

*“Fibromyalgia: Awareness, Advocacy, and Action”
Report of the Select Empowerment Seminar on Fibromyalgia*

Sponsored by The International Institute For Human Empowerment, Inc.



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“Fibromyalgia: Awareness, Advocacy, and Action”

Report of the Select Empowerment Seminar on Fibromyalgia

Abstract

Fibromyalgia is causing needless human suffering and expense. The following people need to come together to support Fibromyalgia patients: medical community, employers and human resource personnel, legislators, government health and human rights agencies, educators, and caregivers.

*The Select Empowerment Seminar Report represents the findings of 21 Capital District of New York professionals from a broad range of perspectives, who worked together for four days in the summer of 2009 to address the issues surrounding one illness: Fibromyalgia. **The International Institute For Human Empowerment, Inc.**, sponsored this seminar.*

The Report is divided into two distinct parts. Part I represents the thinking of all 21 participants, and is written in general language for patients, caregivers, and medical, legal, legislative, business, and educational communities. Part II contains Expert Summaries for those wanting more specific information, and includes articles by physicians, medical researchers, complementary therapists, as well as social security disability and human rights attorneys, and a patient advocate.

As a seminar participant, Fibromyalgia patient, and the writer of Part I of the final report, I am grateful to be able to bring to you professional expertise and insights for addressing the impact of Fibromyalgia.

*Sue Kidd Shipe, Ph.D.
Executive Director*



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The SELECT EMPOWERMENT SEMINAR Process

The Select Empowerment Seminar is a newly-created model based upon a think-tank process used by the Capital Area School Development Association (CASDA), an affiliate institute of the State University of New York at Albany. The CASDA Select Seminar process has been utilized by educators for action research for approximately 30 years. This process was developed by Dr. Nelson Armlin to assist schools in the Capital District of New York State to find solutions to the challenges educators face. Each CASDA Select Seminar resulted in a published document containing the findings of the seminar participants, and was broadly disseminated.

The new Select Empowerment Seminar process is designed to move beyond the confines of public and private educational institutions, to involve the wider community in addressing a health related issue that impacts the well-being not only of the patients and families, but also business, and social and governmental systems. The impact of one illness, Fibromyalgia, is growing daily as more and more patients are diagnosed, losing jobs and insurance, and needing to rely upon governmental programs. The human and financial cost is staggering.

This new model grew out of a need to bring great minds together to learn about the medical issues and implications of Fibromyalgia. Each seminar participant was carefully selected because of what he or she could contribute. Three of the 21 participants are Fibromyalgia patients. All seminar participants represent medical, education, legal, advocacy, and business professions. The result of our combined expertise far exceeded even our greatest expectations! The participants, all volunteers, gave freely of their expertise and experiences. Each of the four seminar days, held during the months of July and August, 2009, was composed of presentations by experts followed by small group deliberations to address relevant questions. The results of the thinking of our participants and contributors are found here. We have far to go in addressing this healthcare and social challenge, and we hope that this Select Empowerment Seminar Report will help illuminate the way.

Acknowledgments

We want to thank each of the presenters and contributors; our Medical Advisor Dr. Jonathan Cooper, Physiatrist; and our graphic artist Ms. Jody Morgenegg of CustomWebCare. Warm appreciation by each participant was expressed to our hostess Kathy Schoolcraft, and her husband Jim Schoolcraft, for the wonderful and creative environment of their beautiful estate on the Mohawk River in Niskayuna, N. Y., called "Niska Isle".

We are grateful to Assemblywoman Audrey I. Pheffer, Senator Elizabeth Little, and the New York State Assembly and Senate, for their Resolution proclaiming Fibromyalgia Awareness Week in the State of New York as the foundation for all of our Fibromyalgia activities. A copy of the Resolution is included.

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- 26. **Complementary Therapies**
 - 26. Vandita Kate Marchesiello, Yoga Teacher, KYTA
 - 30. Jeanette Perkins, Hypnotherapist
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- 35. **Legal / Advocacy**
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 - 40. b. Ira Mendleson III, Esq.
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Seminar Location/Cover Photos: Niska Isle Niskayuna, N.Y.

Fibromyalgia: Awareness, Advocacy and Action

Part I

Report of the Select Empowerment Seminar on Fibromyalgia

Introduction

We've waited long enough! Patients are becoming disillusioned and falling through the cracks while the academic debate continues.

“Is Fibromyalgia real?”

“Where's the evidence?”

“Are patients just malingerers?”

“Even after diagnosis, can anything be done?”

These are the voices of the people we expect to depend on.

No wonder patients are scared, frustrated, and depressed!

That's why this Select Empowerment Seminar project was initiated. The National Fibromyalgia Association estimates that 10 million people are diagnosed with Fibromyalgia in the United States alone. More are being diagnosed daily. Many more are undiagnosed. After diagnosis, too often the patient is left to flounder without proper treatment, resources, and support.

Currently the average time to diagnosis is 5 years. By then jobs, insurance and sometimes homes and spouses are often lost. The untreated pain, which has been compared to the pain of Rheumatoid Arthritis, has caused some to consider, and even commit, suicide. The burden on Social Security Disability is becoming greater. We now know that early intervention can sometimes prevent Fibromyalgia from becoming chronic and disabling. What are we waiting for? Scientific evidence now confirms what Fibromyalgia patients experience.

There IS something we can do. Let's get started! Once we understand the problem, the solution is at hand.

This report will tell you what 21 professionals and patients from a wide variety of perspectives, who studied the problem intensively, recommend. Our vision is to make each Fibromyalgia patient an empowered patient, living well and contributing to society.

Join us in the journey because, no matter who you are, you are an important part of the solution..

“...I struggle to live a happy, ‘normal’ life. I worry about my body and how I will feel when I get older. I worry about having children, being pregnant and taking care of babies. I struggle to get comfort and understanding from my friends and family. Invisible diseases are difficult because I look fine and people such as coworkers don't realize my daily struggle. I feel depressed about my situation and it often feels hopeless.”

(Fibromyalgia patient)

Fibromyalgia

Fibromyalgia is a multi-symptom, chronic, pain syndrome of unknown cause. Pain can be accompanied by severe fatigue and sleep disorders, cognitive issues such as memory problems and mood disorders, TMJ, irritable bowel syndrome, carpal tunnel syndrome, allergies, underactive thyroid, Raynaud's Phenomenon, multiple chemical sensitivities, muscle spasms, depression, restless legs syndrome, as well as increased sensitivity to temperature and weather changes, lights, sounds, and smells.

The pain of Fibromyalgia has been compared to the pain of Rheumatoid Arthritis. However, unlike many forms of Arthritis, Fibromyalgia does not cause joint deformity. Medications often used to treat other forms of Arthritis may exacerbate Fibromyalgia symptoms. In addition, patients tend to be sensitive to medications and their side effects, leaving a huge challenge for the physician to assist with managing pain.

We have learned much about Fibromyalgia in recent years. Once considered to be caused by inflammation in the muscles, recent research has concluded that Fibromyalgia is actually neurological, as evidenced by increased Substance P in the spinal fluid, changes in the structure of the brain thought to be related to a decrease in dopamine, and lack of oxygen to parts of the brain. Scans now reveal areas in the brain affected by chronic pain. Objective evidence is now available that proves the existence of the syndrome known as Fibro(fibrous tissue)-my(muscle)-algia(pain).

Although the American College of Rheumatologists determined the criteria for diagnosing Fibromyalgia in the 1990's as: pain in all four quadrants of the body, for a period of at least three months, with clinical evidence of pain in 11 of 18 tender points, information about Fibromyalgia is rarely taught in schools of medicine. The average time for diagnosis is five years with the patient seeing multiple physicians until finding one educated about Fibromyalgia. In an era of mounting medical and social security disability costs, lack of physician awareness and ability to diagnose this syndrome has led to much patient suffering, and waste of opportunities for early intervention. **It is believed that early diagnosis and treatment may prohibit acute pain from becoming chronic, thus relieving suffering for patients and families, as well as decreasing reliance upon government programs.** Public awareness and education have the added value of less strain on our economic systems.

Fibromyalgia can be Primary (exist alone), or Secondary to other, sometimes, major illnesses such as Lupus and Cancer. Each patient should have a thorough medical work-up to rule out other possible illnesses. Once the patient is suspected of having fibromyalgia, he or she is often referred to a Rheumatologist. Fibromyalgia is also considered to be a diagnosis of exclusion, as there are no specific laboratory tests currently available for the diagnosis of Fibromyalgia. (For more information on Fibromyalgia including current research, go to the National Fibromyalgia Association website at www.fmaware.org).

Impact

The impact of Fibromyalgia is far-reaching and multi-dimensional. Patient suffering, loss of employees in the workforce, families needing increased support, as well as a dramatic strain on the social security system are a few of the major impacts of this syndrome.

What's a physician to do with these little-understood complexities?

What's a patient to do to cope with change in all areas of life---job, income, prognosis for long-term health, self-image, pain, inability to plan due to the unpredictable changes that disrupt life? The patient asks, "How do I know that I'll be able to get out of bed to get to an appointment? to walk? to remember? to be a good employee? to take care of my children, or grandchildren?"

What's a teacher to do with a student who frequently complains about being sick, but looks fine?

What's an employer to do with an employee who may be outstanding, creative, and reliable, but frequently misses work?

What's the child to do when his parent can't take care of him?

What's the patient to do when the spouse gets tired of the unpredictable and restrictive lifestyle, and wants a different life?

What's the spouse to do when the person he or she married, seems now like a different person?

For some patients, jobs and careers may be gone; insurance may be lost as a result; and even if Social Security Disability is secured, it generally barely provides adequate financial relief. Homes can be lost; relationships are sometimes lost; and patients have even resorted to suicide in the face of unrelenting pain.

Fibromyalgia patients lose significant quality of life without adequate support. This support can be found through education such as electronic and hard copy resources from the National Fibromyalgia Association and others (see Resource section), local support groups, and physicians and other health-care providers knowledgeable about Fibromyalgia. Social Security Disability attorneys and the New York State Division of Human Rights are also important resources.

Fibromyalgia will not be addressed by one solution or one attempt. This effort will require the input of many voices, the resources of many minds and institutions, and the development of a long range plan with many short range goals. It will be incremental. It will be tedious. It will be time-consuming. It will be frustrating. But the victory of success will be worth it all!

"How has Fibromyalgia affected me? It has caused me to feel alienated from my peers. I can't keep up with my friends. I struggle with the discrimination that fibromyalgia is not a real condition. My own father thinks that I am weak and if I tried harder and pushed past the pain I would be fine. In college I struggled to stay awake in class. Now I live on my own.... Money is tight. I spend approximately 1/4 of my money on my health---doctor co-pays, physical therapy co-pays, medicine. It is so frustrating and expensive. The cost of healthcare makes it prohibitive to try alternative medicine such as acupuncture. (Fibromyalgia patient)

Treatments

Once the initial diagnosis of Fibromyalgia has been made, and other illnesses that can accompany it such as Lupus and Cancer have been ruled out, the physician focuses on treating the Fibromyalgia patient. If other illnesses have been diagnosed, they will need to take priority due to their potential serious impact. However, the chronic pain and fatigue, as well as the other concomitant symptoms, must be addressed.

It is extremely important to note that every patient is unique, and a cookie-cutter approach will not only be unsuccessful, but may exacerbate symptoms. Some patients respond well to pharmaceutical interventions, while others are more responsive to complementary therapies. It is important to consider the wide range of traditional and complementary therapies when treating the patient. Often, trial and error must be employed to learn what the patient can tolerate, as well as benefit from.

Traditional Western treatments generally include medications, physical therapy, occupational therapy, gentle exercise, and weight management. Pain medications can be used with attention to patient sensitivities. Unfortunately, many times Fibromyalgia patients develop sensitivities to medications that otherwise hold much promise. As each patient is individual, this needs to be assessed and monitored regularly.

The pain of Fibromyalgia can be migratory, burning, cramping, sharp or dull, or any other possibility. Initially the patient may feel she/he is going crazy until there is an understanding developed that pain can indeed migrate to many parts of the body. Anti-inflammatories (NSAIDS) are sometimes the first line of medications offered. However, patients need to be aware that they can have many serious side effects such as elevated blood pressure, edema, or abdominal bleeding. Often NSAIDS are prescribed to get the pain to a tolerable level while the patient considers other healthy lifestyle changes.

To date only three medications have been approved by the FDA for Fibromyalgia. All were formerly approved for neurological concerns such as epilepsy, depression, and anxiety. Some patients have found relief using these medications while others have been intolerant of the side effects. These medications are marketed as Lyrica, Cymbalta, and Savella.

