

Lyndonville News

Information and Support for the ME/CFS/FM Community
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Introduction

Welcome to the *Lyndonville News*. This is really the second version of *the Lyndonville News*. The first newsletter published several years ago by Mary Robinson. After a while, we ran out of things to say. Recently, some thoughts, ideas and impressions have been coming to mind, so here they are.

The format of the newsletter is relatively simple. There will be a number of sections: A **Literature Review** section will look at some of the more interesting articles in the medical literature concerning ME, CFS or FM, summarizing the specific article and adding comments about what I would consider its importance. A **Guest Editorial** piece may be written by one of the many great minds committed to solving the mysteries of this illness. My job will be to con them into writing something, preferably about their current research interests. A **Section for Rookies** will be an article designed for those persons new to the illness, or those who may have an interest, but have not been following the complex politics and science of the illness. An **Old Timer Section** will discuss some aspect of one of the many complex and interesting issues that may be of interest to persons involved in ME/CFS/FM for a prolonged period of time. The **Lyndonville Research Group Report** will be a report on one or more of the projects being undertaken by the Lyndonville Research group. This group consists of persons interested in ME/CFS/FM and wishing to pursue special projects. Currently we are writing a paper on blood volume and vasopressin as well as considering projects on pediatric clinical definitions and education for children with the illness. **Question and Answer** section will attempt some specific questions that I feel are interesting. Readers are encouraged to submit questions for this section, and I will work on one or more that is of general interest. There are many good topics and I will not discuss those that I have no experience in or knowledge about. In **Reader's Notes** statements by readers will be presented as sent in, but I will choose those to present to the larger audience. I will not present those that sound like advertising for a product, but I am always interested in comments or discussions about a specific treatment or treatments. I will not present defamatory statements or politically charged statements unless I feel like it. In a **Case Reports** section, aspects of the clinical presentation will be discussed, particularly as regards alternative diagnoses. There are some persons with ME/CFS/FM where an alternative diagnosis is present

and the treatment outcome is positively affected by finding this alternative diagnosis. A **History** section will be for discussion of historical aspects of the illness. For example, presenting the original descriptions of Dr. Melvin Ramsay may have value to a larger audience.

Not every edition of the *Lyndonville News* will have each of these sections. The Newsletter is free, and is available by e-mail or hard copy. The address to subscribe for free e-mail is LynNews@Lakeplains.Net. Because of time, personnel and mailing costs, the hard copy edition will cost \$10 per year. One reason that the newsletter is free is that it is not clear if we will be able to go long term with it. If it is something we are enjoying and it is continuing four or more times a year, we may add a charge for it. If a section or part of the newsletter is reprinted or published elsewhere, credit should be given to the *Lyndonville News* and to the specific author of the section cited. I would hope that the newsletter would come out every six to eight weeks or so, but no promises are made. Who knows, this may be the last issue.

I enjoy writing. I had always wanted to be either a writer or a farmer, but not really having talent in either of these areas, I became a doctor instead. For me, writing is enjoyable, and a way of relaxing. It also serves as a method of focusing thoughts around specific issues, and it is a lot cheaper than a psychotherapist. If these thoughts are of value to others interested in ME/CFS/FM, then great, here they are. I would enjoy feedback from readers of *the Lyndonville News*, but I may not be able to respond to them.

Patients with ME/CFS/FM are in a really difficult position. They feel lousy but look great. Because they look great, no one thinks they are sick. Because no one thinks they are sick they are disrespected. Because they are disrespected, they feel even more lousy. Someday soon, the day will come when the important people in medicine will say, “I knew they were really sick all along.” –David S. Bell MD

Section for Rookies

Educational materials relating to any specific illness face the challenge of being educational to those new to the illness but not boring to those whose lives have been preoccupied with the disease for twenty years. Some of the readers of the *Lyndonville News* may be hearing about “chronic fatigue syndrome” for the first time today. Last week I saw a patient who was diagnosed with ‘fibromalasia’ (as in malaise or Malaysia) by a next-door neighbor. That neighbor’s diagnosis was better than that of the five doctors she had seen in the previous year. So this section is for those interested in getting up to speed.

