



Charitable tax no. (BN) 89183 3642 RR0001

ISSN 1205-786X

Quest

COMMUNICATION # 66

WEB: www.mefmaction.net

FALL 2004

Dear Subscriber:

At the last board meeting held in September, the directors of the National ME/FM Action Network decided to bring some changes to the format and the number of pages to the newsletter "QUEST". From now on, the newsletter will be distributed quarterly and it will also have more pages in the number of issues.

We hope these changes will please you and make the newsletter easier to read. We would appreciate receiving your comments.

Lydia Neilson, President CEO

WHEN DOCTORS SAY PSYCHOSOMATIC – WHAT DO THEY MEAN?

By: Angela Kennedy, RGN, MA

A 'holistic' model of care, when referred to in the health professions should mean that all aspects of an individual's health should be considered. This may include their emotional feelings and psychological reactions to illness, any social or material inequalities they may suffer (e.g. poverty, social exclusion), as well as the physical and biological aspects of their illness, including, for example, pain, vomiting, lung capacity, or mobility problems. A 'holistic' model could be classed also as a 'bio-psychosocial' model of health care: in principle. This also means that 'psychosomatic' should mean the complex interplay between the body and mind

in all aspects of health, for ALL states of health, from cancer to AIDS, to asthma, to spinal and head injuries. A holistic model of care in the case of ME/CFS, or lung disease, diabetes, asthma or spinal injury, for example, might involve the health professional considering the psychological impact of serious illness on the individual, and seek to employ strategies to alleviate suffering.

In the past 20 years, however, people suffering with ME, or CFS (also known by other names) have found that the term psychosomatic has come to mean something else, often not clearly delineated, but which has resulted in actions causing devastatingly adverse effects on all aspects of their health.

Bartol and Eakes (1995), in trying to define what the term 'psychosomatic' means to health care workers, found four broad categories: they were:

1. imaginary (that is, an imagined physical disorder);
2. functional (that is, a disturbance of the function of an organ mediated by emotional tension);
3. structural (a physical structure disturbance mediated by emotional tension.)
4. holistic (an approach to any state of the body taking into consideration psychic factors in physical conditions and physical factors in psychic conditions).

Bartol and Eakes found that the term 'psychogenic' was often used interchangeably with psychosomatic. 'Psychogenic' implies the illness is 'all in your head/mind', and with this there is an inference that a person "chose to be ill, perhaps to get attention, or that the person could become well simply by making a choice for health and giving up the benefits its illness affords." (Bartol & Eakes, 1995, p. 28) Such a belief often leads to a stigmatization of the victim.

The issue of stigmatization is particularly interesting. Here the stigma is related to a culturally constructed label of 'deviance'. Deviance is defined as being or doing outside cultural norms (Macionis and Plummer, 1997, p.208). Labels of deviance are not 'natural'; they are socially constructed, i.e. by the culture we live in. Crime is an example of 'deviance', but not all criminals are considered deviant. For example, stealing a pad of Post-It Notes from one's office stationary cupboard does technically make one a criminal (i.e. one who has committed a crime): it does not necessarily make one deviant (as so many people seem to do it, and it is usually considered a relatively minor crime) 'Deviance' usually involves moral value judgments of 'good' or 'bad' being applied to an act, or, more worryingly, a person. In recent times, especially with the advent of New Public Health initiatives (for example, the Ottawa Charter for Health Promotion, 1987), the idea that lifestyle or behavioural factors can influence our health has come, unfortunately, to be also associated with various cultural myths of 'mind over matter' (my term), very problematic notions that somehow we can often exert control over our biophysical health through our minds, or 'willpower'. (Wendell, 1996, p 93-116)

In this context, health problems become merely a signifier of character flaw, a 'deviance'. One example of this could be said to be 'obesity', where a fat body is very frequently assumed to be a result of 'overeating' (or 'greed') and 'laziness' (or 'sloth'), usually considered as 'deviant' acts, even though other reasons for 'obesity' or weight gain, such as metabolic disorder or side effects of medication are possible, 'overeating' is extremely difficult to define, and a 'sedentary lifestyle' often means working long hours at a desk or in a vehicle, rather than idling on a couch.

My concern is that ME/CFS sufferers (and sometimes their caregivers, when sufferers are children) very frequently have similar, categories of 'deviance' (and associated categories of 'bad') assigned to them based on such myths, by health professionals, the media, and by people around them, as an implied meaning underlying any psychological terms used to describe them. Terms include but are not limited to 'psychological', 'psychogenic', 'somatization', 'psychosomatic' 'neurasthenia', 'hysteria' and 'hysterical'. Sometimes, confusingly, these terms are used interchangeably in the literature. Anecdotal information suggests they may also be used thus in patient's notes.

With this in mind, after carrying out a preliminary but nevertheless large amount of study of what has been written about ME/CFS sufferers by British psychiatrists and other doctors such as paediatricians and GP's, I have tentatively identified the following implied categories of meaning that might be attached to any psychological or psychiatric term applied to an ME sufferer. It can reasonably be assumed that these written deliberations in form both the practice and attitudes of the authors themselves, of other practitioners, as well as the media and those who access the media. The categories are:

Imaginary (the illness or symptoms are not 'real', but imagined);

Malingering (the 'sufferer' is lying about the extent or even the existence of their illness, in order to receive financial or other benefits, including social or familial attention. Sometimes this can be implied to be occurring on an 'unconscious' level, i.e. 'lying to one's self');

Hypochondria (the 'sufferer' has odd or 'aberrant' illness beliefs, for example, believing they need to rest, when they 'should' be exercising);

Personality disorders (the sufferer has a personality disorder, related to categories 1, 2, 3 5 or 6, sometimes more than one simultaneously. This categorization is exemplified by the recent paper by Henderson and Tannock, 2004);

Functional (that is, a disturbance of the function of an organ mediated by emotional tension, as described by Bartol and Eakes);

Structural (a physical structure disturbance mediated by emotional tension, as described by Bartol and Eakes);

Holistic (an approach to any state of the body taking into consideration psychic factors in physical conditions and physical factors in psychic conditions as described by Bartol and Eakes).

The first four categories are the most extremely problematic for ME/CFS sufferers, as these will lead to inappropriate refusal of assistance or benefits, social exclusion, and ostracism by others; a common effect of being considered 'deviant' is social and material inequality (e.g. poverty, social exclusion), and ME/CFS sufferers are at particular risk of this (Hyde et al, 1992, p 25-37).

These categorizations might also lead to enforced treatments such as Graded Exercise Therapy or psychiatric incarceration, for example, of children, and removal from parents, and lack of suitable medical treatment. Categories 5 and 6 are also problematic, in that they imply, problematically, an exclusively unidirectional relationship between the mind and body, privileging the mind's effect on the body without considering the body's effect on the mind, therefore manifesting as another variation of the cultural myth of 'mind over matter'.

Most diagnoses utilizing categories 5 and 6 cannot be verified (as is also the case for 1-4), and this appears to be particularly the case with ME/CFS. They are likely also to lead to inappropriate focusing on treatments such as anti-depressants or Cognitive Behavioural Therapy AT THE EXPENSE of investigations and treatment of serious physical and organic pathology. Indeed, this is already the case for many ME sufferers.

Categories 1 to 4 are those most likely to be accompanied by an assignation of 'deviance' implied by those applying them to others. Categories 5 and 6 can, however, often though not always, be related to the first four, and therefore can also have assignations of deviance accompanying their application. Categories 5 and 6 do allow for beliefs or theories that stress, for example, can affect bodily function. The effects of stressful life events, or, for that matter, of either reactive or clinical depression on the adrenal system, and whether this is related in any way to ME/CFS is outside the scope of this study, as I am not a medical doctor or research scientist. In any case, as I understand it, this has not yet been verified one way or the other, although various studies have appear to have found marked differences between ME/CFS and depression which indicate they are NOT the same illness. But even a health professional's belief that stressful life events have somehow contributed to ME/CFS is at risk of leading to one of the first four categories of 'deviance' eventually being applied to the sufferer. And discussions

around 'depression' in the deliberations I studied often led back to the categories 1 to 4 and value-judgment type assignments of 'deviant'.

Category 7, an approach endorsed by the World Health Organization, has been, so far, conspicuous by its absence in the deliberations on ME/CFS by certain psychiatrists, and certain key paediatricians and GPs, and nursing professionals. The other six, unfortunately, are often used, frequently interchangeably, and without critical reflection.

