



NATIONAL
ME / FM
ACTION NETWORK

Charitable tax no. (BN) 89183 3642 RR0001 ISSN 1205-786X

Quest

COMMUNICATION # 75

WEB: www.mefmaction.net

FALL 2007

HOPE 2007 AWARD

CONTENTS

Hope 2007 Award	1
CFS Associated with Chronic Enterovirus Infection	2
Fibromyalgia – How I See It and Treat it	2
Piecing Pain Together– Understanding Pain in Fibromyalgia	4
Coping with CFS	7
National Doctors' Roster	12
Books/subscriptions/etc	13
Network Notes	13
Resources	14

THE NATIONAL ME/FM ACTION NETWORK website has been awarded the **Hope 2007 Award** in recognition of the positive support and encouragement it gives to people suffering from chronic illnesses.

The IBS Tales Hope Awards 2007 are currently being presented to websites that offer positive support and encouragement to anyone suffering from a chronic medical problem; in particular, the awards recognize websites that :

- offer accurate information and resources for patients;
- encourage sufferers to search for new treatments and hope; and
- refuse to accept inadequate medical advice or doctors who tell us to "learn to live with it".

Our website was kindly created by Bob van de Sande, B. Sc. EE and the content of the website was developed/edited by Marj van de Sande, B. Ed., Grad. Dip. Ed. Congratulations and thank you to both of you.

Chronic Fatigue Syndrome- Associated with Chronic Enterovirus Infection

**Summarized by Dr. Philipa Corning, PhD,
BSc, CD, Vice-President, and Director of
Science.**

The following text is a summary of the original research article entitled "Chronic fatigue syndrome is associated with chronic enterovirus infection of the stomach" by John K.S. Chia, and Andrew Y. Chia, which was published in the Journal of Clinical Pathology 2007; 0:1-6. doi: 10.1136/jcp.2007.050054.

Certain viruses and bacteria have been reported to cause prolonged fatigue, fevers and many other symptoms of CFS in small subsets of patients, e.g., Epstein-Barr, cytomegalovirus, parvovirus B19, Burcella, Toxoplasma, Coxiella burnetti, Ross river virus and Chlamydia pneumoniae. This recent analysis of 200 patients by the Chia team suggested there were a number of potentially treatable infections associated with CFS, and that enteroviruses may be the causative agent in more than 50% of the cases.

Enteroviruses have been associated with acute infections of the respiratory and gastrointestinal (GI) tract, as well as infections of the nervous system, and cardiac and muscle tissue. Thus, this research team and two other laboratories treated CFS patients with interferon and ribavirin. This treatment resulted in the symptoms of CFS and amount of viral RNA in white blood cells in the blood being significantly reduced. Once drug treatment was discontinued, the symptoms of CFS returned and viral RNA increased. Such results support the role of enterovirus in CFS.

Enteroviruses are acid- and bile-resistant, and are believed to commonly cause acute

gastritis. Most CFS patients have persistent or periodic GI problems. This could explain the presence of enterovirus protein in 82% of stomach biopsies of CFS patients having GI complaints. It is recognized that in some cases, CFS was probably initiated by GI tract problems, as evidenced by the associated presence of enterovirus protein in the stomach biopsies, which persisted in similar symptoms and biopsies taken years later from the same individuals. Indeed, since there are more than 70 species of enterovirus associated with humans, re-infection is probably very common. Furthermore, a second infection may be more severe and therefore more difficult to get rid of.

Although the persistence of enterovirus infection remains controversial, it has been associated with chronic myocarditis, type 1 diabetes, and neuromuscular diseases. Thus, the results of this team's research clearly supports the concept of viral persistence in human tissues, and that its presence may account for the diverse symptoms of CFS. More significantly, this team of researchers has demonstrated the improvement of CFS symptoms with antiviral therapy. This fact suggests that active and persistent viral infection is a critical consideration in the treatment of certain CFS patients.

This research suggests that if stomach biopsies confirm the presence of virus (especially enterovirus), antiviral therapy should be considered as an option to alleviate the symptoms of CFS.

Fibromyalgia –How I See It and Treat It

By R. Paul St. Amand, M.D.

Your Editor, Lydia, asked me to write something about my treatment of fibromyalgia. Whenever I write, I wonder what can I tell people who already know the illness, first-hand and all too well? Easy enough; I suppose: just review it sufficiently to remind

each one he or she is not alone and that there is indeed hope.

Fibromyalgia is sneaky and at first, often cycles with symptoms so separated as to obscure any correlation. How many of you remember being told those were just “growing pains” in childhood? Come puberty, they went away despite the most rapid growth period of your lives. Headaches may have appeared near puberty and then those insidious little pains here and there during the school years, something your peers may not have suffered.

