

Paradigm Change

Information about Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, Toxic Mold Illness, Chronic Lyme Disease, Gulf War Illness, Fibromyalgia, Autism/ASD, Environmental/Food Sensitivities and Other Neuroimmune Conditions

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CFS & Exercise Quotes from Doctors and Researchers

Except where indicated, quotations were supplied by the named individuals specifically for this document.

LUCINDA BATEMAN, M.D.

Research shows that these disorders respond somewhat to cognitive behavioral therapy and exercise. "Somewhat" means you can improve symptoms a little with better coping and improved physical conditioning. We work on that every visit. It doesn't mean you have cured the disease. There are many patients with CFS who are severely intolerant of physical activity, and suffer greatly from attempts to exercise.

There are many factors that determine how well a person can improve from their symptoms. Some of it relates to motivation and discipline, but much of it relates to fate, the disease state, how long they've had it and how severe it is. I frequently encounter the stereotyping that patients who don't get better just aren't trying hard enough and that smart motivated ones do, but I don't believe it is that simple. It isn't consistent with my clinical experience.

Lucinda Bateman, M.D.

Salt Lake City, UT

DAVID BELL, M.D.

The most important consideration is finding a person who understands CFS. They need to be willing to listen to your child on what is good and what is hurting them. They need to understand that the problems that your child is having are not due to deconditioning but to the nature of the illness. If you are fortunate to find someone knowledgeable about CFS and willing to listen and work with you, this may be another route to getting a little exercise.

For some people exercising can be of great benefit, while for others, it can cause them to melt into relapses. Our recommendation is to encourage as much activity as can be tolerated. Walking, sports where breaks can be taken frequently, shopping, swimming are all examples of activities that have been tolerated by _some_ children with CFS.

The tolerance of these treatments varies from individual to individual.

David Bell, M.D.

Lyndonville, NY

<http://www.wicfs-me.org/wicfs-5.htm>

KEITH BERNDTSON, M.D.

Media coverage of the PACE study created the false impression that CFS is potentially correctable with a disciplined approach to exercise, goal setting, and stress reduction techniques. The reporting reflected the bias of the paper's authors, who went out of their way to lend truthiness to the idea that persons diagnosed with CFS are depressed and/or lazy. The study showed that after 1 year of exercise support, CFS patients could walk about 70 feet further than untreated CFS patients. That the groups managed to walk only three football fields in length is the real news here.

When the false impression gained wide publicity, it added an element of danger to the care of CFS patients. Physicians who encourage CFS patients to exercise beyond their capacity can further damage the patients' health. CFS patients and the experienced physicians who treat them are happy to share their knowledge on this subject.

Reporters who dig deeper into the CFS story will find rich content of interest to the general public; they will generate valuable discussion and heartfelt expressions of thanks from the patient community; and they will find broader implications concerning the medical profession's paradigm for the care of chronic illness in general.

The public should know that physicians who treat patients with CFS recently revised how cases of CFS should be defined. The public should know that CFS patients can suffer from any combination of infectious, toxic, immune, neurohormonal, neurocognitive, or nutritional imbalance. Mechanisms of illness include genetic susceptibilities, toxic exposures, energy deficits, poorly controlled immune responses, loss of neuropeptide regulation of immune defenses, blood volume and blood flow, differences in gene expression following exercise, excessive oxidative stress, chronic inflammation, and more. CFS is a poster child for a systems biology approach to chronic illness.

Scientific controversies, thrilling detective work, environmental mysteries, stirring testimonials, intellectual challenge, and oceans of gratitude await journalists and others who want to help the public understand the real CFS story and its broader implications.

Keith Berndtson, M.D.

Park Ridge, IL

JEFFREY S. BLAND, Ph.D.

The one symptom that distinguishes CFS from other conditions is poor exercise tolerance. Formerly enjoyable physical activities become exhausting, and even after modest exercise the individual with CFS is fatigued for more than a day. This poor exercise tolerance, which has been identified as a disturbance in energy production and utilization by the body, is related to defects in the energy producing machinery of cells in the brain, muscles and other tissues.

Poor cellular energy production may also explain why chronic fatigue sufferers experience nervous system problems. CFS patients have poor cognitive function, can't concentrate on tasks and have brain biochemical disturbances that are revealed by SPECT scan.

Physiologists and medical scientists who have studied CFS find that the muscle cell mitochondria (the cells' energy furnace) of the individual with CFS are changed in shape and function from those of people who don't have this illness. CFS sufferers' mitochondria are swollen and have less energy-production ability, which may explain their fatigue and poor exercise tolerance.

In essence, a person who suffers from CFS is unable to support aerobic metabolism (metabolism in the presence of oxygen) effectively. His or her cells, after even minor stress, begin to produce energy in the absence of oxygen. Called anaerobic metabolism, this condition builds up acid debris in the cells, causing cells to become "poisoned" and reducing energy efficiency and function of the tissue or organ.

One body system that's highly dependent upon proper energy production and utilization is the immune system, the set of specialized cells which help the body defend against disease.

The white blood cells of the immune system are active metabolizers, and debilitation of their mitochondria by conditions such as poisoning can result in poor immune function. Poisoning of the white blood cells' mitochondria may account for the immune abnormalities in the CFS patient.

Jeffrey S. Bland, Ph.D.

BRUCE CARRUTHERS, M.D.

Research from the "organic school" identified many pathophysiological abnormalities in patients with ME/CFS resulting from dysfunction in a number of vital control systems of the body such as the central nervous system, the autonomic nervous system, the endocrinological system and the immune system.

The attitude of the "psycho-social school" continues to be to largely ignore this research. It seems they can only maintain their hypothesis by discouraging the search for an organic basis and by denying the published evidence, which they are certainly doing.

This unseemly battle of ideas has been settled politically by proclamation and manipulation, not by science, and not by fair and open means.

CBT and GET appear to be based on the rationale that patients with CFS/ME have "faulty" belief systems concerning the "dangers" of activity, and that these aberrant beliefs are significant perpetuating factors.

If CBT to “correct” these “false” beliefs can be combined with a graded exercise programme to re-condition these patients, it is virtually promised that a significant proportion of them will improve both their attitude and their physical functioning, and thus cure their illness. Using CBT, patients are therefore to be challenged regarding their “aberrant” thoughts and expectations of relapse that the “psycho-social school” psychiatrists believe affect symptom improvement and outcomes.