Other medications used to treat Fibromyalgia include those for the specific symptoms of the syndrome, such as inability to reach a deep level of sleep, fall asleep or sustain sleep. Sleep is known to be the body's time for the repair of micro-tears within the muscles. The inability to reach delta level sleep impairs that recuperative process.

In Fibromyalgia, the fascia can become constricted resulting in pain and loss of mobility. Fascia is the thin filmy covering over the entire body under the skin. This can be seen on raw chicken as the thin, white, film throughout. When the human fascia becomes constricted, or "bunched", mobility is restricted. The technique of Myofascial Release used by some Physical Therapists, Occupational Therapists, and Massage Therapists has been found to be effective for many Fibromyalgia patients. This technique is often combined with another technique called Craniosacral Therapy which concentrates on mobility of the fluids within the tissues. Complementary therapies employed for Fibromyalgia are covered in detail in the Expert Summaries in Part II. Many patients report relief from these non-invasive therapies including yoga, hypnosis for stress management and pain relief, water therapy, stretching, meditation, breathing exercises, acupuncture, gentle chiropractic, and gentle massage.

The mind-body-spirit connection implies that we need to treat the whole patient. Stress reduction, supportive relationships, time and energy management, spiritual practices, and psychological and cognitive therapy as indicated, all work together to improve patient quality of life, ability to work and contribute to family and society, and the ability to derive pleasure in daily activities.

What Needs To Be Done

1. Public recognition of Fibromyalgia as real

Current state:

-Patients have been victimized by the lack of understanding and knowledge about this syndrome, as well as available treatments

2. Physician continuing education about Fibromyalgia and inclusion of Fibromyalgia in the medical school curriculum. Inclusion of pain as a stand alone component in all medical curricula for the purpose of the team approach in teaching, diagnosing, and treating patients.

Current state of medical treatment for Fibromyalgia:

-Five year average to obtain diagnosis

-Diagnosed, but often not treated

-Dismissed as depression only, or emotional problem

-Perception of patient as malingerer

-Lack of awareness that Fibromyalgia can be primary, or secondary to other serious illnesses such as Lupus and Cancer

-Lack of adequate pain management for Fibromyalgia patients

3. Patient access to education, support, medications, pain management services, medical and non-medical therapies

4. Research on chronic pain and chronic fatigue

5. Research on new medications specifically for Fibromyalgia

6. Job accommodations for Fibromyalgia patients

7. Employer and Human Resources personnel education of Fibromyalgia patient rights under New York State Human Rights Laws

8. Education about Fibromyalgia for Human Rights Agencies

9. Enforcement of existing New York State Human Rights Laws

10. Education and training provided by government health agencies

11. Legislative support for Fibromyalgia patients and their families

12. Efficient Social Security Disability process

Current State of Social Security Disability process:

-Patients losing jobs, insurance, homes, and spouses during application process

-Social Security Disability physicians uninformed about how to diagnose Fibromyalgia

-Lack of Hearing Officers delays process currently up to 1 1/2 years after initial denial, for a total period of approximately 3 years until ruling

What Needs To Be Done -- cont'd.

13. Housing that is affordable, safe, and available for disabled Fibromyalgia patients

Current state:

- *Waiting lists for several years for low-cost housing*
- *Housing currently often in high-crime areas*

14. Patient access to physicians educated about Fibromyalgia, and FDA approved products including supplements

Current state:

- *Desperate patient vulnerability to charlatans using questionable treatments*
- *Lack of FDA approval of products making unsubstantiated claims of effectiveness*

15. Efficacy studies to learn what works for people who have Fibromyalgia

16. Insurance companies to provide coverage for treatments found to be helpful for Fibromyalgia including but not limited to: Massage, Myofascial Release, Craniosacral Therapy, Water therapy, Hypnosis, and Yoga

“For much of the past 27 years one phrase has stuck out...whenever asked, ‘How are you today?’ That phrase--- ‘I’m tired.’ It didn’t matter how much sleep I had.....I was always tired. ..But anytime I’d mention it to my doctors, they’d check for infections or write it off as stress. It wasn’t until my sister and mother suggested I see a Rheumatologist....that the pieces finally fell into place. The doctor extensively checked for all types of other explanations before presenting me with the Fibromyalgia brochure to read. I was skeptical at first, but as I read through the material I was shocked by how many of my medical problems were explained by this condition..... Although I’m new to being treated--I am already noticing a change in my life since being placed on medication to help me have restful sleep. The pain is always there--but it seems easier to deal with on a good nights sleep. My only thought is how different the last 27 years (might) have been if I (had been) diagnosed earlier.” (Fibromyalgia patient)

“...The fact that insurance does not generally pay for many of the kinds of therapies that are most helpful for people with this conditionmakes a big impact because it means one can’t access care in many cases...” (Fibromyalgia patient)

Fibromyalgia Action Plan / Recommendations

What You Can Do:

a. Patient

- Learn about Fibromyalgia
 - Learn what it is, and isn't
 - Rule out other illnesses
 - Research reputable sources such as the National Fibromyalgia Association at www.fmaware.org (see our Resources section)
 - Find the right physician who treats Fibromyalgia
 - Refuse to take mental or emotional abuse from anyone
 - Focus on what you CAN do.
 - Take responsibility for improving your health.
- Join a support group.
- See yourself as a “whole” person.
(You may become a person with a disability, but you are not a disabled person.)
- Become a Fibromyalgia Advocate for others. Join with others in this cause.
Help newly diagnosed patients.
- Recognize your strengths; accept your losses.
- Make a “new you” and develop new strengths.
- Explore treatment options. (see Expert Summary by Lorraine Calleri, OTR/LMT)
- Insist on a Medical Team approach and become the “Captain” of your team.
(see Expert Summary by Jonathan Cooper, M.D.)
- Teach your family and friends about Fibromyalgia.
- Know your Rights under the Federal Americans with Disabilities Act (ADA) and New York State Human Rights Laws. (see Expert Summary by John Herrion, Esq.)
- Be pro-active in your request for disability benefits. Fibromyalgia can be a long term condition causing significant limitations. If you are turned down for Social Security benefits, do not give up. Appeal the decision and ask for a hearing.
- Become empowered; claim your rights when necessary.
- Take your lemons, and make Lemonade!

Fibromyalgia Action Plan / Recommendations

What You Can Do: -- *cont'd.*

b. Physicians and other Healthcare Professionals

- Learn about Fibromyalgia diagnosis, treatment, and scientific understanding to date. Rule out other potentially serious diseases for which Fibromyalgia may be secondary including Lupus and Cancer.
- Keep current with research on Fibromyalgia.
- Learn about the variety of Fibromyalgia treatments. Practice integrative medicine that provides a holistic approach including Western and Eastern approaches.
- Listen to your patients; each Fibromyalgia patient experience is unique.
- Refer your patients to reputable resources (see Resource section).
- Tell patients of potential side effects of recommended medications.
- Provide educational resources on Fibromyalgia in your Office such as this Report, and brochures from the Arthritis Foundation and the National Fibromyalgia Association.
- Include sleep studies for every Fibromyalgia patient.
- Be ready to support your Fibromyalgia patient with Job Accommodation and Social Security Disability paperwork when indicated. Do not allow them to lose jobs, insurance, homes, and spouses as a result of lack of proper support.
- Know your community resources such as Fibromyalgia Support Groups.
- Educate your Fibromyalgia patients on what Fibromyalgia is, and isn't. Practice early intervention that may prevent chronic pain and fatigue.

c. Education Professionals

- Learn about Fibromyalgia and its symptoms.
- Provide staff development for all Human Resources Personnel about Fibromyalgia and possible Job Accommodations. (see Resource section, Job Accommodation Network)
- Require all School Health Educators to recognize and understand Fibromyalgia. Provide training as necessary. Recommend that they report possible student cases of Fibromyalgia to parents.
- Review existing employment policies to be sure that they provide appropriate job accommodations for Fibromyalgia patients.
- Provide professional development on ADA and NYS Human Rights Laws pertaining to Fibromyalgia for all Building Level Administrators, School Attorneys, and Union Officials.
- Require annual updates and training on Fibromyalgia.
- Develop and maintain appropriate Job Accommodations policy guidelines.
- Support employees and students with Fibromyalgia to assist them to continue to be productive in the education environment.

Fibromyalgia Action Plan / Recommendations

What You Can Do: -- *cont'd.*

d. Employers and Human Resource Professionals

- Provide education about Fibromyalgia and its symptoms and impact.
- Provide education and training regarding Federal ADA and NYS Human Rights Laws.
- Provide Annual notice to all employees about Fibromyalgia.
- Provide Job Accommodations for patients with Fibromyalgia.

e. Elected Officials

- Provide continued Resolutions on behalf of New York State Fibromyalgia Awareness Week.
- Educate constituents and the medical profession in your areas about Fibromyalgia via letter, email or website.
- Create Legislation to require New York State Health Agencies to provide education and training to all government health employees as well as all medical personnel in the field about Fibromyalgia.

f. Health Insurers

- Eliminate “fail first” test, and provide FDA approved medications for Fibromyalgia.
- Provide coverage for complementary therapies found to be effective in the treatment of Fibromyalgia including but not limited to: Massage, Myofascial Release, Craniosacral Therapy, Water Therapy, Hypnosis, and Yoga.

g. Researchers

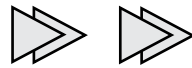
- Conduct efficacy studies to learn what treatments work for Fibromyalgia patients.
- Conduct research for medications developed specifically for Fibromyalgia.
- Conduct research on cause of Fibromyalgia.
- Conduct research on chronic pain and chronic fatigue.
- Focus research on the mechanisms of pain.

h. Human Rights Agencies

- Educate all Human Rights employees and volunteers about Fibromyalgia.
- Know Federal ADA and NYS Human Rights laws as they apply to Fibromyalgia.
- Enforce laws that prohibit discrimination against Fibromyalgia patients.
- Provide education and outreach regarding patient rights under federal and state law.

Shifting Attitudes

FROM



TO

PATIENT

Passive in one's healthcare
Single Physician approach
Physician as head of team
Feeling victimized
"Poor Me" attitude
Few treatment options
Barely living with Fibromyalgia
Focus on lost abilities
Getting value from doing
Feeling unworthy
Advocating for self
Therapist developed goals

Active in one's healthcare
Healthcare Team Approach
Patient as Captain of team
Knowing Patient Rights
"Take Charge" attitude
Many treatment options
Living well with Fibromyalgia
Focus on abilities
Getting value from being
Finding ways to contribute
Advocating for self and others
Patient developed goals

PHYSICIAN

Frustration with Fibromyalgia
Demeaning toward Patients
Viewing patient as lazy
Closed-minded to Fibromyalgia
Treating all patients the same
Judgmental toward patient
Blaming on Depression only
Prescribing for "typical" patient

Knowledgeable re: Fibromyalgia
Understanding their experience
Recognizing patient challenges
Understanding its impact
Recognizing patient differences
Empathic toward patient
Depression as one symptom
Aware of chemical sensitivities

COMPLEMENTARY HEALTHCARE PROVIDERS

Treating all patients the same
Exacerbating pain
Lack of Fibromyalgia treatments
Cookie-cutter approach

Recognizing touch sensitivities
Adjusting for Fibromyalgia
Traditional and complementary
Individualizing treatments

FAMILIES/FRIENDS

Seeing patient as lazy
Seeing patient as undependable
Wanting to "fix" the problem
Frustrated with limitations
Expecting life to remain the same
Living with unpredictability
Seeing patient as shirking home responsibilities
Giving patient "down time"
Requiring time together
Meeting "my" needs
Expecting predictability

Understanding the symptoms
Recognizing limitations
Learning to simply "be there"
Finding new things to do together
Becoming more flexible
Learning to adapt
Changing home responsibilities
Giving oneself "down time"
Balancing together / alone time
Meeting our needs
Seeing unpredictability as normal

Seminar Outcomes: Why This is Important

Because of the work of the Select Empowerment Seminar:

- Physicians will have a variety of treatment options to offer their patients.
- Healthcare providers will understand the individuality of the Fibromyalgia patient experience, and offer help from a continuum of possible treatments.
- Family and friends will understand that persistent symptoms of chronic pain and fatigue are real.
- Government health-related agencies will be provided positive direction and educational assistance to help them provide education and training.
- Legislators will feel assured that their actions on behalf of Fibromyalgia patients are supported by research and experience.
- Institutions of learning will understand more about the health concerns of some students and staff.
- Researchers will have a foundation from which to seek funding for much needed Fibromyalgia research.
- Children will be believed when they complain of chronic pain and fatigue, and other vague symptoms.
- Employers will understand their responsibilities for reasonable accommodations.
- Human Rights agencies will better understand and protect patients from discrimination.
- The General Public will understand that Fibromyalgia is not a hopeless diagnosis, and that there are many resources available to help the patient.