I have decided to release this short, preliminary summary of my tentative findings, because I believe this will provide useful information for sufferers and their caregivers, when faced with those health professionals who appear hostile to the idea that ME/CFS (ICD-10 G93.3) is the neurological disease that the World Health Organization classifies it as. It is my hope that health professionals using any ideas related to psychology will be required eventually to clarify to patients exactly what they mean, and that this will help to prevent the scandalous problems caused by the frequently incorrect meanings assigned by some health professionals to the ideas of holistic care and psychosomaticism. I hope this information will enable patients to successfully challenge some of the negative value judgments that some health professionals are harbouring when dealing with ME/CFS sufferers.

I also hope that any health professionals who have access to this short, informal article will be encouraged to reflect on their use of psychological terms when applied to physical illness particularly, and the possible material, social and even psychological effects of this on their clients/patients.

This work is not completed yet, and forms part of a larger study. I may have to modify and develop my interpretations in the future, as my research continues. Examples of the use of these categories are large in number, and will be presented in the future. The germ of this research project (and my interest as a social scientist) arose when I saw the work of both Margaret Williams and E.P. Marshall in their document 'Denigration by Design', and Malcolm Hooper's 'The Mental Health Movement -persecution of patients' document. The evidence contained in these papers is particularly worrying, because the problematic categories identified in this article (especially categories 1- 4) appear, from the evidence, on occasions to have been constructed with malicious intent rather than just erroneously, and this is a slightly different issue, with critical ramifications, which needs to be addressed as a matter of urgency.

[Angela Kennedy is a RGN, has a MA, and is presently working towards a Ph D. She teaches sociology for a number of British Universities, including the Open University, Middlesex University, and City University. Mrs. Kennedy is also a caregiver for a youth severely ill with ME.]

REFERENCES

Bartol, G. M., & Eakes, G. G. (1995). A study of the meanings assigned to the term psychosomatic among health care professionals. *Perspectives in Psychiatric Care* 31, 24-9.

Henderson, M. Tannock, C. 'Objective assessment of personality disorder in chronic fatigue syndrome' *Journal of Psychosomatic Research*, Volume 56, Issue 2, February 2004, Pages 251-254.

Hyde, B. Bastien, S. Jain, A. *The Clinical and Scientific Basis of ME/CFS* (1992) Nightingale Research Foundation, Canada.

Macionis, J.J. Plummer, K. *Sociology: A Global Introduction* (1997) Prentice Hall, London.

Ottawa Charter for Health Promotion (1987) *Health Promotion* vol.1, no. 4 p iii.

Wendell, S. The Rejected Body: Feminist Philosophical Reflections on Disability (1996) Routledge, New York.

DONATIONS TO THE NATIONAL ME/FM ACTION NETWORK

By: Odile Gerin, Director – Public Relations

The National ME/FM Action Network needs the financial support of as many people as possible in order to meet its objectives: information, support, and advocacy. You can help us in different manners, such as

- Making a donation with your subscription renewal;
- Sending post dated cheques;
- Making a donation in memory of a deceased person. A card will be sent to the family of the deceased informing them that you have made a donation to our Network and you will receive a receipt from us.
- Contributing through the United Way Campaign in the workplace (mostly in the Public Service, but also in some companies) or in at home. You can, personally, or invite members of your family or friends to do so, designate part or the total amount to our Network who qualifies as a registered charity. On the form to fill, indicating the amount you wish to be withdrawn from the payroll, there are three possibilities: donate to the United Way, donate to partners of the United Way (major organizations) and third, donate to any registered charities of your choice, thus allowing you to donate to the National ME/FM Action Network.

That option is also offered in some brochures sent at home by United Way. A minimum gift of \$20.00 is required for this option. The registered charity number to write down is: **89183 3642 RR0001**. We thank you in advance for your support.

FLU VACCINATION AND CHRONIC FATIGUE SYNDROME

By: Dr. Alison Bested

Greetings! As we enter the flu season, I am writing to you about the flu vaccine as my patients with Chronic Fatigue Syndrome (CFS) often ask me whether or not they should have it. This depends on a number of factors:

- If you are allergic to eggs, you should not get a flu shot as the vaccine contains egg protein.
- If you have never had it before, then the first question is whether you need it. If you are totally isolated in your own home and your caregivers and family are very aware that they should not come to visit you or care for you if they are ill, then your risk of exposure is minimal.
- If you go outside your home, then you could take the following precautions. Take a disposal paper mask with you if you have to visit public places, e.g. doctors' offices, churches, stores. If anyone is coughing then put your mask on immediately so that you do not breathe in viral particles. Try to keep your hands off your face, especially after coming into contact with another person (e.g. shaking hands) or an object just used by another person (e.g. a pen), so that you do not transfer viruses from your fingers to your eyes and nose. These are easy entry routes for viruses into your body.

If you decide you would like to be vaccinated, then I recommend starting with an injection of one third the usual adult dose. If there are no side effects, then the same dose can be repeated in a month's time, and the same again after one further month. The reason for this is that physician's specializing in CFS, including myself, have reported cases of flu symptoms in some patients with CFS for 4 or more weeks after the full dose of flu vaccine has been given.

It is unknown whether patients with Fibromyalgia or Environmental Sensitivities / intolerances are more prone to such a response. However, overlap of these conditions with CFS has been reported in the medical literature, and so caution is probably wise. Having symptoms for this length of time is not normal after a flu shot. It is called an adverse vaccine event and needs to be reported to the Department of Health. There is an Adverse Vaccine Event Form that must be filled out by the doctor. Each region has its own Department of Public Health (in Toronto, 416-392-1250).

All the best to you and yours,
Dr. Alison Bested
EHC Staff Physician and Hematopathologist.

[Ed. Note: Permission to reprint granted by The Myalgic Encephalomyelitis Association of Ontario <http://www.meao-cfs.on.ca>]

TO: ALL BARRISTERS & SOLICITORS

Dear Sir/Madam:

Re: NATIONAL ME/FM ACTION NETWORK – Application for Intervener Status
Issue: Can Accident Victims Sue Insurance Doctor

I'm asking for money.

I'm doing it on behalf of the **National ME/FM Action Network** which is a support network for persons with Chronic Fatigue Syndrome and Fibromyalgia.

The group fights to establish legal principles, among other things, that help victims of motor vehicle accidents and Independent Medical Examinations.

The present project, which I'm happy to support, involves a case of a DAC (Designated Assessment Center) doctor who was sued for a bad DAC report. The case is on its way to the Court of Appeal to determine whether the DAC doctor must act in good faith when coming to conclusions and recommendations.

The National ME/FM Action Network has applied for and was granted Intervener Status to argue the consumers' point of view.

As you may know, one of our cases, the ***Cividino*** case, the high water mark case, was argued in Hamilton and found that a DAC does have a responsibility in good faith to act scientifically in keeping with the contemporary standards of the DAC person's credentials.

The low watermark is the ***Margulies*** decision which says Defence Medical Examiners are immune from lawsuits because they are experts and, essentially, belong to the court.

A distinction to be drawn is that ***Margulies*** deals with an expert's report under the *Rules of Practice* authored for the use of the Court and, of course, the Insurance Medical Examiner or the DAC doctor is in a decision-making capacity with respect to access to healthcare services and in that sense acts as a gatekeeper. Gatekeepers should be subject to different rules than expert witnesses and that's the issue in the case when all the dust clears.

The Court of Appeal may very well suggest the DAC Medical Examiner has immunity from any litigation and that, of course, would signal to the IME (Independent Medical Examination) community that it's open season on accident victims and it would certainly give them courage to be more outlandish and more destructive in their approach.

My concern arises because I have in the past brought lawsuits against DAC and Insurance Medical Examiners and I've discovered some very disturbing facts once I started getting into their files and all of my worst fears, in most cases, were confirmed. This system is not as clean as one would want it to be and shutting out the Court and prohibiting a Judge from reviewing the conduct of the DAC or IME would, in fact, only increase the abuse that I know exists due to personal experience on examination at Discovery.

So it comes down to my request for \$500.00.

I've promised the **National ME/FM Action Network** that I would help raise money for their cause. I've already sent them my contribution of \$500.00 and I'm wondering if you would send \$500.00 made **payable to the National ME/FM Action Network** so I can send it to them and encourage this very good work.

I ask you urgently, as a colleague, and as someone whom I believe has a great interest in

ensuring that insurance consumers are heard at the Court of Appeal, to contribute \$500.00 to the cause and to do so today.

If there's any doubt in your mind, please call me today at **(905) 522-8702** so I can further impress upon you the urgency of the need to support this organization and its good work on behalf of all accident victims.

