

Quest

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Announcement – Update: Lydia Neilson

Oooooopppppssss - We are behind in our newsletters. One of our Directors became ill and her work had to be redistributed among the other Directors. Hence, our sincere apologies for the lateness of "QUEST". We are happy to report that everything is back on track and the outstanding issues will be published shortly. We will be publishing two issues followed shortly by a third issue.

Now Available for Purchase: Canada Pension Plan Disability Benefits Guidelines

New up-dated guidelines have been developed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. Understand the criteria, important items to include and how to proceed through the various steps of the process. – **Cost \$7.00**

We are also pleased to advise you that a number of our other resource projects are near completion. See "**RESOURCE BOOKS**": at end of this newsletter.

In addition, Haworth Press has advised us that, **Fibromyalgia Syndrome: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document**, *Journal of Musculoskeletal Pain* 11(4), 2004, which is in press should be available in **May 2004**.

Pharmacological Stress Test

Philipa Corning, Ph.D., B.Sc.
Vice-President

In the last issue of Quest (No. 60), the article entitled, "ME/CFS Post-Exertional Malaise/Fatigue and Exercise" by Marjorie van de Sande, described abnormal responses to exercise exhibited by ME/CFS patients and the consequent dangers of exercise stress tests for these patients. In view that some ME/CFS patients may require a stress test in special circumstances, such as following a heart attack, this article presents an alternative stress test, which is safer for ME/CFS patients.

Stress Tests

The purpose of any type of stress test is to determine if the heart muscle is getting the blood supply it needs in order to function properly. When your heart works harder, it requires more oxygen, which is carried by the red blood cells. If it does not get the required increased oxygen during increased workloads, you experience chest pain, irregular heart rhythms (arrhythmias) and other problems. Usually a treadmill stress test is administered. While appropriate for many people, the article in the last issue of Quest described abnormal, adverse reactions to treadmill stress tests, which can cause severe relapses in ME/CFS patients. The treadmill stress test is inappropriate for ME/CFS patients as it has been demonstrated that it can cause decreased cerebral blood flow, cerebral oxygen, body temperature, breathing irregularities, impaired oxygen delivery to the muscles and cognitive processing, and gait abnormalities.

The maximum oxygen uptake during exercise is approximately one half of sedentary controls. Most importantly, ME/CFS patients usually have an elevated resting heart rate, a reduced heart rate during exercise, and can not achieve age-predicted target heart rates. As these abnormalities can be due to a sub-optimal level of heart functioning and/or autonomic disturbances, not only is it inappropriate for ME/CFS patients to undergo a treadmill stress test or be pushed toward age-predicted target heart rates, but this is potentially DANGEROUS.

The Cardiolite Stress Test - The pharmacological or Cardiolite stress test provides the doctor with an alternative method to assess the heart's ability to work under stress for the individual who cannot perform a treadmill test. This two-stage study allows the physician to see pictures of the heart when it is first at rest, and second, following stress. An intravenous line (IV) is placed in the arm before the first injection of pharmaceuticals. During the resting study, a small amount of radioactive material or tracer (Cardiolite) is injected to create pictures of the heart at rest. In the stress study, Persantine is administered to induce stress, and then another injection of Cardiolite is given to take pictures of the heart under stress.

Cardiolite, the radioactive tracer, decays in order to reach a more stable state and in doing so emits energy in the form of gamma rays. This tracer temporarily marks the red blood cells, which allows the doctor to document blood flow to your heart muscles. The level of radioactivity used is extremely low and has no side effects. In fact, the amount of radioactivity received is about the same amount a person is exposed to in 1 to 2 years from natural (background) radiation present in the environment. A special camera (gamma scintillation camera), which detects the gamma rays emitted from the radioactive tracer, is installed in a piece of equipment similar to a CAT or MRI scan. The individual is placed inside the cylinder of the scanning device and the camera takes pictures of the heart at various angles. These pictures will show the amount of the radioactive tracer that reaches the heart muscle. As the tracer moves through the heart muscle, areas that have good blood flow absorb the tracer. If an area of heart muscle does not adequately absorb the tracer, it means either that blood flow is severely reduced (ischemia) and/or there has been a previous heart attack. The tracer is eliminated by the body, usually in the urine or stool in less than 24 hours.

