



Paradigm Change

M.E. and Societal Issues

According to government estimates, about 1 million people in the U.S. currently suffer from the disease that it calls “Chronic Fatigue Syndrome” (and which currently encompasses Myalgic Encephalomyelitis (M.E.)). About half of these are disabled and a substantial percentage are bedridden.

A 2008 study estimated the total annual cost burden in the U.S. of “Chronic Fatigue Syndrome” (CFS) as between \$18.7 billion to \$24 billion.

People with M.E. usually get sick in their prime of life -- often in their 20's or 30's, sometimes in their teens or earlier. Few recover from the illness enough to ever be able to return to work. Although M.E. sufferers often die decades earlier than would be expected if they did not have the disease, they usually remain wholly disabled for decades.

For people who suffer from M.E., the challenges of the disease itself tend to be compounded by the lack of societal recognition for its characteristics. To the extent that many people are aware of the illness that the government has historically called “Chronic Fatigue Syndrome,” they often think of it as something trivial, consisting of mild tiredness of the sort that everyone gets from time to time.

Clinicians and researchers focusing on the illness, on the other hand, describe a disease rivals the debilitation experienced by cancer or AIDS patients in their final months of life. “My HIV patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested,” said Nancy Klimas, a physician and researcher. “Many of my CFS patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses (in 2009) I would rather have HIV. But CFS, which has a million people in the United States alone, has had a small fraction of the research dollars directed towards it.”

Although CFS is defined by the CDC as a chronic rather than a deadly illness, this obscures the fact that specific types of deaths tend to be associated with M.E. Deaths from non-Hodgkins lymphoma and heart disease are particularly common in severe sufferers, for example. One study suggested that although M.E. patients have the same top two causes of death -- heart attacks and cancer -- as people in the general population, they die of those causes on average 20 years earlier than the average. The third leading cause of death in the study was suicide.



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Compared to other similarly severe chronic illnesses, government funding for the illness that it calls “CFS” is miniscule. For instance, the NIH budget for 2012 allotted \$6 million for “CFS.” This contrasts to \$135 million for Multiple Sclerosis (a disease affecting half as many Americans as CFS); \$115 million for Lupus (1.5 million sufferers); \$46 million for West Nile Virus (less than 4,000 sufferers and 30 deaths); and \$25 million for Lyme disease (150,000 sufferers).

Appropriate medical care is similarly lacking for M.E. sufferers. For years, medical school students were taught that CFS was likely a psychological illness, and many practicing doctors still harbor that belief. While most doctors have heard of the disease and some can cite the CDC criteria for it, few have substantial knowledge about the medical literature related to M.E. or about the aspects of the immune system (such as natural killer cell dysfunction) that seem particularly associated with it.

M.E. is a complex disease with a wide variety of symptoms, and it thus can be difficult for doctors to get a comprehensive understanding of their patients’ conditions within the context of a typical office visit. Many patients remain undiagnosed or misdiagnosed. Most doctors are unaware that commonly used medical treatments (including certain antibiotics, antidepressants, anesthesia and exercise) can have negative effects on M.E. patients, and also have little knowledge about what treatments actually might be helpful for them. Frequently doctors become overwhelmed with the wide variety of symptoms that M.E. sufferers report, and thus fail to appropriately diagnose additional illnesses that might be effectively treated.

Many M.E. patients report that interactions with the medical community are particularly stressful for them. Doctors’ offices and hospitals tend to be high-stimuli environments, meaning that patients with sensitivities to noise, light or chemicals can find them to be intolerable or unpleasant. Bedridden or housebound patients have a hard time getting to the doctor and can take a long time to recover from the exertion. Many M.E. patients have cognitive difficulties that make it difficult for them to persuade skeptical physicians that they are suffering from physiological rather than psychological illnesses. M.E. patients often are particularly heavy users of dietary supplements but do not always feel comfortable discussing what they’re taking with their physicians. Many severely ill M.E. patients report that subsequent to presenting at emergency rooms with severe symptoms, they have been committed to psychiatric facilities.

Insurance companies often deny benefits or coverage to people with M.E. patients, thus leading many doctors familiar with the disease to diagnose it as something else. Because of lack of insurance coverage or frustration with quality of care, many M.E. patients -- including those who are bedridden and desperately sick -- drop out of the medical care system entirely. The right to die also has become an issue for some severely ill M.E. patients wanting to put an end to their suffering.



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Regardless of how sick they are or how many medical test abnormalities they display, most M.E. patients have a difficult time getting approval for government or workplace disability. Although severely ill M.E. patients almost invariably display a variety of specific test results, the fact that none has been accepted as a universal biomarker for all cases of the disease generally makes those abnormalities not be taken into consideration in hearings. The cognitive difficulties, fatigue and pain that are most problematic for M.E. sufferers tend to be viewed as difficult to prove by those granting disability requests. Some M.E. patients resort to exercise challenge tests in order to prove the extent of their disability, with some taking months to recover from the exertion.

Whether or not M.E. patients get approved for disability benefits, a high percentage fall into poverty due to the inability to work during the years that for other people are the ones of prime earning potential.

Budgetary constraints and sensitivities to toxic mold, chemicals and noise can make finding appropriate housing a challenge for M.E. patients. Patients who are mostly or fully bedridden face additional difficulties. Few medical practitioners know how to properly treat severely ill M.E. sufferers who are hypersensitive to a wide variety of stimuli. Just finding someone to help with chores or errands can be a challenge for many patients. Almost all assisted living facilities have minimum age requirements and are designed for residents with much different health issues than M.E. patients. Some patients receive shelter and support from their families, but this often dwindles as the years and decades pass.

