Agreement #40665071

REACHING OUT

WINTER 2008

Keays v. Honda, Supreme Court Makes a Decision on a Wrongful Dismissal

Earlier this year, the Supreme Court of Canada gave a ruling on an employment law case involving Kevin Keays, a man who has M.E./CFS and who was fired by Honda in 2000. This case drew national attention due to its potential impact on employment law and how employers handle the dismissal of employees with disabilities.

Kevin Keays had worked at Honda for 14 years. He developed M.E./CFS and was on and off work due to disability for more than two years. He had been on LTD until the insurance company reported that they felt Mr. Keays could return back to the workplace. When he returned to work, the company made some accommodations, but Mr. Keays' M.E./CFS continued to cause him to be absent off and on for another year.

The company consulted two doctors regarding Mr. Keays' disability and both doctors recommended that further testing should be done on Mr. Keays. Honda asked Mr. Keays to meet with an occupational medicine specialist. Mr. Keays was advised by his lawyer to refuse and instead request further information as to the nature and scope of the testing that would be performed. Honda fired Mr. Keays for disobeying this order to have the assessment.

Mr. Keays took Honda to court and the court found that the termination had been without cause and awarded Mr. Keays a total of 24 months pay in lieu of notice plus a further $500,000 in punitive damages. This was the largest punitive damages award ever in Canada.

Honda appealed the decision. The Ontario Court of Appeal upheld the 24 months in lieu of notice but reduced the punitive damages to $100,000.

Both Honda and Mr. Keays appealed this decision and the case was taken to the Supreme Court of Canada.

Honda decided to change their position that Mr. Keays' dismissal was for cause and the Supreme Court reduced the notice period award from 24 months to 15 months.

ALSO IN THIS ISSUE:

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO (MEAO)
www.meao-cfs.on.ca

REACHING OUT
is published 4 times a year by
The Myalgic Encephalomyelitis
Association of Ontario (MEAO),
a registered charitable organization.

Our Mission Statement

- ***To provide M.E./CFS sufferers with support, current information and direction to the best possible professional services***
- ***To educate the public on the illness, its debilitating effects, and concomitant social and economic consequences, and***
- ***To promote, facilitate and raise funds for research on the causes and cure for Myalgic Encephalomyelitis.***

Our mailing address is:
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Our INFO LINE is:
416 222-8820, or 1 877 632-6682.

Visit us on our new web site at:
www.meao-cfs.on.ca.

Charitable Registration No:
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THE ONTARIO TRILLIUM FOUNDATION

Continued from page 1

In addition, regarding the $100,000 punitive damages (originally $500,000) the Supreme Court concluded that the "normal distress and hurt feelings resulting from dismissal are not compensable" and that in this case Honda's dismissal of Keays had not been unfair or in bad faith. Notably, the Court took into account the advice Honda had received from medical counsel and the Court agreed that Honda's request for Mr. Keays to have an assessment was reasonable.

The Impact: The case is already being taught in Employment Law courses at Canadian Law Schools. The Supreme Court's decision will impact how companies approach employees who have an illness or disability and will encourage employers to create a comprehensive disability management and accommodation program. It also highlights that disability management and accommodation in the workplace is a two-way street: both the employer and employee must cooperatively work together.

It is important to note that the decision of the Supreme Court was not related to whether M.E./CFS is a legitimate disability - that was never in question, but rather whether Mr. Keays' dismissal was in bad faith.

Most significant for people living with a condition like M.E./CFS is that the Supreme Court's ruling points towards a need on the part of the employee to work with an employer's disability management program. Mr. Keays' employer had requested a doctor's note for each absence (which Mr. Keays was unable to provide) and asked him to have an assessment with an occupational specialist (which he refused on the advice of legal counsel) in order to determine future accommodation in the workplace. The Supreme Court did not see those requests as violating Mr. Keays' human rights citing that Honda's absentee program for employees with disabilities made many accommodations and allowances for absence due to disability. The reality for a person living with M.E./CFS and trying to maintain employment is that getting a doctor's note for every absence can be difficult as doctors are often booked for weeks in advance. Also worrisome is the potentiality that the assessor or physician selected by the employer to conduct an assessment may not have a great deal of knowledge about M.E./CFS and that could impact the results of the assessment.

The full decision of the Supreme Court is available to read online at www.canlii.org (type in "Honda" and "Keays" in the search engine).

FROM THE PROVINCIAL COORDINATOR

Hello and Happy Holidays!

This newsletter will arrive at your door around the time of the United Nations' International Day of Persons with Disabilities (Dec. 3rd). M.E./CFS has been shown to be as disabling as multiple sclerosis, late stage renal failure and many other severely disabling conditions, and yet we still have struggles with funding and recognition. The theme for this year's International Day of Persons with Disabilities is: "Dignity and justice for all of us".