With or without some kind of mental or physical stress, your foray into adulthood eventually created a bunch of sticky symptoms that eventually glued together. They became difficult to ignore and finally far too recurrent not to connect. Those with high pain thresholds first experienced fatigue, and overwhelming brain problems such as cognitive impairment, depression, anxiety, irritability and insomnia. Wimpier individuals also developed secure friendships with the same evils, but were simultaneously ravaged by multiple, fast-shifting aches and pains.

The irritable bowel, urinary and vaginal tortures, the deteriorating skin-hair-fingernail trio soon joined the entourage. The mish-mash of complaints seemed like a demonic Cuisinart-blender busily mulching away at the entire body. In this condition, who would dare go to a doctor and begin reciting myriad symptoms? Most people hold back and only offer those that seem pertinent to a particular specialty. Many of you have gone through that restricted drill and still emerged with negative success as candidates for the looney bin!

Perhaps you have the so-called “chronic fatigue syndrome” without too much hurting. Possibly you were once an athlete who easily took pain in stride. People such as you have high pain thresholds since wimps don’t usually do sports. Thus, you simply wallow at the other end of the fibromyalgia spectrum. The brain may be wiped out, but muscles still think

they could perform if given go ahead signals of available energy

Nowadays the diagnosis of fibromyalgia is more frequently considered. That achievement alone provides some comfort. But soon, dejection resurfaces when a flood of prescribed medications further zombies the already-deluged person. Pill for pain; pill for depression; pill for sleep; pill for energy; pill to offset pill, and pill for what maybe doesn’t even ail the patient are combined in an amplified assault on a body already lifeless and in hibernation.

I don’t think that’s the way to do it. I collect my patient’s *subjective* ailments first and then feel the body looking for the widespread, *objective* swellings that have been almost totally ignored. The combination easily confirms the diagnosis. I palpate the recommended eighteen tender point locations and a host of other frequently-affected places. I sketch each of them on a body caricature, using a technique I call **mapping**. Thirty or more places show up as lumps and bumps (swelling and spasms) throughout the torso and on all four limbs. With a bit of practice, they are easily felt. Since there are no diagnostic tests for fibromyalgia, sequential maps allow me to follow a patient’s reversal.

We next prescribe the safest medication I’ve ever known, **guaifenesin**. It is marketed to increase and soften sticky mucus. This is the most powerful of the medications we have successfully used to treat fibromyalgia. I will avoid great detail since our Website fibromyalgiatreatment.com well explains how this works. Suffice it to say, it nudges the kidneys into excreting phosphate excess, which I think is the root cause of this inherited, biochemical disturbance.

Tiny little organelles called mitochondria are abundantly distributed inside most cells. One of their functions is to convert food remnants into energy. Physiologists are aware that excess mitochondrial phosphate slows the formation of energy. Guaifenesin seems to

open kidney faucets and siphons phosphate out of the bloodstream. That in turn ultimately extracts surpluses wherever they lurk in cells. This is the complete opposite of the process that promoted accumulations and induced the disease. Our protocol is just that: a simple reversal.

The most laborious part of our treatment is in avoiding salicylates. Aspirin is an example of that chemical. All plants make salicylates and manufacturers lace many of their products with that misfit. A good example is BenGay or IcyHot, muscle pain relievers that directly deliver methyl *salicylate* through the intact skin. It absorbs within seconds. Mint, peppermint, spearmint, wintergreen, menthol are all ingredients that contain the same methyl salicylate. Therefore, applied to the skin, the lips, or swallowed, salicylates are rapidly absorbed and enter the bloodstream. They then attach themselves within particular kidney cells exactly at sites where the beneficial action of guaifenesin is totally blocked.

Thus, a mandatory part of our protocol is the meticulous avoidance of salicylates. I repeat, our Website and its volunteers will provide guidance through this seeming quagmire. Our papers and listings specifically detail what must be done. Chat-group members and the administrative team give their time unselfishly to promote adherence to the treatment details. *Guaifenesin will not work if patients ignore our warnings about salicylates.*

Some of you will feel a bit overwhelmed about our process of attacking fibromyalgia. Since nothing else reverses the disease, don't be daunted. It becomes relatively simple and the rewards are immense. Those of us rejuvenated in health are zealous missionaries who repeat our sermon for all who will listen. Fibromyalgia is a miserable illness that stealthily robs the brain of its faculties and the body of its metabolism. Begin to resuscitate yourself and watch for those first few good hours and days that scream out: "look, my body can do it!" They eventually cluster and

confidence mounts. You'll be surprised at what a fine human being you once were and are again.