Yours very truly,

Lou Ferro, Barrister & Solicitor
One King Street West, 5th Floor
Hamilton, ON L8P 1A4

INTERVENOR STATUS – Lowe v. Guarantee Company - Update

Please find below a letter from Mr. Norm Cuddy who is part of our National Lawyers' Roster appealing to the legal community as follows:

NationalME/FM Action Network
3836 Carling Avenue
Nepean, Ontario
K2K 2Y6
Attention: Ms. Lydia Neilson, President and CEO

Dear Madam:

Re: Application for Intervener Status

We are responding to the appeal made by Lou Ferro on behalf of your organization. We are pleased to contribute to this innovative piece of litigation and we are enclosing herein our firm cheque in the sum of \$500.00. We wish you and Mr. Ferro (the Lowe's solicitor) the best of luck in this matter.

Yours truly,

Per: Norm Cuddy
TAPPER CUDDY
1000 - 330 St. Mary Avenue
Winnipeg, Manitoba R3C 3Z5
Phone No. (204) 944-3260
Enclosure

YOUTHS AND PARENTS
Re: Sourcebook for teachers

By: Margaret Parlor, Advisor – Youth Issues

The Myalgic Encephalomyelitis Association of Ontario's Placement of *TEACH-ME: A SOURCEBOOK FOR TEACHERS OF CHILDREN with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (CFS) and/or Fibromyalgia (FMS)*

The Myalgic Encephalomyelitis Association of Ontario submitted the **TEACH-ME: Sourcebook** to the previous Ontario Minister of Education, Elizabeth Witmer MPP, for her review.

In Minister Witmer's letter of response to the Association, dated March 21, 2003, she stated: "I appreciate the information you included in your letter, as well as the resource document **Teach-Me: A Sourcebook for Teachers of Children with ME/CFS and/or FMS**. Both provide excellent background information about these conditions."

Following Minister Witmer's direction, The Myalgic Encephalomyelitis Association of Ontario consulted with Mr. Alex Bezzina, Director, and Special Education Branch for the Ministry of Education, to obtain his advice for the placement of the **TEACH-ME: Sourcebook**, published by the National ME/FM Action Network. Mr. Bezzina stated that ideally, every Principal and Special Education Consultant in Ontario should have a copy of the Sourcebook.

As funding permits, the ME Association of Ontario will place the **TEACH-ME: Sourcebooks** with the Special Education Consultants of Ontario's Elementary and Secondary Public and Separate School Boards and with Ontario's Principals.

The ME Association of Ontario is very grateful for the donations that they receive to assist them with their Project.

The Myalgic Encephalomyelitis Association of Ontario has placed the **TEACH-ME: Sourcebook** with the following locations. Please check back to their web site as they will list other areas of placements as they occur.

ADMINISTRATIVE

Ontario Council for Administration in Special Education; Council for Exceptional Children; "SNOW", Adaptive Technology Resource Centre; Ontario Principals' Council; Catholic Principals' Council of Ontario; Ontario Elementary and Secondary Teachers Federation; Ministry of Education.

ONTARIO SCHOOL BOARDS

Upper Grand District School Boards: Special Education Consultants of the Primary and Secondary Special Education Coordinators of the Upper Grand District School Board that covers Guelph, Erin, Mt. Forest, Palmerston, Orangeville and Fergus:

Toronto School Boards: Special Education Consultants of the Elementary and Secondary Public and Separate School Boards.

Peterborough School Boards: Special Education Consultants of the Kawthra Pine Ridge District School Board, the Peterborough Victoria North Catholic School Board, the Rhema Elementary Christian School Board, the Grace Christian Academy School Board.

Ottawa Carleton School Board: In May, 2004, Margaret Parlor gave a presentation on ME/CFS to the Trustees of the Ottawa Carleton District School Board at which Ron Lynch, interim Director of Education, attended and was presented a copy of the **TEACH-ME: Sourcebook**. Mr. Lynch is now in charge of Special Education.

ONTARIO'S ME/CFS SUPPORT GROUPS

ME/FM Association of Peterborough and District; Peterborough Public Library; Waterloo Wellington Myalgic Encephalomyelitis Association, and will continue to place the Sourcebook with other Provincial Support Groups.

To order the TEACH-ME: Sourcebook:

The TEACH-ME: Sourcebook can be ordered from the National ME/FM Action Network by calling 613-829-6667. Cost is \$22.00 Canadian.

NATIONAL LIAISON COMMITTEE ESTABLISHED

The **National ME/FM Action Network** has established a National Liaison Committee. This group will be composed of at least one representative from each province and territory. The purpose of such a committee is to exchange information with provincial support groups and to establish a line of communication with them. Where no provincial group exists, there are other types of essential tasks in which a volunteer from any province can become involved.

The Vice-President, **Dr. Philipa Corning**, has been appointed as the National Liaison Officer, and will coordinate the work of this Committee. Members of this committee will become involved in meaningful work such as the following:

- Advocacy
- finding and submitting names of ME/FMS friendly doctors and lawyers for the national rosters
- distribution of our pamphlets on ME and FMS
- pass on information on provincial activities to us
- distribution of information regarding the Chronic Fatigue Syndrome and Fibromyalgia Clinical
- Case Definitions and Diagnostic and Treatment Protocols documents.

If anyone is interested in working to assist those in our ME/FM community, please contact the Vice-President at the following email address at: pcorning@nb.sympatico.ca or contact the President at our phone number indicated in this newsletter.

U.S. LAWYERS – ADDITION :

Contact: **Justin C. Frankel**, Esq.
FRANKEL & NEWFIELD, P.C.
585 Stewart Ave., Suite L50
Tel. **(516) 222-1600** Fax **(516) 248-8711**
Garden City, NY 11530 U.S.A.
E-mail: jcf@frankelnewfield.com
Web: www.frankelnewfield.com

HOW TO HIRE A LAWYER

By : Norm Cuddy

At a recent seminar on disability law I spoke to several people about their problems in retaining counsel. I heard complaints of lawyers who seemed disinterested in their cases or who lacked the skills to bring cases to completion. One woman advised that her lawyer was on a 54% contingency. Another person reported a contingency rate of 44%. WCB claimants and CPP disability claimants advised that for the most part they were unable to retain a lawyer at all.

1. Finding the right lawyer.

Disability law is a narrow sub-specialty of civil litigation. Practice in this area requires medical knowledge, litigation skills, tenacity and the ability to empathize with your client's problems. It takes a special set of skills and grasp of the tactics to successfully take on large insurance companies. Few lawyers practice to any extent in this area. Unfortunately, many lawyers take on disability cases without the requisite knowledge or experience of how best to handle them. As a result these files often do not receive the attention they deserve and languish at the back of a file cabinet; or worse still they may be pressed forward without adequate preparation and without thought of the consequences. The best way to find a lawyer who is proficient in disability law is by "word of mouth". Ask others with conditions similar to yours about their experiences with lawyers and ask for recommendations. Self help groups like the **National ME/FM Action Network**, Fibromyalgia support groups etc. keep lists of lawyers. Most provincial law societies have lawyer referral services and can direct you to a lawyer. Avoid lawyers who advertise in the yellow pages or on television.

2. Contingency Agreements versus Fee for Service

A lawyer can either be hired on a contingency (percentage of recovery) or on an hourly rate. Virtually all disability claimants require a lawyer who will work on a contingency.

Not all lawyers take contingency cases. Some lawyers only work on an hourly rate. These lawyers will likely have little experience in disability cases.

Even a lawyer who accepts contingency cases will not accept all cases on that basis. In any such case the lawyer is taking a risk, putting at stake his or her time, money and firm resources. The lawyer must have confidence in your case and think it has merit before taking it on.

A contingency means your lawyer receives a fee only if you succeed in settling your claim or win at trial. You will still be responsible for disbursements (filing fees, cost of medical reports, transcripts etc.) in any event. The normal contingency fee is 33% with a slightly higher (usually 40%) if the case proceeds to the Court of Appeal.

Contingencies are negotiable. It is reasonable to ask for a sliding contingency (for example 20% if the case is settled before a Statement of Claim is filed, 25% if settled before Discoveries etc.)

Just because the contingency agreement is presented in a polished and elaborate format, don't think it cannot be changed to suit your particular circumstances.

Do not agree to a contingency agreement in excess of 33%. The proposal of a higher percentage suggests your lawyer has little confidence in your claim or is over-charging. Find another lawyer.

A contingency agreement that is unreasonable may be set aside even after it has been signed. There are court rules and provisions in law society legislation for the variation of agreements that are either unfair or work unreasonably against the client.

3. Workers Compensation and Canada Pension Plan Benefits

My advice to claimants under WCB and CPP is that they should not hire a lawyer although for different reasons.

Workers compensation legislation has been designed to exclude lawyers from the process. WCB tribunals never award costs to a successful claimant, and the awards often refer to future benefits which cannot be used to pay contingency fees.

More importantly it is a sad fact that WCB tribunals seldom rule in favor of claimants after the initial denial. As a result few lawyers are prepared to take cases on a contingency unless there are unusual or compelling circumstances.

