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ME/CFS Post-Exertional Malaise / Fatigue and Exercise

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Post-exertional malaise and/or fatigue of inappropriate severity can temporarily immobilize the patient and worsen her/his symptoms following normal physical or mental activity. It takes the patient an inordinate amount of time to recover – 24 hours or more.(1,2,3,) De Becker et al (4) assessed 2073 consecutive patients with major complaints of prolonged fatigue. Of the 1578 patients that met the Fukuda criteria,(2) 97.3% had post-exertional malaise with a severity of 2.7 out of three. Of the 951 who met the Holmes criteria,(3) 98.8% had post-exertional malaise with a severity of 2.8 out of 3. Post-exertional malaise and/or fatigue are necessary criteria in the Clinical Case Definition for ME/CFS.(1)

Even though post-exertional malaise is a hallmark feature of ME/CFS, exercise programs are often prescribed with little thought to the effect they may have on patients. The panel of experts for the ME/CFS clinical consensus document(1) stressed that a thorough evaluation of patients and their total illness burden, optimizing medical management, and a careful evaluation of pain generators and risk factors must be done before even considering an exercise program. As much care must be taken in prescribing appropriate exercise for ME/CFS patients as in prescribing pharmaceuticals.(5)

ME/CFS patients do not respond to exercise in a manner that is expected of healthy people. The following chart summarizes some of the abnormal reactions to exercise which ME/CFS patients often experience.

Response to Exercise	Healthy People	ME/CFS Patients
Sense of well-being	**Invigorating Anti-depressant effect**	**Feel malaise, fatigue and worsening of symptoms**
Resting heart rate	**Normal**	**Elevated**
Heart rate at maximum workload	**Elevated**	**Reduced heart rate**
Maximum oxygen uptake	**Elevated**	**Approximately ½ of sedentary controls**
Age-predicted target heart	**Can achieve it**	**Can NOT achieve it**

rate		
Heart functioning	**Increased**	**Sub-optimal level**
Cerebral blood flow	**Increased**	**Decreased**
Cerebral oxygen	**Increased**	**Decreased**
Body temperature	**Increased**	**Decreased**
Respiration	**Increased**	**Breathing irregularities: Shortness of breath, and irregular breathing**
Cognitive processing	**Normal, or more alert**	**Impaired**
Recovery period	**Short**	**At least 24 hours but can last days or even weeks**
Oxygen delivery to the muscles	**Increased**	**Impaired**
Gait kinematics	**Normal**	**Gait abnormalities**

1. ME/CFS patients have lost the anti-depressant effect of exercise, and it can make them feel worse. Healthy people or those who are depressed receive an increased supply of blood and oxygen to the brain during exercise and they feel better afterwards. ME/CFS patients receive less blood and oxygen to the brain making them feel worse after exercise.(6,7)

2. While ME/CFS patients have elevated resting heart rates on average, they have a significantly reduced heart rate at maximum workload and an inability to reach the age-predicted target heart rates.(8,9) The maximum oxygen uptake and maximum workload attained by ME/CFS patients was only approximately half that of sedentary controls.(8) **As this could be due to the heart functioning at a sub-optimal level and/or autonomic disturbances, patients should not be pushed towards age-predicted target heart rates,(9) as this is potentially dangerous!**

3. **ME/CFS patients have hypoprofusion in specific areas of the brain.(10) SPECT scans indicate that exercise causes a further marked decrease in cerebral region blood flow, and a worsening of symptoms.** Goldstein(11) used a SPECT scan to test pre-exercise and post-exercise hypoprofusion of the brains of CFS patients. There was resting hypoperfusion in the anterior temporal lobes (more often in the right) and hypoperfusion in the prefrontal cortex. SPECT scans done both the same day after exercise and the following day showed there is usually a much greater degree of hypoperfusion after exercise.(11) This effect is the opposite of normal.