R. Paul St. Amand, M.D., Associate Clinical Professor Medicine, Endocrinology – UCLA, 4560 Admiralty Way, Marina del Rey, CA 90292 USA, E-mail: fmsdoc@aol.com Website fibromyalgiatreatment.com Phone: (310) 577-7510 - Fax : (310) 821-0664

Piecing Pain Together – Understanding Pain in Fibromyalgia

By Dave J. Hayes

That the word pain is derived from the Latin word for punishment probably doesn't surprise anyone who experiences it on an everyday basis. Pain is one of the major factors in the pathogenesis of Fibromyalgia (FM). This fact is exemplified by the two essential diagnostic criteria that must be met: three months of wide spread pain and the existence of up to 18 tender points¹. Defined by the International Association for the Study of Pain as an unpleasant psychological experience, pain is a conscious and thus subjective event².

The subjective nature of pain, coupled with the fact that FM frequently coincides with psychiatric disorders such as major depression, mood and anxiety disorders, may have made it difficult for FM patients to receive appropriate treatment³. In many cases, researchers and clinicians have looked for a psychosomatic origin of the illness, but thankfully, the last few decades of FM research have revealed a biological basis, ultimately changing the approach of many primary care givers⁴. Regarding pain in particular, recent work has focused on nociception as a key factor, as this term refers to the nerves and biology associated with signaling the brain of potentially noxious stimuli.

Abnormal pain processing

The main idea that has surfaced in this regard is that FM-associated pain may be due to the abnormal processing of these nociceptive signals within the central nervous system (i.e. the brain and spinal cord). The nervous system learns to anticipate these nociceptive signals over time and begins to respond in full force at the slightest hint of them. Instead of ignoring these repeated signals (much like what happens with the sensory signals from our wrist watches or jewelry, allowing us to eventually forget we're wearing them), the FM brain responds by activating the pain response. This abnormally elevated or 'sensitized' response may be a hallmark of chronic pain. Ultimately, it is hoped that a better understanding of the nociceptive mechanisms behind this aberrant response will help to provide more effective treatments for those with FM.

Some evidence that would support this idea of pain sensitization has been summarized in a recent review by Dr Roland Staud⁵. Staud explains that while all studies do not agree on the main factors involved in chronic pain, nearly all studies of FM patients have shown abnormalities in pain sensitivity. While the cause of heightened pain sensitivity in FM patients is unknown, the bulk of studies point to factors involved in either abnormal nociceptive processing in the central nervous system or peripheral tissue abnormalities that give rise to constant nociceptive signals.

Nociceptive signaling abnormalities in the central nervous system appear to involve the dysregulation of pain-associated neurochemicals and nerves leading to improper learning within the brain's pain circuitry⁵. For instance, in 1965, Mendell & Wall showed that repetitive stimulation of nerve C-fibres (those nerves involved in the dull, aching, or burning pain sensation associated with chronic pain) could result in the progressive increase in activation of more C-fibres, effectively resulting in the amplification of pain⁶. Staud (2006) explains that recent studies in FM

patients have shown that this effect is due to central, not peripheral, nervous system sensitization, and this is demonstrated by the fact that FM patients exposed to experimentally regulated pain stimuli (e.g. mechanical, heat, cold, chemical) perceive greater increases in pain intensity over time versus healthy control subjects. FM patients also experience the pain over a prolonged period and they are more likely to report pain for non-noxious stimuli.

Staud (2006) also points to peripheral abnormalities in contributing to chronic pain, such as those recently found in skin and muscle. Evidence for muscle abnormalities is particularly strong, as studies have shown increases in the probability of abnormally shaped, moth-eaten and ischemic (i.e. not getting enough blood) muscle in FM patients as well as a tendency for the muscles to lack the proper amounts of energy (e.g. low levels of adenosine triphosphate and phosphocreatine) required to function properly. Like central nervous system nociception abnormalities, these peripheral abnormalities also increase the activity of pain-signaling neurochemicals. In addition, peripherally abnormal signals may be responsible for constantly and consistently activating those central nociceptive signals in FM patients, leading to the relentless sensation of chronic pain. This may explain why the simplest and seemingly harmless of daily tasks, such as house chores or walking to the corner store, may contribute to the maintenance of pain signaling.

Many neurochemicals that increase the likelihood and intensity of nociceptive signals, and thus the likelihood of experiencing pain, have been shown to be increased in FM patients. Some examples include increases in substance P, excitatory amino acids, neurotrophins and proinflammatory cytokines, which all provide biological puzzle pieces regarding how nociceptive signaling has gone awry in FM patients – putting these pieces together is the more difficult task at hand.

FM-specific factors: looking for differences

Current research looks not only for genetic, biological and physiological correlations between pain and FM, but often focuses on potential key differences, such as those that may exist between central and peripheral actions, or differences between the FM state and its comorbid illnesses. An example of such research is that of Laske et al. (2007). This group has investigated the levels of brain-derived neurotrophic factor (BDNF) in the blood serum of forty-one FM patients; compared to forty-five age-matched healthy controls⁷.