It is unwise to offer to pay a lawyer hourly fees to represent you on a WCB claim. Many lawyers will not even accept such a retainer because the likelihood of success is so slim.

The only realistic way a lawyer can be retained is through the support of a union. Some unions have a policy of assisting members in WCB claims that the union deems to have merit.

The best (and usually the only) choice for WCB claimants is to obtain representation through "Workers Advisors" or a similar government funded agency. Reports of the quality of such service are mixed but the likelihood of success with a workers advisor is probably no worse than with a lawyer.

Canada Pension Plan tribunals are much more fair minded than WCB but they likewise designed to make it unnecessary to have a lawyer represent you. The procedures are informal and the staff is helpful. CPP has stringent requirements for coverage, your disability must be "Prolonged and Severe" in order to qualify.

CPP seems more concerned with the content of medical opinions than in the evidence at the hearing. Therefore the best way to win a CPP appeal is to make sure that your medical evidence supports the CPP criteria. My advice to many people is to save the money they were about to pay to a lawyer and obtain a better medical report instead.

Lawyers are sometimes criticized as being mercenary and unfeeling. I have heard it said that "Everyone hates lawyers except the people who need one." Disabilities are difficult in all respects and disability law is no exception. The challenges of suing large insurers with endless resources can be daunting. It is my experience that the lawyers who practice in this area do so because they have a social conscience, and believe they are helping people who badly need their help.

NORM CUDDY of TAPPER CUDDY, Barristers & Solicitors, 1000 - 330 St. Mary Ave.,
Winnipeg, MB R3C 3Z5 Tel. (204) 944-3253 Fax (204) 947-2593 E-mail: Mac@tcwpg.com
Web: www.tcwpg.com

[Ed. Note: Mr. Cuddy Practices with Tapper Cuddy in Winnipeg, MB. and as a "Visiting Lawyer" in British Columbia and Alberta. Mr. Cuddy is also on our National Lawyers' Roster]

With Fall soon ending, the Canada geese are on their way to the south. Here is the GOOSE STORY adopted by the National ME/FM Action Network and therefore reflected in its logo. It represents what we believe support is all about.

THE GOOSE STORY

Next Fall, when you see Geese heading South for the Winter...
flying along in a "V" formation...
you might consider what Science has discovered.

As each bird flaps its Wings, it creates
an Uplift for the bird immediately Following.
By flying in "V" formation the whole flock adds
at least 71% greater flying range,
than if each bird flew on its own.

PEOPLE WHO SHARE A COMMON DIRECTION
AND SENSE OF COMMUNITY
CAN GET WHERE THEY ARE GOING MORE QUICKLY AND EASILY
BECAUSE THEY ARE TRAVELLING ON THE THRUST OF ONE ANOTHER.

When a goose falls out of Formation
it suddenly feels the Drag and Resistance
of having to go it alone....and quickly
gets back into Formation to take Advantage
of the lifting power of the bird in front.

IF WE HAVE AS MUCH SENSE AS A GOOSE
WE WILL STAY IN FORMATION WITH THOSE WHO ARE HEADED THE SAME WAY WE ARE.

When the Head Goose gets tired it rotates back
in the Wing...and another goose flies Point.

IT IS SENSIBLE TO TAKE TURNS DOING DEMANDING JOBS
WITH PEOPLE OR WITH GEESE FLYING SOUTH

Geese honk from behind to Encourage those up Front
to keep up their Speed.

WHAT DO WE SAY WHEN WE HONK FROM BEHIND?

Finally...and this is important, when a goose gets sick,
or is wounded by Gunshots, and falls out of Formation,
two other Geese fall out with that goose and
follow it down to lend Help and Protection.

They stay with the Fallen Goose until it is able to fly
or until it Dies; and only then do they launch out
on their own or with another Formation
to catch up with their Group.

IF WE HAVE THE SENSE OF A GOOSE
WE WILL STAND BY EACH OTHER LIKE THAT.

Author Unknown.

INTER-GROUP/CONTACT INFORMATION:

FIBROMYALGIA PROVINCIAL CONFERENCE HOSTED BY FIBROMYALGIA ASSOCIATION
NIAGARA

DATE: April 9th & 10th 2005

LOCATION: Americana Conference Resort & Spa
8444 Lundy's Lane, Niagara Falls, Ontario.

KEYNOTE SPEAKER: Dr. I Jon Russell MD, PhD, FACR, Director, University Clinical Research
Centre, University of Texas Health Science Centre, San Antonio, Texas. Top International
Researcher, Clinician, and Speaker.

OTHER SPEAKERS:

Sherry Torkos PhD, Pharmacist and Nutritionist; **Richard Bogoroch**, Lawyer and Author of
FM issues; **George Cameron-Caluori**, Editor, Canadian Disability; **Gloria Fraser RN**, Nurse
Education Coordinator, Sunnybrooke Hosp.

COST: Members: \$50.00 Non-members: \$65.00

CHECK OUT THIS WEBSITE FOR MORE INFORMATION:

www.fibromyalgiaassocniagara.org or call **Pat: (905) 374-1263**

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
Workplace Safety & Insurance Board (WSIB) 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, advocates, support groups wishing to receive a copy or copies of the
Form, or to inquire about specific IME doctors, please contact: **National ME/FM Action
Network** – Or download the Form from our website at
www.mefmaction.net/medexac.html.

RESOURCE BOOKS:

• **Fibromyalgia Syndrome: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document.** *Journal of Musculoskeletal Pain* **11(4), 2004** will also be available as a soft cover book entitled **The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners, Haworth Press, 2004.** Both the journal and the book will be available through The Haworth Press, Inc. 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.haworthpress.com/store/product.asp?>

• **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>

- -

Prices below include Shipping and Handling. Cheques Payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.

• **QUEST COLLECTION I 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): 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 For Fibromyalgia Syndrome and Myalgic Encephalomyelitis / Chronic Fatigue Syndrome:** 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. **NOW AVAILABLE FOR PURCHASE Cost \$60.00.**

MEMBERSHIP: \$25.00 per year which includes quarterly newsletters

**Payment can be made by CHEQUE, VISA or MASTERCARD to:
NATIONAL ME/FM ACTION NETWORK, 3836 Carling Ave., Nepean, ON K2K 2Y6
Canada Tel/Fax: (613) 829-6667 E-mail: ag922@ncf.ca
Web: <http://www.mefmaction.net>**

COPYRIGHT NOTICE:

The National ME/FM Action Network newsletter "QUEST" is published quarterly. Its contents are © 2004 by the National ME/FM Action Network, EXCEPT where authors of articles are indicated. These items are copyrighted by the authors and written permission must be obtained from the author in order to reprint them. Other articles may be reproduced by other non-profit publications as long as copyright notices are included and items are clearly attributed to the NATIONAL ME/FM ACTION NETWORK, citing its name, address, telephone number and website.

DISCLAIMER:

The NATIONAL ME/FM ACTION NETWORK serves as a clearing house for information on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia. Some of the information contained herein is intended to help patients and their physicians make informed decisions about their health. However, the NATIONAL ME/FM ACTION NETWORK does not dispense medical advice or endorse any specific medical hypothesis or product and assumes no responsibility for any treatment or action undertaken by its readers.

Psssssst NEXT ISSUE – WINTER 2004

Chapter 2

Understanding Fibromyalgia Syndrome (FMS) in Young People

By

Marjorie I. van de Sande, B.Ed, Grad. Dip. Ed.
Consensus Coordinator for the Canadian FMS Consensus Document
National ME/FM Action Network, Advisor

Bruce M. Carruthers, MD, CM, FRCP(C)
Co-Editor of the Canadian FMS Consensus Document
National ME/FM Action Network, Medical Advisor

Introduction

This chapter will give educators a better understanding of Fibromyalgia Syndrome (FMS). The Clinical Diagnostic Criteria for FMS are included in order for educators to be aware of the many

symptoms, in addition to pain, that FMS potentially encompasses. It is hoped that this understanding will enhance the educator's ability to accommodate young people with FMS in the school setting.

What is FMS?

Fibro refers to fibrous tissue – ligaments and tendons, **myo** refers to muscle, and **algia** refers to pain. Fibromyalgia involves widespread pain of the muscles, ligaments, and tendons. A syndrome is a set of medical signs and symptoms that are seen together. Fibromyalgia is a soft-tissue pain syndrome that is classified as non-articular rheumatism in the World Health Organization's International Classification of Diseases. As in other medical conditions, the severity of FMS varies from mild to severe and it can be debilitating.

What Causes FMS?

