CDC Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Stakeholder Engagement and Communication (MECFS-SEC) Webinar/Conference Call

Alison C. Bested M.D. FRCPC

Pacing in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome & Fibromyalgia

June 3, 2019

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention
Pacing:
Learn how to stop crashing and increase your energy
in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome & Fibromyalgia

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June 3, 2019
Disclosures

None
Acknowledgements:

• Drs. Lynn Marshall, Riina Bray, Kathleen Kerr, John Molot, John MacLennan and Ellie Stein–Canadian Contingency

• Institute for Neuro-Immune Medicine–Dr. Nancy Klimas and Clinicians: Drs. Maria Vera Nunez, Irma Rey; ARNPs Violetta Renesca & Irina Rozenfeld

• Dean Elaine Wallace–Vision of Integrative Medicine Program Nova Southeastern University, Davie, FL

• My patients who continue to amaze me with their grace under pressure, who are my teachers & who inspire me to continue to learn
Goals of Pacing: ME/CFS, FM & Chronic Physical Illness

1. Improvement of current symptoms, functioning and quality of life

2. Secondary prevention of worsening of presenting chronic complex medical condition
Judy age 52

Started after **fourth whiplash injury** after being rear-ended while driving her car

6 months later she has:

1. Pathological severe fatigue: energy 4/10 & post-exertional fatigue
2. Non-Restorative Sleep
3. **Pain in her muscles all over** & joints
4. Brain fog & poor memory
5. Dizzy when standing up
Noelle age 56

**Flu** at Xmas party where everyone got sick, they recovered.

6 months later she has:

1. Pathological **severe fatigue**: energy 4/10 & **post-exertional malaise**
2. Non-Restorative Sleep
3. Pain in her muscles & joints
4. Brain fog & poor memory
5. Dizzy when standing up
Fibromyalgia Criteria

• Widespread Pain-11/18 +ve Tender points
• Fatigue
• Sleep Dysfunction
• Neurological Manifestations
• Autonomic/Neuroendocrine Manifestations
• Stiffness

FM Tender Points
CFS/ME Clinical Criteria

• Fatigue—severe, physical + mental; –post-exertional
• Sleep dysfunction
• Pain
• Neurological symptoms
• Autonomic, neuroendocrine & immune symptoms
• Chronic: adults >6 months, kids >3 months

SEID Definition by IOM
“Systemic Exertion Intolerance Disease”

1. Impairment in ability to maintain pre-illness levels of occupation or personal activities that lasts more than 6 months with fatigue and not improved with rest

2. Post-exertional malaise

3. Unrefreshing sleep

Plus 1 of:

1. Cognitive Impairment

2. Orthostatic Intolerance

Commonalities

1. Fatigue - abnormal
2. Non-Restorative Sleep
3. Pain muscles/joints
5. Parasympathetic/Sympathetic Nervous System Imbalance: dizzy when standing up
ME/CFS: CHRONIC, COMPLEX MULTISYMPTOM DISEASE

Brain Dysfunction:
- Cognitive Dysfunction
- Sleep Disorder
- Anxiety
- HPA Axis Dysregulation

Pain:
- New headaches, migratory muscle & joints

Autonomic Dysfunction:
- Orthostatic Intolerance
- Low Blood Volume + Mass

Immune Dysfunction:
- ↓ NK activity

Severe Fatigue/
Post-Exertional Fatigue:
- Abnormal Metabolism
FIBROMYALGIA: CHRONIC COMPLEX MULTISYMPTOM DISEASE

Brain Dysfunction:
- Cognitive Dysfunction
- Sleep Disorder
- Anxiety
- HPA Axis Dysregulation

Widespread Pain:
- Muscles
- GI Irritable Bowel Syndrome

Autonomic Dysfunction:

Immune Dysfunction:
- ?autoantibodies

Severe Fatigue/
Post-Exertional
Fatigue:
- Abnormal Metabolism

Muscle Stiffness
Unrest: the Documentary: A Snippet-Jessica's Birthday
Sundance Award Winner

https://www.dropbox.com/s/00oijwxucvpprg9/Unrest_Publicity_Clip_2.mov?dl=0
https://www.dropbox.com/s/00oijwxucvpprg9/Unrest_Publicity_Clip_2.mov?dl=0
Diagnosis!