The group focused on BDNF because of its role as a neurotrophin – a protein that helps regulate neuronal survival and plasticity. In addition, it has been shown to regulate serotonin (a neurotransmitter which may be involved in signaling pain), be involved in major depression (high comorbidity) and acts as a mediator of pain signals throughout the nervous system. It is a chemical that participates in cell growth and plasticity within the nociceptive pathways of the nervous system, normally helping our nervous systems to ‘learn’ about noxious vs. non-noxious stimuli. Some animal studies looking at chronic pain have demonstrated an increase in BDNF levels.

Indeed, Laske et al. (2007) also demonstrated that blood serum levels of BDNF were much greater in people with FM over healthy controls. Interestingly, this finding is in contrast to the low levels of BDNF found in individuals with major depression; illustrating one way that current studies are finding differences between comorbid illnesses. Also, the high levels of BDNF were independent of age, gender (though reflective of the population, it should be noted that there are very few males in the study), and the preexistence of major depression or antidepressant use. These results suggest that BDNF plays a role in FM-mediated chronic pain despite age, gender or the

existence of comorbid major depression, and may be a future target for therapy.

Despite the prevalence of pain throughout society – one of the hallmarks of Fibromyalgia – its basic mechanisms remain shrouded. Despite the subjective nature of pain, however, it is becoming clear that many factors contribute to its biological, physiological and psychological/emotional components. This newfound knowledge is helping to piece together the clinical picture of disorders involving chronic pain; serving to promote the development of newer, more effective, therapies; and making sure that sufferers need not remain unheard.

The author is currently a PhD Candidate in Neuroscience at the University of Alberta, Centre for Neuroscience & Dept of Psychiatry. His work focuses on the brain mechanisms of motivation and reward with specific reference to the serotonergic and GABAergic neurotransmitter systems.

References

1. Wolfe, F., et al. 1990. The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia. Report of the Multicenter Criteria Committee. *Arthritis Rheum.* **33**: 160-72.
2. International Association for the Study of Pain. Retrieved May 2007 from <http://www.iasp-pain.org>
3. Mease, P. 2005. Fibromyalgia syndrome: review of clinical presentation, pathogenesis, outcome measures, and treatment. *J Rheumatol Suppl.* **75**: 6-21.
4. Lash, A. A., L. Ehrlich-Jones & D. McCoy. 2003. Fibromyalgia: evolving concepts and management in primary care settings. *Medsurg Nurs.* **12**: 145-59, 190; quiz 160.

5. Staud, R. 2006. Biology and therapy of fibromyalgia: pain in fibromyalgia syndrome. *Arthritis Res Ther.* **8**: 208.
6. Mendell, L. M. & P. D. Wall. 1965. Responses of Single Dorsal Cord Cells to Peripheral Cutaneous Unmyelinated Fibres. *Nature.* **206**: 97-9.
7. Laske, C., *et al.* 2007. Increased BDNF serum concentration in fibromyalgia with or without depression or antidepressants. *J Psychiatr Res.* **41**: 600-5.

Coping with CFS

By: Janette M. Collier, Ph.D.

My name is Dr. Janette Marie Collier. I am a Clinical Psychologist by profession, but more importantly, I am a young woman whose parents were both stricken with CFS over 15 years ago.

The impact CFS has had on our lives is significant. Over the years, I saw my parents change from two vibrant, healthy, active people excelling in their respective professions, to ones who struggled on a daily basis with the impact CFS had on their lives. Social events posed a challenge, extracurricular activities became nonexistent, and oftentimes they were unable to carry out the functions of normal everyday life, like cooking meals, or doing laundry. At times they were completely bedridden for weeks.

Through the years I have watched them struggle to find information to explain their symptoms, and a doctor who would believe they were ill and diagnose their condition. The sheer volume of medications and homeopathic remedies they have tried is more than I can recount.

I have witnessed the emotional impact CFS had on them. The anger at the unfairness of having a chronic illness and at the lack of

information available. The anger, disbelief, and grief at the lack of understanding and acceptance by not only friends and family, but also the medical community. The hope when a new medication was tried, and the eventual despair when yet another one failed to bring relief. The struggle to accept the limitations that the disorder brings with it, and the balance that must be obtained to preserve energy levels so that important events are not missed (and even then, having to miss some). The change in self-concept as they struggled to redefine themselves and adjust to the new lifestyle that had been imposed on them. Significant relationships changed or were lost, as friends and family responded with lack of understanding or compassion ("sure, I get tired, too, just go to sleep, you'll feel better").

I also saw how my own efforts to provide support were at times unhelpful. For example, assisting with household chores would sometimes result in conflict as my parents struggled with feelings of low self-esteem and a sense of failure as they were again reminded of what they were unable to do for themselves.