A physical trauma, particularly a whiplash or spinal injury, can trigger FMS in many patients. There appears to be a genetic factor involved in some patients. In other patients, FMS comes on gradually with no known cause.

How Prevalent is FMS?

Studies estimate that between 2% and 10% of the general population have FMS(1,2,3). In a prevalence study of randomly selected school children, 6.2% met the criteria for FMS (4). It is two to five times more common than rheumatoid arthritis.

Who Gets FMS?

FMS affects all age groups, including children, all racial/ethnic groups, and all socioeconomic strata.

As in many painful conditions, such as arthritis, there is a higher prevalence of FMS in females. Although all the mechanisms are not fully understood, some gender differences are known (5). Females generally have a more flexible and delicate skeleton, longer necks, and thinner, less massive muscles than males. Thus, females are more prone to neck and spinal injuries. Females generally have a narrower spinal canal than males. A study found that those (particularly females) who had persistent whiplash injury symptoms had a significantly narrower cervical (neck) spinal canal (6). As the spinal canals of children are narrower than adults, they may be more vulnerable to such injuries. Studies have found that females have a lower pain threshold (the point when a stimulus is perceived as painful)(1) and a greater increase in pain over time than males (7). Females produce more of some brain chemicals that increase pain signals and less of some other brain chemicals that decrease pain signals. A remarkable finding was that when endogenous (inside the central nervous system) tryptophan was depleted, there was only a 7-fold drop in synthesis of serotonin (a chemical that decreases pain sensation) in males but there was a dramatic **42-fold drop** in the synthesis of serotonin in females (8). This finding would certainly be an important factor in females having lower pain thresholds. Both the direction and magnitude of the brain's response to pain differs in males and females with females being more sensitive to pain (9).

What is the Natural Course of FMS?

An eight year study indicated that once FMS is established, symptoms generally did not improve and functional disability slightly worsened (10). In another study, all patients still had FMS fifteen years later (11).

What is the Difference Between FMS and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)?

There is an overlap of symptoms between FMS and ME/CFS and many think they may be variants of a similar disease process. FMS is often triggered by a physical injury with pain and dysfunction of the muscles, ligaments and tendons being more prominent. ME/CFS is often triggered by a viral

infection and there is more pronounced fatigue, post-exertional malaise and dysfunction of cognitive abilities and other body systems.

Clinical Definition of Fibromyalgia Syndrome (FMS)

The International Expert Consensus Panel, selected by Health Canada, consisted of thirteen doctors who were actively diagnosing/treating FMS and/or were researchers in this illness. Collectively, they had diagnosed and/or treated more than 20,000 FMS patients. They agreed that the 1990 American College of Rheumatology criteria were well established, accepted worldwide, and had good sensitivity and specificity for research. The Clinical Definition encompasses the potential spectrum of the symptomatic expressions of FMS. There was 100% consensus among panel members on the final document.

Canadian Clinical Working Case Definition of FMS (12)

The two compulsory pain criteria (adopted from the American College of Rheumatology 1990 Criteria [13]) are merged with Additional Clinical Symptoms & Signs to expand the classification of FMS into a Clinical Working Case Definition of FMS.

1. Compulsory HISTORY of widespread pain. Pain is considered widespread when all of the following are present for at least three months:

- Pain in both sides of the body
- pain above and below the waist (including low back pain)
- axial skeletal pain (cervical spine, anterior chest, thoracic spine or low back).

Shoulder and buttock involvement counts for either side of the body. "Low back" is lower segment.

2. Compulsory PAIN on PALPATION at 11 or more of the 18 defined tender point sites.

3. Additional Clinical Symptoms & Signs. In addition to the compulsory pain and tenderness required for research classification of FMS, many additional clinical symptoms and signs can contribute importantly to the patients' burden of illness. Some of these features are present in most FMS patients by the time they seek medical attention. On the other hand, it is uncommon for any individual FMS patient to have all of the associated symptoms or signs. As a result, the clinical presentation of FMS may vary somewhat, and the patterns of involvement may eventually lead to the recognition of FMS clinical subgroups. These additional clinical symptoms and signs are not required for the research classification of FMS but they are still clinically important. For these reasons, the following clinical symptoms and signs are itemized and described in an attempt to expand the compulsory pain criteria into a proposed Clinical Case Definition of FMS.

a) Neurological Manifestations: Neurological difficulties are often present such as hypertonic and hypotonic muscles; musculoskeletal asymmetry and dysfunction involving muscles, ligaments and joints; atypical patterns of numbness and tingling; abnormal muscle twitch response, muscle cramps, muscle weakness and fasciculations. Headaches, temporomandibular joint disorder, generalized weakness, perceptual disturbances, spatial instability, and sensory overload phenomena often occur.

b) Neurocognitive Manifestations: Some neurocognitive difficulties usually are present. These include impaired concentration and short-term memory consolidation, impaired speed of performance, inability to multi-task, and/or cognitive overload.

c) Fatigue: There is persistent and reactive fatigue accompanied by reduced physical and mental stamina, which often interferes with the patient's ability to exercise.

d) Sleep Dysfunction: The patient experiences unrefreshing sleep. This is usually accompanied by sleep disturbances including insomnia, frequent nocturnal awakening, nocturnal myoclonus, and/or restless leg syndrome.

e) Autonomic and/or Neuroendocrine Manifestations: These manifestations include cardiac arrhythmias, neurally mediated hypotension, vertigo, vasomotor instability, sicca syndrome, temperature instability, heat/cold intolerance, respiratory disturbances, intestinal and bladder motility disturbances with or without irritable bowel or bladder dysfunction, dysmenorrhea, loss of adaptability and tolerance for stress, emotional flattening, lability, and/or reactive depression.

f) Stiffness: Generalized or even regional stiffness that is most severe upon awakening and typically lasts for hours commonly occurs. It can return during periods of inactivity during the day.

Jain AK, and Carruthers BM, co-editors. van de Sande MI, Barron SR, Donaldson CCS, Dunne JV, Gingrich E., Heffez DS, Leung F Y-K, Malone DG, Romano TJ, Russell IJ, Saul D, Seibel DG.

FIBROMYALGIA SYNDROME: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document. *Journal of Musculoskeletal Pain* 11(4):3-107, 2003. Published simultaneously in: **The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners.** I Jon Russell, Editor. *Haworth Medical Press*, pg. 3-107, 2004. © Copyright 2004 Haworth Medical Press Inc., 10 Alice Street, Binghamton, NY 13904-1580, **reprinted with permission.** (The FMS Consensus Document may be viewed on the website of the National ME/FM Action Network at <http://www.mefmaction.net>. Instructions for ordering this informative book are also on our website.)

Symptoms and Signs of FMS

As indicated in the clinical definition, in addition to the two compulsory pain criteria, patients with FMS are expected to exhibit many of the additional symptoms. However, it is unlikely that a patient will exhibit all the additional symptoms and they may vary over time in different combinations. The severity and hierarchy of severity of symptoms tend to vary more dramatically from day to day in young people.

1. Pain: Do you recall the fairy tale where the princess could feel a pea under her mattress? FMS patients are extremely sensitive to pain and a fold in their night-clothes may cause enough pain to wake them up. How long can you hold a muscle in a flexed state before it becomes tired – 5, 10, 15 minutes? Many FMS patients are living with muscles that are permanently contracted and relentlessly pulling on their joints. Muscles that are shortened by contractures constantly ache, are dysfunctional, and are chronically fatigued.

Although the pain may begin as regional pain from an injury, instead of the pain going away, over the course of months it becomes widespread and increases in severity. Thus, there is a delay in the onset of FMS. Many research studies suggest that there are abnormalities in the interaction between the peripheral nervous system and the central nervous system in processing pain (12). FMS patients have higher levels of some chemicals that increase pain signals to the brain and lower than normal levels of some other chemicals that decrease pain signals. These unusual levels result in miscommunication between the brain and the body. Unopposed pain signals are being sent from the body to the brain and from the brain to the body.

Types of Pain: The sensation of pain varies in type, severity and its location often quickly shifts. Young people may describe their pain as burning, tingling, deep, shooting, sharp, stabbing – like a knife stuck in them, deep aching, feeling bruised all over, like someone used them as a punching bag, or any combination of these.

Understanding FMS Pain: It is easy to understand that a bruise or cut can cause pain. However, it is often difficult for those who are not well informed about FMS to believe that a young person could possibly experience so many types of pain, particularly when they say they are always in pain, the pain migrates to different parts of the body, and there is no visible evidence of injury. For example, if a child complained of pain in one leg and was favouring that leg when s/he was walking and then a few minutes later you observed that s/he was favouring the other leg, what would be your reaction? Would you smile to yourself and think that the child was faking it and couldn't even remember which leg s/he said was hurting? In actuality, when someone with FMS walks favouring one leg it puts more stress on the joints and muscles in the other leg and those muscles may spasm and/or send pain signals to the brain causing the pain to shift to the other leg.