“...I realize now how uninformed most fibro patients are of their rights and the processes to help themselves get the financial relief or employment support that they need and are entitled to. I feel patients will be more empowered to stay in the workforce with some simple education of their rights. Patients can also empower themselves to get what they are entitled even if denied initially. (Seminar participant)”

Resolution for New York State Fibromyalgia Awareness Week

State of New York

Legislative Resolution

Senate No. 1856



Assembly No. 565

By: Senators Little, Duane, Hannon, Adams, Addabbo, Alesi, Aubertine, Bonacic, Breslin, De Francisco, Diaz, Dilan, Espada, Farley, Flanagan, Foley, Fuschillo, Golden, Griffo, Hassell-Thompson, Huntley, C. Johnson, O. Johnson, Klein, Krueger, Kruger, Lanza, Larkin, LaValle, Leibell, Libous, Marcellino, Maziarz, McDonald, Monserrate, Montgomery, Morahan, Nozzolio, Onorato, Oppenheimer, Padavan, Parker, Perkins, Ranzenhofer, Robach, Saland, Sampson, Savino, Schneiderman, Serrano, Seward, Skelos, Smith, Squadron, Stachowski, Stavisky, Stewart-Cousins, Thompson, Valesky, Volker, Winner and Young

By: M. of A. Pheffer, Destito, Amedore, Bacalles, Barclay, Barron, Bing, Boyland, Bradley, Burling, Cahill, Calhoun, Castro, Christensen, Conte, Cook, Corwin, Crouch, Cusick, DelMonte, DenDekker, Dinowitz, Duprey, Eddington, Errigo, Espaillat, Farrell, Fields, Fitzpatrick, Gabryszak, Glick, Gottfried, Gunther, Jaffee, Koon, Lupardo, Magee, Maisel, Markey, McDonough, McEneny, McKeivitt, Millman, Molinaro, Oaks, Paulin, Peoples, Perry, Rabbitt, Reilich, Reilly, Robinson, Rosenthal, Sayward, Schimel, Schimminger, Schroeder, Scozzafava, Spano, Sweeney, Tedisco, Thiele, Titone, Tobacco, Townsend, Walker, Weinstein, Weisenberg and Zebrowski

Memorializing Governor David A. Patterson to
proclaim May 11-17, 2009, as Fibromyalgia Awareness
Week in the State of New York

WHEREAS, An estimated 10 million people in the United States, six to eight percent of the population, and millions of people worldwide have been diagnosed with fibromyalgia, a disease for which there is no known cause or cure; and

WHEREAS, A chronic disorder that increases at alarming rates, fibromyalgia causes fatigue and debilitating pain in women, men, and children of all ethnicities; and

WHEREAS, Patients with fibromyalgia often have to learn to live with widespread pain throughout their bodies, extreme fatigue, sleep disorders, stiffness and weakness, migraine headaches, numbness and tingling and impairment of memory and concentration; and

WHEREAS, It often takes an average of five years to receive a diagnosis of fibromyalgia, and medical professionals frequently are inadequately educated on the diagnosis and treatment of fibromyalgia; and

WHEREAS, Increased awareness and expanded knowledge of the realities of life with fibromyalgia will allow the community at large to better support people who struggle with the challenges of this chronic pain disorder; and

WHEREAS, A nonprofit charitable organization and the publisher of Fibromyalgia AWARE, the first and only consumer magazine for fibromyalgia, the National Fibromyalgia Association has joined together with other groups around the country to promote fibromyalgia awareness and support, including improved education, diagnosis, research and treatment; and

WHEREAS, In addition, the National Fibromyalgia Association is urging fibromyalgia patients and their supporters, healthcare providers and the general public to demonstrate their caring by sharing the road patients walk, the facts about fibromyalgia, and evergrowing awareness about the etiology of this disorder and potential treatments; and

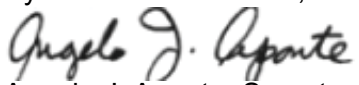
WHEREAS, The community's focus on fibromyalgia and its impact on patients' lives will help guarantee hope for a better future for people with fibromyalgia; and

WHEREAS, This Legislative Body recognizes the needs of those chronically ill people who suffer from fibromyalgia and urge all of our citizens to support the search for a cure and assist those individuals and families who deal with this devastating disorder on a daily basis; now, therefore, be it


RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor David A. Paterson to proclaim May 11-17, 2009, as Fibromyalgia Awareness Week in the State of New York; and be it further

RESOLVED, That copies of this Resolution, suitable engrossed, be transmitted to The Honorable David A. Paterson, Governor of the State of New York, and the National Fibromyalgia Association.

ADOPTED IN SENATE ON
May 12, 2009

By order of the Senate,

Angelo J. Aponte, Secretary

ADOPTED IN ASSEMBLY ON
By order of the Assembly,
May 12, 2009


Laurene R. Kretzler, Clerk



Part II

Expert Summaries -- Medical

Treatment of Fibromyalgia

Jonathan E. Cooper, MD

Physiatrist

The World Health Organization (WHO) and the International Association for the Study of Pain (IASP) have strongly endorsed the concept of treating pain, especially chronic pain, (which is qualitatively distinct from acute, “nociceptive” pain) in a graded, stepwise manner, referred to variously in the medical literature as the Pain Ladder, or, preferably the Treatment Pyramid. It emphasizes that as one ascends the ladder or pyramid, potency of the interventions portrayed as steps or rungs on the model increases, and so do the risks involved. Hippocrates’ first injunction to physicians was “First, do no harm!” We always run the risk by our attempts to relieve our patients’ suffering, of making a bad situation worse. The ladder or pyramid model emphasizes the great importance of starting with low-risk, safer interventions, using them as the base or foundation for our treatment structure, adding rungs, or layers, as we increase our efforts to obtain relief of pain and suffering.

The base of the pyramid consists in approaches that represent common sense and minimal to no risk. The primary emphasis is placed on establishing rapport, trust and communication with the patient and caregivers; without this essential 1st step, the entire foundation is absent and the structure will fail. Included in education is reassurance that although FMS is severely upsetting to one’s equilibrium and quality of life, it is not a disease in the strict sense, like cancer, AIDS, Lupus, etc., but a chronic condition, that the physician and team (team approach is absolutely essential) help teach the patient to manage, as the condition is often life-long.

Postural hygiene is necessary to be taught and practiced continuously. Exercise, focusing on flexibility and endurance, pursued very gently and gradually, is also essential. Strength-building is not a priority. Stress management and relaxation training are potent interventions, needed in most cases, as FMS is likely stress-induced in a majority of cases. Sleep hygiene is always needed, as sleep in FMS is never normal, and poor sleep lowers the pain threshold. Rather than resorting to medications right away, cessation of caffeine and nicotine, and other stimulants, often suffices to restore proper sleep. Use of low-dose tricyclic medication (Elavil, Doxepin, etc.) has a long track record of success, and these also act as muscle relaxers.

Analgesic medication must start with the safest agents, namely Tylenol (not to exceed 3-4 grams a day, or used with impaired liver function), before proceeding to stronger drugs, which are associated with greater risks. In this regard, special caution must be conveyed to patients to avoid non-steroidal antiinflammatory drugs (NSAID’s), as these have a great risk profile, and are no more effective in general than Tylenol.

Topical creams and patches are generally safe & well tolerated, such as EMLA and Lidoderm and capsaicin. Physical therapists and massage therapists /“body workers” and myofascial therapists can be of enormous help, as can OT’s, helping with posture, fitness, and ergonomics.

Support groups can be of enormous help to patients, as long as they can be kept from being just symptom-swapping sessions, and instead emphasize self-management and control.

Generally, my experience over 30+ years has indicated that very few patients need to go beyond the base of the above-described pyramid, with proper guidance from professionals and peers. A positive attitude is a “sine qua non”, and is defeated when Websites and literature state that there is “no cure” for FMS!

Treatment of Fibromyalgia -- cont'd.

Jonathan E. Cooper, MD

Physiatrist

The pharmaceutical industry has discovered FMS, and there are now 3 drugs on the market approved for FMS by the FDA. I feel that the cost/benefit and risk/benefit ration for these expensive and powerful drugs (originally designed to combat seizures or major depression) are not favorable, and I have had little need to resort to them. If patients are already taking them, and tolerating them, I allow them to continue, but the question arises: for how long? A trial of drug withdrawal (gradual and closely monitored) is advisable for any of the medications to be tried. The goal of drug-free self-management should be the agreed-upon goal of patient and treatment team from the beginning.

POWERPOINT PRESENTATION -- Controversies in Fibromyalgia

3 Crucial queries for any scientific datum

“Is it true?”

“Is it new?”

“If so, so what?”

So What?

Pain #1 reason for seeking medical care

Chronic pain disables more and costs more than cancer and heart disease combined

Numbers are increasing as population ages

FMS major cause of chronic pain

8-10 million FMS sufferers

Inadequate response by mainstream medicine has caused growth industry in
alternative/complementary arena, and thriving of chiropractic

Loss of confidence/trust in mainstream medicine

Un-/undertreated chronic pain has numerous, debilitating physical and psychological
consequences.

Opportunities for salvaging devastated lives

Is it New?

Rheumatism: Ancient Greece

Muscular rheumatism

Muskelschwiele/Muskelhaerten

Fibrositis (Gower, 1902)

Travell & Simons (1980)

Is it True?

Amer. College of Rheum. 1990 Consensus Criteria

ICD-9 code 729.1

“Chronic Widespread Pain Syndrome” (analogy to CRPS)

IASP Classification

Roots of Controversy

Lack of “real” pathology

Medicalization of common life experiences

Involvement of Big Pharma (\$\$\$\$\$\$\$)

Mimicry of other Dx’s

Tendency to ascribe every Sx to “trash-basket” Dx

Disability \$\$\$\$ costs to industry/society

By Charles E. Argoff, MD
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Written in collaboration with Michael R. Clark, MD, MPH, and Steven P. Stanos, DO

Taken from: **“Issues in the Diagnosis and Management of Fibromyalgia
A Report from the Cases and Conversations Workshop”**

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Introduction

Fibromyalgia (FM) is a pain disorder of uncertain etiology that is characterized by widespread somatic complaints, including pain localized to the axial skeleton, joints, muscles, and supporting tissues. In addition to a decreased pain threshold, patients with FM may complain of morning stiffness, paresthesias, disturbed sleep, and psychological distress. FM is more common in women than in men (3.4%-10.5% vs. 0.5%, respectively), with a gender differential that widens with age; women are 6 times more likely to develop FM after the age of 50.

FM has a significant impact on function and quality of life (QoL) and poses considerable diagnostic and therapeutic challenges. No biologic markers have been identified for the diagnosis of FM or objective evaluation of disease activity, thus the condition often is undiagnosed. Moreover, similar to other chronic pain conditions, response to treatment is judged solely by subjective means.

Diagnosis of FM

FM is an idiopathic chronic widespread pain condition characterized by diffuse musculoskeletal and soft tissue pain that cannot be traced to a specific structural or inflammatory cause.

Triggering factors, such as emotional stress, medical illness, surgery, and trauma, have been implicated in the onset and severity of FM in genetically predisposed individuals. Indeed, FM appears to have a genetic component, as evidenced by its strong familial aggregation. Studies also have revealed associations between FM and polymorphisms in genes affecting the metabolism or transport of monoamines, molecules with central roles in the perception of external stimuli and the stress response. These analyses, however, have not been reproduced reliably and may be complicated by the presence of psychiatric comorbidities commonly seen in patients with FM.

Recent evidence suggests that FM results from underlying central nervous system (CNS) dysfunction leading to central sensitization. Possible etiologies include altered CNS physiology, including increases in cerebrospinal fluid (CSF) levels of substance P, a peptide neurotransmitter involved in transmitting peripheral nociceptive signals to the CNS. Additional studies have demonstrated elevated levels of excitatory amino acids and neurotrophic factors in the CSF of patients with FM, although these findings may be associated with chronic pain in general. Finally, functional deficiencies in the serotonin and norepinephrine systems have been noted in FM, suggesting that the increased pain levels may result from reduced descending inhibitory modulation of nociceptive signaling.

Charles E. Argoff, MD -- cont'd.

The diagnosis of FM may be difficult, as the physical symptoms are highly variable and there are no biologic markers. Patients tend to complain of discomfort at multiple sites, including the back, buttocks, legs, neck, and upper back, and describe this pain as burning, soreness, and aching. Patients with FM sometimes complain of paresthesia or a sensation of swollen joints in the absence of corroborating physical findings. Other symptoms may include fatigue, insomnia, and cognitive impairment.

FM diagnostic criteria from the American College of Rheumatology stipulate the presence of widespread pain of at least 3 months' duration in the axial skeletal system bilaterally, above and below the waist, and at 11 or more tender points located in 9 pairs of specified sites. Tender points are identified by applying pressure (approximately the pressure required to blanch the examiner's fingernail) to each of the predefined anatomic sites; a patient report of pain signifies a positive tender point.