I don't tell you all this to reveal anything new to you. Anyone who has had contact with CFS knows what I am talking about all too well. Rather, I am trying to provide a backdrop for you, an understanding that when it became time to choose a topic for my graduate research, the choice to study CFS was an easy one. It was born not out of a need to complete my doctoral degree, but rather out of a personal need to help in any way I could, to bring some hope and help to people with CFS, including my parents.

A few years back, I had the privilege of working with 40 CFS patients who agreed to fill out questionnaires related to what factors helped them adjust to their illness. The majority came from the Toronto area, although some responded via internet and email from other provinces and within the U.S.A. It must be noted that while these people were often quite debilitated by their illness, they had

enough energy and concentration to complete the questionnaires, so they were not representative of all CFS sufferers.

In doing the research, I was interested in 3 specific variables: coping style, social support, and belief in degree of control over the illness (locus of control) to determine how they related to quality of life, and adjustment to illness. This research truly was groundbreaking, as up to that point, few studies had looked at how PWC's coped on a daily basis while the medical community tried to find effective treatments. Patients were left on their own (and often still are), wondering how to survive yet another day with their illness. Despite a large body of literature looking at coping and adjustment to other chronic medical illnesses such as MS, Lupus, or arthritis, many researchers in the area of CFS were focused on clarifying diagnostic issues, rather than having a biopsychosocial perspective. Such a perspective takes into account not only the biological aspects of the disorder, but also the psychological and social costs associated with it.

Chronic illness requires ongoing adaptation on the part of both patients and the people around them (Enevoldsen, Bowsher & Keep, 1995). Individuals typically experience uncertainty about the future, a sense of loss of control, distress, and helplessness (Taylor, Helgeson, Reed & Skokan, 1991). Many CFS sufferers are unable to work due to the debilitating nature of the disorder, resulting in financial difficulty. Relationships can become strained as fatigue forces social isolation and family members assume the bulk of the household responsibilities (Levy, 1991; Ware, 1999). More recent literature regarding CFS has begun to focus more on the roles of coping, social support, and locus of control in CFS management (Levy, 1991; Ray et al., 1997; Schmall, 1991).

The following discussion is a brief summary of the results from my doctoral dissertation research. Each of the three variables, coping

style, locus of control, and social support, will be addressed separately.

Coping Style:

People can cope with illness in many ways, including trying to change the health problem itself, reducing the distress associated with it, or changing what the illness means to them, and the impact it has on their lives (Pearlin & Aneshensel, 1986). One of the primary focuses of coping in response to illness tends to be trying to alleviate the symptoms, with patients seeking information and help and/or complying with treatment schedules set out by health professionals (problem-focused coping) (Pearlin & Aneshensel, 1986). Often, however, the nature of the illness itself may dictate certain behavioural responses to it, including the readiness of the person to seek out treatment. For example, irreversible or chronic health problems are often not responsive to medical intervention. In such cases, coping shifts from actively trying to change or reverse the health problem to adjusting to its presence and reducing the emotional distress associated with it (emotion-focused coping) (Pearlin & Aneshensel, 1986). This is particularly true of CFS as it typically begins with relatively minor flu-like symptoms for which people would not generally seek out treatment. It is not until patients are in distress and generally experiencing impaired everyday functioning that they will seek medical assistance. Even then, as the disease progresses and it becomes apparent that the doctor is unable to effectively deal with the myriad of physical complaints, patients can stop seeking treatment and focus on reducing their emotional distress.

The majority of the research across many different chronic illnesses points to the importance of problem-focused coping for patients, and the same is generally true of CFS. It is clearly important for patients to focus on finding solutions to their problems,

whether they be directly related to their symptoms (e.g. the stomach upset, the headaches, or the lack of energy) or to problems that are secondary to the illness (e.g. being too tired to run the household...or even get dressed each day).

One of the major difficulties with CFS, of course, is that there is a limit to what can be done to find solutions. For example, one has to live with the physical limitations of the illness, learn to accept the lifestyle changes that come with it, and accept the changes in social interaction and relationships.

There comes a point for most patients when it becomes healthier to employ emotion-focused coping strategies, learning to accept the feelings they have about situations and cope with what they are feeling. For example, it is very important for patients to recognize the anger and grief that they may feel over the losses they may have experienced throughout the course of their illness. Many patients experience loss of friendships, family support, employment, and self-concept. In addition, many patients understandably harbour a great deal of anger at the lack of information and acceptance of CFS; however, there is a limit to what one can do to increase knowledge and acceptance in others. At such a point, it becomes important for people to recognize their own feelings, and work towards accepting them as valid, but not allowing them to lead to despair and hopelessness.