Preparation for the Stress Test

Before a pharmacological (medication) stress test:

- Talk with your doctor regarding things you must do to prepare for the test and any other concerns or questions you may have;
- Absolutely no foods, drinks or drugs containing caffeine can be taken for 24 hours prior to the test in order to avoid (1) stomach upset and (2) major redirection of blood flow toward the digestive tract during the procedure;
- Patients may or may not be able to take heart and blood pressure medications, depending on whether or not they interfere with the accuracy and effectiveness of the test;
- Wear unrestricting clothes so that you will be more comfortable during the procedure; and
- Prior to the test you may be asked to sign a consent form. Read it carefully and question the doctor or technician supervising the test regarding any concerns you may have.

Important Info to Provide Physician

For women, it is important to notify your supervising physician regarding:

- pregnancy, and nursing. The scan is contraindicated in these cases.
- presence of breast implants. These can obscure the pictures.
- advise the supervising physician that you have ME/CFS.

The Resting Study

Following the first injection of Cardiolite, the patient is placed under the special camera in the scanning device. Pictures are taken and information is relayed to a computer that generates a corresponding image. The camera, which does not produce any radiation, is placed close to the chest, and pictures are taken for approximately 30 – 40 minutes. During that time it is important for

the patient to remain very still while the pictures are being taken. Following the study, EKG electrodes are placed on the chest to constantly monitor the heart during the stress test.

The Stress Study

Instead of using treadmill exercise, the heart is stressed with the use of medication (Perdantine), which causes the healthy coronary arteries (but not the blocked ones) to dilate or get wider thus increasing the blood flow to the heart. During the test, the patient is constantly monitored by a nurse or physician. The preparation takes up to 30 minutes, but the actual stress portion of the test takes about 10 to 15 minutes. Before the end of the stress test, a second injection (Cardiolite) is administered. This radiopharmaceutical is taken up by the heart muscle and can be visualized by the camera in the same manner as the rest study. The imaging portion of the stress study takes approximately 45 minutes.

Common Responses Experienced During Studies

Normal responses during testing include feeling tired, shortness of breath, sweating and discomfort in the chest, arm or jaw. Severe shortness of breath, extreme tiredness, dizziness, lightheadedness, leg cramps or soreness should be reported to the technologist immediately. The supervising practitioner will alter or stop the test early if it is unsafe to continue.

After the Stress Test

When the test is over, patients may eat or drink and return to their normal routine. They may resume all medications.

Data Comparison

The images and other data of the resting stage study are compared with those of the stress study to give the doctor the information needed to evaluate how your heart is functioning. Your doctor will provide you with feedback.

Summary

The pharmacological stress test provides more precise information on heart function than a treadmill stress test, such as:

- its images provide valuable information as to why you may be experiencing chest pain or angina;
- if you have recently had a heart attack, it can assist the doctor in determining the damage sustained by the heart during the attack;
- if you are about to experience surgery, it can help the physician assess whether the heart is strong enough to withstand a long or complicated operation; and
- the images reliably identify Coronary Artery Disease in women, which is advantageous if diagnosed early, as it provides the opportunity for effective early treatment.

If you require a stress test, it may be of assistance to provide your doctor with the article, "ME/CFS Post-Exertional Malaise/Fatigue and Exercise" as well as this one.

Improving Sleep Quality Despite Fibromyalgia and/or Chronic Fatigue Syndrome

Richard N. Podell, MD, M.P.H.

[Dr. Podell kindly gave us permission to reprint the text of a talk he gave to the Fibromyalgia & Chronic Fatigue Syndrome Association of Connecticut in April, 2003]

Our topic today is how to improve sleep particularly for people who suffer from fibromyalgia, chronic fatigue syndrome and related health problems. I want to emphasize, to be sure, that what we don't know about better sleep is much greater than what we do. And while we are beginning to ask the right questions, most of the answers are not yet in hand.

For example, we know that both CFS and FMS, by their very nature, prevent restorative sleep. This not only leaves us feeling tired, but also worsens our illness in direct physical ways. For example,

poor sleep turns up the “loudness” or “volume knob” on the pathways in our central nervous system that transmit and augment pain.