Unfortunately, today in Ontario, many people living with M.E./CFS have neither, as they struggle to find a doctor who can treat them, a chemical-free home in which to live and enough financial security to get through to the end of the month. The M.E. Association of Ontario is working to change that!

This newsletter brings you a wealth of information as well as news and developments both for The M.E. Association of Ontario and for the future of M.E./CFS. Maries St. Paul has worked extremely hard on these newsletters to ensure that you get news and articles of interest and value.

As you will read, the Annual General Meeting, held in September, was very successful with almost double the number of attendees as compared to last year, as well as a wonderful panel of experts.

I want to say a special thanks to the dedicated volunteers who answer the Info Line every day. They provide such a valuable service to people living with M.E./CFS. Everyday they receive calls from people looking for doctors, a lawyer or other information. I hear from many callers that they so appreciate the time and the caring these volunteers put into answering these calls.

There is an exciting future ahead for The M.E. Association of Ontario and the M.E./CFS community. As you will read on pages 6 and 7, Christiane and Maureen, representing the Association, attended the recent conference and meetings in Calgary. They are to be commended for their hard work and dedication and thanked for the significant amount of personal time they spent preparing for and attending the conference.

Christiane Garcia is currently working with other members of the Board of Directors to finalize a Strategic Plan. We have some exciting plans for the future of the MEAO, plans that affect you and hopefully involve you as well.

There are many ways that you too can participate and assist us in reaching our goals - whether it is to talk to family and friends and help us raise money, or to join one of our committees. Perhaps you'd like to help by donating an hour or two each month to help write for the website or make phone calls. Or perhaps there is another way you'd like to help! We want to hear from you! Please email us at: info@meao-cfs.on.ca or phone the Info Line and leave a message 416-222-8820 (Toll free 877-632-6682).

We are currently looking for a Toronto location for an office. If you know of a company or small business with empty office space that they could donate or rent at a reduced rate to the Association, please let us know. **We cannot do this without your support!**

On Dec. 17th the Association is hosting a Holiday Social at the Granite Brewery; I hope you will be able to join us!

Please be well this holiday season, try to pace your activities to conserve your energy and may 2009 bring you and yours much joy!

Kimberley Dowds, Provincial Coordinator

NEWS and UPCOMING EVENTS

REPORT ON MEAO'S AGM

On Saturday Sept. 20th, 2008 the M.E. Association of Ontario held its 2007 Annual General Meeting at Women's College Hospital in Toronto. This event began with our very special and 1st Annual MEAO Awards Ceremony.

Directors of the Board presented framed **"Volunteer of the Year"** awards to each of the following volunteers: *Katherine Cartwright, Theresa Dobko, Nelson Lau, Margaret MacQuarrie* and *Margaret Parlor*. *Diane Meitz*, a long time Director on the Board and dedicated volunteer, received **"The Audrey MacKenzie Memorial Award".**

Following the Awards Ceremony, Arvinder Bindra, a Director, introduced each of the individuals in our **Panel of Experts**: *Dr. Alison Bested*, Haemotological Pathologist, *Dr. William van Hoogenhuize*, M.D., Allergist, and *Christiane Garcia and Christopher Pike* (Directors of MEAO). Both Christiane and Christopher have Myalgic Encephalomyelitis and answered questions on how they manage their illness. Dr. Bested answered questions pertaining to M.E./CFS, while Dr. van Hoogenhuize provided a great deal of information on allergies.

Following the Question and Answer period, President Tony Rovito opened the 2007 Annual General Meeting. The Annual Report and Financial Statements for 2007 were tabled, discussed and unanimously accepted by the membership.

MEAO extends a sincere thank you to all of our 2007 Directors who, along with Kim Dowds, our Provincial Coordinator, actively participated in the planning and running of our 2007 AGM. In fact, thanks are also extended to them for agreeing to continue as Directors for 2008. This year, MEAO also welcomes Denise Magi and Brenda Van Ginkel to the MEAO Board of Directors.

In 2008, the AGM for MEAO may actually be moved to the early Summer. We will communicate the new date to you when it is firmed up.

Panelists at the AGM (from left): Chris Pike, Christiane Garcia, Dr. Bested and Dr. van Hoogenhuize.

Awardees and Board Executive at the AGM (from left): Theresa Dobko, Maries St.Paul, Diane Meitz, Katherine Cartwright, Maureen MacQuarrie, Nelson Lau and Tony Rovito.

October 26, 2008 - Memorial for Audrey MacKenzie and M.E./CFS Awareness Social Event

The friends of Audrey MacKenzie organized an afternoon get-together for coffee and a short walk in High Park at the Grenadier Cafe. Although the weather was chilly, 60 people plus 1 baby attended. High Park was a favourite of Audrey's for walks or coffee, playing Scrabble or holding a Board meeting. **Thank you Diane for all your hard work in organizing this event.** Through her efforts and the generosity of the participants, $320 was donated to the MEAO.