It is most important for educators of FMS students to be cognizant of the fact that these young people have a dysfunction in the areas of the central nervous system that process pain resulting in inappropriate pain signals being sent to different parts of the body. Not only are these young people abnormally sensitive to pain, but after a painful stimulus the pain lasts for a much longer period than normal. Most readers have experienced a time when they were out walking and discovered that their shoes didn't fit properly and were causing blisters. How eager they were to get home quickly and take their shoes off their sore feet! How would they react to someone telling them to forget their pain and get in the gym and run? Similarly, young people who are in pain have a low endurance and are apt to be reluctant to participate in activities which involve physical contact and/or increases their pain. If their hands hurt, they may have difficulty writing and may not want to hold hands with other students.

Young people with FMS often fidget and squirm in their desks either because they are trying to find a different position that will relieve their pain or they are fatigued and are trying to stay awake. FMS students usually are unable to sit for extended periods of time because staying in one position increases their pain and may cause muscle spasm. They need to be accommodated by allowing them to stand up and walk around for a few minutes as required. On the other hand, some FMS patients can only stand for a very short time, particularly in one spot, and need to avoid doing so.

Because young people with FMS have extremely low pain thresholds and often have seemingly bizarre pain patterns, they may be labelled as whiners. It is most unfortunate that children who are suffering often are not taken seriously, or their pain is dismissed as "growing pains". Growing should not cause this much physical pain. Young children are eager to please and gain respect. When adults do not understand the depth of pain these children feel, there is a risk that they become withdrawn for fear of being ridiculed, and may not receive appropriate medical treatment in a timely fashion. **It is essential that educators know that the pain these young people experience is real, there is a physiological reason for their pain, and it can be severe and exhausting.**

Exercise: As exercise is often prescribed to young people with FMS, it warrants special attention. Out of 1,808 multi-disciplinary studies that were systematically reviewed,(14) only seven met the criteria for methodology, and of these two included exercise for FMS patients. The results were disappointing. Another review(15) of 26 studies of exercise intervention programs for FMS also gave disappointing results and attrition rates ran as high as over 60%, while some studies failed to report attrition rates. There is no reliable evidence that explains why exercise will reduce pain (16).

As much care must be taken in prescribing exercise programs as in prescribing pharmaceuticals (17). The Expert Consensus Panel recommends that a thorough history and examination be completed in order to determine the patient's total illness burden. Risk factors and pain generators, such as prior injuries, hypermobile or restricted joints, taut muscles, balance problems, and risk for adverse cardiac reactions must be identified and addressed. There are no exercises that can strengthen or heal lax or injured ligaments. The tighter the muscles, the easier they are activated – even when they shouldn't be. The opposing muscles appear weak, but are dysfunctional. The longer the muscles have been contracted, the more dysfunctional they are. The reality of biological dysfunctions and limitations must be acknowledged and accommodated. Medical management must be optimized before introducing exercise. The patient's treating doctor should direct and coordinate all rehabilitative efforts and all rehabilitation personnel must be knowledgeable about FMS. Exercises must be individualized and specific to the physical pathology of FMS. Young people with FMS, particularly if they also have ME/CFS, must never be pushed to increase their heart rate to average acceleration. This is potentially dangerous because their hearts may be functioning at a suboptimal level! It is essential to warm and stretch tight muscles and these muscles must be released before trying to strengthen 'weak' dysfunctional muscles. Taut muscles are pain generators. When a healthy person becomes stiff, exercise alleviates the stiffness. However, a person with FMS often stiffens with exercise because the muscles tighten to prevent further injury. It is of prime importance that the exercise does not worsen the patient's condition. There is an informative section on guidelines for exercise for FMS patients in the Consensus Document.

2. Tender Points: There are specific, distinctive points on the body called "tender points". When they are touched with a force that is not painful to healthy people, they produce pain in patients with FMS. It is incongruent that they are called "tender points" because it is considered a negative finding if these point present as tender: They must be painful. Many of the tender points are located where ligaments, tendons, or muscles attach to bones.

Some lay people rather dismissingly think that if you poke a person with FMS in some places it hurts, and that's all FMS is. However, the painful tender points are simply a diagnostic tool. Just as a painful left arm can indicate malfunction of the heart, painful tender points indicate that there is dysfunction in the central nervous system related to pain processing.

3. Additional Symptoms

a) Neurological Manifestations: People with FMS usually have a number of neurological manifestations.

- **Ligaments, tendons and muscles are usually involved in producing pain in FMS:** Although the pain is most often felt in the muscles and joints, ligaments and tendons are also sensitive to pain. When ligaments are overstretched, they are easily injured and are difficult to heal because they have a limited blood supply, particularly where they attach to the bone. Lax or injured ligaments do not hold the joints in place properly so there is abnormal joint movement. When there is abnormal movement of a joint, muscles around the joint tend to react by contracting in order to help stabilize the joint and prevent further damage. However, muscles cannot do the job of ligaments so the contracted muscles constantly stress the joints, including vertebrae, and sometimes pull them out of alignment. This stress puts even more stress on the muscles, which in turn puts more stress on the joints, and so the vicious circle continues. The lax/injured ligaments may cause the joints to be hypermobile, or restricted due to muscle contraction. Over an extended time period, often years, the posture of FMS patients may become abnormal and their body may become lopsided. Due to muscle contraction, typically their head is too far forward, and their shoulders are too high, too far forward and become rounded. One leg often becomes functionally shorter (the legs measure the same length but one is shorter due to the pelvis being tilted and/or rotated).

It is important that educators know that failure of the joints and other supportive structures causes pain and structural fatigue, which inhibits the length of time a person can stand (12). Those whose posture has become abnormal are often told to stand up straight and put their shoulders back. Although these young people would love to have good posture, they simply can't achieve it. Young people are sensitive so it is important not to draw attention to these abnormalities.

- **Other muscle abnormalities:** As mentioned, many muscles may be contracted and taut. When one muscle is contracted, its opposing muscle accommodates by remaining lax and it is dysfunctional. Youth with FMS are prone to muscle cramps, twitching, and weakness. They may also have generalized weakness.

- **Numbness and tingling** are common, particularly in the legs, feet, arms and hands.

- **Headaches,** including migraines, are common and usually are accompanied by spasms in the neck and shoulder muscles. Some young people may get double vision, see spots in front of their eyes, or have trouble focusing their eyes shortly before the onset of a migraine. If an educator has a student prone to migraines, it is helpful to be alert to these pre-onset symptoms and the student should be picked up by his/her parent as soon as possible.

- **Temporomandibular joint disorder (TMJ):** In FMS patients, TMJ is usually caused by chronic contraction of the muscles that are involved in jaw movement. Some students with TMJ may find it too painful, or be unable to open their mouths wide enough to sing. In these cases, they should be excused from singing or at least not be expected to open their mouths wide.

- **Perceptual disturbances and spatial instability:** Young people may periodically have difficulty focusing their vision, which may be brought on by exhaustion or

precede a migraine. It can be confusing to the educator when FMS students say that they can't read the writing on the blackboard or in a book when they could shortly before and may be able to again an hour or so later. The problem is not that they suddenly become shortsighted or longsighted but rather the muscles that focus their eyes are not working properly. In addition, eye fatigue may be increased by straining to try to focus their eyes and many FMS patients have abnormally dry eyes. If students are prone to eye fatigue, consider suggesting the following quick exercise to be done periodically as a preventative measure: "**Palming**"(12) is a simple technique that temporarily reduces eye strain. Simply close your eyes and cup your hands over your eyes putting gentle pressure on the top of the cheek bones from the base of both palms. Hold for one minute and then blink several times.

Young people may not be able to hear or understand instructions because background noise may be more pronounced than the instructions. Their brains may be unable to give the appropriate relevance to auditory input in much the same way as not being able to tune a radio to one station. They may experience ringing in their ears, which usually comes and goes rather than being constant. At such times, children find it more difficult to hear and may become frustrated.

Some young people may have difficulty timing and sequencing their actions, walking in a straight line, and they may bump into things and appear clumsy. They may have difficulty with depth perception and walking on uneven surfaces. It is best not to draw attention to these abnormalities and to be aware that when these difficulties become more pronounced, it is a sign that the student is over-fatigued and needs to rest.