Many M.E. patients become isolated, due to difficulties navigating the outside world. Orthostatic intolerance prevents some from standing or even sitting up, and most public places are not designed for horizontal people. Some patients stop driving because of issues with disorientation or seizures. Environmental sensitivities can make many places intolerable for them.

M.E. patients often find that they have a difficult time getting friends, family, employers, medical professionals and others to take their condition seriously. The disease has historically received little media coverage, and the name "Chronic Fatigue Syndrome" has misled people about its seriousness. The CDC and certain advocacy organizations have focused public attention mostly on milder cases, meaning that most people are unaware of how severe the disease can be. A cultural stereotype of the "Yuppie Flu" still is pervasive, with many people believing that the disease is due to a combination of depression and laziness.

-Lisa Petrisson, Ph.D.



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M.E. AND SOCIETAL ISSUES

RESEARCH LITERATURE

Societal Costs:

Lin JM, Resch SC, Brimmer DJ, Johnson A, Kennedy S, Burstein N, Simon CJ. The economic impact of chronic fatigue syndrome in Georgia: direct and indirect costs. *Cost Eff Resour Alloc.* 2011 Jan 21;9(1):1. PMID: 21251294

In Georgia, a state with roughly 5.5 million people age 18-59, illness could account for \$452 million in total healthcare expenditures and \$1.2 billion of lost productivity.

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Jason LA, Benton MC, Valentine L, Johnson A, Torres-Harding S. The economic impact of ME/CFS: individual and societal costs. *Dyn Med.* 2008 Apr 8;7:6. PMID: 18397528

The direct and indirect cost of ME/CFS to society was estimated to be \$18,677,912,000 for a community sample and \$23,972,300,000 for a tertiary sample.

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Reynolds KJ, Vernon SD, Bouchery E, Reeves WC. The economic impact of chronic fatigue syndrome. *Cost Eff Resour Alloc.* 2004 Jun 21;2(1):4. PMID: 15210053

The authors looked at a surveillance study of CFS in Wichita, Kansas, and estimated a 37% decline in household productivity and a 54% reduction in labor force productivity among people with CFS. This would translate to an annual total value of lost productivity in the United States of \$9.1 billion, which represents about \$20,000 per person with CFS or approximately one-half of the household and labor force productivity of the average person with this syndrome.

Health Care System:

Arroll M, Arroll B. Chronic fatigue syndrome--a patient centred approach to management. *Aust Fam Physician.* 2013 Apr;42(4):191-3. PMID: 23550241



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This article presents to doctors a hypothetical case to give guidance on methods for negotiating the diagnosis and treatment of chronic fatigue syndrome.

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Erueti C, Glasziou P, Mar CD, van Driel ML. Do you think it's a disease? a survey of medical students. *BMC Med Educ*. 2012 Apr 3;12:19. PMID: 22471875

Medical school students were more likely to believe that patients with “myalgic encephalomyelitis” had a disease state than patients with “chronic fatigue syndrome.”

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Aslakson E, Szekely S, Vernon SD, Bateman L, Baumbach J, Setty Y. Live sequence charts to model medical information. *Theor Biol Med Model*. 2012 Jun 15;9:22. PMID: 22703558

Live Sequence Charts (LSC) were used to formalize the narrative text obtained during an interview with a patient eventually diagnosed with CFS.

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Burns D. Chronic fatigue syndrome or myalgic encephalomyelitis. *Nurs Stand*. 2012 Feb 22-28;26(25):48-56; quiz 58. PMID: 22455228

This article written for nurses focuses on the knowledge, understanding and skills necessary to recognise, assess, manage and support patients with CFS/ME.

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Carvalho Leite JC, Drachler MD, Killelt A, Kale S, Nacul L, McArthur M, Hong CS, O'Driscoll L, Pheby D, Champion P, Lacerda E, Poland F. Social Support Needs For Equity In Health And Social Care: A Thematic Analysis Of Experiences Of People With Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis. *Int J Equity Health*. 2011 Nov 2;10(1):46. PMID: 22044797

Changes in attitudes of health practitioners, policy makers and general public and more flexibly organised health and social care provision are needed to address equity issues in support needs expressed by people with CFS/ME, to be underpinned by research-based knowledge and communication, for public and professional education.

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Jason LA, Paavola E, Porter N, Morello ML. Frequency and content analysis of chronic fatigue syndrome in medical text books. *Aust J Prim Health*. 2010;16(2):174-8. PMID:21128580

After reviewing 119 medical text books from various medical specialties, the authors found that 48 (40.3%) of the medical text books included information on CFS. However, among the 129 527 total pages within these medical text books, the CFS content was presented on only 116.3 (0.090%) pages. Other illnesses that are less prevalent, such as multiple sclerosis and Lyme disease, were more frequently represented in medical text books.

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Comiskey C, Larkan F. A national cross-sectional survey of diagnosed sufferers of myalgic encephalomyelitis/chronic fatigue syndrome: pathways to diagnosis, changes in quality of life and service priorities. *Ir J Med Sci*. 2010 Dec;179(4):501-5. PMID: 20872086

The authors measured time to diagnosis and services accessed, and concluded that there is a greater need for education on this condition to alleviate the burden on the CFS sufferers.

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Brimmer DJ, Fridinger F, Lin JM, Reeves WC. U.S. healthcare providers' knowledge, attitudes, beliefs, and perceptions concerning Chronic Fatigue Syndrome. *BMC Fam Pract*. 2010 Apr 21;11:28. PMID: 20406491

In a survey, overall, 96% of physicians had heard about CFS, more than 40% reported ever giving a CFS diagnosis, and more than 80% of correctly identified CFS symptoms.