It was suggested that MEAO should expand the get-together to have it become an annual event –**The Audrey MacKenzie Memorial Walk for M.E./CFS**; and to move the event to early June when the weather would be warmer. It was also suggested that, in conjunction with the annual walk, an annual Silent Auction be held at the Grenadier Café.

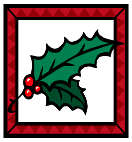
Dr. Bested's newly released 2nd edition of her book, "Hope and Help for Chronic Fatigue" was also available for purchase.

Celebrate the Holiday Season!

The Board of Directors of the M.E. Association of Ont. invites you to join us to celebrate the holiday spirit with an afternoon social:

Wed. Dec. 17th, 4:00 – 7:00 p.m.
Granite Brewery Restaurant,
245 Eglinton Ave. E., Toronto
(South east corner of Mt. Pleasant and Eglinton)
FREE underground parking off Mt. Pleasant

Dress is "casual with the holiday spirit"!
Everyone is welcome.
Cost: Pay only for what you eat or drink
RSVP: Diane by leaving a message on the Info Line, 416 222-8820 (1 877 632-6682) with your full name and the names of any guests who are coming.



A Letter of THANKS to our VOLUNTEERS

To our dear **Volunteers**,

It's been a spectacular and memorable year! **But where would we be without YOU?** There are so many of you who tirelessly give of your time, energy and heart, despite the fact that most of you live with M.E/CFS. The **GIFT** of your time impacts the lives of thousands of people who have M.E./CFS throughout Ontario. And the M.E. Association of Ontario wishes to thank you – **for you are the hands and heart of the Association**. Without your GIFT of time and commitment, we would not be here.

Our heartfelt gratitude goes to (in alphabetical order):

Arvinder, Brenda, Chris, Christiane, Debbie, Denise, Diane, Izzat, Maries and Tony – the Directors on the MEAO Board
Carlos, who sends out emails & e-notices
Cathy, Youth / Parent Resource Person
Cathy and Dr. John – Research for the Newsletter
Christiane, Lisa, Rita and Suzanne – our INFO LINE team
Dan and Theresa, whenever we get 'stuck' for help
Denise, Katherine, Lydia, Maries and Suzanne – our Newsletter editing team
Margaret, Advocate, and Youth & Education Coordinator
Mary Lou, our Volunteer Admin. Assistant
Maureen, Advocate
Our many Members who distribute our brochures and flyers
The Support Group leaders
And last - only because her name begins with 'Y' - Yvonne, our Provincial Membership Coordinator.

From an appreciative M.E./CFS Community

The MEAO Working for You

By Christiane Garcia and Maureen MacQuarrie

Demonstrating the importance of working together, the MEAO is pleased to report its work this year with PHAC (Public Health Agency of Canada), CIHR (Canadian Institutes of Health Research); and, its attendance at three of the four days of the First Canadian Conference on M.E./CFS held in Calgary October 24th, November 7,8 and 9th, 2008.

PHAC, CIHR and the Canadian Clinical Case Definition

As reported in the summer issue of *Reaching Out*, representatives from MEAO, National ME/FM Action Network and doctors specialized in M.E./CFS met with representatives from PHAC and CIHR, in Ottawa, on May 7th, 2008 to discuss research opportunities. As a result of the very comprehensive presentations made by Dr. Bested and Dr. Stein at this meeting and, work subsequently done by your Association and others, the following have occurred:

- PHAC has provided a link from their website: (www.phac-aspc.gc.ca/dpg-eng.php) to the National ME/FM Action Network website, which has the overview of the **Canadian Consensus Document on M.E./CFS entitled, "Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: A Clinical Working Case Definition and Guidelines for Medical Practitioners".** You should be able to access this document by clicking on "Chronic Diseases" in the Guidelines on Disease Prevention and Control section of the PHAC website. However it is very difficult to access this information through PHAC without the website address provided above. These guidelines are designed to inform doctors of the criteria to use in diagnosing and managing M.E./CFS.

  These guidelines are called Canadian as they were drawn up in Canada by an expert panel of internationally renowned researchers and clinicians, and spearheaded by Canadian doctors, with the participation of Health Canada. These guidelines are considered to be more descriptive and specific of M.E./CFS than the previously approved Fukuda guidelines and are used extensively to diagnose and treat ME/CFS.

  It is crucial that these guidelines be made more readily available to all clinicians across the country. MEAO is working with other advocacy organizations to ensure PHAC resolves this problem. Fortunately, the information is also available through our MEAO site, www.meao-cfs.on.ca, and by typing in "Consensus Guidelines for ME/CFS" on any search engine.