Additionally, guidelines published by the American Pain Society (APS) focus on 6 recommendations for the assessment and diagnosis of FM. These suggest that evaluation of a patient with suspected FM begins with a complete history, characterization of the quality and temporal profile of the pain, assessment of functional status, and a physical examination that follows the diagnostic criteria from the ACR as a framework for diagnosis. Particular attention should be paid to conditions that may mimic, exacerbate, or occur concurrently with FM. Patients may require treatment for other symptoms commonly associated with FM, including disturbances of sleep, mood, and cognition. Finally, tests examining muscle enzymes, ESR, liver and thyroid function, and CBC can help rule out other potential conditions and facilitate a diagnosis of exclusion.

The Fibromyalgia Impact Questionnaire (FIQ) has been validated as a tool useful in assessing specific baseline deficits and subsequent changes in response to therapy. The FIQ was developed to capture the biopsychosocial elements of FM, by including questions about patients' mood and ability to work, perform activities of daily living, and sleep. The self-administered instrument requires approximately 3 to 5 minutes for completion and is scored on a scale of 0 to 100. The average score on the FIQ for individuals with FM is 50.

Conclusion

A diagnosis of FM should be considered in patients with widespread persistent diffuse musculoskeletal pain in the absence of other medical findings. The diagnosis can be difficult because of the many disorders that occur comorbidly or mimic FM and requires thorough patient assessment and perhaps expert consultation. Effective treatments for FM include both pharmacologic and nonpharmacologic strategies, and as in any chronic condition, should be reevaluated regularly to ensure effectiveness.

Fibromyalgia Pathology and Human Society: Integration of Treatment Therapies

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Fibromyalgia is a debilitating condition characterized by widespread pain, sleep disturbances, and fatigue. Although rather detailed descriptions of similar symptomology is described in the mid to late 1800's (along with questionable treatment practices), it was not until 1990 that the American College of Rheumatology published classification criteria, marking the first time physicians had a clearly defined diagnosis. Since that time, fibromyalgia research has flourished (well-over 250 peer-reviewed, pubmed citations in 2009), demonstrating several identifiable traits and pathologies, as well as several theories as to the etiology of the disorder. Aberrations identified with the condition include altered blood levels of neurotransmitters, neuromodulators, and cytokines, amino acid changes indicative of possible malabsorptive disorders, changes in cortical processing, and by central sensitization mechanisms in the dorsal horn of the spinal cord, among others. Stress and genetic predisposition may also be underlying causative factors. As with other chronic pain disorders, fibromyalgia patients often present with affective co-morbidities, including depression, anxiety, and/or substance abuse. The identification of specific fibromyalgia pathologies gives some emotional relief to those who suffer chronic pains in the absence of known, identifiable pathologies, and the associated social disbelief which surrounds fibromyalgia (and other) chronic pain conditions.

Advances in fibromyalgia research have led to the FDA approval of several distinct classes of pharmaceuticals with positive benefits to some patients. Unfortunately, like the numerous other chronic pain conditions, these treatment options are few, often only work for a limited time compared with the chronicity of symptoms, and cause unwanted side effects. For these reasons, many fibromyalgia and chronic pain patients are actively seeking alternative therapies outside the realm of pharmaceuticals to enhance their quality of life. Importantly, many of these non-traditional medicinal practices prove very safe and effective for some patients. So the question remains, what is the most effective means to create a long-term positive effect?

More recently, pain specialists are coming to appreciate that multi-modal treatment regimen are required, bringing together several medical and "non-medical" disciplines, including such therapies as chiropractic, acupuncture, hypnosis, massage, and yoga.

Societies across the World live with different fundamental customs and belief systems. Within each of these cultures there lies medicine. The attempted routine practice/art/magic involved in the healing/helping of people can be found in every human society. The shaman, medicine man, spiritual healer, and clinical MD all serve this purpose, and utilize various methods and/or agents to effect their medicinal practices. A cultural society not only chooses the methods and/or agents involved in the medicinal practices, but the criteria for determining a successful outcome in each case as well. Treating pain and discomfort are among these and a broad separation can be made between a Western, newer technology-based empirical medicine, and one of an Eastern, more traditional energy and spiritual medicine.

Fibromyalgia Pathology and Human Society: Integration of Treatment Therapies -- *cont'd.*

Western medicine describes humans as collections of cells, which we are, distinctly separate from our external environments and functioning as independent, cooperative organs. Our bodies, and our mind and consciousness (which are manifestations of our brains), are unhealthy when foreign pathogens invade, physical injury occurs, or another known dysfunction exists. Western medicine describes several pain disorders with identified cellular causes, such as nerve injury and damage (neuropathic), excessive inflammation (demyelinating), or excessive glutamate (excitotoxicity), and treats these afflictions by treating the perceived direct problem. Yet, numerous well-documented disorders remain without a Western defined and empirically tested cause, for example Fibromyalgia.

Eastern medicine describes humans as energetic wholeness (flowing in harmony with the greater universe), which we are, and relies upon the concept that pains and suffering result from imbalances of the energy flow through a person. The body and the mind/consciousness are dual entities united in maintaining energetic balance, and treatments focus on bringing harmony back to the patient, recognized and treated as such, without regard to direct cause, simply because they exist as human concerns. These energy balance medicinal practices are centuries old, proven through trial, and fundamentally involve connections between the mind and body.

The dichotomy of the philosophies seems vast, yet cannot one ascribe to both? Indeed, it would appear that crucial elements of each of these broad generalizations of two distinctly advanced theories of human life and medicine are needed to balance what is truly individual medicine.

Indeed for the fibromyalgia patient, finding a treatment regimen that is effective and largely without unwanted side-effects is a daunting challenge, and many of these patients have turned to non-traditional treatments. These types of therapy often refer to the healing of the mind-body connection as a fundamental aspect of the treatment, and that through this realignment or harmonizing of the energy, comes health. The absence of clear western-based evidence for the effectiveness of such therapies has not limited the observation by patients and clinicians alike, that many of these therapies produce marked benefit to the patient.

A major point to this select seminar on fibromyalgia revolves around the empowerment of the patient; that is, that the patient has the power to literally heal themselves. A prime example of such phenomenon is the well-established placebo effect of delivered substances. Simply, if people are given the right situational context and brought to the mental motivations/attitudes/beliefs that a given treatment will work, some of the time, it succeeds. How then is “mind over matter” possible? In a western world it is not and when it does happen, it becomes a complete science of its own, researching the placebo effect to figure out the how/why. In an eastern world, it is not only possible, but wholly embraced as such, attributed to the mind healing the body. To western medical society, these concepts seem illogical because there is no tangible element to see or investigate, but that should not cloud the recognition of the true benefits to patients, nor the acceptance of these non-traditional therapies as medicine in the same vein as any pharmaceutical. Particularly now more than ever, a fibromyalgia patient and their medical team must advocate for treatments that combine multiple disciplines and effect a long term positive benefit, most likely through the combined use of certain pharmacotherapies in conjunction with various other “alternative” therapies.

Fibromyalgia Pathology and Human Society: Integration of Treatment Therapies -- *cont'd.*

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Fibromyalgia Pathology and Human Society: Integration of Treatment Therapies

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The Problem of Fibromyalgia and the Treatment of Chronic Pain

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Fibromyalgia is a mysterious, distressing, continuously painful condition that afflicts millions of people within the United States alone. The source of chronic pain associated with Fibromyalgia, as well as a wide variety of other neuropathic pain conditions, is unknown. Unlike many afflictions, such as shingles-related neuropathy where nerve endings in the skin are damaged by a rash, fibromyalgia often occurs with no known triggering event. The prevailing view of chronic pain is that something has gone wrong in or among those parts of the nervous system that are involved in the normal, acute pain that occurs when there is an injury. Indeed, normal acute pain, which normally exists only during an injury and the subsequent period of repair, is important to warn us against impending injury. There are some rare individuals who are born with an absence of pain. While those suffering from chronic pain might envy those born without pain, these pain lacking individuals may have mutilated hands and feet.

Our beliefs about pain start with special type of nerve cells – called the sensory neurons – that detect different types of stimuli that contact our body from our surrounding environment as well as signals that come from all the organs and tissues within our body, which is our internal environment. Our brain uses the activity of these sensory neurons to monitor everything, all the time in order to perceive everything around us and to make sure that everything is functioning properly within us. If everything is functioning normally within us, we don't need to bother paying attention to it, so all of that activity is going on at a subconscious level. This lets us pay attention and be consciously aware of our surrounding environment through our senses of touch, vision, hearing, smell and taste.

Pain is generally considered as part of our sense of touch or somatosensation (i.e. sensation of the body). Our skin detects a wide variety of stimuli which include physical contact, temperatures and chemicals. Moreover, we can distinguish between different forces of contact, different frequencies of vibration, the direction the stimulus, where the stimulus is located on our body, etc. We can detect the weight and location of a fly. The stimuli that contact our skin is detected by our sensory neurons. Our sensory neurons have a long thin process called the axon - that can be up to five feet long – which connects the skin to the brain through our nerves. Each nerve connected to the various body parts contains thousands of axons that belong to thousands of sensory neurons. Axons are like wire that carry electricity from one place to another, and a nerve is like a cable that contains bundles of wires. In this case, the axon begins in the skin where a sensory ending detects a stimulus which triggers an electrical-like signal called an action potential to race up the axon to notify the brain that a stimulus to the skin has just occurred. But, axons differ from wires because they are living structures – thin tubes of cytoplasm - that have grown out from living nerve cells. So in addition to carrying electrical signals to the brain, the axons contain tiny molecular highways that transport the molecules that keep the axon alive. These molecules come from the body of the nerve cell.

The Problem of Fibromyalgia and the Treatment of Chronic Pain -- *cont'd.*

Every cell, including nerve cells, has a cell body composed of a nucleus, which contains the chromosomes (i.e. DNA), and the cytoplasm where the cell makes all the chemicals (proteins, sugars and fats) that keep the cell alive. The DNA is the set of instructions that tells the cell what to make. This activity requires energy that the cell gets from the food that is digested by our digestive system and that is distributed through the blood by our circulatory or vascular system. Likewise, the sensory neurons have cell bodies. Now, the axon that comes from the cell body of the sensory neuron connects all the way from the skin to the brain, and there are thousands of axons bundled together within each nerve. So, where are the cell bodies located that are the source of these axons? Well, the cell bodies are lumped together in swellings called ganglia that are located close to where the nerves are attached to the spinal cord. Now let's put this in its proper scale.

A single axon can be up to five feet long. How thin is it? Well, each axon is so thin that you need a microscope to see it. So how big is the cell body of a sensory neuron? Well, you need a microscope to see those, too. Think of it this way, if we imagine that an axon were a mile long, it would only be as thick as a pencil and the cell body would be the size of a tennis ball. Now shrink that down to the scale of a nerve that runs the length of our leg. Wow, these axons are really, really thin, and the cell bodies are really, really small. It is on such thin threads that we are dependent on the sensation from our skin. Now, let's think about this in relation to just one of the nerves to our leg, called the sciatic nerve. Anyone have a painful condition called sciatica? Yup, it's that nerve! The sciatic nerve is about as big around as an index finger, so that means that it contains thousands and thousands of these microscopically thin axons. There is some connective tissue as well, to provide some structural support, but this means that that big nerve is composed of a lot of really delicate axons. These axons carry our electrical signals to convey information from our skin, but remember that they are alive and are dependent upon the molecules that are manufactured in the cell bodies (located near our spinal) and that have to be shipped down the inside of the entire length of the axon. Unlike a wire that can be cut and simply reconnected, if an axon is cut, that part which is disconnected from the cell body will die. So if a nerve is cut, we will lose sensation from the part of the body that the nerve supplies. While there is some capacity for the sensory neurons to grow a new axon back down the nerve, this takes about two weeks for one inch. Importantly, if an axon is just slightly traumatized (but not broken) or if there is poor nutrition, this can affect the molecular support from the cell body which can cause the axon to behave erratically. The axon can become unresponsive sending too little electrical information to the brain, or it can become irritable and send excess information. Now let's get back to the sense of touch (somatosensory sensation) which includes pain. So why are there thousand and thousands of axons in each nerve which are supplied by thousands and thousands of sensory neurons in the ganglia?

First, in order for the brain to identify precisely where a stimulus has occurred in or on the body (i.e. where did the fly land on my arm), each microscopically small piece of our bodies is uniquely connected to a unique set of axons from a unique set of sensory neurons. So when an electrical message comes from those sensory neurons, the brain knows that the stimulus came from that part of the body that is supplied by those sensory neurons.