Cognitions concerning fatigue-related conditions are to be addressed; these include any alleged “over-vigilance to symptoms” and reassurance-seeking behaviours, and are to be dealt with using re-focusing and distraction techniques. It is when a therapy such as CBT begins to interfere with the natural warning systems, of which both pain and fatigue are a part, that the increased risks arise. In particular, musculo-skeletal pain and fatigue have essential function in modulating activity when the body is in a state of disease as in ME/CFS.

NICE [National Institute for Health and Clinical Excellence in the UK], however, recommends overriding this essential safety-net, thus the risk of serious harm is increased in this situation of simultaneous activity and symptoms denial. This will become a more serious risk in patients with more severe ME/CFS.

The Guideline does not indicate how the clinician can tell whether patients’ beliefs concerning their symptoms are aberrant and/or when the symptoms accurately point to the underlying state of the disease process.

Dr. Bruce Carruthers, M.D., CM, FRCP(C)

Vancouver, Canada

PAUL CHENEY, M.D., Ph.D.

The whole idea that you can take a disease like this and exercise your way to health is foolishness, it's insane.

The most important thing is not to have patients do aerobic exercise. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA.

There are a lot of diseases that have chronic fatigue. In fact, most chronic illnesses have an element of chronic fatigue. But often in those diseases, people push through it. My patients will do minimal effort, like just walking across the room, or fixing dinner and standing too long, and they're wiped out for days. And I don't know of another disease where that is the case.

The one piece of advice that I would have is, do not rationalize exercise. The rationalization of exercise goes something like this: I'm going to get up and I'm going to walk a mile on Monday and two miles on Wednesday. That doesn't work in this illness. What tends to work is: I'm going to walk around the house today, and then I'm going to answer the question the next day whether I did okay. And if I did, maybe I'll advance a little bit and ask the question: Am I all right? Sometimes it's not quite evident whether you overdid it or not at the time, but you kind of begin to internalize a sense of self -- "I think this is helping me at some deep level, I almost intuit it." When you start going from your brain thinking about exercise to feeling what it's doing, then you start to exercise correctly.

There are several good exercises for this disease. The best exercise that I know of that's simple and inexpensive is simply to walk on flat ground. Try to do it every day if you can, but not too far. As much as you can but don't overdo it. This is best because the human being is designed to walk very efficiently. When we walk, our legs are squeezing blood, so we actually pump blood up into the heart so that you actually fill the heart. People do pretty well when they walk. You don't have to walk fast, just walk. That's very good for this disease.

Pilates is excellent for this disease, because you are going to be supine. Your energy goes up 30% when you're lying down. Just gentle types of pilates. The important thing is not get into the vertical positions.

Resistance exercise can be good, but don't use heavy weights, just use light ones. Work on range of motion with light resistance for very short periods of time. That seems to be good.

Another one is vertical inversion in water. People will just stand in water to their neck. The pressure in your body goes down as a square of the depth, so the further down you go, the pressure differential that pushes blood back up into the intravascular space and improves lymphatic drainage is excellent for Chronic Fatigue Syndrome. I think that the mobilization of lymphatic fluid is an immune modulator for these patients. They don't have to do very much. They just have to float or stand vertically for an average of 20 to 40 minutes, three times a week. It's functionally or logistically difficult sometimes for these patients to get to the pool, or the water temperature isn't right though.

What is not good is running, bicycling or significant aerobic activity. That's not good for these people. They don't fare well. Resistance training is a little better tolerated, if there isn't too much of it.

So don't be rational in exercise. Be intuitive in exercise. Don't overdo it, but do something.

Paul Cheney, M.D., Ph.D.

Asheville, NC

<http://cfspatientadvocate.blogspot.com/2013/04/paul-cheney-lecture-march-22-2013.html>

STEPHANE DELLIAUX, M.D., Ph.D.

On one hand there is a consensus on exercise intolerance of patients suffering from Chronic Fatigue Syndrome (CFS). On the other hand there is the paper from White et al published in May 2011 in the medical journal of record The Lancet reporting that exercise could improve CFS patients' self-reported fatigue. There are not many possibilities to integrate these facts together: first, this paper is a cat among the pigeons challenging all the scientific achievements characterizing CFS of the last decades; second, this paper is an epiphenomenon in the scientific literature; or third, CFS is the victim of its complexity and then of an approximate communication.

Consensual definition (also retained by U.S. Centers for Disease Control and Prevention) of the CFS highlights the cornerstone that is fatigue (as a symptom) lasting more than 6 months. On the same way, the scientific and medical consensus defines fatigue (MeSH database, <http://www.ncbi.nlm.nih.gov/mesh?term=fatigue>) as the state of weariness following a period of exertion, mental or physical, characterized by a decreased capacity for work and reduced efficiency to respond stimuli. According to these two definitions, how exercise (MeSH database, <http://www.ncbi.nlm.nih.gov/mesh?term=exercise>), a physical activity associated to physical exertion when of usual level, could be accepted to improve CFS patients' fatigue, and then how White et al paper could be accepted as a cat among the pigeons? It's clear that we don't think this paper sweeps away by a stroke the robust literature about negative effects of exercise on CFS.

Chronic fatigue is associated with reduced exercise capacity and reduced daily activity, leading to the well-known physical deconditioning targeting among others cardiac, respiratory, muscular, and aerobic functions. Physical reconditioning, used in several medical specialties, even at very low level, is consensually accepted to improve objective (physiological functions, morbidity, mortality) as well as subjective (Quality Of Life that includes Fatigue items) criteria. Thus, reconditioning CFS patients by Graded Exercise Therapy as used in White et al study could probably improve (slightly) 6-minute walk test determinants and self-reported fatigue. But according to these well-known deconditioning and reconditioning phenomenons in sport medicine, how does this paper measure up? We don't think that White et al paper is an epiphenomenon of CFS scientific literature but we think that authors have just highlighted deconditioning experienced by CFS patients.

Finally, we think that that the main problem highlighted by the White et al paper is more linked to the approximate communication usually and often made on this very complex topic that is Chronic Fatigue Syndrome than to the interpretation of their results. Because the concept of fatigue is approached by so many different ways and specialties, we often forget fundamental and basic definitions, leading to cumulative approximation and distortion and justifying some regular tunings between scientists, researchers, physicians, people, media and politicians.

Stéphane Delliaux, M.D., Ph.D.

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DEREK ENLANDER, M.D.

The PACE study, GET/CBT idea, is a repeat of the old theory that the ME/CFS patient is imagining that they are sick and that exercise and psychological consultation will make them better.

The PACE study is flawed. The psychiatric group cannot be allowed to strangle patients and new research with their old theories.

Derek Enlander, M.D.

New York, NY

<http://forums.phoenixrising.me/index.php?entries/pace-trial.668/>

FRED FRIEDBERG, M.D.