4. Body temperature normally increases with exercise. **In ME/CFS patients, body temperature usually decreases in response to exercise,(7) which is the opposite of normal**.

5. **ME/CFS patients usually experience breathing irregularities during or immediately after exercise.** Shortness of breath and irregular breathing are most common.(7) Automatic respiration is regulated by the limbic system.

6. **Cognitive processing becomes more impaired in response to challenging physical exertion.**(12)

7. **Recovery period is prolonged.** It takes at least 24 hours but can take several days or weeks or even longer to recover.(4) A long recovery period after exercise is included in the criteria for ME/CFS.(1,2,3)

8. **Orthostatic intolerance, low circulating blood volume and blood pooling in the legs often play a role in post-exertional malaise and fatigue**.(13)

9. **Significantly impaired oxygen delivery and consumption levels during exercise have been reported**.(8)

10. **Gait abnormalities have been found in ME/CFS patients when compared to sedentary controls**. These abnormalities may be due to balance problems, muscle weakness, or central nervous system dysfunction.(14)

Research studies on graded exercise for ME/CFS vary greatly in their inclusion and exclusion criteria and many subjects do not meet the criteria for ME/CFS. In the study by Fulcher and White,(15) which compared aerobic exercise to flexibility therapy, patients who had considerable sleep disturbance were excluded. This is puzzling, as sleep disturbance is a necessary criterion in the clinical definition.(1) In the De Becker et al study,(4) 94.8 of the 951 patients meeting the Holmes criteria(3) had sleep disturbance of 2.5 out of 3 average severity, and 91.9% of the 1578 patients meeting the Fukuda criteria,(2) reported sleep disturbance of an average of 2.4 out of 3 severity. This raises the question as to whether the results of the Fulcher and White study even apply to ME/CFS patients. Most of the graded exercise studies reviewed by Whiting et al,(16) used the Oxford criteria which are much less restrictive. Patients who meet this less restrictive definition may include patients who respond to exercise more positively and have a much better prognosis than those who meet the more restrictive criteria for myalgic encephalomyelitis / chronic fatigue syndrome. In a systematic review of prognosis of numerous studies, Joyce et al(17) concluded that the less stringent the criteria, the better the prognosis. Therefore, it is of the utmost importance that patients meet all the criteria for ME/CFS or the validity of the study is in question.

In a British study,(5,18) 1214 of 2338 ME/CFS patients had tried graded exercise. Of these 417 found it to be helpful, 197 reported no change and **610 (50%) indicated that it made their condition worse. This was the highest negative rating of any of the pharmacological, non pharmacological and alternate approaches of management covered in the questionnaire and may help explain the high drop out rates noted in some of these programs.**

It is essential that the treating physician and all other personnel involved with treatment programs are very knowledgeable about the more discriminating criteria for ME/CFS, the biological reality of the illness with it severe and fluctuations of symptoms and activities boundaries, and the overload phenomena. As the treating physician knows the patient best and s/he is responsible for the patient's ongoing care, s/he should oversee any exercise/rehabilitative programs. Exercise must be individualized to accommodate the patient's total illness burden, and fluctuation in severity and triggers of exacerbation. The patient must have autonomy over the pacing of any exercise program and be able to incorporate rest periods as required. Great care must be taken in order that patients do not exceed their activity boundaries, which fluctuate, as this can cause post-exertional relapse. The consensus document, "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols"(1) has an excellent section on the goals and guidelines for individualizing ME/CFS exercise programs.

Bruce Carruthers, MD, CM, FRCP(C), kindly reviewed this article for medical accuracy. Dr. Carruthers was lead author of the ME/CFS Consensus Document and co-editor of the FMS Consensus Document.