Another example of better questions than answers: is the role of inflammation. One of the great insights of recent medical research is that inflammatory reactions are biochemicals called cytokines are often high among many people with FMS/CFS, although not as high or in the same way as they are among people with more traditional inflammatory disorders such as rheumatoid arthritis. Surprisingly, hardening of the arteries (arteriosclerosis) is accompanied by inflammation, as is psychological depression. Indeed, just going without sleep, all by itself, can create inflammation. The question is what should we do with this inflammation? Should we suppress it to help our body heal? Or are these inflammations needed, as part of the body’s self-defense? Again, the research we need is not being done.

So, while we are waiting for the researchers, what have people with FMS and CFS along with their doctors learned about practical approaches you can use now to improve your odds of gaining better sleep?

The first part of my talk focuses on the broad principles that I and other physicians who treat CFS and FMS believe we have learned by listening to our patients and by sharing their experience of which approaches have been more likely to help.

I want to emphasize that this kind of anecdotal trial and error wisdom is not a perfect guide. The recommendations they lead to will not be the “right answer” for everyone. Indeed, the main principles I have learned are in some respects contrary to those that most doctors have learned about how best to help sleep. That is because FMS/CFS are in important respects different from the “usual run” of illness, different enough so that the principles that make sense for most other illnesses, don’t here.

The second section will introduce the concept of integrative or functional medicine, adding holistic support for the body’s natural healing systems. This is not a treatment for sleep per se but an attempt to identify and correct obstacles to healing that arise as complications of the illness. You can find out more about this on my website DrPodell.org, especially in the subsection entitled “8 Vicious Cycles That Interrupt Healing.”

Third, we will review many of the medicines, herbs and nutrients that potentially help sleep—both the common choices that are usually prescribed for sleep, as well as several innovative therapies, typically used for other purposes, that also have the potential for helping better sleep.

The following conclusions or broad principles should be considered in approaching Sleep Problems for people with FMS/CFS

1. Nearly all persons with FMS and/or CFS have non-refreshing, non-restorative sleep. This occurs in almost all circumstances whether you lie awake at night or sleep all the way through; whether or not you have a primary sleep disorder such as sleep apnea or periodic leg movement disorder (PLMD); whether or not you are anxious or depressed; no matter if your EEG tracing while asleep shows sleep architecture abnormalities.
2. In addition to non-restorative sleep that is almost always present, a substantial number of people with FMS and CFS also have a primary sleep disorder. The data is especially strong for CFS, where somewhere in the order of 10% of patients have a significant degree of sleep apnea. On the order of 1-4% have a muscle twitching syndrome called periodic leg movement disorder (PLMD)

A bed partner can suspect obstructive sleep apnea by noting snoring, and/or repeated pauses in breathing of >10 seconds and/or snorting and/or struggling for breath. Sleep apnea is most common among persons who snore heavily, but can also occur among people who do not snore. A bed partner might suspect PLMD after noting frequent small muscle twitches, gross limb jerks or excessive tossing and turning. However, even with a bed partner who stays up to observe for at least 30 minutes, we may still miss a substantial proportion of sleep apnea, and perhaps a majority of PLMD.

Therefore, if affordable, every person with CFS/FMS and non-restorative sleep should have an overnight sleep study.

3. *Even modest improvements in sleep quality can make a meaningful difference in quality of life by helping to remove an important obstacle to healing.*
4. *Trial and Error is one of the best strategies—despite its frustrations.* Methods that help one person often fail for others. View each treatment trial as an opportunity, and each treatment failure as clearing the decks to make way for the next potential option. If you keep trying, and don't get discouraged, the odds are you'll find one or more medicines that can make a difference.

Many sleep medicines work within one to a few nights. Therefore, a series of brief trials should be practical. Drop any medicine that causes problems on night #1. Continue non-disruptive medicines for a fair-trial period of 4 days to four weeks.