- A collaborative grant application, between the MEAO, AQEM (Association Québécoise de l'Encéphalomyélite Myalgique), the ME Society of Edmonton, and the ME-FM Society of Alberta for $10,000 was approved by the CIHR to fund advertising to offset the translation costs from English to French for the Canadian guidelines, assumed by the AQEM; and, to offset some of the expenses of patients travelling to Calgary from all these groups to attend the Symposium on M.E./CFS and Fatiguing Illnesses organized by Dr. Stein and her team.

Calgary Symposium on M.E./CFS and other Fatiguing Illnesses

Dr. Eleanor Stein and her team are to be commended for the wonderful work they did in organizing a four day event on M.E./CFS and other fatiguing illnesses. The four days consisted of:

- A two-day Continuing Medical Education session devoted to educating clinicians on how to diagnose and manage M.E./CFS.
- An Interdisciplinary Research Symposium on Disabling Fatigue in Chronic Illness, which was an opportunity for researchers to discuss their findings with one another concerning fatiguing illnesses;
- A Public Lecture on ME/CFS entitled, “Research Update and Clinical Tips from the Experts”, held on Sunday afternoon aimed at patients and their families, which was attended by over 250 people and was the largest gathering ever devoted to ME/CFS in Canada.

The Conference also provided an opportunity for researchers, clinicians and patient advocates to exchange on the best way to approach research concerning ME/CFS. Among other things, there was agreement on the importance of adopting a common research definition for the illness; in the same way, that the “Canadian” definition has become a generally accepted clinical definition for a large number of clinicians worldwide. The currently used Fukuda Guidelines, which focus on “fatigue” at the expense of other symptoms of endocrine, immunological or neurological origins, are thought to be less descriptive and specific of M.E./CFS; and, hence, less effective in comparing research data and conclusions worldwide.

The excellent work to further the cause of M.E./CFS, being done by the International Association for Chronic Fatigue Syndrome (IACFSME), was illustrated at the Calgary Conference. Their President, Dr. Nancy Klimas, spoke at the Symposium and at the Public Lecture. IACFSME is planning a conference for Reno, Nevada in March of 2009. Information is available at the IACFSME website at www.iacfsme.org and includes a March 12 one-day patient conference.

Christiane Garcia and Maureen MacQuarrie are extremely grateful and honoured to have attended the Conference on behalf of MEAO. It was a great opportunity to meet and to exchange ideas with patients and researchers from Canada and the United States.

Christiane Garcia held an informal meeting of representatives of M.E. Associations from across Canada to get to know one another; to discuss the work presently undertaken by each organization; and, to identify issues of common interest to all. One specific outcome of this meeting is a planned joint follow-up with PHAC to discuss ways in which we can further the cause for ME/CFS in Canada.

All four days were filled with outstanding presentations from a myriad of doctors. More details will be provided in the spring newsletter; but, in the meantime, thanks to funding from the Australian-based, Alison Hunter Memorial Fund (www.ahmf.org) , three of the four days of the symposium held at the University of Calgary were recorded and will be podcast from the University site. These podcasts will be accessible, free of charge, to everyone at http://podcast.med.ucalgary.ca/groups/cfs/blog/. Part 1, featuring 4 speakers from the October 24th, 2008 session, is already available on-line and the others are expected to be available shortly.

ASK AN EXPERT

Faced with unexplained medical symptoms and varying degrees of frustration with conventional treatments, some people with M.E./CFS and Fibromyalgia are trying alternative / complementary modalities. The following article is an example of such alternative practices. The author, Susan Fairman, is a registered practitioner of Esoteric Healing.

What alternative therapies can I consider for my healing?

Energetic Healing and Chinese Medicine.

Disease (or lack of harmony) is an imbalance in the body system(s). According to various sources, we have four of these systems:

1) The Physical body,
2) The Etheric or Energetic body that attracts and holds the patterns for our physical body to exist,
3) Our Mental body,
4) Our Emotional body.

This idea is not new, but it is different. Our Western Society is generally focused only on the physical aspect of our being, to the exclusion of the other 3 “parts” of ourselves; consequently we lose the ability to help our whole selves.

When **“stress”** impinges on our mental (mind) and our emotional (feeling) bodies, especially when it is focused for a long time on one particular thing, or one particular emotion, it interrupts the natural flow of energy (energetic body) and proceeds to disrupt the major glands or endocrine systems in our body, thereby opening the physical body to a host of ailments. Every major gland has a frequency or a sound. When in harmony, we have good health. When a note of discord is sounded, it sets the stage for a very off-key symphony. A great amount of recent literature and a host of advanced thinkers discount “genetic predisposition” to diseases in favor of stating that what we feel and what we think have a much greater impact on our health than previously thought. In fact, only 5% of disease has a genetic predisposition. If our mothers had rheumatoid arthritis and we keep thinking “oh no, I hope I don’t get it”, you can bet you are upping your chances of getting it because you keep focusing on it. **This is called negative reinforcement.**

M.E./CFS and Fibromyalgia share a number of similarities and commonalities. It has also come to light that **people suffering from these two diseases are usually over-achievers and expect so much of themselves and others, that their circuits are “burnt out”.** Energy isn’t flowing, disruptions have occurred and imbalanced patterns have taken their place. It is difficult to re-direct or re-wire the physical, when the causes are hiding in the emotional and energetic bodies. Not to say there are no physical connections; multiple chemical sensitivities, genetic predisposition, diet (e.g. sugar and yeast), etc. are also contributing to and exacerbating these symptoms.