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Guise J, McVittie C, McKinlay A. A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. *J Health Psychol*. 2010 Apr;15(3):426-35. PMID: 20348363

CFS patients described themselves as experiencing limited medical care and attention but restricted criticisms to 'legitimate', pragmatic or ancillary matters such as a clinicians' unwillingness to prescribe untested treatments. Participants also described themselves as active in seeking a resolution to their problems. They thus attended to possible negative attributions of being 'complaining' or unmotivated to seek recovery.



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Torres-Harding SR, Jason LA, Cane V, Carrico A, Taylor RR. Physicians' diagnoses of psychiatric disorders for people with chronic fatigue syndrome. *Int J Psychiatry Med.* 2002;32(2):109-24. PMID: 12269593

Physicians' diagnosis of a psychiatric illness when at least one psychiatric disorder was present ranged from 40 percent in the psychiatrically explained group, 50 percent in the control group, and 64.3 percent in the CFS group.

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Chew-Graham C, Dowrick C, Wearden A, Richardson V, Peters S. Making the diagnosis of Chronic Fatigue Syndrome/Myalgic Encephalitis in primary care: a qualitative study. *BMC Fam Pract.* 2010 Feb 23;11:16. PMID: 20178588

GPs in Britain hesitated to confer a diagnosis of CFS/ME, suggesting that the label could be potentially harmful for the patient.

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Van Hoof E. The doctor-patient relationship in chronic fatigue syndrome: survey of patient perspectives. *Qual Prim Care.* 2009;17(4):263-70. PMID: 19807959

In Belgium, heterogeneity of CFS and the controversy surrounding this condition seemed to overwhelm GPs and strain medical encounters with patients. Patients with CFS seemed unsatisfied with the interaction with their doctor. CFS is not addressed well by the medical community, and the failure to diagnose leads to a lack of empathetic care.

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Lin JM, Brimmer DJ, Boneva RS, Jones JF, Reeves WC. Barriers to healthcare utilization in fatiguing illness: a population-based study in Georgia. *BMC Health Serv Res.* 2009 Jan 20;9:13. PMID: 19154587

CFS patients have a hard time using healthcare services.

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Brimmer DJ, McCleary KK, Lupton TA, Faryna KM, Hynes K, Reeves WC. A train-the-trainer education and promotion program: chronic fatigue syndrome--a diagnostic and management challenge. *BMC Med Educ.* 2008 Oct 15;8:49. PMID:18922184

A program designed to train physicians and other medical practitioners about CFS was implemented.

*

Gilje AM, Söderlund A, Malterud K. Obstructions for quality care experienced by patients with chronic fatigue syndrome (CFS)--a case study. *Patient Educ Couns.* 2008 Oct;73(1):36-41. PMID: 18486415

A qualitative study suggested that medical scepticism and ignorance regarding CFS shapes the context of medical care and the illness experiences of CFS patients, who report patronizing attitudes and ignorance amongst doctors.

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Solomon L, Reeves WC. Factors influencing the diagnosis of chronic fatigue syndrome. *Arch Intern Med.* 2004 Nov 8;164(20):2241-5. PMID: 15534161

The CDC confirmed CFS diagnoses in a population of residents of Wichita, Kansas. Only 16% had been previously diagnosed as having CFS. Only 21% had sudden fatigue onset, and tender lymph nodes (23%) and a sore throat (19%) were the least common symptoms.

*

Hyams KC. The investigation of chronic fatigue syndrome: a case-study of the limitations of inductive inferences and non-falsifiable hypotheses in medical research. *Med Hypotheses.* 2003 May;60(5):760-6. PMID: 12710915

The unsuccessful investigation of CFS illustrates how non-falsifiable hypotheses are insufficient to advance medical knowledge, even when there is an abundance of empirical data.

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Jason LA, Taylor RR, Plioplys S, Stepanek Z, Shlaes J. Evaluating attributions for an illness based upon the name: chronic fatigue syndrome, myalgic encephalopathy and



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Florence Nightingale disease. *Am J Community Psychol.* 2002 Feb;30(1):133-48. PMID:11928774

Attributions about CFS were measured in three groups of medical trainees. All groups read the same case study of a person with classic symptoms of chronic fatigue syndrome, with the only difference being in the type of name given. Across name conditions, most trainees appeared to consider the symptom complex of CFS a serious illness resulting in poor quality of life. In addition, findings indicated that the name, chronic fatigue syndrome, may be regarded less seriously than the Myalgic Encephalopathy name.

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Afari N, Eisenberg DM, Herrell R, Goldberg J, Kleyman E, Ashton S, Buchwald D. Use of alternative treatments by chronic fatigue syndrome discordant twins. *Integr Med.* 2000 Mar 21;2(2):97-103. PMID: 10882883

Individuals with CFS frequently used alternative medical treatments yet rarely communicated this use to their medical doctor. Future research should ascertain the usefulness of alternative practices in the management of CFS.

*

Richman JA, Jason LA, Taylor RR, Jahn SC. Feminist perspectives on the social construction of chronic fatigue syndrome. *Health Care Women Int.* 2000 Apr-May;21(3):173-85. PMID: 11111464

The authors contrast Western medical views of chronic fatigue syndrome (CFS) etiology, diagnosis, and treatment with views maintained by a predominantly female CFS population, arguing that the failure of Western medicine to demonstrate a viral etiology for CFS led to a paradigmatic shift in research perspectives, which then embraced psychiatric and sociocultural explanations for CFS.