5. *Dumb Simple Common Sense Sleep Hygiene and Psychological Maneuvers can make an important difference* (See the Sleep Hygiene table below) Don't neglect these important issues even though they're "low tech".
6. Make staying asleep an interim goal on the way toward sleep that refreshes. Restful, restorative sleep is the goal but, despite sleeping through the night, many patients still wake feeling tired. However, all else being equal, you're better off waking tired after sleeping through the night than waking tired after not sleeping through the night.
7. *Usual opinion is that we should use sleeping pills only as a last resort and only occasionally and for short periods.* However, since for FMS/CFS bad sleep is chronic and harmful to your health, my judgment is that often for FMS/CFS a different role makes better sense: If you benefit, take sleep medicines regularly to support better sleep.
8. *Usual opinion is that we should prefer non-addicting medicines, especially those that improve slow-wave sleep and which also often help fibromyalgia pain e.g. the tricyclic anti-depressants at low doses (Elavil, doxepin, Pamelor), the tricyclic muscle relaxant Flexeril, the anti-depressants trazadone and Serzone, the newer anti-depressant Remeron, and the newer sleep medicines Ambien and Sonata.*

These medicines should still be first choice—when they work. However, since many people with CFS/FM are very sensitive to medicines' side effects, fairly often these medicines aren't tolerated, or they don't work. So, other less standard sleep options are very often worth a try.

9. *Usual opinion is that we should avoid diazepam/Valium-like medicines except for occasional use because they are "habit-forming", tend to disrupt rather than improve the EEG pattern during sleep, and because for some people over-time they tend to stop working.* This is all true. However, my experience and that of other specialists is that a proportion of people with FMS/CFS do surprisingly well with this class of medicines, even with long term use. So, don't dismiss the benzodiazepine group automatically, as many physicians tend to do. Among the benzodiazepines, many FMS/CFS specialists prefer Klonopin/clonazepam.
10. *Usual opinion is that we should not combine different sleeping pills to be taken at the same time.* Again, the rule often makes sense, but there are times when it may not, especially for people who tend to get side-effects at standard dose levels of many medicines. Combining several different types of medicines and/or herbs at low doses sometimes adds effectiveness while minimizing drugs' side effects.

One combination that's sometimes useful is a low dose of a tricyclic antidepressant plus the benzodiazepine, Klonopin. Another might be a short acting sedative e.g. Sonata or Halcion along with a longer acting medicine e.g. Ambien or trazadone. Another option: rotate several different medicines, so you won't get too used to any one.

(Caution: The more different medicines you take in a given day, the more potential there is for drug interactions. Remind your doctor to look up each interaction combination each time you add

a new medicine. Or get a PDR and look it up yourself. This can get complicated, though. And, many, possibly most potential interactions have not been studied systematically.

If you take nutrients or herbs, some health food stores and pharmacies have a computer data base on herb/nutrient/drug interactions. Healthnotes is one company that supplies this service. For example, Willner Chemist, the sponsor of the Willner Window Radio show I co-host on WOR radio in New York, has a computer with the Healthnotes data base. (See Willner.com)

11. *Many CFS/FMS patients react adversely to medicine doses that most others would tolerate.* If a medicine seems "too strong", consider trying it again at 10% to 25% of the previous dose. For example, the usual dose of a tricyclic anti-depressant for sleep is 10-30 mg at night (versus 75-150 mg when used for depression). However, the best dose for "sensitive" people might be 1 or 2 mg instead. The tricyclic, doxepin, comes as a liquid suspension, with a dropper bottle, so you can titrate down to 1 mg doses. Flexeril, usually used at 10-20 mg, sometimes does better at 1-2 mg.

(You can fold wax paper over the pill, smash it into powder, then estimate the dose e.g. 10% of the powder made by the pill.)

