providing free legal assistance to low-income people in civil matters. <http://www.lsnj.org>

Bergen County Elder Care

http://www.co.bergen.nj.us/bcdhs/divisions/senior_resources.htm

This is a small sampling of services. See the website for more information.

Division of Community Transportation 201-368-5955

The Division provides transportation for persons with disabilities, older county residents and veterans. Services are provided for medical visits, therapy, adult day care, employment, attendance at senior activity centers, shopping and recreational events. Over 500,000 trips and one million miles are logged each year.

Division on Disability Services 201-336-6500

The Division develops and implements programs for residents with disabilities and serves as the clearinghouse on matters concerning the Americans with Disabilities Act (ADA). Services provided: PASP, Post-Stroke & Disabled Adult Support Group, Respite Care

Program, Meals on Wheels and Socialization Conference Call

NJEASE <http://www.state.nj.us/health/senior/sanjease.shtml> 1-877-222-3737

Office of Community Choice Options

Most seniors and people with disabilities in need of long-term care services prefer to get help in their home or in a community setting rather than in a nursing home. This office helps individuals learn about and access those services.

Office of Global Options for Long-Term Care & Quality Management

This office administers a number of home and community-based programs that help seniors, people with disabilities and their caregivers

NOTE: See website for more information about these and other available services. For those of you who live outside NJ, you may find that many of these services are also available in your area.

In the News - ME/CFS

<http://www.intelihealth.com/IH/ih/IH/EMIHC267/9273/35323/1019194.html?d=dmthMSCContent>

What Makes a Disease Real?

February 11, 2009

By Robert H. Shmerling, M.D.

Beth Israel Deaconess Medical Center

Doctors can be a skeptical bunch. I have colleagues who flat out deny that a condition can be "real" unless they can observe it or detect it with a test.

Yet, many physicians deal with conditions all the time whose symptoms can't be measured. For example:

- **Depression** – A depressed person will usually have normal physical examinations, blood tests and, if necessary, a normal brain MRI.
- **Headaches** – Most people who have headaches have normal test results.
- **Joint pain** – People can have joint pain (arthralgia) without any joint inflammation (arthritis). The pain could be due to tendonitis, bursitis, vitamin D deficiency or thyroid disease. But often we can't find any cause of the pain.

Doctors rarely do extensive testing for these conditions because abnormal results are rare and the tests are almost never helpful.

Millions of people are affected by diseases that have "subjective" symptoms and can't be confirmed by observation or tests. These include fibromyalgia, most headaches (including migraine), irritable bowel syndrome. So, does this mean that these conditions aren't "real?" They're certainly real to the people suffering with them.

"It's All in Your Head"

When a symptom can't be explained, it doesn't mean that it's imaginary or due to a mental illness, psychiatric disorder or psychological distress. That's what is implied when a doctor tells a patient, "It's all in your head." At the very least, we should assume that the pain or unpleasant experience is real regardless of test results.

In the end, all pain is perceived by the brain. So, in a way, all pain is "all in your head." Yet there is a tendency to relegate unobservable symptoms to the realm of the psychiatrist.

Never mind that a psychiatric disease is "real" even when imaging and blood test results are

normal. If you've ever witnessed psychotic behavior or been with someone who is severely depressed, it is clearly real.

Unexplained symptoms could be due to a disease that hasn't been detected yet. Ideally, doctors and patients should identify the cause if possible, rule out a dangerous condition, and treat the bothersome symptoms. And that's true whether the symptom is measurable or not.

What's in a Name?

We usually expect the doctor to make a diagnosis and recommend a treatment when we have a problem. It's reassuring to know that your particular problem has a name. It means that other people have experienced it and that studies have assessed the effectiveness of various treatments.

Yet for many conditions, the name is only a label. It's convenient to apply a name to a particular combination of symptoms, even though the cause is unknown and no clear-cut abnormalities can be found. Examples include fibromyalgia syndrome and irritable bowel syndrome. Assigning a name to symptoms can be reassuring but it does not make the condition more or less "real."