Examples of ways to approach specific problems associated with CFS can include the following:

- For financial difficulties, it is important to seek assistance from relatives and/or friends, contact social service agencies such as welfare and long-term disability programs, and/or visit foodbanks if necessary. Consider doing some part-time work from home if possible;

- Prioritize tasks around the house, eliminate what does not need to be done, and enlist the

assistance of others on a regular basis with specific chores (even during “good periods”. For example, neighbourhood children or teenagers and/or seniors might be willing to do small tasks such as preparing meals, laundry, raking leaves, cutting grass etc. for minimal payment. Consider having a friend or relative prepare a number of meals for you that can be frozen and used on days when you do not have the energy to cook. Use delivery grocery services...the extra cost will far outweigh the cost in energy for yourself.

- Organize your life to minimize stressors as much as possible, and to prepare for events that will require extra energy on your part. For example, in planning my wedding, it was vitally important to my parents and myself that they have chances to rest as much as possible so that they could attend. Arrangements were made for them to be driven from place to place by a relative, a hotel room close to the church and hall was booked so that they could rest between the ceremony and the reception, and some of the ‘duties’ of the parents of the bride were eliminated altogether (for example, taking numerous family pictures). Preparations were also made to control the amount of contact they would have with people who were highly critical of them and unsympathetic of their illness, to reduce any emotional stress they may have encountered.

With respect to emotion-focused coping, it is extremely important for patients with CFS to seek out support from someone who is nonjudgmental, supportive, and willing to listen. Many patients with CFS find this difficult to do with family and friends, as the illness naturally has an impact on those people as well. In addition, no one likes to feel that they are complaining about the same issues all the time. In fact, what is needed is not just someone to listen as people vent, but also someone who can help them work through their emotions so that they are less distressing.

It is also important for patients to learn to redefine themselves, to build up their sense of who they are now that their lifestyle has changed. Oftentimes, people define success through their profession and ability to work, they identify with a certain role that can then be lost when one has to stop working. It is important for patients to examine that aspects of themselves that have not changed or that they are just discovering, and develop a sense of pride in who they are as people. Unfortunately, many patients with CFS are reluctant to seek out help for their emotional distress from professionals such as psychologists, as in the past it was not uncommon for other medical professionals to dismiss the patient's complaints as being psychological rather than biological in nature. However, as you will see below, receiving positive emotional support is one of the keys to adjustment to any chronic illness.

It is important to note that different stages of CFS often bring about different problems that may require different coping strategies. In the early stages, individuals may be searching for information on CFS or trying to find suitable doctors. In later stages, financial concerns may be paramount if the person is unable to work. Across all stages of the illness, individuals continually struggle to cope with particular aspects of the disorder such as fatigue, or consequences of the disorder such as loss of employment or friendships. Therefore, it makes sense that patients employ multiple strategies, and that no one coping strategy is effective in all situations. In fact, using several coping strategies is common in chronic illness groups, serving an adaptive function by allowing a person to match strategies to a particular problem or to use new strategies when others become dysfunctional or inappropriate (de Ridder et al., 1998). It is important for patients to recognize that they may continue to use old coping strategies even if they have become maladaptive simply because as the illness progresses they do not have the mental energy or desire to try alternative strategies. For example, they may continue to seek

support from family members who themselves are unable to provide the necessary support because they are suffering from caregiver burnout. Flexibility is a key factor in coping with CFS.

Locus of Control

Closely linked to coping style is what is called locus of control. In general, people differ with respect to the amount of control they believe they have over events in their lives. Some people tend to believe that they have control over what happens to them (internal locus of control), while other people believe that what happens is largely due to external factors such as chance or fate, the actions of other people such as doctors or other factors such as religious figures/God (external locus of control) (Wallston et al., 1994). These beliefs in degree of control can have a significant impact on how people approach their lives. Those who believe they have control are more likely to face problems as challenges rather than stressful events or crises, and are more likely to seek out solutions. Those who believe that they do not have control over events in their lives tend to take a more passive role, leaving the decisions up to other people, or allowing events to just happen to them. This can lead to feelings of inadequacy, helplessness, and depression, particularly if very few positive events occur.

With regards to CFS, having an internal locus of control, or a belief that your own behaviour can have an impact on your illness, is associated with better adjustment, and better quality of life overall. This was especially true in areas of employment, domestic chores, social activities, and relationships. In areas associated with health care, of course, a belief in the efficacy of doctors was associated with better overall adjustment; that is, the bitterness and reluctance to seek medical aid is related to poor adjustment.

On a cautionary note, it is very important to recognize that a belief that one should have complete control over every aspect of life is

not a healthy one, either (Kuehan & Winters, 1994). There are very few things in life that can be completely controlled, and with a chronic illness such as CFS, there are in fact, many aspects that simply cannot be controlled. For example, there are times when patients are doing everything right, resting, eating well, taking their medications, and they can still “crash” and become very ill for no apparent reason. Thus, it is very important for patients to recognize that there are things in their lives that they can control, but to be flexible in this belief, and to accept that in fact there are some things that they have to learn to accept and live with.