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Disability Insurance

Norm Cuddy, Lawyer

(This article first appeared in "FMS Today, Volume 10, No. 1 Fall 2003, the newsletter of the Winnipeg Fibromyalgia Support Group Inc., 825 Sherbrook St., Winnipeg, MB R3A 1M5 - (204) 975-3037)

A great many people are insured for disability through their employment. In some cases, the employee pays for their own insurance and, in others, the employers pay for disability insurance as part of an employment package. In turn, the employer contracts with a disability insurer, who then issues a policy of insurance covering all employees.

This policy of insurance, which is often termed "peace of mind insurance", is designed to provide benefits in the event an employee is injur3ed or becomes ill and is unable to continue with employment.

There are about six major carriers of disability insurance and they all issue policies that are fairly similar. Usually for the first two years, an employee is considered disabled if they are unable to perform their own job. After the first two years, a person is only considered disabled if they are unable to perform any job for which they have the training and aptitude.

The Courts describe disability policies as policies of "ultimate good faith". This means that insurance companies have an obligation to deal with claimants fairly, objectively and without favoring their own interests over that of the claimant. This is where the system of disability insurance breaks down.

In a November 2002 edition of 60 Minutes on CBS, Ed Bradley reported on the practices of UNUM Provident, a giant disability insurance carrier in the United States (UNUM as well issues policies in Canada). In that story, 60 Minutes reported that UNUM was intentionally denying claims to meet financial goals without reference to whether claimants were actually disabled or not. Supervisors were instructing claims managers to terminate legitimate claims, resulting in savings of somewhere between $7 million and $14 million per month to the company.

Insurance companies use various strategies to deny claims. The most usual is a very well worded and comprehensive letter which advises the claimant why they are not entitled to benefits. The letter will quite often contain the terms "no objective evidence of disability" or that the claimant is "capable of performing light sedentary work" or that the recent independent medical examination "does not support continuing total disability".

The terminology used in these letters is rarely, if ever, found in the policy. There is no requirement that claimants provide "objective evidence of disability", and it is recognized that in disease syndromes such as fibromyalgia, which are subjective in nature, there can be no objective evidence. Pain cannot be measured objectively.

Insurance companies like to use independent medical examinations performed by either physical medicine physicians or functional capacity evaluations performed by occupational therapists to prove that an individual is capable of performing certain types of light activities. Once again the insurance companies skew the information in their own favour as the issue is not whether someone can pick up a five pound weight, but whether they can pick it up on a regular basis, go home and get a night's sleep, and be able to come back to work and do the same the next day.

The response of the Courts has been very much in favour of claimants. Judges who hear disability claims almost always recognize that the claimant is legitimately disabled and that the insurer has twisted language to meet its own ends. As a result, disability insurers are almost never successful in Court and rarely take cases to trial as they are aware that they will lose.

In response to the policies and practices of insurance companies, the Courts have begun to award what are known as "aggravated" and "punitive" damages. Aggravated damages are awarded in disability claims to compensate the claimant for the aggravation and frustration that results in having income terminated. As the Courts have recognized that disability insurance is designed to ensure peace of mind, when the insurance company refuses to comply with its obligations, there should be compensation.

Of even more significance are the bad faith judgments which have been coming from the Courts in Canada. In cases where insurance companies have deliberately ignored the evidence which supports disability or acted maliciously or dishonestly in dealing with a claimant the Courts will award punitive damages to punish that insurance company and to hold them up to an example in the community of inappropriate behavior. These awards of damages may be up to a million dollars. The possibility of such an award makes insurance companies increasingly eager to settle cases without proceeding to trial.

For anyone who is dealing with a private insurance company, the most important thing to remember is never take no for an answer. Insurance companies proceed on the assumption that if they deny one hundred claims and only ten of those one hundred retain lawyers and sue them, they have already won.

The other ten claimants, the ones who retain lawyers and contest the insurance company's decision, will have their cases settled on favorable terms.

The strategy for a claimant who is denied coverage then is obvious. You should make sure that you are one of the ten who does not take no for an answer.