Chinese Medicine and Acupuncture work on the premise of Qi (energy) in the body. There is Yin (cold/water) and Yang (hot/fire) - opposites which are needed to sustain “life” or animation of the body. With Acupuncture, needles are inserted to re-direct and re-wire the major organs. Needle therapy is followed by Chinese herbal therapy to sustain the effect of the former, until the next treatment. It is efficient but not quick - as is the case with most alternative modalities, it takes time and patience to stay the course; there are ups and downs. There is the age factor, the chronic nature of disease, once it is imbedded, and the toxic releases through each stage of the healing.

Another element added to the practice of Chinese Medicine and Acupuncture is **Esoteric (Energetic) Healing**, the study of the major power centres in the Energetic Body - Seven master “switches” that power up the body proper and 21 minor centres that feed off the majors. Esoteric healing **balances energy** in the form of “triangles”, re-directing energy along its natural course. These centres are not seen (unless the practitioner is gifted with this type of sight), but almost every practitioner can “feel” the energy working. A sensitive practitioner can work with these centres, hold the energy in patterns and change the “frequency” in the energetic layer, changing the course of a disease. It’s a bonafide science taught in classrooms across the world, with chalkboards and notes and working on other bodies, but it is not popular because there are no drugs and no scalpels. It can be sent long distances because energy isn’t stationery: energy follows thought; moving, oscillating and changing. Chinese Medicine and Acupuncture is founded on the idea of changing energy and has been around for over 5,000 years. It’s a proven methodology and Esoteric Healing brings the theory into a more modern application.

Many diseases, including M.E/CFS and Fibromyalgia have something in common – pain. Pain simply put, is the body’s signal that something is wrong. If you keep taking an aspirin every time you have a headache without questioning the source of the headache, you are only treating the symptom, not the cause. Not surprisingly, there will be no improvement. One must logically treat the cause in order for the symptoms to disappear.

So what can one do? There are many practitioners of Traditional Chinese Medicine and Acupuncture now in Canada and the United States. They are well educated not only in the fundamentals and basic working theory of TCM, but they are taught all of the sciences available today as well. In other words, there is no mystical East meets West here – they are integrated and integrating and evolving. Self-help books are available - a very good one is “Acupressure’s Potent Points” written by Michael Reed Gach, which teaches the reader how to employ acupressure in a simple step-by-step way, perhaps as an introduction. No better way than to experiment first to see if there is some improvement by employing some of the methodology. As for Esoteric Healing, there is a listing of Esoteric Healers on websites devoted to this particular modality worldwide including Canada and the United States. The writer can refer to specific geographic locations if necessary.

Why don’t we get to the source?

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TIP

It is so frustrating to search all over my home for little scraps of paper with important information; especially when I can’t find them.

SOLUTION: I bought a spiral notebook that I keep handy, and is small enough to take with me when I go shopping. In it I write my ‘TO DO’ list, new telephone numbers, quotes on service costs, measurements of windows / rooms, gift ideas, grocery lists, etc., etc.

A notebook like this costs $1 at the Dollar Store, and has become indispensable!

YOUR HEALTH

Editor's Note: We present here 2 articles: Part I is written by someone with M.E./CFS who describes his 'pacing' strategy and how this has improved his health; Part II provides a useful method of identifying the CLUES that warn us when we have pushed ourselves too far.

'Pacing' - Part I

by Chris

Radical courses of change are difficult for most people and for me - **pacing** has demanded that I radically change just *how I do life* after getting very ill with M.E./CFS. I have required much support and discipline in this process.

I can no longer afford to do whatever I wish whenever I want. I need to plan, organize, and be methodical most days about exactly what I am doing and for how long I am doing it. I have learned I need to be pretty clear about how much I can do given where I am in the M.E./CFS disease / recovery process, and then I do a little bit less to bank energy. I pepper activity with rest and I carefully chart my activity and energy levels using Dr. Bested's Functional Capacity Scale (http://www.thedoctors.ca/links.html). With the support of the Integrative Care Centre of Toronto and my family, I see that if my energy levels are fluctuating or if I am crashing, I need to pull back and do much less until I stabilize. Thankfully I can still live with some spontaneity.