Second, in order for the brain to detect what type of stimulus occurred (i.e. mechanical, thermal or chemical), the sensory neurons come in several varieties. Some varieties of sensory neurons are designed to detect preferentially mechanical forces. These are referred to as mechanoreceptors. Not only that, but some of these mechanoreceptors preferentially detect compression of the skin, others stretch, and still others low frequency or high frequency vibrations. Other varieties of sensory neurons are designed to detect temperatures (thermoreceptors), and subtypes of these can be for low temperatures and others for high temperature. Other varieties detect chemicals (chemoreceptors) for different types of acids and bases and the various chemicals found in sweat. So, we not only have separate sensory neurons that are responsible for each spot in the body, each spot in the body is supplied by many types of sensory neurons that detect the various features of the stimulus that is contacting each spot on the body. Importantly, this means that every time we contact something with the skin, this sets up a lot of electrical messages coming in simultaneously from a lot of different types of many sensory neurons.

The Problem of Fibromyalgia and the Treatment of Chronic Pain -- *cont'd.*

The brain then deciphers this complex pattern of activity and learns to associate with the activity that just occurred. This is our basis for something that a consciousness calls sensation or sensory perception.

Importantly, there are many types sensory neurons whose electrical messages are triggered by stimuli that can or do cause damage to the skin, and these electrical messages create an unpleasant, noxious sensory perception that we call pain. These sensory neurons are referred to as nociceptors. Some of these particularly respond to painfully high temperatures, others to painfully low temperature, others to mechanical damage, and others chemical damage. So there are thermal nociceptors, mechano-nociceptors, and chemo-nociceptors. Some sensory neurons called polymodal nociceptors even respond to a mix of two or more different painful stimuli.

So when our skin or another body tissue encounters a damaging or potentially damaging stimulus, such as a hot light bulb, this can generate electrical activity in many types of sensory neurons which will cause a perception of pain, so that we know to avoid further damage. Fortunately, this pain normally stops or substantially diminishes when we disengage from the painful activity, or the pain gradually subsides as the damaged tissue is repaired. This normal pain is called "acute pain". Now let's remember how delicate the axons are in the nerves and how easily they could be traumatized causing them to behave erratically. This could cause inappropriate, sustained activity that may be misperceived as "chronic pain". The problem is that there can be many ways that this inappropriate activity could be triggered, some obvious such as damage by shingles or crushed nerves in an accident, and some not so obvious such as a nutritional or metabolic problem such as diabetes.

So one source of chronic pain could be due to problems within the nerves themselves, and such pain which is linked to a nerve problem is referred to as neuropathic pain. However, another source of chronic pain could be within the brain itself, especially where the electrical activity within the nerves is conveyed to that part of the nervous system where the nerves connect, which is the spinal cord or a transition site from the spinal cord to the brain called the brainstem. In the spinal cord and brain stem, the axons from the sensory neurons connect to other nerve cells that process the incoming electrical messages and eventually send them to the level of our cerebral cortex where our brain creates our conscious sensory perceptions. In this case problems may have occurred within these spinal cord and brainstem neurons which are making them behave erratically resulting in sustained, inappropriate chronic pain.

Pain which is thought to be due to erratic activity within the spinal cord or brainstem is not regarded as neuropathic pain, but in truth much of the erratic activity in the spinal cord and brainstem may be due to unknown problems within the nerves. Unfortunately, fibromyalgia is a condition where a lot of dickering and disagreement occurs over whether the chronic pain is neuropathic (i.e. has its source in the nerves) or whether it is a problem within the spinal cord, brainstem or even higher such as the cerebral cortex itself (central nervous system pain). This is an important distinction, because it determines where we should focus strategies to treat the pain: towards the nerves or the spinal cord. Regardless of the source, to date, very few medications for fibromyalgia and other chronic pain work reliably and continuously without being administered at such high doses that the side effects can be as bad or worse than the pain.

In truth, while the most common belief is that fibromyalgia is a central nervous system problem, the source is not really known. Instead a lot of new findings have occurred in research on the skin and nerves which indicate that our prior assessments were not sensitive enough to detect many of the problems, and which have revealed previously unknown potential sources of chronic pain.

The Problem of Fibromyalgia and the Treatment of Chronic Pain -- *cont'd.*

For example, our laboratory has discovered an elaborate sensory supply to the tiny blood vessels in the skin, which indicates that our brain has a more detailed subconscious perception of the activity throughout our blood vessels than we previously realized. Problems in this blood vessel sensory innervation could surface as conscious chronic pain. Also, our laboratory and others have discovered far more nerve endings in the skin that seem like they should be involved in acute pain but don't respond to experimentally tested pain stimuli. It is quite likely that these mysterious sensory endings are involved in a highly elaborate system that constantly monitors the general health of our body tissues which is a process called homeostasis. This could be a system that is also operating normally at a subconscious level at a very low level of activity, and that subtle problems in this system may contribute to consciously perceived chronic pain. Finally, research in our laboratory has revealed that the chemistry in the body tissues themselves can be subtly altered without any obvious symptoms, and that these alterations in tissue chemistry may trigger inappropriate nervous system activity perceived as chronic pain.

So where are these new findings taking us for the future in treating fibromyalgia? First, these findings will hopefully lead to more effective therapeutics without severe side-effects. But, perhaps of greater importance, they are leading us to rethink the whole question of what pain really is. In this case, there is emerging evidence that chronic pain is not due to problems within a specific type of pain sensory nerve cell or a specific site in the brain as we previously believed. Instead pain, and especially chronic pain, is a default sensation generated in the brain in response to conditions where normal sensory processing has gone awry in some way. Thus, the pain could occur due to any number of problem sites and combinations within the body and the nervous system. In summary pain, may not be an entity in itself, but may be the perception that occurs when there is interference with normal sensation.

So where is our hope? Surprisingly, our research and that of others has revealed that many people have the same nerve damaging diseases as others, but in some they naturally lose their pain whereas others are left with intractable pain. However, those who lose their pain have restored skin sensation that does not necessarily feel like normal sensation. This suggests that the nervous system does have some inherent capacity to find a strategy to find its way out of chronic pain. This could be through any number of treatment options that have worked for some but not others, and may include physical therapy, acupuncture, prayer, meditation, or other complementary therapies.

Harnessing a better understanding of these inherent capabilities will hopefully lead to better and more consistent treatments. What is clear, however, is that in pain management, those people who take an active role in their pain management and make an effort to engage the world around them fare better than those who withdraw from the world and wait for something to be done for them. For whatever the brain is looking for to solve the pain problem, the brain is very dynamic and it needs to be stimulated and engaged to facilitate the process.

Expert Summaries -- Complementary Therapies

Summary: Yoga as a strategy for addressing symptoms of Fibromyalgia **Vandita Kate Marchesiello**

www.YogaNowandThen.com

August 2009

Yoga is an ancient system dating back thousands of years. One part of this complex system is Hatha Yoga which incorporates stretching, postures/asanas, breathing, meditation, and deep relaxation techniques to promote optimal health and wellness. It is adaptable and beneficial for people of all ages regardless of physical ability. For the purposes of this summary I will simply use the term yoga.

Regarding pain and discomfort:

The result of chronic and debilitating physical pain and discomfort in the body leads to a variety of other symptoms associated with FM. Yoga postures, breathing, deep relaxation, and meditation work individually and together to help relieve pain and discomfort from the following:

- Joint and muscular pain
- Insomnia
- Stress
- Anxiety
- Depression
- Irritability
- Digestive disorders
- and most other symptoms related to FMS

How yoga helps:

A yoga practice includes postures, breathing exercises, deep relaxation techniques, and meditation. These practices help to regulate the functioning of the sympathetic and parasympathetic nervous systems, those systems related to our flight or fight response and the regulation of blood pressure, heart and respiration rates. Yoga also builds strength and increases flexibility in the mind as well as the body and strengthens the immune system.

The systems in the body of those suffering with FM are often out of balance. Chronic worry, stress, pain, and anxiety activate the sympathetic nervous system which causes the blood pressure to raise, the breath rate to speed up, and stress hormones to flood the body. When this system is over stimulated it may cause a number of health concerns and symptoms that fuels the vicious cycle of worry, stress, pain, and so on... The parasympathetic nervous system on the other hand lowers the blood pressure and slows respiration and the heart rate, creating a more calm and relaxed manner. The immune system is strengthened, the body's ability to heal more effectively is increased, and the body-mind becomes more relaxed. Deep relaxation, breathing exercises, and meditation all contribute to the balancing of these two systems. Yoga postures help with the balancing of these systems as well as increasing flexibility, strength, and range of motion.

Practices are easy to adapt for various body types and physical abilities. When considering a yoga class, one must find an instructor compassionate and sympathetic to FMS. Not all yoga classes are created equally. Regardless of pace or intensity in ones practice, anyone with FM can benefit from the practice of yoga postures. Staying focused and attuned to sensation and breath, while in a yoga posture is important. It empowers the practitioner and helps one to determine how long and to what degree of intensity to hold a posture.

Summary: Yoga as a strategy for addressing symptoms of Fibromyalgia -- cont'd.

Mindfulness also provides a respite from the on-going chatter of the mind which often sets into motion the fight or flight response mentioned above related to the sympathetic nervous system and prepares the mind for meditation and deep relaxation experiences.

An expert yoga teacher will encourage the student to let go of judgments and stories around pain and simply notice it as sensation. Visualizing the areas of the body being stretched and released as circulation increases and organs are massaged holds the attention of the practitioner in the moment and increases the benefits mentioned above. This is the body-mind connection in practice. When the attention is focused in the manner described above, there is a shift in consciousness in that moment and the mind is anchored in the now versus the past or future. Since the mind plays such an integral role in the level of anxiety, happiness, or depression we experience, it is helpful to shift out of habitual thinking and find an 'in the moment focus.' Sensations in the body and on the breath as well as visualization techniques, help to make this shift.

What better testimony to the healing and therapeutic benefits of yoga than the story that follows from Debra, who at 16 was diagnosed with fibromyalgia. Not only did she find a respite in yoga, she was compelled to become a yoga teacher so she may help others with the same diagnosis and shares some tips to others who are teaching yoga to this population.

Yoga for Fibromyalgia

by Debra Risberg

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To get a sense of what fibromyalgia feels like, imagine fibrous webs growing into the soft tissues of your body and tightening around the muscles and nerves. The constrictions cause points of extreme pain that radiate into other areas of your body. Imagine having to rest several times as you struggle to wash the dishes or do laundry and being in too much pain to enjoy a simple conversation. You haven't had a good night's sleep in months. You're exhausted and often depressed.

Fibromyalgia is believed to be an immune system disorder much like lupus, allergies and arthritis. It usually comes on after illness, an accident or extreme and chronic stress. An overreaction to these stressors forces the energy and material bodies into a state of painful contraction, causing extreme and prolonged pain that feels much like being in the worst stages of flu. Sleep is also affected, preventing the body from repairing itself and increasing the problems dramatically. One theory holds that fibromyalgia is actually caused by a sleep disorder that keeps the body from going into deep sleep.

Fibromyalgia can develop in childhood as well as adulthood, and women are much more susceptible than men. There is no known cure; unfortunately, some doctors still believe that fibromyalgia is a psychosomatic illness and consider sufferers hypochondriacs. When I developed the illness 31 years ago, as a 16-year-old high school athlete, it was devastating both physically and emotionally. All the doctors could do was put me in a painful brace and prescribe tranquilizers. Today, physicians treat fibromyalgia with antidepressants and non-addictive pain medication, which is often not enough.

Yoga offers many benefits to those with fibromyalgia. Deep breathing and gentle stretching open up constricted energy. Postures and pranayama increase circulation, oxygen and prana. In addition, yoga lifts the heart and opens us to compassion for ourselves and others.

Summary: Yoga as a strategy for addressing symptoms of Fibromyalgia -- cont'd.

I teach a class for people with fibromyalgia that includes gentle and restorative yoga, meditation, deep relaxation and group support. Here are some of the most important areas to focus on in classes for this population.

Have your students sit with their pain, much like holding a yoga posture. By focusing on the pain, we can begin to loosen up as we let go into sensation and allow ourselves to move and breathe fully. Help your students to recognize the difference between pain and the fear of pain, between stiffness and the fear of movement. Help them to locate tension and relax it, and to appreciate even the most limited physical abilities.

Be patient and creative with modifications for each individual. These students should do as little as possible until they are stronger and have more confidence in their ability. Restorative postures help the body begin to soften; warm-ups and gentle postures move the blood and energy through the many blockages. Use blankets, pillows or other props as needed; some people may have to stay in chairs. Let them do only as much as they care to and encourage them to listen and go through the rest mentally. When they learn that yoga will relieve pain and that they can do less or even rest during class, they'll be more comfortable coming even on their worst days. Some will eventually be interested in developing a more rigorous practice and can join your more advanced classes.