12. *Many medicines that are not normally used to help sleep may, nevertheless, have sleep enhancing effects, at least for some persons e.g. the anti-histamines Benadryl, Unasom* Or they may help indirectly such as by suppressing pain e.g. ibuprofen, Relafen, Ultram, Celebrex. Also useful in some are medicines that are normally used for entirely different purposes. For example: Zanaflex or Baclofen—which reduce muscle spasm in multiple sclerosis medicine; Zofran—an anti-nausea medicine; Neurontin or Gabapril—anti-seizure medicines; perhaps also Dextromethorphan—the "DM" cough medicine.
13. *If you are also depressed or anxious or tend toward rapid, shallow chest breathing (hyperventilation syndrome) then any form of anti-depressant is likely to improve sleep after a month or so of steady treatment. This will be true whether or not the medicine helps or hurts sleep during the first days or week. Thus, antidepressants such as Prozac or Wellbutrin, tend to over-stimulate during the first days of treatment. They can worsen anxiety and insomnia, especially if you take them later in the day. However, over several weeks as their anti-depressant effect takes hold, these medicines then act to improve sleep and to lessen anxiety.*

In contrast, sedating anti-depressants such as *Elavil, Trazadone and Remeron* may help sleep within days, even at fairly low doses, long before the 4 to 8 weeks it may take to have a direct affect on depression. If you are not depressed, anxious or prone to disordered breathing, then *Elavil, etc.* are still likely to help sleep, but stimulating antidepressants like Prozac or Wellbutrin are not likely to help, even after a month.

(Suspect depression if there is loss of enthusiasm; suspect anxiety if you feel nervous or tense; suspect hyperventilation syndrome if you feel dizzy while seated, light headed, brain fog, or if symptoms worsen within seconds after rapid breathing or with exertion.).

14. Most FMS and CFS patients should ask their doctors to use lower doses than usual, when they start treatment. That reduces the severity of side effects and makes it more likely you'll be able to build toward effective doses.

Another option with stimulating medicines like Prozac is to temporarily add a benzodiazepines such as Valium, Ativan, Xanax, or Klonopin to be used intermittently as needed until your body becomes accustomed to the new medicine, and the over-stimulation begins to fade. Unless there is a personal or family history of drug abuse, the risk of addiction or psychological dependence is minimal, since you would only be using these tranquilizers for two or three weeks at most, until the body gets used to the anti-depressants.

15. *While controlled studies are limited, some patients report benefit from various "natural" or "alternative" vitamins or herbs.* These are relatively safe and may be worth a try. But be wary of interactions with drugs e.g. 5 hydroxy tryptophan should not be mixed with Prozac or with St. John's Wort.

A More General Approach for Holistic Support of the Body's Natural Healing Systems

Until we find a "magic bullet" that specifically cures FMS/CFS, we may find important value in identifying and removing obstacles that may block the body's natural mechanisms for healing. We call this a functional or integrative or holistic or complementary/alternative approach.

Holistically-oriented physicians believe that all the body's mind and body systems interact and communicate in a complex web of interactions. Strengthening any part of our physiology, we hope, can feed through and improve healing functions in other parts as well, therefore, supporting healing overall. I discuss this in further detail on the FMS and CFS pages of our website (DrPodell.org)

For example, "adaptogenic" herbs such as Rhodiola, Cordyceps, Ginseng, and Ashwaganda may improve the general ability to resist physical stress. No formal studies of this approach have yet been reported for CFS or FMS. However, anecdotal reports by clinicians have been encouraging.

Other holistic approaches that may help: re-train slow, deep diaphragmatic rhythmic breathing (which is abnormal and causes symptoms in at least 50% of persons with severe CFS/FS); reverse the increased loss of magnesium that typically occurs with CFS; supplement anti-inflammatory omega-3 fatty acids/fish oils; improve digestive function; improve liver detoxification function; improve the crucial biochemical pathways of methylation—the folic acid/vitamin B 12, S-adenosyl Methionine pathways; identify specific food sensitivities such as gluten or sugar; optimize hormones such as thyroid, adrenal, testosterone, growth hormone, and DHEA.

The following table provides an overview of the medicines that are most commonly used and/or most often helpful for improving sleep among people who suffer from FMS and/or CFS. Use this table to generate ideas for potential treatments that you can discuss with your physician.