Social Support

A person who is ill has a need for many different types of support, each of which becomes important at different stages of the illness (Pearlin, 1986). Specifically, patients may face different tasks as the illness progresses. When the illness is first diagnosed, patients may have to appraise their symptoms and begin treatment, tasks that would require informational support. They may feel uncertain and fearful about the future and many need information to help clarify the situation. As the illness progresses, however, patients may find themselves in need of more tangible support as they begin to have difficulty meeting the responsibilities in the home. They may also need validation and reassurance that the feelings and fears experienced are a normal consequence of the illness. They may also experience a threat to their self-concept and may require emotional support and reassurance that family and friends will love them.

Of the various different kinds of support, across many illnesses, it is the perception of positive support that is most related to adjustment and quality of life. Whether this support comes from only one person, or many, the mere perception of having emotional support had positive effects. In addition, with the exception of sexual relationships, receiving tangible support or

practical assistance, did not appear to be related to adjustment to CFS. This is somewhat surprising, as the majority of people, including myself, would have expected that doing household chores would be of great assistance. And, as I said previously, in some respects, it is helpful; however, it also appears to have a negative impact on people's self-concept, which counterbalances its positive effects. So, for CFS sufferers, it is very important that they feel that they are getting positive support in the form of acceptance, love, and empathic listening. It is equally important that they think about what types of support they need when, and communicate these needs to the people around them.

A further aspect of social support lies in the perception of negative support, such as criticism, frustration, anger, disbelief in the legitimacy of the illness, and subsequent blaming of the patient. In general, results from this study showed that such negative support was strongly related to poor adjustment, poor quality of life, and emotional distress. This suggests that it is very important that CFS patients avoid, as much as possible, ongoing interaction with people in their lives who provide such negative interaction.

Clinicians such as psychologists have much to offer individuals with chronic illnesses in terms of helping them learn to cope with the illness. One of the most important components of this work would be the presence of a non-judgmental clinician who is willing to work with the patients to enhance their perceptions of support. Clinicians can also assist CFS patients in learning how to respond effectively to the lack of understanding and support they encounter in their daily lives to minimize its impact. It may also be helpful to include significant others (family, friends) in treatment sessions to educate them on the impact CFS can have not only on the patient's lives, but their own lives, and to provide suggestions for coping appropriately with conflicts that may arise as a result. It is also important to help patients find practical solutions to their

problems if possible, so that their sense of control increases. Finally, patients must remember that they are not alone in this; there are others out there willing to help.

As I say to my parents, together, we will get through this.

Dr. Collier is a Clinical Psychologist. She received her doctoral degree in October, 2000, from the University of Windsor.

NOTE: "This article originally published in the year 2000 and based on the research done at that time".

[Ed. Note: This article was written for ME/CFS but of course also applies to Fibromyalgia]

References

De Ridder, D. & Schreurs, K. (1996). Coping, social support and chronic disease: A research agenda. Psychology, Health & Medicine, 1 (1), 71-82.

Enevoldsen Bowsher, J. & Keep, D. (1995). Toward an understanding of three control constructs: Personal control, self-efficacy, and hardiness. Issues in Mental Health Nursing, 16, 33-50.

Kuehn, A.F., & Winters, R.K.V. (1994). A study of symptom distress, health locus of control, and coping resources of aging post-polio survivors. IMAGE: Journal of Nursing Scholarship, 26, 325-331.

Levy, F.C. (1991). The relationship of family dynamics to the onset, severity, and course of chronic fatigue immune dysfunction syndrome. Dissertation Abstracts International, 52 10-B. (Abstract No. 291177403).
Dissertation Abstracts International, 53 (5-A). (Abstract No. 301274718).
Taylor, S.E., Helgeson, V.S., Reed, G.M., & Skokan, L.A. (1991). Self-generated feelings of control and adjustment to physical illness. Journal of Social Issues, 47, 91-109.

Wallston, K.A., Stein, M. J., & Smith, C.A. (1994). Form C of the MHLC scales: A condition-specific measure of locus of control. Journal of Personality Assessment, 534-553.

Ware, N.C. (1999). Toward a model of social course in chronic illness: The example of chronic fatigue syndrome. Culture, Medicine and Psychiatry, 23, 303-331.

Doctors' Roster – US Addition

R. Paul St. Amand, M.D.

Associate Clinical Professor Medicine
Endocrinology – UCLA
4560 Admiralty Way
Marina del Rey, CA 90292
USA

fmsdoc@aol.com

Web: www.fibromyalgiatreatment.com

Phone: (310) 577-7510

Fax : (310) 821-0664

National Doctors' Roster Addition

Janette M. Collier, Ph.D., Clinical Psychologist

Great Hands

Oshawa Centre Mall

419 King Street West

Oshawa, Ontario L1J 2K5

Phone: (905) 433-9520

Books/Subscriptions/etc.