- **Overload phenomena:** Young people may be hypersensitive to a variety of sensory inputs such as bright or fluorescent lights, sound, noise, speed, odours, or any combination of these. It is important that the learning environment be as free from distractions as possible. Cold intolerance is very common and some may have heat intolerance. Cold temperatures can cause these young people's muscles to spasm so they may not be able to go outside on cold days.

b) Neurocognitive Dysfunction: The cognitive difficulties of young people with FMS are generally less severe than those who suffer with ME/CFS but never-the-less they can be debilitating. The symptoms are often more associated with pain and cognitive fatigue than fixed impairments. The cognitive fatigue experience by FMS patients is commonly referred to as "fibro fog", and is characterized by confusion, difficulty consolidating short-term memories, forgetfulness, and difficulty with word and information retrieval.

A notable feature is that their cognitive functions and responses become markedly slower. It is not that they are unable to understand the concepts when they are feeling better, but rather that their brains process information slowly and it takes them a long time to complete a project or assignment. It may be difficult for them to understand what is being said when someone speaks quickly. They may have difficulty with reading, writing and math, and taking notes may be very challenging. Their responses become even more markedly slower as their fatigue increases, which is a sign that they need to rest.

Young people with FMS quickly experience cognitive overload when they receive information at a faster rate than they can process. They will have difficulty making decisions, multi-tasking, and may "crash" (become temporarily immobilized by fatigue).

d) Fatigue: Chronic pain and stiffness are exhausting. The fatigue and stiffness experienced by young people with FMS are generally worse in the morning but can come unexpectedly from activities that would not tire a healthy person. This reactive fatigue can

be delayed by a day or more and is almost always accompanied by increased pain and worsening of other symptoms. Recovery time is longer than normal.

Structural fatigue, due to abnormalities in the joints or discs, results in the body being unable to support itself for sustained periods. This type of fatigue is common in FMS and is relieved by sitting or lying down. Muscular fatigue is prominent in FMS and is associated with muscle dysfunction. It is triggered by movement and relieved by stopping the movement but recovery may take a long time. Most FMS patients have arousal fatigue as a result of poor sleep quality and quantity. This poor sleep quality usually plays an important role in their cognitive fatigue. Oxygenation fatigue may be experienced. In some young people with FMS, the muscles around the chest and between the ribs are contracted so tightly and are so painful that the motion of the chest wall is markedly restricted, causing their breathing to be very shallow. This shallow breathing decreases the body's ability to deliver enough oxygen to the tissues and brain. It is helpful for educators to be aware of the types of fatigue young people with FMS experience and accommodate their fatigue appropriately.

e) Sleep Dysfunction: Young people with FMS usually have difficulty falling asleep often because they cannot stay in one position long enough as a result of their pain. Many wake up frequently and have trouble getting back to sleep. Most patients with FMS do not spend enough time in the deep stages of sleep where the body restores itself and becomes rested (18). This poor sleep quality is a contributing factor to their widespread, diffuse pain and cognitive difficulties. A research study(19) had demonstrated that insufficient deep sleep causes painful tender points upon palpation, suggesting that the lack of deep sleep plays an important role in FMS. Patients wake up feeling utterly exhausted. It is very hard for them to get going in the morning. Some of these young people also have other sleep dysfunctions, such as restless leg syndrome. How often have you heard someone complaining that they are so exhausted because they hardly slept the night before? Children and youth with FMS experience a lack of sleep quality and usually sleep quantity night after night, week after week, month after month, and year after year. Please allow them to take short rests as needed.

f) Autonomic and/or Neuroendocrine Dysfunctions: Many young people with FMS experience some dysfunctions of the autonomic nervous system. It is very common for them to become dizzy, lightheaded, and lose their balance when they extend their neck, quickly rotate it, or get up quickly. These symptoms are usually relieved quickly by lying down and being still. Some FMS patients have a lower than normal body temperature, and may experience bizarre patterns of hot and cold sensations. For example, one side of their body may feel cold and the other feel hot. Cold temperatures often cause muscle spasm and pain. At other times, they may sweat excessively after limited physical activity. Some have swelling of their feet and hands while others may have dry eyes and mouth. If an FMS student does have a dry mouth, they may need to take sips of water or juice periodically. Others may have to be excused to go to the bathroom more often as a result of increased urinary frequency and/or bowel dysfunction. Teenaged girls often have very painful menstrual periods.

Young people with FMS usually have less tolerance for stress and easily become overwhelmed. It is helpful if they are given one task at a time.

g) Stiffness: Nearly all young people with FMS are stiff when they wake up and it usually lasts for hours. Stiffness can return at other times during the day, generally when the young person has been inactive for some period, such as sitting in their desk too long. Exposure to drafts or cold weather can also trigger stiffness.

Summary

Young people with FMS have a dysfunction in the areas of the central nervous system that process pain. In addition to the generalized, widespread pain, they experience inappropriate and sometime rather bizarre pain sensations. The pain can quickly migrate from one place to another. Although many of their pain sensations fluctuate, contracted muscles and abnormal joint movement can cause constant pain and are easily aggravated. Their pain can be severe and exhausting.

Educational Implications

Young people with FMS face many physical, mental, educational, social, and emotional challenges, which also affect their families and friends. The pain and the numerous types of fatigue experience adversely affect their cognitive abilities and educational studies. Because of their slowed cognitive processing and fatigue, it is difficult for them to complete their school work and keep up with their classmates. They easily become confused and overwhelmed. Many FMS students require special educational considerations.

Goals and Guidelines for Educational Planning

(Adapted from the FMS Consensus Document [12])

The goals and guidelines for educational planning for FMS students are basically the same as for ME/CFS students. However, with FMS patients there is greater emphasis on accommodating pain symptoms and with ME/CFS there is greater emphasis on fatigue, post-exertional malaise, and cognitive symptoms. Many of these patients have overlapping symptoms and indeed some meet the criteria for both illnesses. For those educators who are specifically looking for information to assist them in accommodating FMS patients, the goals and guidelines are basically repeated from chapter 1.

Goals

The Expert Consensus Panel emphasizes the following top priorities in any rehabilitative efforts:

1. The support and well-being of the patient: Because FMS is a poorly understood chronic illness, educators can lessen the confusion and uncertainty often experienced by these patients by being supportive and influencing the opinion of these students' peers regarding the illness.

2. Patient empowerment: It is essential for the patient's physiological and psychological health that s/he is able to maintain autonomy over the pacing of activities. An integral part of empowering youth with FMS is to validate and respect their knowledge of their body and experiences. Educators can assist them in setting personal and emotional boundaries.

3. Optimizing functional ability: The aim is for these young people to achieve activity boundaries in which they can be as active as possible without aggravating their symptoms. Once reasonable boundaries are achieved, patients can very gradually extend their activities at their **own pace as they are able.**

Guidelines

1. The treating physician is responsible for the patient's care and should oversee all rehabilitative efforts. It is helpful if the treating physician provides a letter to educators outlining the patient's condition and limitations. Open communication and feedback is essential so that strategies can be assessed and adjusted. All rehabilitation personnel must be knowledgeable about FMS.

2. Educators should meet with the student and parents: As soon as a student has been diagnosed with FMS and at the beginning of each school term, the educator should meet with the parents and student. It is very challenging for parents to care for a chronically ill child, particularly when the child has a poorly understood illness. Collaboration among educators, parents and the student is advised. Parents should be encouraged to provide written information about their children's difficulties to be given to all of their teachers.

3. The biological pathophysiology of FMS must be respected and reflected in educational accommodations.

- All the patient's symptoms must be taken into consideration. The complex and varied dysfunctions and their interactions must be taken into account when determining what accommodations need to be made.
- The patient's physical symptoms, cognitive difficulties due to brain dysfunction, fatigue and emotional symptoms are a biological reality of FMS.
- The patient's activity boundaries fluctuate from day to day, and even hour to hour, and s/he lacks stamina. The longer the patient has suffered a symptom, the more limited her/his activity boundary is likely to be. Patience is required because it is essential that the student does not exceed his/her limitations. Special considerations for physical education classes are particularly important.
- Educational programs must not exacerbate the patient's symptoms.

4. Educational accommodations must respect the patient's autonomy, be conducive to healing, and individualized: The severity and hierarchy of symptoms, aggravators, and activity limitations will vary with each youth who has FMS. It is important that educators be sensitive and accommodate the young person's limitations when planning her/his program.