When exercise is individualized to the patient with CFS/ME -- using gradual, incremental steps, sometimes starting with as little as 1-2 minutes of leisurely walking (not brisk walking) -- it helps about one in two patients. That is a significant number and so is worth trying for patients with CFS/ME who have few options for effective treatment.

The other side of the data shows that a large number of patients (the other half) are not helped by exercise. Also, prescribed exercise is not intended to increase aerobic fitness, but to improve

tolerance of physical exertion. Thus standard recommendations to healthy people for exercise, say 20 minutes of walking, do not apply to the CFS/ME population. Standard exercise is likely to worsen the illness.

Also, exercise however prescribed has not been shown to be a curative intervention in any published CFS/ME study that I'm aware of. Unfortunately, that message has not been clearly conveyed in many GET studies.

Fred Friedberg, M.D.

Stonybrook, NY

KENNETH FRIEDMAN, Ph.D.

I believe it is erroneous to treat all ME/CFS patients similarly or to subject them to the same therapy regimen. There is sufficient evidence now, and more emerges daily, that there is high variability of symptoms amongst ME/CFS patients. Some patients may benefit from mild exercise; others will have their condition worsened by exercise.

If exercise is of benefit to ME/CFS patients, and I must emphasize the if, it would be of benefit to a subset of ME/CFS patients. Unfortunately, too little attention has been paid to the task of identifying the subsets of ME/CFS. Accordingly, until such time as the subsets are clearly defined, those studies which attempt to demonstrate a therapeutic value to a one-exercise-regimen-benefits-all, are foolish and unworthy of serious consideration.

Kenneth Friedman, Ph.D.

Department of Pharmacology & Physiology

New Jersey Medical School

STUART GRAY, Ph.D.

The use of exercise as a treatment in CFS is never likely to solve the many problems associated with the condition. The small benefits in the CBT and GET groups in the aforementioned study still leave these patients very far away from what would be considered normal physical function. Regular light exercise may be of small benefit to some patients but it is unlikely to be suitable for all patients (especially those who are more ill) and suggesting it to all patients may cause more harm than good.

There is now some information that suggests oxidative stress and inflammation after exercise actually results in beneficial adaptations (i.e. mitochondrial biogenesis) after a period of malaise. This is clearly not the case in CFS patients, and detailed and extensive research is needed to establish the precise cause of this malaise and subsequently ways to treat it. This may help managing symptoms and further research should also investigate the underlying cause of the disease itself.

Stuart Gray, Ph.D.

Lecturer in Exercise Physiology

Institute of Medical Sciences

University of Aberdeen

Scotland

BYRON HYDE, M.D.

There are a large number of cardiac dysfunctions that can regularly appear in an M.E. patient. Without a clear understanding of these significant problem areas it is simply indefensible and potentially dangerous to place an unsuspecting patient in a graduated exercise program. This is particularly true if the patient is not being tested in a cardiac unit.

Possibly due to the fact that some Fibromyalgia patients can be improved by a gradual increase in exercise, or possibly due to the so-called Protestant ethic that all you have to do to get better is to take up your bed and walk, some physicians have extended the concept of passive or forceful increased exercise to Myalgic Encephalomyelitis patients. This is a common and potentially dangerous, even disastrous misconception.

Doctors Jay Goldstein and Ismael Mena, using Zenon SPECT brain scans, demonstrated that the physiological brain function of an M.E. patient rapidly deteriorates after exercise. They also demonstrated that this physiological dysfunction could persist for several days following any of several stressors. The physiological dysfunction occurs whether the activity (or stressor) is physical, intellectual, sensory or emotional.

M.E. is a variable but always serious diffuse brain injury and permanent damage can be done to the M.E. patient by non-judicious pseudo-treatment.

I have yet to have examined a new M.E. or CFS patient (they are by definition quite different) who has ever had a complete cardiovascular or CNS investigation, or for that matter any complete technological examination. In other words, when physicians or insurance or government agencies make such statements concerning the theoretical benefits of graduated exercise program, they have no idea who or what the pathology is that has injured or destabilized the M.E. patient.

In terms of the patients whose illness is consistent with the various CFS definitions, none of these patients I have ever seen have been seriously examined and as far as I am concerned, CFS is simply a missed diagnosis in which we have uncovered missed malignancies, missed MS, missed cardiac and cardiovascular disease, missed autoimmune disease. The CFS diagnosis is largely indefensible and since it can represent so many different pathologies and illnesses, it is absurd to consider a uniform treatment, whether this treatment is graded exercise or some theoretical pharmaceutical. It is essential to first discover the underlying pathologies before one considers treatment by any modality.

Byron Hyde, M.D.

Ottawa, Canada

LEONARD A. JASON, Ph.D.

In our 2009 energy envelope paper (Jason L, Benton M, Torres-Harding S., Muldowney K., The impact of energy modulation on physical functioning and fatigue severity among patients with ME/CFS, Patient Educ Couns, 2009 Nov; 77(2):237-41, PMID: 19356884), we found that the two groups of patients with ME/CFS had different outcomes on measures of physical functioning and fatigue severity after participating in a non-pharmacological intervention.

In general, those patients who exerted more energy than they had available did not improve, whereas those patients who were able to stay within their energy boundaries made significant improvements over time.

These findings suggest that when an individual with ME/CFS avoids over-exertion, maintaining an optimal level of activity over time, it might be associated with some improvements in physical functioning and fatigue. This study suggests that being overextended and going beyond energy reserves can be an impediment to improving functionality and fatigue levels.

Kindling is an explanation for what might occur when patients with ME/CFS overexert themselves and deplete energy reserves. The kindling hypothesis suggests that once this system is charged, either by high-intensity stimulation or by chronically repeated low-intensity stimulation, activities that involve going beyond energy reserves might enhance an already high level of arousal.

In a sense, patients with ME/CFS might have this type of cortical excitability that might be due to kindling, and then when they go beyond their energy reserves, the kindling produces high arousal that has implications for the hypothalamus, the autonomic nervous system, as well as the immune system.

Leonard A. Jason, Ph.D.

Director, Center for Community Research

DePaul University

Chicago, IL

NANCY KLIMAS, M.D.

You can overdo exercise and relapse (it's in the diagnostic criteria for the illness, after all). The exercise physiology group at the [University of the Pacific Fatigue Lab](#) presented data at the IACFS/ME conference on next-day decreases in exercise capacity after an exercise stress test. It's a great model, one that we too use in our studies using formal exercise physiology lab studies to ground our work on mediators of persistent illness.