Breathing exercises should be relaxed and easy. People with fibromyalgia tend to be extremely shallow breathers. It is painful to breathe and each breath reminds them of their condition. The decrease in breath causes more pain and exhaustion. At first, deep breathing can be so intense for fibromyalgia sufferers that it may cause faintness, but that will soon subside. Begin with two- or three-part breath and ujayii breath and move on to alternate nostril pranayama.

Have fresh water available in class and encourage them to drink often. People with fibromyalgia tend to be dehydrated, which makes the muscle tissue sticky and brittle. The drugs used to treat the illness may increase the dryness.

Emotional bonding has a powerful healing effect. The group support model I have used in class involves breaking up into couples or triples and doing co-active listening. We also come together for potlucks and other forms of social networking.

Be compassionate with your students and yourself. Expect that they will have flare-ups, setbacks and disappointments. They may complain of soreness after even the easiest postures and stretching. Respect their limitations. Don't be discouraged-just listen carefully and modify. Continue to offer support and understanding. Let go of any ideas you may have about success with this population and keep the process organic and flexible. Enjoy and celebrate even the smallest victories. Yoga may not "cure" fibromyalgia, but with yoga, sufferers can learn to live with the condition and still be functional, joyful and useful members of society.

“I took yoga classes in the past. It helped with anxiety and although I did not 100% understand why, I left with a smile on my face. That creates a good reason to do something. I do think it is important to keep active--for everyone no matter what the history.”

(Seminar Participant)

“One...sense I have is that many of the issues, strategies and practices associated with Fibromyalgia can be the same kinds of support that can be beneficial in other kinds of pain and stress. Maybe as we highlight and discuss these in a general setting, we can make a positive contribution to the human condition.” (Seminar Participant)

“I was a nurse in newborn intensive care for 17 years, living very much in the Fight or Flight mode. In 1998 (I) started a terrible divorce after years of verbal and some physical abuse. My husband kept me up every night, (I also was working nights 3 X wkly.) This has made sleep difficult for many years. By 2000--(I) was experiencing severe pain, weakness, poor sleeping and poor memory. I have been blessed with a supportive family and fiance though after 8 years our relationship is taking a toll. I try every day to function as “a normal individual”. I have changed jobs 3 X in 6 years to find the right fit. But I pride myself that I have only called in once due to fibromyalgia pain.... I thank God for a wonderful physician...who works hard to keep me going as a normal person. Pain management is #1 for me. I believe that medications used properly can give you a great life and allow you to do the things you want to. Hopefully through more education it will only get better.” (Fibromyalgia Patient)

“I am divorced and my 3 children are adults and on their own. I am living by myself and own my home. I have a part-time job to supplement my disability. I just can't work and take care of my home. My home is a cluttered mess. Now that it is spring I look out at my yard and want to cry! I work the part time hours because I NEED the money. I want to do it as long as I can. I have no one to help me and no money to pay someone to help me. I am actively looking for an apartment but am not finding anything I can afford. Low Income places all have long waiting lists. This is a quandry that is impacting my life. I am going through a lot of stress and anxiety.” (Fibromyalgia Patient)

HYPNOTIC MANAGEMENT OF CHRONIC PAIN

By: Jeanette Perkins

I'm going to discuss the management of chronic pain using hypnosis, specifically fibromyalgia. Many of the techniques for pain control apply to any kind of pain. There are some techniques that are particularly suitable to fibromyalgia. When working with a client with chronic pain, it is always mandatory to custom tailor what techniques and suggestions are used and what self-hypnosis techniques are taught to the individual.

For a hypnotist to work with a person with fibromyalgia, it is essential to have a medical referral. Hypnosis can be very powerful and it would be terrible to mask a symptom unless that client has been worked up medically and is under treatment. It is also important to work within the framework of the diagnosis of the referring physician. A client should never be put into the middle of opposing opinions or approaches.

There are some feelings and experiences that are common to many sufferers of chronic pain. By understanding them, one has a better idea of what to look for, what questions to ask, and ultimately what kinds of ego strengthening suggestions will be best for that person.

Fibromyalgia is chronic pain and, therefore, needs to be treated differently than when preparing a person for childbirth, dental work, etc. Many of these clients may be getting benefit from medical treatment, but not sufficient relief to satisfy them or their physician. Others are strongly against taking medication and, therefore, want to get as much relief as possible through hypnosis. Because the majority of sufferers of fibromyalgia are women, I will refer to the patient at "she" for ease of discussion.

Often, ailments such as chronic pain are spoken about in purely psychological terms or suspected of giving them secondary gain. This means they use their ailment to get attention or get out of doing unpleasant work. This is thought to be on a totally subconscious basis. However, this actually makes up an extremely small percentage of chronic pain sufferers. Yet, when a physical cause is difficult to pinpoint, these people are often sent to a psychiatrist or treated as though they were neurotic – they are not taken seriously. Because in many cases there is an absence of objective pathological findings, such as abnormalities of x-ray or blood tests, the patient feels the need to convince the physician that something really is wrong. Often a physician may be encouraging initially, but if the patient fails to respond favorably to his treatment, his attitude becomes more aloof and the patient is made to feel that it is somehow her fault. Other doctors may treat the patient as a malingerer from the outset. Because pain is so compelling she continues to seek help, but by now she really is tense, depressed and skeptical. So, if she goes to see a new doctor of some kind, he sees an anxious, upset person who has chronic pain. Of course, the assumption is made immediately that it is her neurotic personality causing the pain. So, chronic pain sufferers often don't have a positive experience going through the medical route seeking help, although fortunately that situation has improved in recent years. The ones who do have a good experience and are doing very well, probably won't seek out hypnosis as an adjunctive tool. The negative experience in combination with the pain itself undermines a person's self-esteem. This must be considered along with the fact that there are also other issues, such as loss of employment, marital difficulties or divorce, and loss of ability to do things. If a person has experienced some or all of these things, she may be angry, pessimistic or overly anxious for positive results.

Chronic pain sufferers often experience anhedonia, which means significant decrease in ability to experience. Many don't feel like going out with friends or to the movies or enjoying sex. This is not synonymous with depression, although certainly many will become depressed. It is controversial whether the tension and depression causes the pain or having chronic pain results in tension and depression. You will hear differing opinions and if the referring physician has made his position clear to his patient, one simply has to respect that. There is evidence that the treatment of the depression often results in a reduction of pain. However, evidence also shows that the abolition of the pain reverses the depression.

HYPNOTIC MANAGEMENT OF CHRONIC PAIN -- *cont'd.*

Certainly, it is understandable that constant pain and suffering can result in anhedonia and depression. If over time the patient does not improve significantly, she inevitably develops feeling of hopelessness and helplessness. Aristotle referred to pain as the “passion of the soul” because it so deeply affects every aspect of the person’s life. Some people begin to feel that the pain is an integral part of themselves. Pain sufferers often give themselves negative messages. This is understandable as their self esteem and ability to participate in life is greatly diminished. This negative thinking, however, only makes the problems worse. There are simple techniques in hypnosis that can be incredibly effective in helping a person recognize and change this pattern.

In addition, with chronic pain there is a pain-tension cycle which occurs and needs to be explained to the client. If a person feels pain, the natural response is to guard the area of pain. Essentially, guarding is tensing the area, which of course makes the pain worse. As the pain becomes worse, the person becomes more anxious, which exacerbates the pain further. Naturally, the same cycle occurs if a person feels anxious, which causes muscular pain – and then the cycle goes on. So, which comes first – does the pain cause the tension or vice-versa? Once started, it’s almost beside the point. One needs to understand about this pain-tension cycle so she can learn ways to break it. Hypnosis uses techniques such as relaxation of muscles, imagery which is pleasant, healing imagery and methods for direct pain removal or reduction on deeper subjects. Often it is trial and error to see what works best on a given individual.

A hypnotist needs to have a thorough history, not so much in terms of medical details, but generally what her experiences have been. It must be kept in mind what she may have gone through. Often, if the experiences with physicians, chiropractors, etc. have been negative or nonproductive, she may have felt the practitioner’s frustration directed at her. She may describe feeling like a non-person, rushed through, never really heard or taken seriously. The hypnotist should sit back, maintain eye contact and listen. One has to get to know the client. How has the pain affected her life? How does she feel about it? How would her life be different if she didn’t have it? Is there any benefit she can think of to having the pain? How often does she have it? How often is it severe or debilitating? What activities or situations trigger this pain. Sometimes there is a pattern that can be discerned.

Sometimes just being able to talk about these things with someone who is truly interested is helpful in itself. The hypnotist must be patient and reassuring. If one method doesn’t work, there are many other methods. It is not the client’s job to fit herself into what the hypnotist does. It is the practitioner’s job to devise a program of hypnosis and self-hypnosis that fits the client. The more that is known about her, the more effectively this can be accomplished. As time goes on it will become apparent what suggestions, types of imagery and which specific pain control techniques are the most helpful and what form of self-hypnosis works best.

In addition to listening patiently and showing care and concern, it is very important for the practitioner to talk about hypnosis. This avoids unrealistic expectations. If it’s clearly understood how hypnosis works and how the client and hypnotist are going to work together, the better the results will be. This is a joint effort in which she plays an active role in participating in her degree of wellness.

There are many varied techniques in hypnosis that work in different ways. In addition, in a relaxed, hypnotic state the brain can produce and release endorphins. Endorphins are the body’s own natural pain killers. The release of endorphins can increase general feelings of increased relaxation and well-being among those who practice self-hypnosis on a regular basis. For a person who lives with chronic pain, one is not only dealing with the pain itself, but also the anxiety about the pain; the worry when it begins if it is going to get out of control, and the feeling of helplessness and frustration that naturally follows. If this person understands her ability to produce powerful, effective pain killers herself while she is in hypnosis and is given strong suggestions for her being able to do so effortlessly just by doing the self-hypnosis program that has been worked out for her, it will be of great benefit.

HYPNOTIC MANAGEMENT OF CHRONIC PAIN -- *cont'd.*

With this, or any treatment that is helpful, a chronic pain sufferer may have a setback. It is important to understand that there is much she can do to help herself feel better and she should do whatever necessary to take care of herself. If and when setbacks happen, anger and disappointment, no matter how normal, only exacerbate the problem. The use of self-hypnosis more frequently will, at those times, help keep her as comfortable as possible. She should tell herself that she can get through this and tomorrow she will feel better. Keeping the self messages as positive as possible will shorten the setback and lessen the severity.

I would like to conclude with a brief technique that works very well to produce a degree of relaxation. This exercise will not produce a state of self hypnosis. It is always helpful to begin with a few deep breaths, exhaling slowly. Focus on the top of your head and mentally say "the top of my head is relaxing." Immediately go to the forehead and say "my forehead is relaxing." Continue with the temples, eyes, cheeks, mouth, jaws and chin, neck, shoulders, arms, back, chest, stomach, lower abdomen, legs and feet. Simply focus on the part of the body you want to relax and repeat that that part is relaxing, and then move on. Once completed say "my whole body is relaxed." If there is a particular area of the body that holds more discomfort, you can take more time with that area. For example, if your back is the problem area you can divide it into the upper back, middle back and lower back, pausing just a moment longer before moving on. This exercise takes about two minutes and can be done repeatedly throughout the day. It can do wonders in relieving stress and discomfort as well as breaking the pain tension cycle.

WELLNESS IDEAS FOR FIBROMYALGIA

by Lorraine A. Calleri, OTR, LMT

I have worked with clients for over 20 years providing instruction, information, and resources to them to optimize their health and well-being. I believe that my approach to treatment of my clients is offering them a place of solstice and solitude to find their own path to the healing that they seek. It is through my own healing and my life experiences and receiving Bodywork myself that I can offer an intuitive and wholistic approach to my clients. I offer a unique approach to those seeking balance in their lives; whatever that may be: freedom of movement, relief from stress and disease, relief of pain and injury, and optimal mental clarity. I facilitate their connection to their own body and mind and ultimately their spirit. Although I am the provider of this comprehensive bodywork, I have the absolute privilege of witnessing those who are embarking on this guided journey, and living in this world, feeling more balanced and alive.

Recently there has been increased interest in a more integrated approach to managing Fibromyalgia. The following resources may be helpful for supporting patient interest in taking charge of his or her own healing process.

“Bodywork for Fibromyalgia”, by Karta Purkh Singh Khalsa in
Massage and Bodywork, May/June 2009, pgs. 80-89. (massageandbodywork.com)

“Well Being, Pain Reliever, Yoga Can Ease the Chronic Pain of Fibromyalgia”, by Catherine Guthrie in Yoga Journal, September 2009, pgs. 40-47. (yogajournal.com).

Numerous articles on Myofascial Release and Fibromyalgia:

www.myofascialresource.com

www.fasciacongress.org/2009

Managing the symptoms of Fibromyalgia includes awareness of the interconnectedness of the mind, body, and spirit. It is important to treat the whole patient rather than seeing him or her as a collection of symptoms.