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NBC's "American Dreams" Dramatizes Polio Survivor's Nightmare

Dr. Richard L. Bruno, *Chairperson of the International Post-Polio Task Force and Director of The International Centre for Post-Polio Education and Research, is co-writing episodes of NBS's award-winning series "American Dreams" (Sundays, 8 PM ET) about the pain of having polio as a child and one polio survivor's battle to become "normal'" at any price.*

"American Dreams' tells the story of the turbulent 1960s, their pain and promise, through the Pryor family,". The Pryor's younger son, nine-year old Will, was not vaccinated against polio because Will's father feared that the vaccine would give him polio. "We believe it is important to tell the story of North America's nearly 2 million polio survivors through that of our nine-year old Will and his parents' desire for him to get rid of his brace, even tough it will mean complicated surgery and painful physical therapy."

"The original experience of polio and its paralyzing aftermath were terrible by themselves," Bruno said. "But polio survivors experienced even more horrors." In Bruno's 1995 International Survey polio survivors reported 34% more physical abuse and 94% more emotional abuse than those who did not have polio. "All of that 'extra' abuse was the result of looking physically disabled and people's fear of 'catching' polio," said Bruno. "So parents wanted to get rid of any evidence of polio -- like the Pryors wanting to remove Will's brace -- and to make children appear 'normal'." Twenty percent of polio survivors in the Survey had orthopedic surgeries and were hospitalized for an average of six months.

NBC has also agreed to air a PPS public service announcement with the "American Dreams" cast. "We're eager to continue spreading information about polio and PPS in the years to come on 'American Dreams,'" said Prince.

For information about polio and Post-Polio Sequelae go to Illnesses in the Menu and then Post-Polio Sequelae **http://www.postpolioinfo.com/postpolio**
[Ed. note: Dr. Bruno is the Honorary Adviser to the National ME/FM Action Network for Polio and Post Polio Sequelae (PPS). He was one of the two keynote speakers at our International Symposium on Parallels Between PPS, ME/CFS and FMS held June 15, 2002. A limited number of videotapes of the Symposium is still available from our Network at $30.00 per copy.]

Press Release: September 5, 2003

Judy Day, a medically retired registered nurse, health care activist and patient advocate, living in St. John’s, Nf. & Lab., believes she was the victim of medical malpractice and has sued the doctors and the hospital board involved. Five years have passed since her lawyer filed the statement of claim in the Supreme Court. Finally, the trial date is set for November 12, 2003. After spending over $15,000 the first year on legal fees and being advised to discontinue the claim, Ms. Day decided to proceed with the lawsuit on her own. Since then, she has represented herself in four court appearances.

Ms. Day believes that the diagnosis of manic depression, placed on her when she was 50 years old, after suffering psychosis due to a toxic drug reaction, is incorrect. In addition, the treatment that was forced upon her due to that misdiagnosis has created further problems for her true condition, that of Fibromyalgia, (FM) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Multiple Chemical Sensitivities (MCS).

Ms. Day led an active and successful life prior to that unfortunate diagnosis. A diagnosis of manic depression at that age is unusual. The prescribed treatment of a drug called Lithium caused a rare side effect “permanent peripheral neuropathy,” irregular eeg’s, ekg.'s, thyroid antibodies and exacerbated her symptoms of Fibromyalgia. Test results show a moderate to severe memory loss and so she is unable to continue in her previous profession as an operating room nurse educator or in any new career based upon her skills and abilities.

“Clinical clerks and residents, who are given a huge responsibility in the management of patients, make erroneous notes and statements on patients’ files because these notes are hastily written, without really knowing the patient.” For this reason, Day is advocating a computerized health history system for the country.

Ms Day is also critical of a system that seems to exist to protect the integrity of the medical system by refusing to recognize that physicians may act negligently and that patients suffer as a result. “The medical litigation system is structured so that claims made against doctors are handled by one, their 'own', insurance company, 'The Canadian Medical Protective Association.' The CMPA generally fights all cases to the bitter end, resulting in costs that are often prohibitive to the injured party.”