The *diagnosis is the key* for understanding your illness.

ME/CFS & FM are Physical Illnesses!
Supportive Symptomatic Care

MANAGEMENT STRATEGIES

1. Improve symptoms, functioning & quality of life
2. Secondary prevention of worsening of chronic complex condition
3. Support patient & family
Multiple Determinants of Health

www.healthyenvironmentforkids.ca

Holistic
Adaptation Mechanisms

Adaptation:

• the process by which the body attempts to sustain ‘the balance within’
Exhaustion: SEEDS of Health

Body Systems

- Exercise
- Sedentary
- Deconditioned

Stressors

- Diet
  - Junk Food
  - Fast Food
- Support
  - Sick Child
  - Rebellious Teen
  - School
- Environment
  - Polluted Air/water/food
  - Infections
  - Physical
- Sleep
  - Insomnia
  - Circadian Rhythm

Homeostasis Imbalance
Weed, Seed, and Feed Approach

1. Weed out known aggravators/stressors
2. Plant “SEEDS” of health:
   • S leep
   • E xercise/pacing
   • E nvironment
   • D iet/Drugs
   • S upport (self, family, social, medical, occupational, spiritual)
3. Feed the SEEDS (nurture whatever helps)
Pacing Treatment

Impaired Function/Fatigue/ Post-Exertional Fatigue or Malaise (PEM)

– Pacing with Activity Logs, Fitbit # steps/day. Alternate activity with rest periods.

– Stop pushing & crashing, honor body’s limits and expand slowly, keep heart rate low & avoid aerobic exercise

Pathophysiology

ME/CFS  – impaired aerobic metabolism
     – two-day bike ergometry testing

FM  – abnormal small nerve fibers discovery
     – abnormal pain pathways
Activity Log and Functional Capacity Scale
Scale from 0 to 10

Incorporates:
• Energy rating
• Activities
• Symptoms/emotions on reverse side
# Activity Log

Name: ___________________________ Date Commencing: ___________________________

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**SLEEP:** Write number of hours you slept and the sleep quality: 1 = very poor, 2 = poor, 3 = fair, 4 = good, 5 = very good

**Functional Capacity Scale:**
Record your activity using one word and your energy rating using the scale 1-10/10 every hour in each square.

**Activities (please specify):**

- 6 a.m.
- 7 a.m.
- 8 a.m.
- 9 a.m.
- 10 a.m.
- 11 a.m.
- 12 p.m.
- 1 p.m.
- 2 p.m.
- 3 p.m.
- 4 p.m.
- 5 p.m.
- 6 p.m.
- 7 p.m.
- 8 p.m.
- 9 p.m.
- 10 p.m.
- 11 p.m.

- # of minutes walked
- # of stairs walked

We encourage you to copy this log to use with your patients.

Dr. Alison Bested PhD
Dr. Lynn Marshall and Dr. Rosemary Underhill
# Activity Log

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**Date:**

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Dr. Alison Bested ©
YOUR ACTIVITY LOG:
- Keep it in a handy place.
- Complete it every day.
- Take your completed logs to your doctor/other health care provider at follow-up visits.
- Your logs assist your doctor/other health care provider to adjust your treatment plan as needed.
- Completed logs may reassure your insurance company of your active ongoing participation in your treatment.

COMPLETING YOUR ACTIVITY LOG:
- You may change the times on the left hand side of the log to suit your usual schedule (e.g. if you usually get up at 10:00 a.m. and go to bed at 2:00 a.m., write 10:00 a.m. in as the first time, and adjust the other times accordingly).
- Please note your activities with one or two word(s) in the appropriate time slots (e.g. dressed, made bed, nap).
- Rest is defined as lying down, eyes shut, meditating or sleeping.