Pacing has meant letting go of all that I want to do in the short-term in order that I might be healthier in the long-term. Hence, pacing means grieving doing as much as I'd like and letting go today so that I can do more tomorrow. Again, not easy. In fact, much research has shown that short-term reinforcement is a significantly more potent motivator of human behaviour than long-term reinforcement.

The concept of pacing was introduced to me by Dr. Alison Bested in early 2004 when I was virtually bedbound with M.E./CFS. I remember her using very clear and strong language to impress upon me just how critical living slightly under the limits of my body's energy envelope would be to my health improvement.

Pacing has demanded I muster all the discipline within myself to not do more than I can and again, I have required lots of help. I am blessed with a partner who will do for me and who will challenge me when she sees me doing more than I need to.

As I have had more energy, I have very gradually and carefully added more to my life, checking in with my supports before saying 'yes' to anything new and trying gentle and brief 'test runs' to ensure I am not over doing it. I am encouraged to check out realistically how much time and energy any new commitment will take and I am encouraged to say 'no' when appropriate. **The slogan "if in doubt, don't" has helped sometimes.**

I have also attended various 12-step programs for years to deal with my people-pleasing/my saying 'yes' when I need to be saying 'no' and my workaholism.

I am convinced pacing has helped me partially recover from M.E./CFS. I started my M.E./CFS journey in 2003, virtually bedbound and at a '3' on the Functional Capacity Scale. Today I have climbed up to a steady '7' and have started a gradual doctor-supervised rehabilitation program that includes graded exercise. This is a miracle for me! While I cannot credit pacing with all of my M.E./CFS recovery, I do acknowledge it as essential.

Pacing – Part II
Recognizing the Clues Before You Crash

By Maries St.Paul

When we began work on this article, we conducted a mini-survey amongst our volunteers to learn what they experienced both physically and emotionally when they pushed themselves too far - and ended up 'crashing'. We were surprised to find that these experiences varied greatly from person to person. While we had expected some differences, on the whole we assumed that people with M.E./CFS who had pushed themselves too far would experience common symptoms, e.g. dizziness. But that was not at all the case.

How do I know I've pushed myself too far? What CLUES are there to warn me that a 'crash' is imminent?

As many people have learned (the hard way), they must plan each day to include regular rest periods for both their body and mind in order to avoid having a 'crash'. And for some people it takes weeks, sometimes months, to work their way out of 'crash mode' and get back to the level of energy they had before they crashed. So it's wise to avoid 'crashing' and we have some ideas that can help you.

Are there CLUES or warning signs that indicate you are on the verge of a crash?

We asked people to describe their warning signs. One person reported that her clues were the following: sweating, dizziness, irritability, increased anxiety, increased difficulty focusing on the task at hand and difficulty putting a sentence together. Another person reported the following: migraine headaches, dizziness, digestive problems; it becomes too hard to hold his body up, increased pain throughout his body, difficulty talking and staying focused on a conversation. Both indicated that when they became aware of these clues, they stopped everything and lay down to rest.

What can you do to recognize your own clues? We suggest you create a chart with 3 columns:

COLUMN #1, SYMPTOMS: list all your symptoms for both 'good' and 'bad' days;

COLUMN #2, GOOD DAY: the intensity of each symptom when you are having a 'good' day; and

COLUMN #3, BAD DAY: the intensity of each symptom when you have crashed or are about to crash.

It's important that you indicate in column #2 and #3 the degree / intensity you experience each symptom, even if it's '0'. For example: if dizziness is one of your symptoms, indicate the level of dizziness between 1 – 10 for a good day and the level of dizziness on a bad day.

Here is a **sample** chart - **1 represents very low, 10 represents very high:**

SYMPTOMS	**'GOOD DAY'**	**'BAD DAY' / CRASH**
PHYSICAL SYMPTOMS:		
Energy	**5**	**1**
Dizziness	**0**	**5**
Sweating	**0**	**7**
Become Clumsy	**2**	**8**
Body Pain	**3**	**9**
Headache / Migraine	**0**	**5**
Digestive Problems / Nausea	**0**	**6**
Difficulty Focusing	**2**	**8**
Difficulty Speaking	**1**	**7**
Difficulty following a conversation	**2**	**8**
Difficulty completing a simple task	**1**	**7**
EMOTIONAL SYMPTOMS:		
Irritablity / Edginess	**2**	**8**
Anxiety / Distress	**1**	**7**
Crying	**0**	**3**
Depression	**0**	**2**

Remember that this chart is a sample, and a tool for you to create your own. It may take you some time to record your good and bad days. Keep the chart close by. **When you**

are having a 'good day' ask yourself 'what is my body feeling and what emotions am I experiencing? How well am I able to focus on what I am doing?' Do the same on a 'bad day'. In time you will be able to recognize the onset of a symptom that you don't have on good days, or a symptom becoming worse, and that becomes your **CLUE!** Likewise if completing a task becomes almost impossible, that is another CLUE.