Commonly Used Medicine for Sleep

Class	Medicine	Prominent Side Effects	Selected Drug Interaction	Comments
Tricyclic antidepressants	Amitryptiline/Elavil. Doxipin, Nortipityline/pamelor	Long sedation: dry mouth, rapid heart, difficulty urinating, Weight gain, heart arrhythmia, depression to manic phase	Drugs metabolized By 2D6 liver detox Path e.g. cimetidine, Quinidine, some SSRIs. Do not use with MAO inhibitors	Especially useful for sleep maintenance, fibromyalgia, caution of heart arrhythmia
Antidepressants	Trazadone (Desyrel), Serzone Remeron	Dry mouth, heart Arrhythmia, Prolonged erection (priapism)	Digoxin, phenytoin	Can help fibromyalgia
Muscle relaxer	Cyclobenzaprine / Flexeril	Dry mouth, dizziness	Like tricyclics	May help FMS
Benzodiazapines	Clonazepam/ Klonopin / Temazepam / Restoril, lorazepam / Ativan, Triazolam / Halcion- short-acting	Tolerance, habituation, Amnesia while taking it, respiratory depression	Different drugs of this class interact adversely with specific SSRI anti-depressants.	Can help PLMD, duration of sedation varies. Don't give if emphysemic.
Sedating antihistamines	Benadryl, Unasom	Sedation, dry mouth, urine obstruction	Phenothiazines, MAO inhibitors	Over-the-counter
Non-benzodiazepine hypnotics	Ambien/zolpidem, Zafepion/Sonata (short acting)	Dizziness, amnesia, anxiety	Sertraline, rifampin, cimetidine	May be habit forming with prolonged use of high doses
Anti-seizure Medicines	Neurontin/gabapentin	Dizziness, sedation, high blood pressure	Cimetidine (Tagamet) modestly increases blood levels of Neurontin. Antiacids reduce absorption.	Probably for migraine, FMS and as a mood stabilizer

Multiple Sclerosis Medicines	Zanaflex (tizanidine)	Low blood pressure, Sedation, liver function Abnormalities	Relatively minor	May be useful for FMS, migraine; obtain periodic liver tests
NSAIDs	Aspirin, ibuprofen, Celebrex, Vioxx	Gastritis, G-I bleeding, allergic reaction, kidney problems, fluid retention	Coumadin and others	May help sleep by reducing pain; a few benefit even if no pain

Herbal / Nutritional Supplements That Might Help Sleep

Melatonin	0.5 mg to 6 mg 1 to 5 hours before sleep; more likely to help night owls, or elderly
5-hydroxytryptophan	Helps sleep onset; do not mix with SRRI anti-depressants or St. John's Wort or MAO inhibitor
Valerian Root	Mediocre when used for single nights, fairly effective at 300-600 mg. at night over 2-3 weeks.
Hops, Lemon Balm, passion flower, skullcap, calcium, magnesium, inositol	Anecdotal helpful; few good studies
Lavender extract as aroma therapy	Relaxes, probably beneficial

Principles of Sleep Hygiene

<ul style="list-style-type: none"> ▪ Discuss whether medicines might be disrupting sleep e.g. decongestants, diet pills, stimulating antidepressants. Also evening caffeine or alcohol. ▪ Keep sleep schedule regular. Shifting sleep time disrupts sleep. Create a habit pattern of staging down activities throughout the evening. This helps condition your body to "expect" to be able to sleep. Consider turning the TV off early. Try music or dull reading. ▪ Keep the bedroom dark and quiet and the mattress comfortable. Leave marital conflicts outside. ▪ Bed should be used only for sleep and sex. Move to a chair or couch when not engaged in either. ▪ Clear your mind of the past day's events and the next day's worries e.g. write down your regrets and plans, then lock them in a drawer so you can go back to them tomorrow. ▪ Don't exercise just before bedtime. Even relaxing medication might alert you too much for sleep. ▪ Consider a hot bath in the early evening. Heat initially prompts alertness; drowsiness then follows as your body temperature drops. ▪ Take a modest carbohydrate snack or warm milk before sleep. This promotes drowsiness for some. ▪ Use relaxation tapes, imagery, slow diaphragmatic breathing or meditation. ▪ Use ear plugs if there's too much noise, eye shades if there's too much light. ▪ Use white noise e.g. a fan or calm music to soothe out and block unwanted sounds.
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Behavioural Techniques for Sleep