You can recondition to the point where you can do more if you are careful not to exceed your energy limit, something that can be determined using formal exercise testing (knowing the VO₂ max and aerobic threshold). But if you push beyond the limit you will experience a relapse.

We are completing a study to understand just why that happens in ME/CFS and in gulf war illness. We have mapped out the cascade of events looking at gene activation patterns of more than 30,000 genes before, during, and after a short "push through" exercise challenge that averaged 8 minutes. It is very clear that the challenge of exercise kicks off a marked inflammatory reaction, which in turn impacts dozens of pathways - autonomic, immune, endocrine, pain, oxidative stress, intracellular metabolism, cell signaling. That patient centric concept of an energy envelope is certainly validated by our work. The use of exercise in the treatment of CFS and GWI should understand these principles.

Having said that, yes, exercise can be helpful, particularly in patients that have had other biologic aspects of the illness addressed in a meaningful way: autonomic, immune, sleep, pain, etc. Then a careful program can be designed that incorporates rest periods after relatively small efforts, and can be even more precise if the clinician has the benefit of an exercise physiologist or physical therapist with the ability to measure the exercise physiology parameters. A well informed physician empowers the patient by respecting their experiences, counsels the patients in coping strategies, and helps them achieve optimal exercise and activity levels within their limits in a common sense, non-ideological manner.

Nancy Klimas, M.D.

Professor of Medicine, Psychology, Microbiology and Immunology

University of Miami Miller School of Medicine

ANDREAS KOGELNIK, M.D., Ph.D.

The PACE study authors have written their case definition to include both people with major depressive disorders and patients who clearly have received an insult to their immune systems and are depressed because they can no longer do things that they used to.

Andreas Kogelnik, M.D., Ph.D.

Open Medicine Institute

Mountain View, CA

<http://www.nytimes.com/2011/03/08/health/research/08fatigue.html>

MARTIN LERNER, M.D.

There are multiple publications describing the progressive cardiomyopathy of ME/CFS. This ME/CFS cardiomyopathy is treatable with appropriate long-term antiviral therapy (Lerner et al, Virus Adaptation and Treatment, 2010). ME/CFS patients, during recovery, are advised to be active, but not to increase their heart rate above 100 beats per minute. Any greater rate worsens ME/CFS.

Martin Lerner, M.D.

Beverly Hills, MI

ALAN R. LIGHT, Ph.D.

We have gene expression data in our Journal of Pain paper ([Light AR](#), [White AT](#), [Hughen RW](#), [Light KC](#)). Moderate exercise increases expression for sensory, adrenergic, and immune genes in chronic fatigue syndrome patients but not in normal subjects. J Pain. 2009 Oct;10(10):1099-112. PMID: 19647494) that matches behavioral data from CFS patient that indicates that patients with CFS have negative consequences following 25 minutes of even very moderate exercise that lasts at least 48 hours. It may last much longer than this, given the information we have obtained from patients.

We have replicated these findings in a larger sample, and hope have the article on this published soon. We would like to stress that these gene expression changes are NOT found in normal control subjects with moderate, or even nearly maximal exercise, and are not seen in fit people, even with extremely intense and long lasting exercise.

Many of the gene expression changes are in the genes that detect normal levels of metabolites produced by exercising muscle. The abnormal gene expression increases indicate that the body perceives the mild exercise as extreme, and is reacting in a particularly extreme way. This leads us to believe that CFS patients bodies cannot detect and react to exercise in a normal way, and therefore, cannot protect itself from the demands of even mild exercise.

Another consequence of the gene expression changes observed is that CFS patients are "punished" for mild exercise by enhanced muscle pain and other symptoms associated with CFS that last at least 48 hours, and mostly likely much longer. This punishment would have the expected effect of making patients fearful (both cognitively and unconsciously) of performing similar exercise and could lead to serious aversion to all forms of exercise.

In our to be published paper, we have gene expression evidence that there may be a subgroup of CFS patients that might be more likely to benefit from exercise, while the majority probably will not. However, this hypothesis remains to be tested and may be false.

From the patients we have observed, it appears that CFS patients who are able to exercise regularly do benefit in their ability to be more active, but still suffer from major symptoms of fatigue and muscle pain that are not much different than when they did not exercise. In other works, they are more functional, but suffer just as much as previously.

There is a potential for harm in CFS patients following exercise, as we have observed (in the paper you describe below, and in our gene expression paper) that antiinflammatory cytokines are increased following moderate exercise, which could leave patients open to infectious diseases, and the development of neoplasms.

Overall, I believe the exercise can help a selected group of CFS patients, and if very carefully administered, by a trained specialist who understands the great limitations, perhaps with feedback from gene expression studies. However, I seriously doubt that the majority of CFS patients will show much benefit from exercise, and that many may avoid exercise at all costs, if placed in an inappropriate exercise program.

Alan R. Light, Ph.D.

Professor of Anesthesiology

School of Medicine.

University of Utah

MICHAEL MAES, M.D., Ph.D.

Our literature review article ([Twisk FN, Maes M](#). A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS. *Neuro Endocrinol Lett.* 2009;30(3):284-99. PMID: 19855350) shows that exertion and thus GET most likely have a negative impact on many ME/CFS patients. Exertion induces post-exertional malaise with a decreased physical performance and aerobic capacity, increased musculoskeletal pain, neurocognitive impairment, "fatigue," weakness and a long-lasting recovery time.

This can be explained by findings that exertion may amplify pre-existing pathophysiological abnormalities underpinning ME/CFS such as inflammation, immune dysfunction, oxidative and nitrosative stress, channelopathy, defective stress response mechanisms and a hypoactive hypothalamic-pituitary-adrenal axis.

We concluded that it is unethical to treat patients with ME/CFS with ineffective, non-evidence based and potentially harmful "rehabilitation therapies" such as CBT/GET.

http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/Twisk%20Maes%20CBT.pdf

In 2006 the Belgian National Health Care Institute (Ministry of Health) evaluated the efficacy of CBT/GET in treating ME/CFS at the Belgian University CFS Reference Centers that were installed by the Ministry of Health in 2002. Hundreds of ME/CFS patients had been treated by the Belgian CFS Centers using a strict CBT/GET program.

Based on the results obtained, the Minister of Health had to admit in the parliament that CBT/GET interventions at those CFS Reference Centers are no curative treatments (Belgian House of Representatives, 2007). But there is more. I analyzed the data of the report of the Ministry of Health. The results are shocking.