Mental health cases are more difficult than other cases to win because the credibility of the victim is in question. A 1910 statement of a judge in the British Court of King’s Bench is still cited by legal experts here in Canada. The statement claims that a lawyer who represents a person with a serious mental disability does so at his own risk. Ms. Day understands now why she had so much difficulty obtaining legal council.

Because the test for negligence requires that a particular doctor must fail to meet the standard of a reasonable physician in the same circumstances, these cases are often difficult and costly to prove. There are no written standards of medical practice, just schools of thought that may differ from physician to physician.

The legal assistance generally requires that the injured party pay expenses of the litigation, as they are incurred, not on a contingency basis, so most people will give up battling with a multi-billion dollar insurance company.

Judy continues the battle with a one in four chance of winning, so that in the future, treating physicians will take more seriously approximately 500,000 Canadians suffering from FM, ME/CFS and MCS. According to statistics, 68% of these patients get diagnosed with a mental disorder before receiving a proper diagnosis and treatment.

In the meantime, Ms. Day continues to use most of her energy and resources in a battle to win damages for the impact of the mistaken diagnosis, imprisonment in a mental institution and incorrect drug therapy. " I went through hell. Hopefully, I can help prevent other people from ever having to experience such unnecessary torture and pain."
Written by **Judy Day, 7 Manchester Street, St. John's, Nl, Canada tel/fax 1-709-754-0036**

PARLIAMENTARY SUB-COMMITTEE REVIEWS CPP(D)

John Wodak, MA, PhD

Background

Last year the Parliamentary Sub-Committee on the Status of Persons with Disabilities (chaired by Dr. Carolyn Bennett, MP) reviewed the disability component of the Canada Pension Plan. The review included a highly successful "e-consultation" in which ordinary citizens were invited to submit their stories and suggestions via the Internet. The Sub-Committee's report can be viewed at http://www.parl.gc.ca/disability/. It includes several recommendations which are directly relevant to individuals with ME and/or FM, and it will be interesting to see how the federal government responds to them.

John Wodak is a member of the National ME/FM Action Network, an advocate listed on the National Roster of Advocates for the National ME/FM Action Network and affiliated with the M.E. Society of Edmonton, Alberta. He sent a submission to the Sub-Committee and was an invited participant at the Sub-Committee's Round Table discussion of CPP(D) on May 13th in Ottawa, Ontario. We are printing an abridged version of his submission below.

SUBMISSION

Accountability

For the purposes of CPP(D), the law of the land is stated in Section 44 of the *Canada Pension Plan*, which can be summarised as: Every applicant who has made sufficient contributions to the Plan and is disabled as defined in Section 42 **shall** be awarded a disability pension. There is no discretion allowed. This is the intent of Parliament.

Like all government departments, Human Resources Development Canada (HRDC) is accountable to Parliament, and discharges its responsibility in this regard by submitting an Annual Report to Parliament. Typically these Annual Reports answer the questions, "How Many (applicants/beneficiaries)?" and "How Much (money)?" but the answers give little insight if the question is, "How Well (is the Plan working)?" To answer the last question we need information on the accuracy of the assessment process: how many applicants who **are** disabled have been denied pensions ("false negatives") and how many who **are not** disabled have been granted pensions (“false positives”). CPP(D) is a social program; there should be social accountability. The goal of all persons who are involved in any way in the process should be to minimise the errors.

We do not know if this goal is being met because we do not have the data. As an advocate I can offer my subjective perception that there are too many false negatives, but I have no proof. HRDC has data from its reassessment initiative from which we can draw inferences about false positives, but with reservations because the process has been shown to be liable to error. External studies in the past, for example, conducted by the Auditor-General in 1996, have addressed issues of fiscal integrity but not social integrity. If any person or agency has investigated the question of false negatives, by conducting a follow-up study on the fates of denied applicants (or otherwise), the results have certainly not been widely publicised.