Technique	Comment
Sleep restriction / consolidation	Restrict total time in bed to 4 hours or less, whether you actually sleep or not. Over a few days you should find yourself consolidating more sleep into the available time. As the proportion of time sleeping increases extend the time allowed in bed.
Paradoxical Intention	For some, trying to stay up later may hasten sleep.
Relaxation skills	Diaphragmatic breathing, visual imagery (e.g. counting sheep) muscle relaxation
Cognitive Behaviour Therapy (See also various books under the name of Feeling Good, by David Burns, MD, a psychiatrist who has produced a workbook version of CBT on can do on one's own.	A form of brief psychotherapy that works to improve coping skills e.g. not turning molehills into mountains. Controlled studies show that persons with CFS/FMS who do several CBT sessions do better 6 months comparably ill person who do not. Also benefits rheumatoid arthritis and other "non-controversially" physical ailments.

2003 BCCA 306 Balzer v. SunLife Assurance Company of Canada

For more information, contact **Wai Cheung at Pierce Law Group, (604) 681-4434.**

On Friday October 31, 2003, the B.C. Court of Appeal confirmed the right of a disabled Abbotsford woman to continue her law suit against Sun Life, her disability insurance company.

Betty Balzer was a florist at Canada Safeway until she became disabled because of breast cancer, arthritis, and fibromyalgia. She has been disabled since 1992.

Sun Life refused to pay after October 1994, and wrote her a number of letters offering to reconsider her case if she had more medical information. She hired a lawyer in 2000, and a law suit was started. Sun Life claimed she had waited too long to sue, even though in all the letters sent to her, Sun Life never said the clock was running or that she had to do anything other than provide the medical information Sun wanted.

Ms Balzer's lawyer, Wai Cheung of the Vancouver law firm Pierce Law Group, said: "Up to now, the rule had always been that there was a one year limitation on these kinds of suits but Mrs. Balzer's case changes all that. This is a very important decision for possibly hundreds of people in British Columbia who have not been paid by their disability insurance company".

Ms Balzer's law suit will be set for trial in the Vancouver Supreme Court in 2004, and she will ask the court to order punitive damages against Sun Life for bad faith. Sun Life has denied that she is disabled, or that any damages should be awarded.

The Supreme Court Rules on Chronic Pain Syndrome

**M^e Marianne Bureau and M^e Michel Gilbert, Lawyers
Grondin, Poudrier, Bernier**

On October 3, 2003, the Supreme Court of Canada rendered a judgement in a case which will be known as *Nova Scotia (Workers' Compensation Board) v. Martin*.

It dealt, for the first time, with the fate of persons suffering from chronic pain, at the administrative and governmental level as well as in society in general. Here is a brief résumé of the situation.

Two employees of different companies sustain work-related injuries. After the usual recovery period for this type of injury, there is still significant pain which prevents the employees from returning to work. The diagnosis is chronic pain.

The *Workers' Compensation Board of Nova Scotia*, the equivalent of Quebec's CSST, refuses to pay any compensation for their loss of revenue in accordance with a statutory disposition that excludes chronic pain from compensation.

The regulation only provides these persons with a functional rehabilitation program lasting a maximum of four weeks. After this period, the employees are not eligible for further benefits which would be available to any other person who sustains work-related injuries. Thus, besides the fact that they are deprived of compensation of revenue, they are also ineligible for a settlement for their medical expenses, nor do they receive adaptability measures or vocational rehabilitation services.

The two employees then claimed that the regulations concerning their case violated their right to equality guaranteed by Article 15(1) of the Canadian Charter of Rights and Freedoms, regardless of any discrimination, notably those based on mental and physical handicaps.

The Supreme Court agreed with the employees' arguments and judged that the aforementioned regulations violated Article 15(1) of the Charter, and in addition, that these regulations could not be justified within a free and democratic society.

To begin with, the Court ruled that the contested regulation provided a different treatment for

persons with work-related injuries who suffer from chronic pain, compared to all other employees suffering from a work related injury, and that it constituted a distinction based on a handicap.

Also, the Court determined that this distinction was discriminatory, because it eliminated all possibility that persons suffering from chronic pain could undergo a personal assessment of their condition and of their residual capabilities.

The Court also judged that, by its special treatment of persons suffering from chronic pain, the Nova Scotia agency was perpetuating stereotypes about the legitimacy of their suffering.