Treatment with "CBT/GET" deteriorates many patients. Up to 50-55% of all patients showed a worsening in their daily (work + leisure) activities. The VO2max worsened in up to 46-86% of the patients. The exercise tolerance (MET) worsened in 43-63% of the patients. Thus, by means of objective measurements, most patients deteriorate by CBT/GET treatments. Also the self-rating scales deteriorated in many patients: fatigue (deterioration in 23-50% of the patients), concentration (32-48%), motivation (33-80%), pain (31-33%), mental health (39-52%), anxiety (37-48%), depression (37-52%), somatic complaints (33-56%), social functioning (29-41%), physical functioning (29-50%), and quality of life (15-52%).

This proves that CBT/GET is not an evidence-based treatment and that it induces adverse effects in many patients. This is in sharp contrast to the fact that treatments should be designed to minimize pain, anxiety, discomfort, etc. But it is in line with previous patient inquiries in the United Kingdom, Scotland and the Netherlands showing that CBT/GET deteriorated the condition in 40-60% of the patients (Action for ME, 2001; CFS/ME Working Group, 2002; Action for ME, 2007; Koolhaas et al., 2008).

Although the Ministry of Health and the CFS Centers are aware that their treatments worsen the conditions of many patients they continue the same CBT/GET treatments in order "to train the patients to think about the psychological factors that may maintain and cause the complaints."

Notwithstanding the fact that the Ministry of Health and the CFS Centers know that their treatments are not evidence-based and deteriorate the condition of many patients, they pretend in official decrees and in "scientific" papers that "CBT/GET is the only evidence-based treatment that has a significant efficacy in ME/CFS." This is a fraud.

Professor Michael Maes, M.D., Ph.D.

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NEIL MCGREGOR, Ph.D.

The PACE trial provided evidence that 31%, 41% and 41% of subjects (Table 5) reported a positive global benefit to adaptive pacing, CBT, and GET, respectively. This meant that 69%, 59% and 59% found no global improvement or a negative change in their responses after 52 weeks of the trial. The

authors concluded that CBT and GET can safely be added to SMC to moderately improve outcomes for chronic fatigue syndrome, but APT is not an effective addition.

The authors of this paper have advocated therapies which only appear to only mildly benefit between 30 to 40% of ME/CFS subjects yet provide no ability to determine which of the patients may benefit from such therapy.

The authors are obliged to define those subjects who may actually benefit from this treatment method and not imply that the treatment should be used on all subjects.

Treatment of all ME/CFS patients with a treatment that only assists only 30-40% of them would impose a considerable cost to the public health costs and only act to alienate many patients as is evident by the objections from patient groups to this treatment method.

In their study protocol paper, White et al (2) describe their treatment as "Rehabilitative". The Oxford dictionary defines "rehabilitate" as "to restore (someone) to health or normal life by training and therapy after imprisonment, addiction, or illness:". The return to normal health is obviously not occurring in this study population and therefore we would contend that the word "Palliative" is a more adapt term for use in this or other trials involved in ME/CFS patients using these methods. Palliate is defined as "to make (a disease or its symptoms) less severe without removing the cause."

References:

1. White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R, DeCesare JC et al. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *Lancet* 2011 March 5;377(9768):823-36.

2. White PD, Sharpe MC, Chalder T, DeCesare JC, Walwyn R. Protocol for the PACE trial: a randomised controlled trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome/myalgic encephalomyelitis or encephalopathy. *BMC Neurol* 2007;7:6.

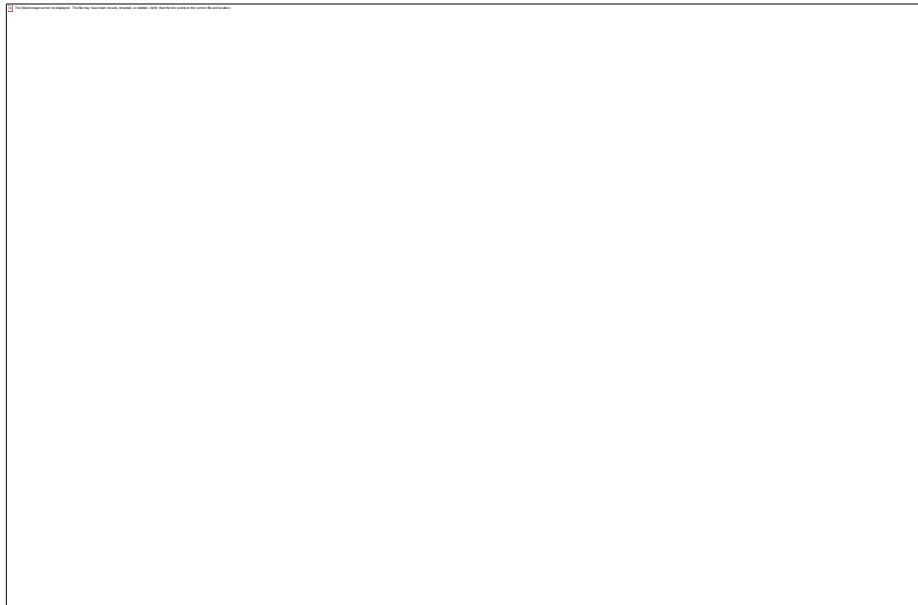
Neil McGregor Ph.D.

South Yarra, Victoria, Australia

SARAH MYHILL, M.D.

I am a doctor with a special interest in treating chronic fatigue syndrome and have treated some thousands of patients over the last thirty years.

What characterises chronic fatigue syndrome is poor stamina and delayed fatigue. My view is that these are symptoms of poor mitochondrial function and indeed I published on this subject in 2009.



<http://www.ijcem.com/files/IJCEM812001.pdf>

What this study showed is that those patients with the worst levels of energy had the worst mitochondrial function tests and vice versa.

The point here is that fatigue is just the symptom. If patients are improved by exercise, then by definition they do not have chronic fatigue syndrome.

Therefore it is self evident that graded exercise therapy will not be a treatment for chronic fatigue and indeed it is my experience that graded exercise almost invariably makes these patients worse.

Sarah Myhill, M.D.

Wales, UK

DANIEL PETERSON, M.D.

What the exercise physiology studies have shown is that in CFS, if you exceed your anaerobic threshold, you are endangering yourself and your wellness. So if you're going to do exercise, it needs to be sub-anaerobic threshold. This is one of the reasons that I always measure the anaerobic threshold, so I can always tell the patient exactly where to exercise.

It is clear that a certain portion of the disability is related to deconditioning, probably about 15%. You can condition yourself by exercise given in a safe and controlled environment. What I usually use is a very very slow rehabilitation program that actually starts with stretching and then advances to resistance weight training. The last thing we add is aerobic exercise.