FUNCTIONAL CAPACITY SCALE:
The Functional Capacity Scale incorporates energy rating, symptom severity, and activity level. The description after each scale number should help you to rate your functional capacity at the beginning and end of each day.

0 = No energy, severe symptoms including very poor concentration; bed ridden all day; cannot do self-care (e.g. need bed bath to be given).
1 = Severe symptoms at rest, including very poor concentration; in bed most of the day; need assistance with self-care activities (bathing).
2 = Severe symptoms at rest, including poor concentration; frequent rests or naps; need some assistance with limited self-care activities.
3 = Moderate symptoms at rest, including poor concentration; need frequent rests or naps; can do independent self-care but have severe post exertion fatigue.
4 = Moderate symptoms at rest, including some difficulty concentrating; need frequent rests throughout the day; can do independent self-care and limited activities of daily living (e.g. light housework, laundry); can walk for a few minutes per day.
5 = Mild symptoms at rest with fairly good concentration for short periods (15 minutes); need a.m. and p.m. rest; can do independent self-care and moderate activities of daily living, but have slight post exertion fatigue; can walk 10-20 minutes per day.
6 = Mild or no symptoms at rest with fairly good concentration for up to 45 minutes, cannot multitask; need afternoon rest; can do most activities of daily living except vacuuming; can walk 20-30 minutes per day; can do volunteer work – maximum total time 4 hours per week, with flexible hours.
7 = Mild or no symptoms at rest with good concentration for up to ½ day; can do more intense activities of daily living (e.g. grocery shopping, vacuuming) but may get post exertion fatigue if ‘overdo’; can walk 30 minutes per day; can work limited hours, less than 25 hours per week; no or minimal social life.
8 = Mild intermittent symptoms with good concentration; can do full self-care, work 40 hours per week, enjoy a social life, do moderate vigorous exercise three times per week.
9 = No symptoms with very good concentration, full work and social life; can do vigorous exercise three to five times a week.
10 = No symptoms, excellent concentration, over achiever (sometimes may require less sleep than average person).

NUMBER OF USABLE HOURS / DAY = Number of hours NOT asleep or resting/meditating with eyes closed.

Dr. Lynn Marshall, Co-Author, Director, Environmental Health Clinic, Sunnybrook & Women's College Health Services Centre
Dr. Allison Bastedo &
Spending your **Energy $$**

1. Physical—walk

2. Mental—pay bills on computer

3. Emotional—fight with mother, husband etc.
Pushing

Crashing Pattern

Pacing

Recovery Pattern
Rest Definition:
- lying down, eyes shut, meditating or sleeping

Relaxation Response/Meditation
- to increase parasympathetic tone and reduce adrenal overstimulation (stop the adrenaline addiction)
Energy used:

1. Physical–walk
2. Mental–computer
3. Emotional–fight with kids
Limited energy:

You can only use it once!

Take control! Use the tool–pace!
# Activity Log

**Name:** NORMAL  
**Date:**

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<tr>
<td>SLEEP QUALITY</td>
<td>1 = very poor</td>
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<td>3 = fair</td>
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<td>5 = very good</td>
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<tr>
<td>Functional Capacity Scale at the best and worst time of the day</td>
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| Activities (please specify) | 6 a.m. | 7 a.m. | 8 a.m. | 9 a.m. | 10 a.m. | 11 a.m. | 12 p.m. | 1 p.m. | 2 p.m. | 3 p.m. | 4 p.m. | 5 p.m. | 6 p.m. | 7 p.m. | 8 p.m. | 9 p.m. | 10 p.m. | 11 p.m. | 60 | 60 | 60 | 60 | 60 | 60 | 60 | 60 |
|----------------------------|--------|--------|--------|--------|---------|--------|--------|-------|--------|-------|--------|-------|--------|-------|-------|--------|---------|
| ENERGY                      | 9      | 9      | 9      | 9      | 9       | 9      | 9      | 9     | 9      | 9     | 9      | 9     | 9      | 9     | 9     | 9      | 9       |
| WALKED                      | 60     | 60     | 60     | 60     | 60      | 60     | 60     | 60    | 60     | 60    | 60     | 60    | 60     | 60    | 60    | 60     | 60       |