Focus on Improving Symptoms

There are times when even the smartest health care provider can't come up with a logical, compelling or even reasonable explanation for a person's symptoms. In those cases, it's important not to get too focused on explaining or labeling them. Instead, the doctor should focus on:

- Not missing some important clue
- Treating the symptoms

In many fields of medicine, doctors spend all day improving symptoms rather than making a diagnosis. Headache specialists, for example, must be convinced there is no brain tumor, no meningitis, and no other serious and treatable cause of the pain. But once that happens, attention turns toward treatment rather than on sorting out a specific cause.

This can be frustrating for both patients and doctors. But until we understand the specific causes of common conditions like headaches, back pain, ringing in the ears (tinnitus) and chronic fatigue, controlling symptoms, not a name, is what will help the most.

The Bottom Line

Once again this shows that there's more uncertainty in medicine than most people think. But that doesn't mean a person is imagining their symptoms.

As I see it, debating the "realness" of symptoms is often a waste of time. Unless a person is deliberately "faking" symptoms (a rare event in most doctors' practices), they are just as real as for those with an observable, measurable and testable condition.

Having names are nice, but they are not always helpful. All other things being equal, I'd rather have a nameless condition that's well-treated than a definite, but untreatable diagnosis.

Robert H. Shmerling, M.D. is associate physician at Beth Israel Deaconess Medical Center and associate professor at Harvard Medical School. He has been a practicing rheumatologist for over 20 years at Beth Israel Deaconess Medical Center. He is an active teacher in the Internal Medicine Residency Program, serving as the Robinson Firm Chief. He is also a teacher in the Rheumatology Fellowship Program

In the News - FM



HEALTH INFORMATION

<http://www.medscape.com/viewarticle/589003?src=mp&spon=27&uac=36722FV>

Combination Therapy Relieves Symptoms of Fibromyalgia Syndrome

NEW YORK

(Reuters Health) Mar 03 - A meta-analysis of nine randomized, controlled trials shows that multicomponent therapy benefits patients with fibromyalgia syndrome, German researchers report in the February 15th issue of Arthritis and Rheumatism.

Lead investigator Dr. Winfried Haeuser told Reuters Health that the German interdisciplinary guideline on the management of fibromyalgia syndrome "recommends multicomponent treatment, at least two components: patient education or psychological therapy and exercise as second-line therapy for patients whose symptoms and restrictions in daily life are not sufficiently reduced by a single therapy -- such as medication."

To investigate the efficacy of this type of treatment, Dr. Haeuser of Klinikum Saarbruecken and colleagues examined pooled evidence from the nine randomized trials of multicomponent therapy involving 1119 patients. All studies included control groups that received no care, usual care or monotherapy.

The findings, continued Dr. Haeuser, "demonstrated that multicomponent treatment was superior to monocomponent treatment in relieving pain, depressed mood and fatigue and improving physical fitness."

The longest follow-up was for 15 months. She and her colleagues conclude: "There is strong evidence that the positive effects of multicomponent therapy on the key symptoms of fibromyalgia syndrome decline with time."

"Strategies to maintain the benefits of multicomponent treatment in the long term need to be developed."

Arthritis Rheum 2009;15:216-224

NJCFSA Notes

If you care to donate items or money to Marissa's auction, please see the website www.njcfsa.org and scroll to "**Marissa's Auction**" to find contact information or email pat.njcfsa@lasrosas.net . **Deadline April 19th**

Next Meeting

The next meeting will be Sunday April 19th from 2-4 PM at the Ridgewood YMCA. Topic – to be announced.

***WEATHER** – In the event of bad weather, or other emergency, we encourage you to check your email before leaving for Ridgewood. If it has been decided that a meeting will be canceled, an email will be sent via the yahoogroups list. The "Y" will also be notified of the cancellation. The email posting also applies to a cancellation of the First Wednesday of the Month lunch gathering. This is an informal gathering, an opportunity for people to gather and chat with other members.*

This newsletter is intended for CFS & FM patients in the area of this support group. The purpose is to share information and support. If you have questions about meetings please contact: Pat LaRosa at pat.njcfsa@larosas.net, Nancy Visocki at ngv.njcfsa@verizon.net, Judy Machacek at judykachacek@msn.com or leave a voice message at the NJCFSA HelpLine 888-835-3677 during business hours.