WOMEN and FIBROMYALGIA

Living with an Invisible Disease

By: Barbara A. Keddy, RN, Ph.d.

For people living with Fibromyalgia, their families and friends, as well as health

professionals and researchers, this information guide explores the lives of women suffering from this painful condition.

Price: \$16.95 U.S.

Call: 1-800-AUTHORS to order or visit

www.iUniverse.com

NETWORKS NOTES

IME/FAE Registry Submission

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**

MEMBERSHIP: \$25.00 per year, which includes quarterly newsletters

Payment can be made by CHEQUE, VISA or MASTERCARD.

Do not email credit card information.

NATIONAL ME/FM ACTION NETWORK

3836 Carling Ave., Nepean, ON K2K 2Y6, Canada

Tel/Fax: (613) 829-6667 E-mail: aq922@ncf.ca

Web: <http://www.mefmaction.net>

RESOURCES

Consensus Documents

Complete Original Consensus Documents :

-FMS Consensus Document - US\$24.95

"The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners".

Haworth Press, 2004. (soft cover book)

ISBN: 0-7890-2574-4

Phone: 800-429-6784 Fax: 607-771-0012

Email: orders@haworthpressinc.com

Online: <http://www.haworthpress.com/store/product.asp?sku=5342>

-ME/CFS Consensus Document US\$14.95

"MyalgicEncephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols".

Journal of Chronic Fatigue Syndrome, Vol. 11, No. 1, 2003. Haworth Press 2003/2004

ISBN: 0-7890-2207-9

Phone: 800-429-6784 Fax: 607-771-0012

Email: orders@haworthpressinc.com

Online: <http://www.haworthpress.com/store/product.asp?sku=4958> CFS46

Overviews of the Consensus Documents:

Fibromyalgia Syndrome, 24 pp, 2006

Chronic Fatigue Syndrome, 20 pp, 2006

can be ordered from **Marjorie Van de Sande** at mvandesande@shaw.ca or at 151 Arbour Ridge Circle NW, Calgary AB T3G 3V9.

ME/CFS DVD Resources

Prices include shipping & handling

- **Dr. Kenny De Meirleir - Physicians' full day workshop \$80.00. This includes 4 DVDs and a CD**

Canadian Consensus Guidelines for Diagnosis, Assessment and Treatment of ME/CFS -What they are and how to use them.

- Research Update
- Diagnostic Work Up and Treatment Algorithm
- Case Examples and Discussion
- CD of Slides

- **Dr. Kenny De Meirleir : Patients' lecture \$25.00**

- **Dr. David Bell's lecture: \$25.00**
(emphasis on chronic orthostatic intolerance)

Payment: must be by **cheque** or **money order** payable to **Marjorie van de Sande**

Mail it to her at **151 Arbour Ridge Circle NW, Calgary AB T3G 3V9.**

Network Resources

The following resources can be ordered from the National ME/FM Action Network. Prices include shipping and handling. Cheques should be made payable to the National ME/FM Action Network or you may pay by VISA or MasterCard.

Quest Collections

By popular request, the **National ME/FM Action Network** has published two collections of important articles which have appeared in 'QUEST' newsletters. The articles in each five-year collection have been grouped into sections according to their focus.

Quest Collection I: presently out of print

Quest Collection II (1999 – 2003): \$38.00

TEACH-ME: A Sourcebook for Teachers (Second Edition): \$22.00 *Discount on bulk orders*

With Dr. D. S. Bell, Dr. B. M. Carruthers and the TEACH-ME Task Force (teachers with ME/CFS and/or FMS)

This educational resource book will enhance teachers' and parents' understanding of ME/CFS and FMS in young people, and assist educators in developing educational modifications and programs.

The Canada Pension Plan Disability Benefits Guidelines: \$7.00.

New up-dated guidelines have been designed to assist those disabled by ME/CFS and/or FMS applying for Canada Pension Plan Disability Benefits. It will help you understand the criteria, important items to include and walks you through the various steps of the process.

Legal Disability Manual: \$60.00

Approx. 400 pages *Editor: M. van de Sande*

The Legal Disability Manual includes sections on: 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 Canada Pension Plan Disability Benefits Guidelines are also included in the Legal Disability Manual. This manual is a must for those in litigation.

COPYRIGHT NOTICE: The National ME/FM Action Network newsletter “QUEST” is published quarterly. Its contents are © 2004, 2005, 2006, 2007 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 in their entirety without alteration 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. Discuss medical treatments with your personal physician.