Dr. Alison Beataed ©
Blue = rest
Yellow = new normal energy level from Functional Capacity Scale
Orange = low energy/activity level

### Activity Log

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<td>SLEEP QUALITY good</td>
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**Functional Capacity Scale at the beginning of the day and the best time of the day. 0 - 10**

| Activities (please specify) | 6 a.m. | 7 a.m. | 8 a.m. | 9 a.m. | 10 a.m. | 11 a.m. | 12 a.m. | 1 p.m. | 2 p.m. | 3 p.m. | 4 p.m. | 5 p.m. | 6 p.m. | 7 p.m. | 8 p.m. | 9 p.m. | 10 p.m. | 11 p.m. |
|-----------------------------|--------|--------|--------|--------|---------|---------|---------|--------|--------|--------|--------|--------|--------|--------|--------|---------|---------|
|                             | 4      | 4      | 5      | 3      | 3       | 3       | 3       | 4      |        |        |        |        |        |        |        |         |         |

| ENERGY | 3 | 3 | 2 | 2 | 2 | 2 | 3 | 0 | 0 | 0 | 0 |
| WALKED | 10 | 10 | 20 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
# RECOVERY PATTERN

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</tr>
<tr>
<td>Energy</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Walked</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
</tr>
</tbody>
</table>

Dr. Alison Bested ©
<table>
<thead>
<tr>
<th>Time</th>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:00 am</td>
<td>Get up</td>
</tr>
<tr>
<td>6:45 am</td>
<td>Feed (L/C)</td>
</tr>
<tr>
<td>7:00 am</td>
<td>Wash up left</td>
</tr>
<tr>
<td>7:30 am</td>
<td>Breakfast</td>
</tr>
<tr>
<td>8:00 am</td>
<td>Get up to see TV</td>
</tr>
<tr>
<td>9:00 am</td>
<td>Walk outside</td>
</tr>
<tr>
<td>10:00 am</td>
<td>Get up to see TV</td>
</tr>
<tr>
<td>11:00 am</td>
<td>Eat lunch</td>
</tr>
<tr>
<td>12:00 pm</td>
<td>Eat lunch</td>
</tr>
<tr>
<td>1:00 pm</td>
<td>Eat lunch</td>
</tr>
<tr>
<td>2:00 pm</td>
<td>Watch TV</td>
</tr>
<tr>
<td>3:00 pm</td>
<td>Walk outside</td>
</tr>
<tr>
<td>4:00 pm</td>
<td>Walk outside</td>
</tr>
<tr>
<td>5:00 pm</td>
<td>Watch TV</td>
</tr>
<tr>
<td>6:00 pm</td>
<td>Eat dinner</td>
</tr>
<tr>
<td>7:00 pm</td>
<td>Feed (L/C)</td>
</tr>
<tr>
<td>8:00 pm</td>
<td>Eat dinner</td>
</tr>
<tr>
<td>9:00 pm</td>
<td>Sleep</td>
</tr>
<tr>
<td>10:00 pm</td>
<td>Sleep</td>
</tr>
</tbody>
</table>

**Number of Hours Sleep: 7**

**Sleep Quality: 3 = fair**

**Functional Capacity Scale at beginning of day:**

- 0 - 10: 3

**Activities note:**

- Get up
- Feed
- Wash up
- Breakfast
- Watch TV
- Eat lunch
- Walk outside
- Eat dinner
- Sleep

**Number of Useable Hours:** 4.5 hours
| Activities (please specify) | 6 a.m. | 7 a.m. | 8 a.m. | 9 a.m. | 10 a.m. | 11 a.m. | 12 p.m. | 1 p.m. | 2 p.m. | 3 p.m. | 4 p.m. | 5 p.m. | 6 p.m. | 7 p.m. | 8 p.m. | 9 p.m. | 10 p.m. | 11 p.m. |
|---------------------------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|
| 6 a.m. | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch |
| 7 a.m. | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep | Sleep |
| 8 a.m. | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch | Stretch |
| 10 a.m. | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast |
| 11 a.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 12 p.m. | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast | Breakfast |
| 1 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 2 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 3 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 4 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 5 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 6 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 7 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 8 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 9 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 10 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
| 11 p.m. | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch | Lunch |
How?