Societal Attitudes and Recognition:

Brooks J, Daghish J, Wearden A. Attributions, distress and behavioural responses in the significant others of people with Chronic Fatigue Syndrome. *J Health Psychol.* 2012 Nov 23. PMID: 23180874



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In this study of significant others of CFS patients, distress and negative behavioural responses were associated with attributing illness events to causes personal and internal to the patient.

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Anderson VR, Jason LA, Hlavaty LE. A Qualitative Natural History Study of ME/CFS in the Community. *Health Care Women Int.* 2012 Jul 24. PMID: 23445264

Issues involving the illness experience for CFS patients, including community response, are examined.

*

Prins JB, Bos E, Huibers MJ, Servaes P, van der Werf SP, van der Meer JW, Bleijenberg G. Social support and the persistence of complaints in chronic fatigue syndrome. *Psychother Psychosom.* 2004 May-Jun;73(3):174-82. PMID: 15031590

In CFS patients and fatigued employees, social support is worse than in disease-free cancer patients and healthy controls.

*

Shlaes JL, Jason LA, Ferrari JR. The development of the Chronic Fatigue Syndrome Attitudes Test. A psychometric analysis. *Eval Health Prof.* 1999 Dec;22(4):442-65. PMID: 10623400

This study created a scale that measured attitudes toward individuals with CFS--the Chronic Fatigue Attitudes Test (CAT).

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Capen K. Chronic fatigue syndrome get court's nod of approval as legitimate disorder. *CMAJ.* 1998 Sep 8;159(5):533-4. PMID: 9757183

A legal case in Alberta, Canada, recognizes CFS as a legitimate disorder.

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Jason LA, Richman JA, Friedberg F, Wagner L, Taylor R, Jordan KM. Politics, science, and the emergence of a new disease. The case of chronic fatigue syndrome. *Am Psychol.* 1997 Sep;52(9):973-83. PMID: 9301342



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Social scientists have the expertise to more precisely define CFS and to develop appropriate and sensitive research strategies for understanding this disease.

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Richman JA, Flaherty JA, Rospenda KM. Chronic fatigue syndrome: have flawed assumptions been derived from treatment-based studies? *Am J Public Health.* 1994 Feb;84(2):282-4. PMID: 8296954

In the absence of an adequate epidemiological database, cultural stereotypes have influenced the characterization of CFS as "the yuppie flu," similar to the 19th century characterization of neurasthenia as a disease of the affluent.

Children and Adolescents

Knight SJ, Scheinberg A, Harvey AR. Interventions in Pediatric Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: A Systematic Review. *J Adolesc Health.* 2013 May 1. PMID: 23643337

The authors review the literature on management strategies for pediatric CFS.

*

Crawley EM, Emond AM, Sterne JA. Unidentified Chronic Fatigue Syndrome/myalgic encephalomyelitis (CFS/ME) is a major cause of school absence: surveillance outcomes from school-based clinics. *BMJ Open.* 2011 Dec 12;1(2):e000252. PMID: 22155938

Chronic fatigue is an important cause of unexplained absence from school.

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Webb CM, Collin SM, Deave T, Haig-Ferguson A, Spatz A, Crawley E. What stops children with a chronic illness accessing health care: a mixed methods study in children with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME). *BMC Health Serv Res.* 2011 Nov 11;11(1):308. PMID: 22078101

Children with CFS in the UK were not diagnosed in a timely manner. Parents described difficulties accessing specialist services because of their own as well as their GP's and Paediatrician's lack of knowledge. They experienced negative attitudes and beliefs



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towards the child's condition when they consulted GPs, Paediatricians and Child Psychiatrists. Parents struggled to communicate an invisible illness that their child and not themselves were experiencing.

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Taylor RR, O'Brien J, Kielhofner G, Lee SW, Katz B, Mears C. The occupational and quality of life consequences of chronic fatigue syndrome/myalgic encephalomyelitis in young people. *Br J Occup Ther.* 2010 Nov 1;73(11):524-530. PMID: 22102767

Teenagers with CFS/ME (12-18 years old) report lower perceived competency, and compromises in physical functioning, school performance, social activities, emotional functioning and general health.

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van Geelen SM, Bakker RJ, Kuis W, van de Putte EM. Adolescent chronic fatigue syndrome: a follow-up study. *Arch Pediatr Adolesc Med.* 2010 Sep;164(9):810-4. PMID:20819962

About half of the adolescents in a study in the Netherlands had recovered from CFS at follow-up. The other half was still severely fatigued and physically impaired. Health care use had been high, and school and work attendance were low. Older age at inclusion was a risk factor, and pain, poor mental health, self-esteem, and general health perception at outcome were associated with an unfavorable outcome.

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Kennedy G, Underwood C, Belch JJ. Physical and functional impact of chronic fatigue syndrome/myalgic encephalomyelitis in childhood. *Pediatrics.* 2010 Jun;12 (6):e1324-30. PMID: 20478937

The quality of life of children with CFS/ME is profoundly reduced, compared with that of their healthy counterparts.

*

Katz BZ, Boas S, Shiraishi Y, Mears CJ, Taylor R. Exercise tolerance testing in a prospective cohort of adolescents with chronic fatigue syndrome and recovered controls following infectious mononucleosis. *J Pediatr.* 2010 Sep;157(3):468-72, 472.e1. PMID:20447647



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Adolescents with CFS 6 months after infectious mononucleosis have a lower degree of fitness and efficiency of exercise than recovered adolescents.