- Accommodations must be individualized according to pain severity and activity limitation, keeping in mind the unpredictable nature of FMS.
- Sometimes a young person is unaware of early warning signs or ignores them because s/he wants to fit in with peers. An alert educator will become aware of symptoms such as pallor, general uneasiness, slowing and deterioration of speech and work, anxiety, and emotional distress, which are signs that the student is experiencing increased pain and/or becoming exhausted. An educator can empower the student by assisting him/her in recognizing and monitoring early warning signs of excessive pain and fatigue. These signs are signals from the body to modify activities or rest.
- Begin the program at a level that will ensure the student's success.
- Patients must learn self-pacing – that is, they are in control of pacing their activities. Help the student learn to pace activities with very gradual increases, only when the student feels able, in order to ensure continued success. Pacing must be flexible and accommodate times when little can be achieved.
- The learning environment should maximize healing and minimize stress, pain and overload phenomena. It should be a comfortable temperature, and free from distractions and confusion. The student's body may not be able to adequately regulate its temperature so the student may need to wear extra or lighter clothing.
- Avoid sensory and information overload and pressure for excessive speed, all of which cause rapid deterioration of cognitive processing and increased difficulties in concentrating, retrieving words and information, and multi-tasking. Forgetfulness is very common and not meant to annoy. These students will require extra time for assignments and exams.
- Keep directions simple, clear and concise.
- FMS students may need to eat or drink in class.
- If these young people stand up quickly or remain standing they can very suddenly become weak, nauseated, and disoriented. They must be allowed to remain seated if they have these difficulties.

- It is helpful for schools to issue these students two sets of books, one for home and one for school, in order to prevent avoid muscle spasms and aggravating their low pain tolerance from carrying books.

5. Student participation: The student is aware of his/her own body and how s/he feels. Educators can empower the student through respect. The student's autonomy is vital to her/his physical and psychological well-being. When the student is involved in establishing priorities and strategy decisions, s/he will be more motivated to succeed and misunderstandings will be minimized.

- Involve the student in setting realistic goals.
- It is important that the student is able to establish the complexity and pacing of activities. One of the most important features of managing FMS is that the patient learns to **self-pace** activities. When the patient is in control of pacing activities, s/he can gradually explore ways to increase activities as his/her ability allows, thus increasing the likelihood of success and continued commitment.
- Rest intervals should be incorporated into the school day as needed.
- Involve the student in developing alternative strategies in preparation for times when s/he is having flare-ups.
- In order to avoid disruption of the class, the teacher and student can develop prearranged signs or the teacher can give the student a 'pass card' to show when the simple agreed upon accommodations are needed, such as taking a short walk, resting, wearing sunglasses, eating a snack to regain strength, not standing in line, or being excused to go to the bathroom. (See note at end of chapter.)

While the basic principles of educational planning are briefly mentioned here, many educational accommodations are more complex and are discussed in detail in later chapters.

It is very difficult for children and young people to live with constant pain and fatigue. School work and physical activities are challenging. These young people should be encouraged to pursue interests that they can do that they might not have pursued if their activities were not limited. Listening to stories on CDs or tapes, or writing, or some hobbies that do not require strenuous physical activity may interest them. Above all else, it is essential for their meaningful others to be supportive and understanding.

The National ME/FM Action Network website <http://www.mefmaction.net> includes a Youth Site where parents and educators can obtain further information. If you have a tip that may help others assist young people with FMS, we would like to hear from you. We also post poems and short stories written by young people with FMS. Submission guidelines and contact information are on our Youth Site. We would be most interested in receiving submissions from your students with FMS and they may find it rewarding to have their poems posted on our national website.

Young people have the right to access education according to their circumstances. It is most imperative that parents, educators, and meaningful others remain patient, understanding, and supportive! Teaching, a demanding profession, can also offer a rewarding experience to an educator, who has the opportunity and privilege of touching the hearts and souls of these young people and making a positive difference in their lives.

Note: Following a report by the Chief Medical Officer's Working Group, which stated that "Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms", the Department of Health in the United Kingdom has endorsed the use of a "pass card" to protect the health of children with ME/CFS while they are in school (20). The "pass card" has the child's photograph, is signed by the principal, and states that the child has permission to use the

school's disabled facilities or obtain other assistance. Accommodations are agreed upon in advance. The child simply needs to show the teacher the card as required. The National ME/FM Action Network would like to spearhead a drive to make a "pass card" available for ME/CFS and FMS patients in Canada. If you are able to assist us or have any suggestions in furthering this cause please contact Marjorie van de Sande at mvandes@shaw.ca

Most medical information in this chapter is from the Canadian FMS Consensus Document. This informative document includes the clinical definition, discussion of the symptoms, diagnostic and treatment protocols, and a research overview. Guidelines for self-management strategies, exercise, and practical appendices are also included. The document may be viewed on the National ME/FM Action Network website, and instructions for ordering the journal are provided.
<http://www.mefmaction.net>

References

1. Wolfe R, Ross K, Anderson J, et al. The prevalence of characteristics of fibromyalgia in the general population. *Arthritis Rheumatism* 38:19-28, 1995.
2. Croft P, Schollum J, et al. Population study of tender point counts and pain as evidence of fibromyalgia. *British Medical Journal* 309:696-699, 1994.
3. White KP, Speehley M, et al. The London fibromyalgia epidemiology study: the prevalence of fibromyalgia syndrome in London, Ontario. *Journal of Rheumatology* 26(7):1570-1576, 1999.
4. Buskila D, Press J. Assessment of nonarticular tenderness and prevalence of Fibromyalgia in children. *Journal of Rheumatology* 20(2):368-370, 1993.
5. van de Sande MI. Gender Differences Make Females More Prone to Fibromyalgia Syndrome (FMS) and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Than Males. In: Legal Disability Manual for Fibromyalgia Syndrome and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Editor: van de Sande MI. *National ME/FM Action Network*, 2004.
6. Pettersson K, Karrholm J, Toolanen G, Hildingsson C. Decreased width of the spinal canal in patients with chronic symptoms after whiplash injury. *Spine* 20(15):1664-1667, 1995.
7. Fillingim RB, Maixner W, et al. Sex differences in temporal summation but not sensory-discriminative processing of thermal pain. *Pain* 75(1):121-7, 1998.
8. Nishizawa S, Benkelfat C, et al. Differences between males and females in rates of serotonin synthesis in human brain. *Proc. National Academy of Science USA* 94:5308-13, 1997.
9. Zubieta JK, Smith YR, et al. μ -opioid receptor-mediated antinociceptive responses differ in men and women. *Journal of Neuroscience* 22(12):100-107, Jun 15, 2002.
10. Wolfe F, Anderson J, Harkness D, et al. Health status and disease severity in fibromyalgia: results of a six center longitudinal study. *Arthritis Rheumatism* 40:1571-1579, 1995.
11. Bennett R. The Scientific Basis for Understanding Pain in Fibromyalgia. *The Oregon Fibromyalgia Foundation*. <http://www.myalgia.com>
12. Jain AK, and Carruthers BM, co-editors. van de Sande MI, Barron SR, Donaldson CCS, Dunne JV, Gingrich E., Heffez DS, Leung F Y-K, Malone DG, Romano TJ, Russell IJ, Saul D, Seibel DG. FIBROMYALGIA SYNDROME: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document. *Journal of Musculoskeletal Pain* 11(4):3-107, 2003. Published simultaneously in: The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners. I Jon Russell, Editor. *Haworth Medical Press*, pg. 3-107, 2004.
13. Wolfe F, Smythe HA, Yunus MB, Bennett RM, Bombardier C, Goldenberg DL, Tugwell P, Campbell SM, Abeles M, Clark P, Fam AG, Farber SJ, Fiechtner JJ, Franklin CM, Gatter RA, Hamaty D, Lessard J, Lichtbroun AS, Masi AT, McCain GA, Reynolds WJ, Romano TJ, Russell IJ, Sheon RP. The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia: Report of the Multicenter Criteria Committee. *Arthritis and Rheumatism* 33(2): 160 – 172, February 1990.

14. Karjalainen K, Malmivaara A, Van Tulder M, et al. Multidisciplinary rehabilitation for fibromyalgia and musculoskeletal pain working age adults. *Cochrane Database System Review* 2:CD001984, 2000.
15. Jones KD, Clark SR, Bennett RM. Prescribing exercise for people with fibromyalgia. *AACN Clinical Issues* 13(2):277-293, 2002.
16. Clark SR, Jones KD, et al. Exercise for patients with fibromyalgia: risks versus benefits. *Current Rheumatology Report* 3(2):135-146, Apr, 2001.
17. Sheperd C. Pacing and exercise in chronic fatigue syndrome. *Physiotherapy* 87(8):395-396, Aug. 2001.
18. Smythe HA, Moldofsky H. Two contributions to understanding the "fibrositis" syndrome. *Bulletin of Rheumatism Diseases* 28:928-931, 1977.
19. Moldofsky H, Scarisbrick P, et al. Musculoskeletal symptoms and non-REM sleep disturbance in patients with "fibrositis syndrome" and healthy subjects. *Psychosomatic Medicine* 37(4):341-351, 1975.
20. Colby J. The Tymes Trustcard. A Young Action Online Document.
<http://www.youngactiononline.com>