1. **Awareness**: record hourly activity and energy level without judgment for a week
2. Find your **best time** of the day
3. Listen to your body and **stop before you crash**
4. **Plan** for health
BESTED™ PACING METHOD
MIND-BODY MEDICINE

**Body**, in the moment, what do I need?
Activity or Rest.

**Body**, in this moment, how many minutes can I do it?
Number of minutes

Scroll through times table 5, 10, 15...until time is chosen.

Set timer and **Stop when timer/alarm rings!**
Airplane Symbolic Shift from

Pilot
Brain

Co-pilot
Body
Airplane Symbolic Shift to

Pilot

Body

Co-pilot

Brain
Exercise/Pacing/Mobility

Monitor via Activity Log:

• Stay as active as possible **WITHOUT CRASHING** (inside your glass box)
• Increase slowly (**10% RULE**)
• Warm up before, stretch after exercise (bath)
• Strength train and prevent osteoporosis
• Learn to trust your perceptions & build gradually

**Strong Women Stay Young** – Miriam Nelson
Examples:

1. Walking e.g. 10 minutes per day is fine
   Good day–increase walking by 10%
   –means increase walking by 1 minute
   –Total walking is 11 minutes

2. Mostly Bedridden –able walk to commode at bedside
   Good day–increase by walking to commode twice before getting back into bed

3. Bedridden–Physiotherapist assessment to begin range of motion exercises in bed passively; teach family members; then actively done by patient with ME/CFS
Results:
Adaptation

Body Systems

Seeds of Health

Support

Environment

Exercise

Diet

Sleep

Homeostasis
“Claire’s” Functional Status
Activity Log/Functional Capacity Scale

Activity Log helps physician to complete insurance reports

• Doctor could explain why she could not work e.g. fatigue was severe, energy was not reliable or sustainable (referring to activity logs)

or

• Why she could work part time or full time
Crashing Pattern

Recovery Pattern
Energy Loan

Pay back your energy loan $$$ to your body on Your Good Days
The Faces of ME/CFS: Dorothy

Age 55

Age 72
Never Give Up!
Boundaries/The Way to Pace

https://www.youtube.com/watch?v=N5sUkY0_wxw
Boundaries are so wonderful to set.
When I sa-ay no-o o to you, I say yes to myself.
Scattered pictures of the life I left behind.
Now I'm lying in bed crashing, from pushing myself...on my good days.
The Way To Pace  part 1

Could it be that if I start to pace. And write in my activity log.

If I persist with keeping it. Tell me could I? Improve my energy?
Boundaries are so wonderful to set. Using my mini-timer, I can choose to stop. When I stop before I crash, I help my body to heal. Whenever I remember, the way to pace, the way to pace.

Melody: Marvin Hamlisch
Lyrics: Alison C. Bested
Patient Resources

Nova Southeastern University’s Institute for Neuro-Immune Medicine’s Website: https://www.nova.edu/nim

- Activity Log and Functional Capacity Scale

Books:


Online Resources


Chronic Fatigue Syndrome/Myalgic Encephalomyelitis: **A Primer for Clinicians 2014 - IACFS/ME** [https://www.iacfsme.org/assets/docs/Primer_Post_2014_conference.pdf](https://www.iacfsme.org/assets/docs/Primer_Post_2014_conference.pdf)

Carruthers B. et al. **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols.** Journal of Chronic Fatigue Syndrome Volume 11, Number 1, 2003 and **Fibromyalgia Syndrome**: ME/FM Action Network Website: [http://www.mefmaction.com](http://www.mefmaction.com)