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Crawley E, Sterne JA. Association between school absence and physical function in paediatric chronic fatigue syndrome/myalgic encephalopathy. *Arch Dis Child*. 2009 Oct;94(10):752-6. PMID: 19001477

Of 211 UK children with CFS, 62% attended 40% of school or less.

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Davies S, Crawley E. Chronic fatigue syndrome in children aged 11 years old and younger. *Arch Dis Child*. 2008 May;93(5):419-21. PMID: 18192312

Disability in the under-12 age CFS group was high, with low levels of school attendance, high levels of fatigue, anxiety, functional disability and pain. The clinical pattern seen is almost identical to that seen in older children.

*

Colby J. Special problems of children with myalgic encephalomyelitis/chronic fatigue syndrome and the enteroviral link. *J Clin Pathol*. 2007 Feb;60(2):125-8. PMID: 16935964

Since 1997, it has been known that myalgic encephalomyelitis/chronic fatigue syndrome constitutes the biggest cause of long-term sickness leading to absence from school, in both staff and pupils. Many affected children struggle for recognition of their needs, and are bullied by medical and educational professionals.

*

Sankey A, Hill CM, Brown J, Quinn L, Fletcher A. A follow-up study of chronic fatigue syndrome in children and adolescents: symptom persistence and school absenteeism. *Clin Child Psychol Psychiatry*. 2006 Jan;11(1):126-38. PMID: 17087490

The experiences of children and adolescents with CFS are considered.

Elderly



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Lewis I, Pairman J, Spickett G, Newton JL. Is chronic fatigue syndrome in older patients a different disease? -- a clinical cohort study. *Eur J Clin Invest.* 2013 Mar;43(3):302-8. PMID: 23397955

Compared to younger CFS patients, older CFS patients demonstrate increased fatigue, a greater tendency toward depression, greater autonomic dysfunction (with reduced parasympathetic function and increased sympathetic function), reduced baroreflex sensitivity, and prolonged left ventricular ejection time.

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Morelli V. Fatigue and chronic fatigue in the elderly: definitions, diagnoses, and treatments. *Clin Geriatr Med.* 2011 Nov;27(4):673-86. PMID: 22062448

Issues involved in the treatment of CFS in the elderly population are discussed. Patient dissatisfaction with the care for their fatigue is a common problem.

Research Funding:

Friedberg F, Sohl S, Schmeizer B. Publication trends in chronic fatigue syndrome: comparisons with fibromyalgia and fatigue: 1995-2004. *J Psychosom Res.* 2007 Aug;63(2):143-6. PMID: 17662750

Increasing amounts of medical research are being done on fibromyalgia, but studies on CFS have remained level.

Symptom & Severity Measurement:

Baraniuk JN, Adewuyi O, Merck SJ, Ali M, Ravindran MK, Timbol CR, Rayhan R, Zheng Y, Le U, Esteitie R, Petrie KN. A Chronic Fatigue Syndrome (CFS) severity score based on case designation criteria. *Am J Transl Res.* 2013;5(1):53-68. PMID: 23390566

The authors present a severity score measure for CFS.

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Jason LA, Unger ER, Dimitrakoff JD, Fagin AP, Houghton M, Cook DB, Marshall GD Jr, Klimas N, Snell C. Minimum data elements for research reports on CFS. *Brain Behav Immun.* 2012 Mar;26(3):401-6. PMID: 22306456

The authors discuss the idea that it has become difficult to compare data collected in different laboratories due to the variability in basic information regarding descriptions of sampling methods, patient characteristics, and clinical assessments. To address this problem, they present their consensus on the minimum data elements that should be included in all CFS research reports, along with additional elements that are currently being evaluated in specific research studies that show promise as important patient descriptors for subgrouping of CFS.

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Jason LA, Evans M, Brown M, Porter N, Brown A, Hunnell J, Anderson V, Lerch A. Fatigue Scales and Chronic Fatigue Syndrome: Issues of Sensitivity and Specificity. *Disabil Stud Q.* 2011 Winter;31(1). pii: 1375. PMID: 21966179

The authors examine the sensitivity and specificity of several fatigue scales that have attempted to define severe fatigue within CFS.

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Lin JM, Brimmer DJ, Maloney EM, Nyarko E, Belue R, Reeves WC. Further validation of the Multidimensional Fatigue Inventory in a US adult population sample. *Popul Health Metr.* 2009 Dec 15;7:18. PMID: 20003524

This study evaluates the Multidimensional Fatigue Inventory (MFI-20) in terms of a population of CFS patients in Georgia.

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Jason L, Muldowney K, Torres-Harding S. The Energy Envelope Theory and myalgic encephalomyelitis/chronic fatigue syndrome. *AAOHN J.* 2008 May;56(5):189-95. PMID:18578185

CFS patients' daily energy quotient was related to several indices of functioning including depression, anxiety, fatigue, pain, quality of life, and disability.

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Stouten B. Identification of ambiguities in the 1994 chronic fatigue syndrome research case definition and recommendations for resolution. *BMC Health Serv Res.* 2005 May 13;5:37. PMID: 15892882

CFS fatigue rating scales are discussed.

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Wagner D, Nisenbaum R, Heim C, Jones JF, Unger ER, Reeves WC. Psychometric properties of the CDC Symptom Inventory for assessment of chronic fatigue syndrome. *Popul Health Metr.* 2005 Jul 22;3:8. PMID: 16042777

This paper introduces the self-report CDC CFS Symptom Inventory and analyzes its psychometric properties.