The Supreme Court concluded by expressing the opinion that the agency's goals related to money (budgetary considerations; fraud prevention) and administrative function (ensuring consistent legal outcomes, prompt medical intervention and expedient return to work) could not, in a free and democratic society, infringe upon the rights of the concerned parties to equal treatment.

It is to be hoped that the Supreme Court's decision will help to decrease the prejudices which may affect persons with chronic pain and to advance the cause of illnesses which are said not to be objectively verifiable, based exclusively on the complaints of the patient.

[Ed. Note: Published with the permission of the lawyers and the Quebec ME Association (AQEM)
Source : AQEM's newsletter " Le ruban bleu", vol. 11, no. 1, English version M. Gilbert and M. Bureau are both on our National Roster of Lawyers.]

IME/FAD Registry Submissions

The **National ME/FM Action Network** continues to urge those who have attended an Independent Medical Examination (IME), Functional Abilities Evaluation (FAE) or any other form of assessment at the request of an insurance company, Canada Pension Plan (CPP) or WSIB to fill out our 7 questions, confidential, independent medical examination Registry Submission Form so that the names of the doctors and healthcare professionals who evaluated you can be put on record.

Patients, doctors, lawyers, advocates, support groups wishing to receive a copy or copies of the Form, or to inquire about specific IME doctors, please contact: **Mary Ellen, Manager Special Projects, Mail: P.O. Box 66172, Town Centre Postal Outlet, 1355 Kingston Rd., Pickering, ON L1V 6P7** – Phone or Fax: **(905) 831-4744** – Email: **marye@pathcom.com** – Or download the Form from our website at **www.mefmaction.net/medexac.html**.

OUR WORLD

HUMOR: THE LIFEBOUY OF DESPAIR. DESPAIR IN PERSPECTIVE. Lorraine Legendre, Ottawa.

RESOURCE BOOKS:

- ***Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols (Journal of Chronic Fatigue Syndrome, Volume 11, Number 1, 2003)*** is available for **U.S. \$14.95** per copy plus \$5.00 Shipping and Handling. To order, contact **The Haworth Press, Inc.**, 10 Alice Street, Binghamton, NY 13904-1580 USA. Telephone in US/Canada: **(800) 429-6784**, Telephone outside **US/Canada: (607) 722-5857**, fax: **(607) 771-0012**, email: **orders@haworthpressinc.com** **Online: <http://www.haworthpressinc.com/store/product.asp?sku=4958>**

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- **QUEST COLLECTION" BOOK - FIVE YEARS (1993 TO 1998)** : By popular request, the **National ME/FM Action Network** has published an easy to read book consisting of a **collection** of important articles which have appeared in our '**QUEST**' newsletters over the years. For easy reference, these articles have been grouped into sections according to their focus of medical, legal and advocacy. **Cost: \$20.00.**
- **QUEST Collection II: 1999 to 2003:** Will be available shortly. Cost: **\$38.00.**

- **TEACH-ME - Sourcebook for Teachers:** An educational resource book full of information and teaching strategies for teachers and parents of children and youth who have ME/CFS and/or FMS – Cost: **\$22.00** Discount on bulk orders.

Please also see our youth and parents' pages on our website at: **www.mefmaction.net**

- **NEW: NOW AVAILABLE FOR PURCHASE: The Canada Pension Plan Disability Benefits Guidelines:** New up-dated guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. Understand the criteria, important items to include and how to proceed through the various steps of the process. – **Cost \$7.00**

- **Legal Disability Manual:** Extensive revisions, updating, and new articles have been added to the new Legal Disability Manual. Sections include: FMS and ME/CFS Overview; The Medical Report and Expert Witnesses; Independent Medical Examinations; CPP Disability Benefits, Disability Insurance and Other Legal Articles; Case Law; Psychological Factors, Tests, and Treatments; and Research Abstracts. Many of the articles have been written specifically for the **National ME/FM Action Network** by lawyers and doctors. Our new Canada Pension Plan Disability Benefits Guidelines are also included in the Legal Disability Manual. This manual is a must for those in litigation. AVAILABLE FOR PURCHASE SHORTLY. **Cost \$50.00**

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