I note that Parliament has the authority - and probably the obligation - to define the criteria for “success” in government programs. Traditionally, the main criterion has been fiscal; if a program has met its budget target, it is successful. The preoccupation with dollars and cents has been intensified in the last ten years because of concerns about the deficit and national debt. I submit that this is not adequate for a social program which has, as its objective, the provision of support to severely disadvantaged citizens, and therefore suggest that Parliament order an independent study designed to assess whether CPP(D) is meeting its legislated goal.

There is another aspect of accountability which, I submit, should receive much more attention: process accountability. The combination of having the burden of proof on the applicant and a *de novo* review of the evidence at each stage of the application and appeal process means that a line is drawn after each stage; the previous decision(s) can be reversed, but they are never scrutinised or commented on. I have no problem with adjudicators who make honest, but wrong, judgement calls; but what recourse do applicants have from adjudicators whose decisions are clearly influenced by factors other than the evidence, or are absurd as they stand, or are consistently wrong? I have encountered all three types of decision, at all levels of the process. As far as I know, the adjudicators who made these decisions were never called to account and were allowed to continue their work.

Transparency

Many applicants for CPP benefits, perhaps a majority, are having their first ever direct encounter with a government bureaucracy, at a time when they are particularly vulnerable. The entry point for this encounter is the application: a total of five forms which require, for completion, the applicant’s name (five times), his/her phone number (five times), address (four times), birth date (twice), children’s names and birth dates (twice each), a description of medical condition with symptoms and impairments (twice; once from the applicant and once from his/her physician), and Social Insurance Number (seventeen times), all certified by the applicant’s signature (four times) and the physician’s signature (once). Surely there are less complicated ways of obtaining this information?

Provided with the application kit is a booklet, a “General Information and Guide to Help You Complete Your Application for Benefits”. Page 1 of this guide outlines the eligibility criteria for disability benefits, including this definition: **“Severe** means that you are unable to regularly carry out any gainful employment.” In earlier versions of the booklet the corresponding sentence read, “**Severe** means your condition prevents you from working regularly at any job.” For comparison, the complete wording of the definition in the Act is:

“A disability is severe only if by reason thereof the person in respect of whom the determination is made is incapable regularly of pursuing any **substantially gainful occupation**.” (*Emphasis added*)

For at least ten years, with very few exceptions, the phrase "substantially gainful" has been omitted from HRDC's information brochures, correspondence with applicants (including denial letters) and Ministerial submissions to Review Tribunals and the Pension Appeals Board. Initially the department could have explained the omission as a simplification of the language in the legislation. However, the same omission began appearing in appeal decisions at both the Review Tribunal and Pension Appeals Board levels, where consistency with the legislation is essential, and two decisions were referred back to the Board after judicial reviews (*Mervyn Martin v. The Minister of Human Resources Development, 1999;* and *Guissepe Villani v. The Attorney General of Canada, 2001*). The implied message in these two decisions is very simple: HRDC has a duty to represent the legislation accurately and completely. (I have a copy of a denial letter written in 1997 in which "prolonged" is explained as "likely to be permanent".)

Responsiveness

I have no direct information about the process used by the department for assessing applications, but I assume:
There is a standard procedure which all adjudicators are expected to use, and
This procedure is based on the 1995 policy directive #04/95–CPP-03, "Medical Determination of Disability under the Canada Pension Plan".

This is the so-called "medical model" of disability, in which the determination of disability relies heavily on the assumption that there is a close correlation between medical diagnosis and level of disability. In practice it is not always valid (if it were always true, outstanding individuals like Christopher Reeve and Stephen Hawking would be incapable of work).