If you just take a note to the rehab center, they'll always start with the treadmill, which actually makes people worse.

Daniel Peterson, M.D.

Incline Village, Nevada

<http://vimeo.com/30567445>

RICHARD PODELL, M.D.

I don't doubt that properly graded exercise can improve physical conditioning to a degree, but my experience with many hundreds of persons is that the degree of improvement obtainable is most often quite limited. What we have seen many times is that persons who push past their limits typically suffer

a prolonged post-exertional flare-up of symptoms. We see a similar pattern of post-exertional flare-up with ME/CFS and with moderate to severe fibromyalgia as well.

Richard Podell, M.D.

Clinical Professor

Department of Family Medicine

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JUDITH A. RICHMAN, Ph.D.

As an epidemiologist, I believe that the conclusions reached from British studies, arguing that Graded Exercise Therapy (GET) and Cognitive Behavioral Therapy (CBT) are beneficial to improving the illness status of ME/CFS patients, are deeply flawed and of potentially great harm to ME/CFS patients.

The main problem of these studies is that the criteria used for the selection of the patient samples involved heterogeneous groups of patients, many of whom had diagnoses of major depression rather than ME/CFS. It has long been known that both GET and CBT are beneficial to patients with depressive disorders. However, by contrast, post-exertional malaise is the hallmark symptom of ME/CFS, and patients with this disorder tend to exceed their capacity for physical exertion and subsequently relapse in contrast to the problem of depressed patients getting too little exercise.

Moreover, CBT can be useful in coping with a variety of chronic illnesses that currently have no cure. But it is crucial to understand the central difference between learning how to better live with an illness that greatly diminishes one's quality of life and the assumption that CBT can improve the actual illness, which it cannot.

Judith A. Richman, Ph.D.

Professor of Epidemiology in Psychiatry

Department of Psychiatry

University of Illinois at Chicago

CHARLES SHEPHERD, M.D.

The disappointing results for adaptive pacing therapy (APT) in the PACE trial (1) do not reflect the feedback from the majority of published patient surveys, including ours (2), where pacing was reported to be one of the three most helpful strategies in managing ME/CFS.

The likeliest explanation is the difference between APT and the form of pacing advocated by most of the patient support groups around the world. Our version of pacing is evidence-based so it does not require patients to function well below their ability and adhere to the 70% rule, an important component of APT. It is based on clinical experience dating back to the 1950s and supported by several controlled trials showing that pacing limits post-exertional exacerbations and improves functioning over time (3). More significantly, it avoids the documented immunological and metabolic abnormalities following over-exertion (4) which are increasingly recognised as a contra-indication for graded exercise therapy (GET).

The fact that the findings of the PACE trial could result in pacing being removed as a treatment option within the NHS is just one of many concerns. The exaggeration of the outcomes, especially in the media (5), deserves to be challenged, particularly as the findings from the trials on GET are inconsistent with almost every patient group survey and audit conducted.

References:

1 White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R et al. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *Lancet* Feb 17 2011

2 ME Association. Managing my ME. What people with ME/CFS and their carers want from the UK's health and social services. http://www.meassociation.org.uk?page_id=1345

3 Brown M, Khorana N, Jason LA. The role of changes in activity as a function of perceived available and expended energy in non-pharmacological treatment outcomes for ME/CFS. *Journal of Clinical Psychology* 2011, 67, 253-260

4 White PD, Nye KE, Pinching AJ, Yap TM, Power M et al. JM. Immunological changes after both exercise and activity in chronic fatigue syndrome: A pilot study. *Journal of Chronic Fatigue Syndrome* 2004; 12: 51-66

5 Got ME? Just get out and exercise, say scientists. *The Independent* 18 February 2011

Charles Shepherd, M.D.

Bucks, England

RITCHIE SHOEMAKER, M.D.

Assessment of use of exercise as a therapeutic modality must begin with understanding the maximum delivery of oxygen (VO₂ max) and the level of oxygen delivery at which not enough oxygen can be delivered to mitochondria to keep burning sugar efficiently as a fuel (anaerobic threshold). These measures, readily obtained in a standard pulmonary lab during stress testing, provide insight to baseline exercise capacity; each impacts on the exercise prescription. Age matters here, as VO₂ max of 24 ml/kg/min is indicative of severe disability in a 24 year old but the same disability rating is reached in a 60 year old at 16 ml/kg/min. Anaerobic threshold of 50% of VO₂ max will prevent a 30 year old from achieving much benefit from efforts to use aerobic (i.e. delivering oxygen) exercise. Similarly, delayed recovery from normal activity (aka "push-crash" or "post exertional malaise") will occur at anaerobic thresholds under 60% of those older than 60.

One cannot neglect the concept of glycogen storage potential here, as forced exercise beyond consumption glycogen reserves -- as is invariably seen in low anaerobic threshold patients being told "No pain, no gain" -- simply means that gluconeogenesis will occur, creating negative nitrogen balance. Exercise in these patients is "all pain and never any gain."

In the presence of significant tissue inflammation, as shown by levels of T regulatory lymphocytes (CD4+CD25+) less than 14, the level of anaerobic threshold is functionally reduced by another 25-33%.

In patients with significant capillary hypoperfusion, as is commonly seen in CFS, manifested by C4a levels over 10,000 and lactate over 1.29 seen on magnetic resonance spectroscopy, the anaerobic threshold is further reduced by another 25-33%.

Simply recommending aerobic exercise in CFS is illogical. One must understand the individual's physiology before telling anyone that exercise is indicated.

Ritchie Shoemaker, M.D.

Pocomoke City, MD

CHRISTOPHER SNELL, Ph.D.

Where I have real reservations about the trial concern what was not said rather than what they do say and the implications that follow from recommending exercise as treatment for ME/CFS without fully explaining what the results of the study really show. Walking for 6 mins at 2-2.5 mph is something even the very sick patients we see could actually do but this does not mean they are able to take on exercise in the traditional sense. If they were cardiac patients, such results would be interpreted to indicate that they would likely benefit from a heart transplant.

Christopher Snell, Ph.D.

Pacific Fatigue Laboratory

Department of Sport Sciences

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Stockton, CA

NIGEL SPEIGHT, M.A., M.B., B. Chir.

I would entirely endorse this carefully worded critique of the claims for GET and CBT. Along the same lines, I would stress that the studies could be faulted by a) possibly including cases of "chronic fatigue" that were not true ME, but were possible depression and b) confusing the issues by combining CBT with GET. The major point that the alleged improvements were clinically pretty insignificant is crucial. Finally, the basic issue is the lack of applicability of any of this to severe cases.