Once your CLUES start to appear, you know it's time to:

- **stop everything, and**
- **lie down.**

If it's not possible to lie down, take whatever steps are within your power to lessen the demands on your body and mind. **You may need to write yourself a list of things to remind yourself what you can do to ease the demands on your energy:**

- **stop doing whatever it is in your power to stop**
- **turn off the radio / TV (you'd be amazed how much better you will feel not having this kind of noise in the background)**
- **turn off or dim the lights**
- **close your eyes and breathe deeply for a count of 20 (or 50, or 100)**
- **put your feet up on a stool**
- **if you're at a party, go to a quiet bedroom or the washroom for a few minutes to do the above.**

Pacing will be different for each person. Pacing is key to preventing a 'crash'. Pacing is key to improving your health and maximizing your energy.

Pacing is like pennies in a jar – the more you rest each day, the more pennies you have to spend; bringing on a 'crash' not only uses up all the pennies, but it takes a long time to get your health back.

ON THE FUNNY SIDE

TO: GOD
FROM: THE DOG

Dear God: Why do humans smell the flowers, but seldom, if ever, smell one another?
Dear God: When we get to heaven, can we sit on your couch? Or is it still the same old story?
Dear God: Why are there cars named after the jaguar, the cougar, the mustang, the colt, the stingray, and the rabbit, but not ONE named for a dog? How often do you see a cougar riding around? We do love a nice ride! Would it be so hard to rename the 'Chrysler Eagle' the ' Chrysler Beagle'?
Dear God: If a dog barks his head off in the forest and no human hears him, is he still a bad dog?
Dear God: We dogs can understand human verbal instructions, hand signals, whistles, horns, clickers, beepers, scent ID's, electromagnetic energy fields, and Frisbee flight paths.
What do humans understand?
Dear God: More meatballs, less spaghetti, please.
Dear God: Are there mailmen in Heaven? If there are, will I have to apologize?
Dear God: Let me give you a list of just some of the things I must remember to be a good dog:
1. I will not eat the cat's food before they eat it or after they throw it up.
2. I will not roll on dead seagulls, fish, crabs, etc., just because I like the way they smell.
3. The litter box is not a cookie jar.
4. The sofa and the carpet are not 'face towels'.
5. The garbage collector is not stealing our stuff.

6. I will not play tug-of-war with Dad's underwear when he's on the toilet
7. Sticking my nose into someone's pants is an unacceptable way of saying 'hello'.
8. I don't need to suddenly stand straight up when I'm under the coffee table.
9. I must shake the rainwater out of my fur before entering the house - not after.
10. I will not come in from outside and immediately drag my butt.
11. The cat is not a 'squeaky toy' so when I play with him and he makes that noise, it's usually not a good thing.

FROM OUR KITCHEN TO YOURS

Chocolate Chip Peanut Butter Cookies

From the kitchen
of Michelle Burgess

Ingredients ------------------------

1/2 cup crunchy-style peanut butter
3/4 cup shortening
1/2 cup firmly packed brown sugar
1/2 cup sugar
1 egg
1 teaspoon vanilla extract
1 1/4 cups all-purpose flour
1/2 teaspoon baking soda
1/4 teaspoon salt
1-6 oz package chocolate chips

Directions ----------------------------

Preheat oven to 375 degrees. Beat thoroughly peanut butter, shortening, sugars, egg and vanilla. Stir together flour, baking soda and salt. Add to creamed mixture and blend well. Fold in chocolate chips. Drop batter 2 inches apart onto baking sheet. Bake 10-15 minutes. Let stand 2 minutes before removing from baking sheet.

A Season for Giving!

The annual holiday season is fast approaching and everyone feels a profound need to ameliorate the suffering within our larger community. Given the current economic climate, charities large and small are now struggling to continue providing much needed support and service to those that depend on them. The M.E. Association of Ontario (MEAO) is one such charity. Please consider supporting MEAO and encourage others to do the same during these difficult economic times, so that we can continue our advocacy and public awareness programs and provide information and service to those in need. THANK YOU!!

HELPFUL WEBSITES

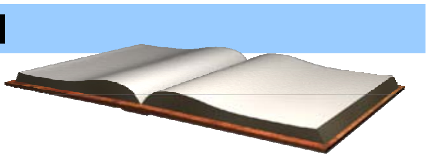
http://mefreeforall.org/, a U.K. organization offering a web site for people with M.E., doctors and researchers to gather, + some fun stuff.

http://pandoranet.info/, not strictly for M.E. but M.E. and other neuroendocrineimmune disorders. P.A.N.D.O.R.A. stands for "Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy". Newsletter too.

http://www.meresearch.org.uk/, a site from the U.K. that deals in M.E. research.

http://www.cfids-cab.org/MESA/, a research-information and advocacy group, the M.E. Society of America.