To say that "disability" encompasses an enormous variety of people and conditions is stating the obvious. I believe that the framers of the legislation may have deliberately left vague the portions of the Act dealing with the determination of disability (in contrast to most of the Act) for precisely this reason. It is also plausible that the information which applicants are required to submit includes details of their education, employment and activities of daily living in addition to their medical histories. Therefore, while it makes some sense to apply the "medical model" to all incoming applications, this should simply serve as a screen to separate the unambiguous from the ambiguous, with a more searching scrutiny subsequently being given to the latter. I see no evidence that this is being done.

A determination of disability which does not consider the whole person and his/her circumstances in their entirety , assessed against the complete definition of disability as stated in the legislation is, in my opinion, simply unacceptable.

A responsive organization would have recognised the significance of the *Densmore* decision and incorporated it into its standard review procedures. It would certainly not, almost ten years after the event, continue to demand non-existent evidence. Similarly, it would have acknowledged the *Martin* and *Villani* decisions by including "substantially gainful" (or an equivalent phrase) in its literature and correspondence. I can cite two other examples: a 1997 policy directive (#16/97–CPP-09) used a case definition for Chronic Fatigue Syndrome which had been obsolete for three years; and as recently as 1999, HRDC staff conducting reassessments were, in effect, requiring beneficiaries to prove they were still disabled, in spite of a series of Pension Appeals Board rulings from 1996 on that in reassessments the burden of proof shifts to the Minister.

Concluding Comments

It is evident from the variations in approval rates that the interpretation of "severe and prolonged" changes with time, and it is interesting to speculate on the factors which influence these changes. One would hope that advances in medical science and improved understanding of the conditions which can lead to disability (and their treatment) will play a part (the recognition of the effects of Multiple Sclerosis is an obvious example). Precedent-setting decisions of the Pension Appeals Board and, less frequently, those of the Federal Court (arising from judicial reviews of the Board's decisions) are obviously important as well, and it seems very likely that government policies also play a significant role. Thus, the decrease in the approval rate from 1994 onwards can be seen as the federal government's response to the marked increase in applications and approvals in the previous two or three years and the "fiscal imperative" of the perceived need to control the deficit.

At Pension Appeals Board hearings the average appellant is heavily outgunned in terms of resources, legal expertise and information. One can therefore visualise decisions in which legal technicalities are resolved in favour of the Minister with the result that, over time, the accumulated precedents will gradually "raise the crossbar" governing approvals. Periodically there is a case which results in a major review and the crossbar is pushed down again. (The *Leduc* decision in 1988 was one such, and the *Villani* decision in 2001 is another.) If this is a correct perception, I predict the cycle will now begin to repeat itself.

A factor which I have never seen discussed in the context of the determination of disability is the prominence given to the work ethic in our society's value system, which implies that there is something seriously wrong with someone who could work but does not wish to do so. I will mention here that I have never met anyone who did not apply for CPP(D) in good faith. It is difficult to believe that a sane person would fake disability for the amount of money involved in a CPP disability pension. It is even more difficult to believe that a person could do so successfully for any length of time.

The determination of disability requires that the adjudicator make a judgement call, and this is the source of a fundamental problem. To the average citizen, the thought that there is a "faceless bureaucrat", who is going to make a judgement call affecting him or her as an individual, is profoundly distasteful. (Tax collectors throughout the world are very familiar with this reaction.) Nor, in my experience, is the distaste significantly alleviated at the higher levels of appeal (Review Tribunal and Pension Appeals Board), where the applicant meets the adjudicators face-to-face. By then, the damage has been done.

If there is not an area of research in the social sciences which studies the social psychology of disability, perhaps there should be. I suspect that asking an able-bodied person to explain what it is like to be disabled is rather like asking a man to describe the experience of childbirth. It is simply not possible. One obvious difference between the two is that childbirth comes to a rewarding conclusion, while disability can be a life sentence. We must try, as best we can, to understand.

January 28, 2003

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IME/FAE 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 Workmen's Compensation Board to fill out our 7 question, 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, 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

Definition of ME: in motion on empty **Definition of FM: What now!**

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