INTEGRATING BODY/MIND/SPIRIT

- identifying and becoming aware of the impact of stress on the body (physical, emotional, etc.) and its physiological response to stress.
- learning the importance of full Diaphragmatic Breathing is paramount, as well as Formal Relaxation Training, Meditation, and Biofeedback modalities.
- understanding the impact of “dysfunctional” muscles, fascial restrictions/imbbalances, and energetic challenges to the body.
- getting comprehensive and specialized therapy from practitioners who have experience in treating Fibromyalgia and who support one’s entire “healing process” (that is help empower an individual, so they can orchestrate and obtain the care that they are seeking).

BODY

- Therapeutic Massage
- Craniosacral Therapy.....upledger.com, and craniosacraltherapy.org

WELLNESS IDEAS FOR FIBROMYALGIA : BODY-- *cont'd.*

- Myofascial Release.....myofascialrelease.com, myofascialwellness.com, myofascialpainrelief.com, and
wholisticphysicaltherapy.com
- Shiatsu
- Energetic Healing.....barbarabrennan.com and joyadler.com/healing
- Yoga
- Tai Chi

TOOLS FOR BODYWELLNESS (to be used under the direction of a qualified therapist)

- Occipivot.....chattgroup.com
- Sacral Wedgy.....sacrowedgy.com
- Still Point Inducer.....stillpointinducer.com
- Theracane.....www.theracane.com
- Nolarola.....nolarola.com
- Myofascial Stretching.....myofascialstretching.com
- Chi Machine.....chinow.com

MIND

- Rational Emotive Therapy (Albert Ellis Institute).....rebtinstitute.org
- Hypno-peripheral processing (HPP) (Llyod Glauberman).....hppcds.com
- Biofeedback Modalities for integrating Body/Mind(EMG, GSR, Temp., etc.)
- Sleep Training.....therelaxationcompany.com

SPIRIT

- Meditation
- Emotional Freedom Technique.....emofree.com
- Spiritual Guidance.....pathwork.org
- Quantum Energy Transformation.....quantumhealingcenter.com
- Books by Carolyn Myss, Wayne Dyer, Deepak Chopra, Bruce Lipton
- And Most Importantly.....*Empowering oneself by creating what is needed for optimal wellness*

Part II

Expert Summaries -- Legal/Advocacy

John P. Herrion, Director of Disability Rights New York State Division of Human Rights

In January of 2009, I was introduced to Dr. Sue Shipe and Mrs. Kathy Schoolcraft who attended a legislative program sponsored by the New York State Division of Human Rights (Division). We agreed to subsequently meet to discuss what rights were afforded to persons with disabilities, including those with Fibromyalgia, under the New York State Human Rights Law (NYSHRL). At our meeting we discussed some of the substantive provisions of the NYSHRL as well as the programs and projects of the International Institute For Human Empowerment, Inc. I agreed at that time to participate and present at the Fibromyalgia Seminar that was being held in July and August of 2009. Below is the substance of my presentation.

The NYSHRL prohibits discrimination by employers, housing providers, and owners of places of public accommodation against persons with disabilities. The Division enforces the NYSHRL. The focus of this presentation will be on the definition of “disability” under the NYSHRL, and the provisions that cover employment and reasonable accommodation.

Definition of Disability under the NYSHRL

The NYSHRL defines “disability” as:

“A physical, mental or medical impairment resulting from anatomical, physiological, genetic or neurological conditions which prevents the exercise of a normal bodily function or is demonstrable

By medically accepted clinical or laboratory diagnostic techniques, or

A record of such an impairment, or

A condition regarded by others as having such an impairment.”

This definition of “disability” is comprehensive, and more inclusive than the federal definition of “disability” under the Americans with Disabilities Act (ADA) which requires:

“A physical or mental impairment that substantially limits one or more major life activities of such individual;

A record of such an impairment; or being regarded as having such an impairment.”

The standard under the ADA is more difficult to meet in that it requires a “substantial limitation of one or more life activities of such individual.” There is no such requirement in the NYSHRL that the limitation be substantial. Nor is there a requirement that the limitation affect a “major life activity”. Rather, the definition of “disability” under the NYSHRL merely requires that a physical, mental or medical impairment prevent the exercise of a normal bodily function; or a record of such impairment; or being regarded as having an impairment.

Given the NYSHRL’s focus on symptoms and prevention of the exercise of normal bodily functions, fibromyalgia would, in most cases, be covered as a disability. This may not be the case for meeting the definition of “disability” under the ADA, which requires a “substantial limitation of a major life activity.” It is therefore more advantageous for persons with fibromyalgia who believe they have been discriminated against based upon disability to

John P. Herrion, Director of Disability Rights -- cont'd.

file their complaint under the NYSHRL, rather than the ADA. Prudent choice of venue can lead to the case being heard on its merits, rather than being dismissed because the complainant did not meet the threshold definition of “disability”.

New York State regulations require the disabled individual to have the requisite job qualifications as well as be able to satisfactorily perform the essential functions of the job. The “essential functions” of the job are defined as those fundamental to the position and are most usually found in an up-to-date job description.

Reasonable Accommodations

Employers are required to reasonably accommodate the known disabilities of an employee or prospective employee.

Specifically, the law states:

“It shall be an unlawful discriminatory practice for an employer to refuse to provide reasonable accommodations to the known disabilities of an employee, or prospective employee in connection with a job or occupation sought, provided however, that such actions do not impose an undue hardship on the business.

The New York State Human Rights Law defines “reasonable accommodation” to include:

- Provision of an accessible worksite;
- Acquisition or modification of equipment;
- Support services for persons with impaired hearing or vision;
- Job restructuring and modified work schedules.

Reasonable accommodation does NOT include:

- Providing non-work-related aids, such as a personal hearing aid or wheelchair, which are the employee’s own responsibility;
- The creation of a completely unique position with either qualifications or functions tailored to the disabled individual’s abilities.

According to New York State regulations, factors to be taken into consideration to determine “undue hardship” include:

- The overall size of the business and its budget;
- The benefit provided by the accommodation toward removing the impediments to performance caused by the disability;
- The hardships, costs, or problems it will cause for the employer, including those that may be caused for other employees.

John P. Herrion, Director of Disability Rights -- cont'd.

Circumstances giving rise to the requirement that the employer consider reasonable accommodation include:

Where the disability and need for accommodation are known to the employer.

When a qualified applicant or employee with a disability informs the employer of the disability (if the employer does not already know of its existence) and requests an accommodation.

When a current employee with a disability informs the employer of the disability (if the employer does not already know of its existence) and requests an accommodation, even if there has been no change in the employee's medical condition.

Employers are prohibited from inquiring about disability for both current and prospective employees. While the issue of whether or not to disclose disability is a challenging and subjective one, persons with disabilities (including fibromyalgia) should disclose if their job performance is weak or weakening based upon disability. The disclosure should be made to their employer's Human Resources department with a view to engage in an interactive process to discuss what reasonable accommodations should be provided to enable the individual to perform the functions of their job. It is recommended that the employee be prepared to identify what those accommodations are, how they will assist with job performance and the cost, if any, to the employer. The employee must cooperate in providing medical or other information that is necessary to verify the existence of the disability or what is necessary for consideration of the accommodation. The employer is obligated to keep these discussions and information confidential.

Persons interested in filing a complaint with the Division may find information to do so by going to the Division's website at www.dhr.state.ny.us, or by calling 1-888-392-3644.

N.Y. Exec. Law §296.

N.Y. Exec. Law § 292(21).

42 USCA 12102(1).

9 NYCRR § 466.11(d).

N.Y. Exec. Law § 296.3(a).

N.Y. Exec. Law § 292.21-e.

9 N.Y.C.R.R. § 466.11(a)(3).

9 NYCRR 466.11(f)(6)-(7).

9 N.Y.C.R.R. § 466.11(b)(1).

9 N.Y.C.R.R. § 466.11(e)(1)-(3).

N.Y. Exec. Law 296.1(d).

9 N.Y.C.R.R. § 466.11(j)-(k).

ADA-NYSHRL Comparison

Americans with Disabilities Act (ADA)

New York State Human Rights Law

Federal law that prohibits discrimination against persons with disabilities.

State law that prohibits discrimination against persons with disabilities

Coverage

Covers employers with 15 or more employees.

Covers employers with 4 or more employees.

Definition of Disability

Defines “disability” as, “a physical or mental impairment that substantially limits one or more major life activities; a record of such an impairment; or being regarded as having such an impairment.

Defines “disability” as, “a physical, medical, or mental impairment resulting from anatomical, physiological, genetic, or neurological conditions which prevents the exercise of a normal bodily function, or is demonstrable by medically accepted clinic or laboratory techniques, or a record of such impairment, or condition regarded by others as such an impairment.”

In all cases dealing with employment, the term “disability” shall be limited to disabilities which, upon the provision of reasonable accommodations, do not prevent the complainant from performing in a reasonable manner the activities involved in the job or occupation sought or held.

Covers “temporary disabilities” stating, “a current employee experiencing a temporary disability is protected by the Human Rights Law where the person will be able to satisfactorily perform the duties of the job after a reasonable accommodation in the form of a reasonable time for recovery.”

Requirement to make Reasonable Accommodations

Discrimination includes not making reasonable accommodations to known physical or mental limitations of an otherwise qualified individual with a disability who is an applicant or employee.

A reasonable accommodation does not have to be provided when it would impose an undue hardship on the operation of the business.

It shall be an unlawful discriminatory practice for an employer to refuse to provide reasonable accommodations to the known disabilities of an employee or prospective employee in connection with the job or occupation sought, provided however, that such accommodation does not impose an undue hardship on the business.

ADA-NYSHRL Comparison -- cont'd.

Americans with Disabilities Act (ADA)

New York State Human Rights Law

Inquiries as to Disability

In the pre-employment stage, an employer may not conduct a medical examination or make inquiries of a job applicant as to whether the applicant is disabled, the nature of the disability, or the severity thereof.

An employer may make pre-employment inquiries into the ability of an applicant to perform job related functions.

The employer may condition an offer of employment on the results of an examination if: all entering employees are subject to an examination, regardless of disability; and information obtained will be kept separate and confidential.

It shall be an unlawful discriminatory practice for an employer to make any inquiry in connection with prospective employment, which expresses directly, or indirectly any limitation, specification, or discrimination as to disability, unless based upon a bona fide occupational qualification.

The employer must not make pre-employment inquiries with regard to the existence of a disability or need for accommodation.

Enforcement

The employment provisions of the ADA are enforced by the Equal Employment Opportunity Commission (EEOC). A plaintiff alleging a violation of the ADA must file a complaint with the EEOC within 180 days of the violation. (See www.eeoc.gov for further information.)

A person claiming discrimination may elect to proceed in one of two ways: file an administrative complaint with the New York State Division of Human Rights within one year of the alleged discriminatory act (see www.dhr.state.ny.us for further information)

-OR-

file a private right of action in court within three years of the alleged discriminatory act.

Remedies

Remedies under the ADA include: hiring, reinstatement, back and front pay, restored benefits, reasonable accommodation, compensatory and punitive damages, and attorney's fees.

Punitive damages will be awarded only in instances of malicious and willful misconduct.

Remedies under the NYS Human Rights Law include: hiring, reinstatement or upgrading of employees, with or without back pay, and compensatory damages.

The New York State Division of Human Rights can also assess civil fines and penalties to be paid to the state by respondent. Fines may be imposed in an amount up to \$50,000.00 dollars, or up to \$100,000.00 where the conduct is found to be willful, wanton or malicious.

Legal Considerations

Social Security Disability

Ira Mendleson III,
Buckley, Mendleson, Criscione & Quinn, P.C.

General

There are two kinds of Social Security Disability programs for adults. The first, Social Security Disability (SSD) provides for disability benefits in the form of monthly checks and basic medical protection for disabled wage earners and their dependents (children under 18). To be eligible, the wage earner (claimant) must have a severe disability and be “insured”. To be insured, the claimant must have accumulated 20 quarters (5 years) of earnings in the last 40 quarters (10 years) before the disability began. In other words, the disabled worker must be able to demonstrate that the disability began within 5 years of the last employment.

The second program for disabled adults is Supplemental Security Income (SSI). To be eligible, the claimant must have a severe disability and must be in financial need. There has to be few assets, and little or no family income. The income and available asset limitations change periodically. SSI provides medical coverage and a monthly income check. The amount payable under SSI is a flat rate based upon family income and the number of persons in the household.

Some disabled individuals will be eligible only for SSD and some will be eligible for only SSI. Some will be eligible for both. Eligibility and benefits under both programs may be tied to other benefit programs such as Workers’ Compensation, short-term New York State DB, unemployment benefits, or private long-term policies. If in doubt, an attorney who specializes in disability should be consulted.