RESEARCH



Research Findings on M.E./CFS

By John Prescott,
DVM, PhD, Professor, University of Guelph

Why don't we know more about what causes M.E./CFS and how to cure it?

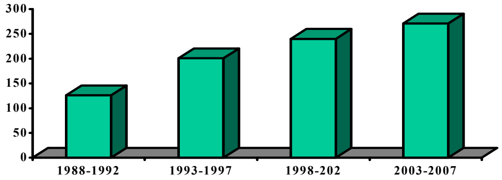
People living with M.E/CFS face multiple challenges, not least of which is uncertainty about what is causing their illness and whether there's going to be a medical breakthrough that will help or cure them. They get conflicting and confusing advice on treatments or cures from numerous people. It's demoralizing! To understand why we don't know all we need to about M.E/CFS, you have to understand **how science works**.

The process of understanding as complex an illness as M.E. is **painstaking and slow**. It involves engaging the attention of the limited number of people with the right background and training to devote their time, energy, minds and reputations on a problem. It's **very expensive**, since it needs sustained effort over many years because of the expertise and laboratory facilities and reagents that need to be developed and kept up.

Another critical element is that the progress of science depends on publication of the findings through a **peer review** process. This involves the findings ("paper") undergoing an anonymous review by several other knowledgeable scientists who will comment to an **editor** about the quality of the science (design, methods, analysis, conclusions). If the editor accepts the work, often after some changes, then the work is **published** in an honoured way for objective analysis of evidence. If a study has not been published in a peer-reviewed article then it is not accepted as science by the science community. It is journal. **This rigorous process sets a high but achievable standard**. It's the time-sometimes disappointing to read in the media about "breakthroughs" in M.E. research, and then to find no trace of the author or the topic in the **peer-reviewed scientific literature**, abstracts of which are almost universally accessible through the National Library of Medicine (PubMed). It's helpful to realize that, even if science findings are published in a peer-reviewed journal, there may be problems because of, for example, errors or misinterpretations in the methods or analysis. This is why the **ability of other scientists to repeat the work** is another critical part of the scientific process.

The good news is that **there are excellent scientists working on M.E., though more are needed**. Taxpayer-based funding is available in countries such as Canada. In Japan, "fatigue science" even has a priority for national funding. However, funding is competed for, based on the quality of scientists' ideas and their track record in delivering results. Of course, there is **competition** with a very large number of other illnesses. The other good news is that money is being raised specifically for M.E. research, particularly in the US and Britain. For example, the US CFIDS organization is trying to raise $1M in 2008.

Encouragingly, the average annual number of articles identified by searching "chronic fatigue syndrome" on PubMed, shown below in 5-year blocks, indicates that **CFS research is increasing**, though not at a rapid rate.



Editors Note: *We are greatly encouraged by the level of enthusiasm and dedication shown by attendees at the recent University of Calgary conference on M.E./CFS and Fatigue. Many new possibilities for research in Canada were discussed and the event was sponsored, in part, by a grant from the Canadian Institutes of Health Research (a government body). (Please see the article on page 7 for further details on this conference.)*

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GENERAL INFORMATION

Did you know that our members receive email announcements about upcoming events that are of interest to those with M.E./CFS? We email them whenever a TV programme, Seminar, etc. is taking place. If you are not on our email list, email us at: **meaocfsnews@gmail.com.**

If you know of an event that may be of interest to our members, please call us at our INFO LINE number below. THANKS!

CONTACT US

Our mailing address:

The Myalgic Encephalomyelitis Association of Ontario, P.O. Box 84522, 2336 Bloor St. W., Toronto, Ont. M6S 4Z7.

Our INFO LINE is:

416 222- 8820, or 1 877 632-6682. Call to receive information on M.E./CFS, Support Group and doctors.

Check out our **new Web Site** at:
www.meao-cfs.on.ca

MEMBERSHIP AND DONATIONS

Our annual membership is $20.00. Donations are greatly appreciated, as they help us increase education and awareness of M.E./CFS throughout Ontario. Donations of $10.00 and over are issued a charitable tax receipt. We also welcome those who request a Complimentary Membership!

Members receive our quarterly newsletter ***'Reaching Out'*** with news on M.E./CFS, Research, Coping Tips, Recipes, Upcoming Events, and much more! Members with emails are also notified regarding updates on: Conferences, Television Programmes on M.E./CFS and special M.E./CFS events.

See our Membership / Donation Form below.

As a resource group, the function of our organization is to provide you with current information on M.E./CFS. As we are not medical professionals, we accept no responsibility for how this information might be applied. We urge you to discuss all aspects of your health with your attending physician.

THE MYALGIC ENCEPHALOMYELITIS ASSOCIATION OF ONTARIO
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