We will be discussing an illness that exists in a spectrum. It may be one illness or it may be twenty closely related illnesses. Because it is part of a spectrum, there will be disagreement over what constitutes the edge of one part, and the beginning of another. There are many illnesses that present in a poorly defined spectrum, Autism Spectrum Disorder being one that comes to mind. Until we are accurately able to define the different components of this spectrum, we will have to use an “umbrella term.”

With the illness we are tackling, some call it myalgic encephalomyelitis (ME), some myalgic encephalomyelopathy (ME), and some call it chronic fatigue syndrome (CFS). It is very closely linked (and part of the same spectrum) with fibromyalgia (FM), orthostatic intolerance (OI), dysautonomia (DA), Gulf War Illness (GWI) and multiple chemical sensitivities (MCS). For the purposes of this newsletter we will arbitrarily use ME/CFS/FM as the umbrella term. It is easier than calling it ME/CFS/FM/OI/DA/GWI/MCS.

Everyone has their favorites when it comes to an umbrella term for this illness. My personal favorite has always been the Tapanui flu (sometime we will explore that in the History

section). Solving the name problem will require a better understanding the illness (the illnesses?) that make up this spectrum. I expect that we will return to this issue many times in the lifetime of the *Lyndonville News*.

Literature Review

In this section of *Lyndonville News*, I would like to present reviews of articles published in the medical literature. The pieces chosen will usually have some relevance to clinical issues, and the first one is a piece on the nature of disability in CFS/ME/FM.

Article: Ross SD, Estok RP, Frame D, Stone LR, Ludensky V, Levine CB. Disability and Chronic Fatigue Syndrome. A focus on function. 2004; Arch Intern Med 164: 1098-1107.

This article reviews the medical literature on disability in CFS/ME/FM, in particular reviews thirty-seven individual studies that met their inclusion criteria. Their objective was to “evaluate evidence on detecting and managing disability in persons with CFS.” There was a higher lifetime incidence of psychiatric diagnoses in patients with CFS as compared to controls, but no relationship between psychiatric diagnoses to disability could be established. Nearly all data was related to self-report of disability status, and only two studies relied on exercise testing. The percentage of patients with CFS unable to work covered a very large range. In 35 separate studies involving 2,652 patients with CFS, only 42% were able to work. In 16 studies looking at full-time and part-time employment, only 19% of 967 patients were able to work full time.

Comment:

What I find so striking in this paper is the degree of disability this illness causes. While anyone who experiences the symptoms is aware of the disability, the medical profession is certainly not. They view the illness as a trivial form of hypochondriasis.

In terms of the relationship with lifetime psychiatric diagnoses, it is important to remember that these studies are all flawed because they employ instruments that are unable to distinguish whether fatigue, cognitive symptoms, and sleep disorders are due to psychiatric disease or ME/CFS. Remember if someone is dying from a malignancy, they are likely to be depressed, even though depression did not cause the malignancy.

What also strikes me in reading this article is that there is no proof of disability in any of the studies other than self-report. That is, no x-ray, laboratory test, or physical finding is accepted as a proof of disability. Yet clearly large numbers of persons with CFS are disabled. Patients and their doctors want objective proof of disability, but we cannot be ashamed of self-report. If a person says they are unable to fly from the top of a tall building we do not ask for objective proof.

This becomes a critical issue when attempting to prove disability to private insurers or social security. Social security has come to terms with this and accepts that disability occurs in ME/CFS/FM, whereas most private insurers do not.

As the authors state, “In summary, no patient characteristics in any impairment domain have been consistently identified that best define or predict improvement or positive work or functional outcomes in the CFS population.” In other words, we do not know how to record the central symptom that causes disability in CFS.

For those patients with CFS who are applying for disability, having this study available will be helpful in designing the legal approach and what studies and/or questionnaires would be potentially useful.

Farm Notes



Disclaimer Any medical advice that is presented in the *Lyndonville News* is generic and for general informational purposes only. ME/CFS/FM is an extremely complex illness and any advice may not be appropriate for an individual with this illness. Therefore, should you be interested or wish to pursue any of the ideas presented here, please discuss them with your personal physician.