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Nijs J, Vaes P, De Meirleir K. The Chronic Fatigue Syndrome Activities and Participation Questionnaire (CFS-APQ): an overview. *Occup Ther Int.* 2005;12(2):107-21. PMID: 16136868

This study provided an overview of design, reliability, and validity of the CFS Activities and Participation Questionnaire (CFS-APQ).

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Jason LA, Fricano G, Taylor RR, Halpert J, Fennell PA, Klein S, Levine S. Chronic fatigue syndrome: an examination of the phases. *J Clin Psychol.* 2000 Dec;56(12):1497-508. PMID: 11132566

This study examined the Fennell Phase Inventory, an instrument designed to measure the phases typically experienced by individuals with chronic fatigue syndrome (CFS).

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Jason LA, Tryon WW, Taylor RR, King C, Frankenberry EL, Jordan KM. Monitoring and assessing symptoms of chronic fatigue syndrome: use of time series regression. *Psychol Rep.* 1999 Aug;85(1):121-30. PMID: 10575979

Behavioral data collection methods were used in a case study to show some of the benefits that can be derived from monitoring CFS symptoms hourly and daily.



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Jason LA, King CP, Frankenberry EL, Jordan KM, Tryon WW, Rademaker F, Huang CF. Chronic fatigue syndrome: assessing symptoms and activity level. *J Clin Psychol.* 1999 Apr;55(4):411-24. PMID: 10348404

This study provides two CFS case studies to illustrate the advantages of using self-reporting rating scales in combination with a device used to measure the frequency and intensity of activity.

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Jason LA, Tryon WW, Frankenberry E, King C. Chronic fatigue syndrome: relationships of self-ratings and actigraphy. *Psychol Rep.* 1997 Dec;81(3 Pt 2):1223-6. PMID:9461755

This study of a 45-yr.-old man evaluated the relationships between scores on self-rating scales used to measure Chronic Fatigue Syndrome and actigraphy. Measured activity was related to predictors of fatigue but not to fatigue.



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MEDIA ARTICLES

Funding:

January 31, 2013
KRNV News (Reno)
Family Wants More Research on Chronic Fatigue Syndrome
By Alyx Sacks

http://www.mynews4.com/news/local/story/Family-wants-more-research-on-Chronic-Fatigue/FGH9Q_IVT06HkM5cVaS8_A.csp

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June 2, 2012
Reno Gazette-Journal
Still Waiting For Proof he Kept His Promise
By Courtney Miller

<http://www.rgj.com/article/20120603/OPED02/306030021>

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October 20, 2009
The New York Times
Op-Ed Contributor: A Case of Chronic Denial
By Hillary Johnson

http://www.nytimes.com/2009/10/21/opinion/21johnson.html?pagewanted=1&_r=1&sq=chronic+denial+johnson&st=cse&scp=1

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ME/CFS Worldwide Patient Alliance
NIH and CDC Funding Comparisons
ME/CFS vs. Other Diseases

<http://mcwpa.org/resources/research-funding-comparison/>



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Children and Teenagers:

December 12, 2011
The Guardian (UK)
Study Warns of Higher ME Rates Among Pupils
By Denis Campbell

<http://www.guardian.co.uk/society/2011/dec/12/chronic-fatigue-syndrome-schools>

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October 5, 2011
San Juan Capistrano Patch
Capo Settles Special Education Suit For \$130,000
By Jenna Chandler

<http://sanjuancapistrano.patch.com/articles/capo-settles-special-education-suit-for-130000>

*

September 29, 2011
Driffield Times & Post (UK)
Rugby Player's ME Battle

http://www.driffieldtoday.co.uk/sport/rugby_player_s_me_battle_1_3822786

*

September 19, 2011
The Wall Street Journal
Health Blog
How to Bring the School Experience to Sick Kids Learning from Home
By Amy Dockser Marcus

<http://blogs.wsj.com/health/2011/09/19/how-to-bring-the-school-experience-to-sick-kids-learning-from-home/>

*



Paradigm Change

September 17, 2011
The Wall Street Journal
Wave of Disabilities Swamps School Budgets
By Amy Dockser Marcus

<http://online.wsj.com/article/SB10001424053111904103404576558730329067142.html>

<http://www.meassociation.org.uk/?p=8115>

*

August 14, 2011
Chorley Guardian
Amy: I Want People to Know More About ME

http://www.chorley-guardian.co.uk/lifestyle/amy_i_want_people_to_know_more_about_me_1_3342721

*

August 2, 2011
The Shields Gazette (England)
Cruel Taunts as Teen Battles Health Condition
By Leah Strug

http://www.shieldsgazette.com/news/health/cruel_taunts_as_teen_battles_health_condition_1_3638517

*

April 18, 2011
Reuters
Chronic Fatigue Rare But Serious in Teens
By Alison McCook

<http://www.reuters.com/article/2011/04/18/us-chronic-fatigue-rare-but-serious-teen-idUSTRE73H3T420110418>

*

April 19, 2011
Time



Paradigm Change

Chronic Fatigue in Teens: Rare but Serious

By Amie Ninh

<http://healthland.time.com/2011/04/19/chronic-fatigue-in-teens-rare-but-serious/>

*

September 14, 2010

Mountain Xpress

Local Family Feels Vindicated by Breakthrough Research

By Nelda Holder

<http://www.mountainx.com/news/2010/091510local-family-feels-vindicated-by-breakthrough-research>

Workplace Issues:

April 29, 2012

Anchorage Daily News

Showing Up For Work Still Major Requirement

By Lynne Curry

<http://www.adn.com/2012/04/29/2445269/showing-up-for-work-still-a-major.html>

*

November 21, 2011

HR Magazine (UK)

GP "Sick Note" Could Be Replaced By Independent Panel to Advise Employer If Staff Are Well Enough to Work, Following Review In To Absence

By David Woods

<http://www.hrmagazine.co.uk/hro/news/1020459/gps-lose-power-sign-sick-review-absence-recommends-independent-panel-advise-employers-staff>

*

March 20, 2011

Globe and Mail (Canada)

Sick and Tired of Being Called Lazy, Chronic Fatigue Sufferers Fight Back



Paradigm Change

By Carly Weeks

<http://www.theglobeandmail.com/life/health/new-health/health-news/sick-and-tired-of-being-called-lazy-chronic-fatigue-sufferers-fight-back/article1947958/page1/>

Disability:

November 18, 2011

CFIDS Association of America

Research First

PFL Testing for Post-Exertional Malaise and Disability

By Staci R. Stevens and Christopher R. Snell

<http://www.research1st.com/2011/11/18/pfl-testing/>

*

March 8, 2011

Courthouse News Service

Man with Controversial Illness Can Get Benefits

By Tim Hull

<http://www.courthousenews.com/2011/03/08/34742.htm>

Healthcare:

April 5, 2013

The Wall Street Journal

A Better Journey to the Final Exit

http://online.wsj.com/article/SB10001424127887324000704578386772400931106.html?mod=googlenews_wsj

*

May 8, 2012

The Telegraph (UK)

Fewer Than 1 in 3 Health Trusts Offering Adequate Care for ME Sufferers



Paradigm Change

By Christopher Hope

<http://www.telegraph.co.uk/health/9247131/Fewer-than-1-in-3-health-trusts-offering-adequate-care-for-ME-sufferers.html>

*

May 8, 2012
Times of Malta
AD Calls For Rights To Persons With ME and FM

<http://www.timesofmalta.com/articles/view/20120508/local/ad-calls-for-rights-of-persons-with-me-and-fm.418953>

*

May 6, 2012
Sunday Times (Malta)
ME Sufferers “Appalled” By Proposed Therapies
By Ariadne Massa

<http://www.timesofmalta.com/articles/view/20120506/local/ME-sufferers-appalled-by-proposed-therapies.418504>

*

April 3, 2012
Te Waha Nui
Trapped In Bed With Chronic Fatigue - Sufferers Call For Better Help
By Eva Evguenieva

<http://www.tewahanui.info/twn/index.php/trapped-in-bed-with-chronic-fatigue-sufferers-call-on-government-to-do-more/>

*

April 16, 2012
Independent (UK)
Free GP Care For Long-Term Sufferers Still Not In Place



Paradigm Change

<http://www.independent.ie/health/free-gp-care-for-longterm-sufferers-still-not-in-place-3081536.html>

*

March 17, 2012

This Is Gloucestershire (UK)

Gloucestershire ME Sufferers Get Small Beer From NHS

<http://www.thisisgloucestershire.co.uk/Gloucestershire-sufferers-small-beer-NHS/story-15542222-detail/story.html>

*

November 25, 2011

CBC Radio

Diseases that Get No Respect

By Dr. Brian Goldman

http://www.cbc.ca/whitecoat/blog/2011/11/25/diseases-that-get-no-respect-encore-parking-mailbag/#.TtAz_RqSC8M.facebook

*

October 2011

European ME Alliance

Norway's Directorate of Health Apologizes for Treatment of ME Patients

<http://www.euro-me.org/news-Q42011-003.htm>

*

October 30, 2009

ABC News

Chronic Fatigue Patients: No Longer Fakes?

By Susan Donaldson James

<http://abcnews.go.com/m/story?id=8950867&sid=26>

Drug Approvals:



Paradigm Change

February 15, 2013
San Francisco Chronicle
Chronic Fatigue Patients Frustrated with FDA
By Erin Allday

<http://www.sfgate.com/health/article/Chronic-fatigue-patients-frustrated-with-FDA-4283890.php>

*

February 5, 2013
Reno Gazette-Journal
Reno Man On Hunger Strike to Call Attention to Disease, FDA Rejection of Chronic Fatigue Syndrome Drug
By Jeff DeLong

<http://www.rgj.com/article/20130205/NEWS/302050059>

*

January 24, 2013
Science Daily
Chronic Fatigue Syndrome Patients Need Effective Therapeutic, Leading Expert Argues

http://www.sciencedaily.com/releases/2013/01/130124183448.htm?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+sciencedaily+%28ScienceDaily%3A+Latest+Science+News%29&utm_content=Yahoo%21+Mail

*

December 20, 2012
The Wall Street Journal
Panel Rejects Drug for Chronic Fatigue Syndrome

<http://online.wsj.com/article/SB10001424127887324731304578191951426646118.html>

*

December 18, 2012
Med Page Today
FDA: Doubts Raised By Chronic Fatigue Studies



Paradigm Change

By David Pittman

<http://www.medpagetoday.com/Psychiatry/sleepdisorders/36514>

Housing:

November 15, 2011
The Sacramento Bee
One Old House, Many Helpers
By Chris Maclas

<http://www.sacbee.com/2011/11/15/4054425/one-old-house-many-helpersdawn.html#ixzz1dnkG738o>

*

October 8, 2009
San Francisco Chronicle
In Marin, It Shakes a Village
What Thousands of Individual Economic Crises Mean for an Entire Community
By Chris Collin