You might take a clutch of severe chronic asthmatics and subject them to GET. As long as none of them had an attack and died you would end up with some slightly fitter

asthmatics at the end of the six months. No one would dream of applying this to someone in the middle of a severe attack!

Yet this is how the proponents of GET behave. I am continually having to protect children with severe ME from court orders to compel hospital admission and compulsory

exercise programmes. When I am unsuccessful the result is invariably that the young person is made much worse. I am willing to accept that relatively mild cases of

stable convalescent ME can get a bit fitter with a gentle exercise programme as long as they don't overdo it. In my experience with young people, the main challenge is to actually restrain them from doing too much so I have hardly ever seen the need to "prescribe" exercise for them.

Nigel Speight, M.A., M.B., B.Chir., FRCPCH, DCH

Southlands Gilesgate, Durham, UK

VANCE SPENCE, Ph.D.

Since 2005, the MRC has funded two large clinical trials of cognitive-behavioural approaches for ME/CFS, at a cost exceeding £3 million. The first of these (the FINE trial 1) reported that “pragmatic rehabilitation” for severely affected patients improved fatigue in the short term compared with GP treatment as usual, but had only a small, non-significant effect after one year. The second (the PACE trial 2) has now reported modest improvements in some ME/CFS patients after cognitive behavioural or graded exercise therapy; a “clinically useful difference” in the primary outcomes of fatigue and physical function after one year occurred in 45%, 59% and 61% of the standard medical care, cognitive behavioural and graded exercise groups, respectively.

Neither of these expensive trials has established cognitive-behavioural approaches as convincing, core treatments for most patients with ME/CFS. Indeed, when their results are placed side-by-side with the most recent Cochrane review 3 and the most comprehensive meta-analysis 4 to date (which reported a small-moderate overall effect size from 13 diverse trials), it is clear that psychosocial interventions have only an adjunctive role. The situation is therefore akin to that in other chronic illnesses, such as multiple sclerosis 5, where these non-specific approaches help with managing symptoms and promoting coping, but form only a small part of the clinical and therapeutic armoury required to address the underlying disease processes.

We conclude therefore that academic interest (and funding) should now focus on biomedical investigation to arrive at specific therapies for this debilitating illness.

References

1. Wearden AJ, Dowrick C, Chew-Graham C, et al. Nurse led, home based self help treatment for patients in primary care with chronic fatigue syndrome: randomised controlled trial. *BMJ* 2010; 340: c1777
2. White PD, Goldsmith KA, Johnson AL, et al. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial . *Lancet* Feb 18, 2011; Epub ahead of print
3. Price JR et al. Cognitive behaviour therapy for chronic fatigue syndrome in adults. *Cochrane Database Syst Rev* 2008 Jul 16;(3):CD001027
4. Malouff JM et al. Efficacy of cognitive behavioral therapy for chronic fatigue syndrome: a meta-analysis. *Clin Psychol Rev* 2008 Jun; 28(5): 736-45
5. Dennison L, Moss-Morris R. Cognitive-behavioral therapy: what benefits can it offer people with multiple sclerosis? *Expert Rev Neurother* 2010; 10(9): 1383-90.

Vance Spence, Ph.D.

Neil Abbot, M.Sc., Ph.D.

ME Research UK

Perth, UK

IRVING SPURR, MBBS, GMC

I consider that the recommendation of CBT and GET as blanket treatments of “clinically excellent” first choice is extremely dangerous to patients.

Dr. Irving Spurr, MBBS, GMC

Weardale, England

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

ELEANOR STEIN, M.D.

The belief that exercise is a treatment for ME/CFS is just plain wrong. The face validity of trials such as the PACE must be called into question if the majority of real patients do not respond similarly to study participants.

It is a laudable goal for anyone chronically ill with ME/CFS or otherwise to maintain the best fitness possible. Exercise improves cardiovascular health, mental health and maximizes the ability of patients to do necessary daily activities.

However, in my 10 years in a dedicated ME/CFS practice, I hear over and over the despair engendered by repeated, unsupervised attempts to increase exercise.

We are experimenting with heart rate, heart rate variability and lactate curves as tools to help patients identify their individual optimal exercise frequencies and intensities and to objectively measure whether exercise programs are helping or hurting.

It remains a challenge to improve fitness and quality of life while respecting the energy envelope limits of ME/CFS. More research is desperately needed.

Eleanor Stein, M.D.

Clinical Psychiatrist

Calgary, Canada

STACI R. STEVENS

Our lab has focused on functionally characterizing CFS/ME patients.

After completing over 1,110 cardiopulmonary exercise tests for a clinical trial in CFS/ME at 12 different locations across the country, we looked at the baseline data and found that all of our patients achieved an oxygen consumption level of 36-76% of predicted values (VanNess, et al, 2003). Half the patients in the study were in the moderate to severe impairment category based on American Medical Association Guidelines for the evaluation of permanent impairment.

Of particular interest was the delayed recovery response the patients routinely reported. This led us to test patients on consecutive days.

Patients are consistently unable to reproduce test results and show reduced work efficiency in the post-exercise state. Our initial findings were confirmed by a group in the Netherlands (Vermeulen, et al 2010).

The symptom of post-exertional malaise (PEM) is a real and measurable finding. Our patients report that it takes several days and sometimes weeks to recover from an 8-12 minute bout of exercise. This is not a normal response to an activity that for healthy people makes them feel better.

The symptom of PEM must be taken into consideration when designing any type of exercise program. If there is metabolic dysfunction, asking a patient to exercise aerobically will not work but will make them worse.

Staci R. Stevens

Founding Executive Director

Pacific Fatigue Laboratory

University of the Pacific

JACOB TEITELBAUM, M.D.

A literature review looking at severe fatigue in cancer patients also noted that counseling and exercise can be helpful in cancer patients ([Cancer-Related Fatigue: A Practical Review](#)). Using the line of reasoning applied by some to the PACE study, this would also suggest that cancer is all in people's minds.

Of course, this is simply an absurdity that points to the simple fact that for most severe debilitating diseases, emotional support and coping skills can be helpful along with maintaining conditioning.

In chronic fatigue syndrome, people are facing an energy crisis so they can only walk or exercise to a certain point, beyond which they crash and burn. So you only want to exercise "as able." This means listening to your body and seeing what feels comfortable.

On the other hand, if you don't exercise at all, your body has a "use it or lose it" approach to efficiency, and you'll decondition.