WHAT IS A DISABILITY?

The definition of disability is established by the Social Security Act. It is the same for SSD and for SSI. To be eligible, a person must have an impairment, either mental or physical (or a combination of both mental and physical) which can be demonstrated by medical proof, which prevents an individual from performing their usual work or other work for which they might be eligible. Social Security Administration (SSA) will consider the medical evidence, age, education and prior work experience in determining whether a person is disabled.

The disabling condition must be long term. Generally, the claimant must be disabled for at least one year. As will be discussed later, one does not need to wait for the full year to apply for benefits. It would be sufficient if the medical condition is expected to last for one year.

WHEN TO APPLY

There are exceptions, of course, but as a general rule, most people apply for Social Security Disability benefits after they have been disabled for about 3 to 4 months.

WHERE AND HOW TO APPLY

The applications (both SSD and SSI) are filed through the local Social Security Office. Applicants will be asked to provide their birth or Baptismal certificates and information about their former work and education, along with information about medical treatment and current medications and a statement about symptoms and daily activities. The applicant will complete and sign a formal application form and several medical release forms. The application may be made in person at the local Social Security Office, by telephone, or through the internet. Some applicants may prefer to apply by using the services of a disability attorney.

Legal Considerations Social Security Disability -- *cont'd.*

THE FIRST DECISION

A Written decision will be sent to the applicant, usually in about 3 to 4 months. Unfortunately, about 2 out of 3 initial applications are denied. If this happens, do not be discouraged. Consult an attorney. Statistics show that 60% of persons who appeal the first denial will ultimately win their cases if they have an attorney.

STEPS IN A SOCIAL SECURITY CASE

If the initial application is denied, the next step would be to apply for a hearing before an Administrative Law Judge (ALJ). Unfortunately, there are long delays in waiting for the hearing. In the Capital District area, the wait at the present time is about one year and four months.

If the decision at the hearing level is unfavorable, a further appeal may be filed with an Appeal's Council of Social Security Administration. If this appeal is not successful, a final appeal may be filed with the Federal Courts.

SOCIAL SECURITY AND FIBROMYALGIA

Unlike most disabling conditions, fibromyalgia is not capable of objective medical proof. There are no Xrays, MRI's or blood tests which show fibromyalgia. Nevertheless, the Social Security Administration (and the Federal Courts) now recognize the existence of fibromyalgia and do acknowledge that it is a condition which can truly disable an individual. The support of the attending physician and the help of an experienced Social Security Attorney are the keys in winning appeals in Social Security cases.

ADVOCACY FOR FIBROMYALGIA

by Stephanie C. Darwak,
Advocacy Relations Consultant

There are many motivated, potential health care advocates who feel confused about how to really make a difference or where to start. Many feel disaffected and helpless to change policies that aren't really working for people. Many feel that it takes a lot of money and/or time to be effective. Too many believe that systems are extremely complex and only professionals can have an impact. The truth is that the average citizen, with minimal time commitments, can be very effective in advocating for a cause. Policymakers are invariably moved by real stories from real people. All that is needed are the right tools. In today's complicated world of HMO's, medications, complementary therapies, clinical trials, registries and social support services – navigating the systems are a challenge for most people, but even more so for those dealing with a chronic condition such as Fibromyalgia (FM). You may have to fight or press for information to get the services you are entitled to or you may have to do it for someone who is unable to do it for himself. This is where advocacy comes into play and is needed.

WE ADVOCATE FOR healthcare access, medication access, social service programs, disability issues, legislation, insurance issues, program funding, and research just to name a few. SUCCESSFUL ADVOCACY starts with defining the problem, finding the answer, identifying the target, creating a plan including resources, implementing that plan, evaluating the outcome, and formulating “next steps” or future plans. Successful advocacy is a vehicle of influence using facts, persuasion, and dialogue to obtain positive change and it must work on 2 levels - by influencing policy and moving public opinion. Advocates can achieve positive change through educating, participating, empowering, and collaborating. To be effective, advocates must possess certain skills such as preparedness, passion, and persistence. One must think of advocacy as education. We need to educate and inform our elected officials, doctors, schools, family members and friends about Fibromyalgia and what patients need. We must educate and influence policy makers to enact legislation that addresses the needs of FM patients and the health care providers that they rely on. We must educate and influence our HMOs to ensure they are providing and covering the services that are approved for and recommended for FM patients. We must take responsibility for educating all of the above by participating in fibromyalgia advocacy initiatives. With collaborative efforts, we can advocate for Fibromyalgia in the political arena to help those who make important decisions about health care reform consider FM patients' needs just as they consider the needs of patients with heart disease, cancer, diabetes, or more common diseases or syndromes. Fibromyalgia needs to be a higher national priority.

PUBLIC POLICY can be generally defined as the course of action or inaction taken by governmental entities with regard to a particular issue or set of issues. These actions can establish laws or policies that when put into practice, can affect our quality of life either in a positive or negative way. We may monitor proposed changes in regulations, programs, and legislation - and their impact on those living with fibromyalgia to ensure quality of care. We can advocate for new policies to improve access to care and remove barriers. Shaping public policy is a complex and multifaceted process that involves the interplay of numerous individuals and interest groups competing and collaborating to influence policymakers to act in a particular way.

LEGISLATIVE MEETINGS are great opportunities to put a face on Fibromyalgia and the issues at hand. Building legislative “champions” will help to shape public policy with positive outcomes for FM patients. Legislative issues will vary from state to state, but national consensus and support on FM issues will help local and state causes. A legislative agenda should be developed and supported statewide and/or nationally. Legislative priorities are developed when the key problems to a group are identified along with a list of recommendations to those problems. For example, we may ask ourselves, “What do Fibromyalgia Support Groups want to see happen in NYS? What are the barriers to accessing recommended care for FM patients in NYS? Why does it take so long to receive a correct FM diagnosis? What rights do FM patients have in the work place and how do we educate employers about their responsibilities?” Answers to questions like these can potentially make up a legislative agenda for Fibromyalgia advocates in NYS.

ADVOCACY FOR FIBROMYALGIA -- cont'd.

TELL YOUR PERSONAL STORY: Personal stories are extremely powerful, moving, and have great impact. Introduce yourself and the advocacy organization you represent (if applicable). Explain your connection to Fibromyalgia and how it has impacted you, your family, or friend. Let them know if you live in the legislator's district and that you are asking for their support. Know your talking points and have them ready. **TALKING POINTS** should include facts on: the **IMPACT OF FIBROMYALGIA** (including the financial, emotional, and physical implications), the **BARRIERS** to needed treatments or therapies, **LACK OF PROGRESS** with timely diagnosis (average of 5 years to diagnose), and **LACK OF AWARENESS** about FM, as well as **LACK OF RESEARCH** or studies relevant to FM. Get the key message across that Fibromyalgia is a chronic, complicated, and disabling syndrome that is financially, physically, and emotionally devastating to the patient's quality of life and how it drastically affects the entire family. Do not hold back details or information. Let the legislators know if FM has cost you your job, marriage, or financial security.

CULTIVATE A RELATIONSHIP: Cultivate relationships by partnering with your local agencies, and state and federal governments to positively impact fibromyalgia research, health care, and ultimately patient quality of life. Don't forget to say thank you to everyone who helps, including staff. Always be polite, provide a briefing packet that summarizes your talking points, and invite them to local events. Follow up after meetings with a thank you note and put them on your mailing list.

EFFECTIVE COMMUNICATIONS: Effective communications are critical to promoting a cause. Be clear and concise with the process from deciding what you are trying to communicate – to whom you are trying to reach – to framing the message – to designing your form of communication. Word of mouth is always good, but written communication is permanent. Consider short, one page fact sheets and decide the best delivery method.

MOVING PUBLIC OPINION: Legislators rarely drive opinion, but respond to it. Changing public opinion is vital to advocacy and larger than just the media – word of mouth is the most powerful tool! Talk to friends, neighbors, and acquaintances about your issue. Do not pass up opportunities to speak to groups. **USE THE MEDIA** – the primary way most of us get information about public policies. Get to know the media and let them get to know you. Do this by writing an Op-Ed or letter-to-the-editor, call into a talk radio show, or be interviewed by a reporter. **INCLUDE THE MEDIA** in any events you are planning.

RESOURCES FOR NYS ADVOCACY:

NYS Legislative Reference Guide – This comprehensive guide provides advocates with information on the members of the NYS Senate, Assembly, their Committees, and the US Congress including contact info, geographic location, leadership roles, and committee assignments. Call 518-462-6805 to purchase.

NYS Senate Website: www.nysenate.gov

NYS Assembly Website: www.assembly.state.ny.us

Resources

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| American Pain Foundation | www.painfoundation.org |
| National Fibromyalgia Association | www.fmaware.org |
| National Fibromyalgia Partnership | www.fmpartnership.org |
| American Pain Society | www.ampainsoc.org |
| American Academy of Pain Management | www.aapainmanage.org |
| American Academy of Physical Medicine & Rehabilitation | www.aapmr.org |
| Web MD | www.webmd.com |
| National Institutes of Health (NIH) | www.nih.gov |
| US Food and Drug Administration | www.fda.gov |
| New York State Division of Human Rights | www.dhr.state.ny.us |
| Arthritis Foundation | www.arthritis.org |
| Job Accommodation Network | www.jan.wvu.edu |
| US Department of Labor Office of Disability Employment Policy | www.dol.gov/odep |
| Americans with Disabilities | www.ada.gov |
| Harvard Medical School | www.health.harvard.edu |
| Neurology Now | www.neurologynow.com search "fibromyalgia" |

The Empowered Patient: “A Personal Resolution”

I resolve to:



FIBROMYALGIA

Are you sick and tired
of being Sick and Tired?

**Become an
Empowered
Patient**

international
institute for
**HUMAN
EMPOWERMENT**

www.humanempowerment.org



“Not everything that seems negative in life turns out to be that way. I’ve had fibromyalgia for 27 years. The work of healing was (is) long and sometimes difficult. In the final analysis, my condition led me to make significant changes in all aspects of my life, work, and relationships. These changes ultimately led me to a life that is happier, healthier, more whole. Fi-bro was a ‘gift’ in very unattractive wrappings. Being ‘pain-free’ is not as important as the wonderful quality of life I received as a result of working towards a healthy life!”

(Fibromyalgia Patient)

Explore my options
Choose what works best for me
Refuse to be denied access
Refuse to accept barriers
Know my rights and responsibilities
Recognize when others lack respect
Respect myself first
Accept nothing less from others

Refuse to be arrogant when facing opposition
Know my ground, and stand it
Recognize abuse from others
Refuse to ever accept it
Work toward peaceful resolution
Never seek ‘peace at any price’
Recognize when to fight for rights
And when to move forward alone

Remember that the spirit must be free
Accept no manipulation
Recognize other’s true motives
Recognize when words don’t feel “right”
Trust my gut instinct
Recognize that our knowing is our safety
Seek safety in all situations
Recognize another’s personal agenda

Be respectful of others’ needs
Allow for individual expression
Allow for my own mistakes
Forgive the mistakes of others
Trust my internal wisdom
Allow myself to love freely
Accept no strings to love
Begin with self-love

Make the world a better place
Seek solutions rather than conflict
Seek consensus when appropriate
Seek to support another’s journey
Let my love be for all humanity
Judge another only by actions
Enjoy the specialness of human diversity
Seek daily to live freely.

The International Institute For Human Empowerment, Inc. is a 501(c)(3) public charity registered with the Office of the Attorney General in New York State.

The primary purpose of the Institute is to promote unity by 'helping individuals and organizations recognize and harness their power'. The International Institute For Human Empowerment, Inc., is dedicated to the mission of empowering all people toward a True Democracy through the attainment of basic human rights including: quality education, healthcare, food, and a peaceful, loving environment.

Incorporated as a not-for-profit in 2000, the Institute maintains a variety of Empowerment programs and materials including:

*Initiating and supporting 13 years of the International Peace Meditation *Initiating "International Unity Day" commemorated annually on 9/11

*Initiating the Select Empowerment Seminar, and Conferences
*Providing an extensive website on Empowerment topics
*Publishing in electronic and hard copy formats on areas of Empowerment

*United We Stand: Reflections on a True Democracy by Sue Kidd Shipe
The Institute has given two public conferences on Fibromyalgia.
It participated in the 2009 New York State Fibromyalgia Awareness Week.

It has also provided articles for publication for the National Fibromyalgia Association.

The Institute website is visited regularly by 100+ countries.

You can learn more about its programs and provide support by visiting:
www.humanempowerment.org

“Fibromyalgia: Awareness, Advocacy, and Action” Report of the Select Empowerment Seminar on Fibromyalgia