<http://www.sfgate.com/cgi-bin/article.cgi?f=/g/a/2009/10/08/onthejob100809.DTL&type=printable>

Hospitalizations:

April 20, 2011
WA Today
Chronic Fatigue Victim Theda Myint Locked Up At Fremantle Hospital After Euthanasia Attempt
By Lucy Rickard

<http://www.watoday.com.au/wa-news/chronic-fatigue-victim-theda-myint-locked-up-at-fremantle-hospital-after-euthanasia-attempt-20110419-1dmuu.html>



Paradigm Change

Right to Die:

April 14, 2011
Daily Mail (UK)
How I Helped My Darling Daughter to Die
By Kay Gilderdale

<http://www.dailymail.co.uk/femail/article-1376605/Kay-Gilderdale-How-I-helped-darling-daughter-die.html#ixzz1JRr2Y3BI>

*

April 14, 2011
London Evening Standard
“How I Helped My Beloved Daughter End Her Life of Pain”
By Peter Dominiczak

<http://www.thisislondon.co.uk/standard/article-23941395-how-i-helped-my-beloved-daughter-end-her-life-of-pain.do>

*

January 29, 2010
Daily Mail (UK)
“How Can They Say I Murdered Lynn When I Just Loved Her So Much?”
Mother Cleared of Murdering Her ME-Stricken Daughter Speaks Out
By Gill Swain

<http://www.dailymail.co.uk/femail/article-1246645/Kay-Gilderdale-Mother-cleared-murdering-ME-stricken-daughter-Lynn-speaks-out.html>

*

January 25, 2010
The Guardian (UK)
Trapped by ME, Lynn Gilderdale Made it Clear She Wanted to Die
By Sandra Laville

<http://www.guardian.co.uk/society/2010/jan/25/lynn-gilderdale-me-assisted-suicide>



Paradigm Change

Media Coverage:

February 7, 2012
The New York Times
Science Times Podcast
Interview with David Tuller (Reporter Covering CFS)
Starts At 21:50

http://podcasts.nytimes.com/podcasts/2012/02/07/science/07science_pod/07sciencepodcast.mp3

*

January 18, 2012
The Open Notebook
David Tuller Untangles The Research History of Chronic Fatigue Syndrome
By Julie Rehmeyer

<http://www.theopennotebook.com/2012/01/18/david-tuller-cfs/>

*

August 19, 2011
The Washington Post
My Illness Gets Overlooked
By Joseph D. Landson

http://www.washingtonpost.com/opinions/chronic-fatigue-syndrome-an-overlooked-illness/2011/08/16/gIQAy7BiQJ_story.html

*

February 6, 2011
This Week in Virology
Science and Journalism with David Tuller
Interview by Vincent Racaniello

<http://www.twiv.tv/2011/02/06/twiv-119-science-and-journalism-with-david-tuller/>

Societal Cost:



Paradigm Change

September 19, 2011
The Argus (Sussex, UK)
ME Costs Millions in Lost Earnings
By Ruth Lumley

http://www.theargus.co.uk/news/9259087.ME_costs_millions_in_lost_earnings/

Philanthropy:

February 23, 2012
The Wall Street Journal
Health Blog
With Help From Author Laura Hillenbrand, Drug Repurposing Comes To Chronic Fatigue Syndrome
By Amy Dockser Marcus

http://blogs.wsj.com/health/2012/02/23/with-help-from-author-laura-hillenbrand-drug-repurposing-comes-to-chronic-fatigue-syndrome/?mod=fbapp_art_onwsj

*

September 19, 2011
Science
Science Insider
Family Puts \$10 Million Into Chronic Fatigue Research
By Jocelyn Kaiser

<http://news.sciencemag.org/scienceinsider/2011/09/family-puts-10-million-into-chronic.html?ref=hp>

*

September 15, 2011
The Wall Street Journal
Health Blog
Applying Venture Philanthropy to Chronic Fatigue Syndrome
By Amy Dockser Marcus



Paradigm Change

<http://blogs.wsj.com/health/2011/09/15/applying-venture-philanthropy-to-chronic-fatigue-syndrome/>

Activism:

July 7, 2011

Baltimore Sun

Fighting Fatigue: CFS Sufferers to Hold Fundraiser in Columbia

By Amanda Yeager

<http://www.baltimoresun.com/explore/howard/news/health/ph-ho-cf-chronic-fatigue-0707-20110630,0,2884426.story?page=1>

*

June 2, 2011

Ms. Blog

Rivka Solomon Acts Up, Chronic Fatigue Be Damned

By Paula Kamen

<http://msmagazine.com/blog/blog/2011/06/02/rivka-solomon-acts-up-chronic-fatigue-be-damned/>

*

May 26, 2011

San Francisco Chronicle

Chronic Fatigue Patients Protest Lack of Funding

By Erin Allday

<http://www.sfgate.com/cgi-bin/article.cgi?f=%2Fc%2Fa%2F2011%2F05%2F25%2FBANA1JL1AH.DTL>

*

May 18, 2011

Galway Advertiser

ME Documentary To Stroke A Chord With Local Sufferers

By Mary O'connor



Paradigm Change

http://www.advertiser.ie/galway/article/39895/me-documentary-to-stroke-a-chord-with-local-sufferers?sms_ss=facebook&at_xt=4dd6933c3a89c172%2C0

*

December 5, 2010

Science 2.0

Chronic Fatigue Syndrome Patients Run Ad in Washington Post

By Anna Ohlden

http://www.science20.com/newswire/chronic_fatigue_syndrome_patients_run_ad_washington_post-74385

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