So basic common sense says that for cancer, chronic fatigue syndrome, multiple sclerosis (which doctors also used to believe was all in people's minds, calling it "hysterical paralysis"), and any severe disease, it is helpful to get emotional support, coping skills, and exercise as able.

The problem occurs when a form of cognitive behavioral therapy is used that includes beating people over the head with the misguided belief that the illness is not real. This then changes from teaching coping skills to being abusive.

Jacob Teitelbaum, M.D.

Kona, HI

ROSAMUND VALLINGS, MNZM, M.B., B.S.

Over the years I have seen many patients with a diagnosis of CFS/ME. The outstanding feature for most is intolerance to more than a minimal amount of exercise, with risk of serious relapse if the ability envelope is exceeded.

It seems that these patients are on a knife-edge, and each needs careful assessment, with any recommendations for exercise being cautiously managed by medical professionals experienced in this illness. Pushing the boundaries beyond the comfort zone does not work. Words such as "training," "getting fit," "aerobics" etc are totally inappropriate.

Most patients are motivated and keen to improve, but usually know their limitations well when it comes to exercise. We need to listen to our patients, and work together as a team, structuring any recommendations according to what is individually possible, without causing escalation of symptoms heralding relapse.

Rosamund Vallings, MNZM, MB BS

Auckland, New Zealand

CONSTANCE VAN DER EB, Ph.D.

When working with children and teens living with ME/CFS, I meet with the child and available family members at the first and at later sessions, as appropriate. A primary goal is to learn (1) from the youngster what symptoms s/he is experiencing and her/his priorities for treatment focus, (2) from the parents their concerns and goals, and (3) from siblings their concerns and questions about their sibling's illness.

We also discuss the critical concepts about the variable nature of ME/CFS and the importance to the sibling ill with ME/CFS of pacing activities (physical, intellectual, social) to keep expenditure of his/her energy within an "envelope" of safe functioning. I also use the concept of battery size to describe available energy: the person with ME/CFS has an AAA-size battery supply while most healthy people

have a D-size battery. The youngster gains practice in deciding when and how much energy to expend (or not) if s/he wants to reduce likelihood of symptom exacerbation. Rigid programs/schedules for increasing "activity" can be harmful physically and disrespectful of the youngster's experience of his/her symptoms.

Using simple forms, the youngster (with parent's help if needed) creates an activity record of energy expended and physical/cognitive symptom experiences.

In subsequent sessions, the youngster's experiences with pacing and parents' observations are reviewed and used to guide next steps. Hopefully, over time, the youngster will become more adept at monitoring symptoms and energy expenditure.

It is very important to inform the youngster's school about the child's ME/CFS so as to access the educational accommodations s/he is entitled to receive. A collaborative approach is critical to support the young person's education at a pace and in a format compatible with his/her health status.

Constance Van der Eb, Ph.D.

Lake Bluff, IL

RICH VAN KONYNENBURG, Ph.D.

Exercise requires an increase in the rate of production of ATP (adenosine triphosphate) in the mitochondria (cellular power plants) of the cells of the skeletal muscles and the heart muscle, because ATP supplies the energy to power muscle contractions.

Unfortunately, there is abundant evidence that people who have ME/CFS suffer from dysfunction of their mitochondria, among many other biochemical and physiological abnormalities.

The mitochondrial dysfunction manifests among other ways as elevated oxidative stress. Oxidative stress results in damage to lipid membranes, proteins and DNA in the cells.

When a person who has ME/CFS undertakes significant exercise, their dysfunctional mitochondria are forced to try to produce ATP at a higher rate. The resulting increase in oxidative stress likely produces additional damage, and the time required for repair of this damage may be at least partly

responsible for the postexertional exhaustion and malaise that is a hallmark of ME/CFS, lasting for a day or in some cases much longer after significant physical exertion.

This is not to say that some exercise is not beneficial and in fact needed. It helps to maintain several body organs and systems, including the muscles, the heart and circulatory system, the lymph system, the digestive system, the vestibular system, the joints, and others. The key is that the amount of exercise that is beneficial but not deleterious is very much an individual property of each patient and their current condition. This amount is best determined by the individual patient, starting with a small amount, and waiting until the next day to see how well it was tolerated, before increasing the amount by another small increment, waiting again to gauge the effect, and so on. It should be recognized that ME/CFS is characterized by relapses, which may decrease the amount of exercise that was previously found to be tolerable.

In my opinion, efforts by other parties to increase the amount of exercise that an individual patient undertakes should be entered upon with a great deal of caution, and should be done in a cooperative manner with the patient, following this procedure.

Rich Van Konyenburg, Ph.D. (Deceased)

MARK VAN NESS, Ph.D.

The Stevens protocol is a two-day series of maximal, cardiopulmonary exercise tests that challenge the physical working capacity of a patient with CFS/ME. The test-retest design is intended to determine physical working capacity when the patient is in a rested and non-exacerbated state on day one of the tests. The stress of doing the exercise test typically exacerbates symptoms and produces a subsequent "flare-up" typical of post-exertional malaise. The second day of exercise testing is identical to the first. Any changes in the cardiac, pulmonary, metabolic or workload observed on the second day compared to the first objectively informs of the systems that may be impaired in the post-exertional state.

There are a number of advantages in this design:

1. Maximal effort on both exercise tests is important and standardized objective criteria are used to judge effort. When maximal effort is given by the patient on both tests, the comparison of performance on the first day compared to the second allows each subject to serve as their own control.

2. The effects of detraining often evident in CFS/ME are precluded in this design.

3. The failure to reproduce performance on cardiopulmonary exercise tests may be a unique finding to CFS/ME and measures the symptom of post-exertional malaise. There is strong support from scholarly literature of a number of pathological conditions that repeated exercise tests produce nearly identical cardiac, pulmonary and metabolic responses.

4. The findings from the exercise testing may be used to support claims of physical disability in job-related litigation.

Mark VanNess, PhD

Pacific Fatigue Laboratory

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WILLIAM WEIR, FRCP

CBT is a psychological treatment. Its application in what is certainly an organic disorder is basically irrational. Its putative mode of action is based on the proposition that patients with ME/CFS feel unwell because they have an “abnormal illness belief,” and that this can be changed with CBT. It has never been proven to be helpful in the majority of patients with ME/CFS.

GET comprises a regime of graded exercise, increasing incrementally over time. A number of patient surveys have shown it to be, at best, unhelpful, and at worst, very damaging. Its application is counterintuitive, particularly when one of the most debilitating and well recognised symptoms of ME/CFS is post-exertional malaise, which can put some patients in bed for days after relatively trivial exertion.

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