

## **Master Symptom List for CFS, FMS, CMP & Lyme Disease** **Melissa Kaplan, *The Carousel Network*, May-June 2003**

As research continues into chronic fatigue syndrome (CFS), fibromyalgia syndrome (FMS), chronic myofascial pain (CMP) and chronic Lyme disease, the differences between these putatively different disorders is blurring.

While the organism responsible for causing the disease we in the United States call Lyme disease (borreliosis) was discovered twenty years ago, researchers, mostly underfunded private researchers in labs around the world, continue to subject various bodily substances harvested from people meeting the clinical diagnostic criteria of CFS and FM to try to find any unique markers, genetic or microbial, that may cause these illnesses. Why some people who suffer physical trauma, as from auto accidents, go on to develop FMS or CMP, and why others don't, is another of life's mysteries still to be teased out.

What we do know is that rare is the patient who meets the diagnostic criteria of just one of these diagnoses. Far more common are people who meet the definitions of two or more of these diagnoses. We also know that those who meet the diagnostic criteria for these diagnoses may not experience every known symptom for each diagnosis. (Okay, so it often feels like we have every symptom, all at the same time, but fortunately for most of us, the number and severity/intensity of each symptom waxes and wanes as the years go on.)

There are many different symptom lists for the different disorders. They are usually found in disease-specific website or books, but rarely do they appear all together, co-mingled. Several years ago, I compiled a combined CFS/FMS symptom list, publishing it in this newsletter and making it available online at my website. This new Master Symptom List takes the old list one--or two--steps forward by including symptoms for CMP and Lyme.

*A Note on Gulf War Illness (Gulf War Syndrome):* It should be noted that, with the exception of birth defects attributed to GWI, the symptoms for GWI are the same as those for CFS. It may ultimately be found that differences in GWI may be attributed to what actually triggered the illness in the individuals so affected: exposure to chemicals (including leaded fuel exhaust and oil fires), vaccines, and other substances they were required to ingest or have injected.

*A Note on Lyme Disease:* It is estimated that 30-50 percent of acute Lyme disease patients develop chronic Lyme (chronic borreliosis; neuroborreliosis). That is, despite antibiotic and other treatment, the *Borrelia burgdorferi* organism remains alive and well, periodically causing a worsening of symptoms or causing new symptoms to appear. Two-thirds of those bitten by an adult tick or tiny tick nymph never even know they've been bitten, and fewer than 50 percent of those finding ticks or nymphs feeding on them develop the "classic" bull's-eye rash that the CDC stipulates as one of its diagnostic criteria; many people with Lyme never exhibit any type of rash.

There are over 300 known strains of Bb and at least six genotypes, increasing the difficulty in testing people for its presence. This is compounded by the fact that the majority of public health and commercial labs such as Quest Diagnostics, LabCorp, Unilab, etc., use a hierarchy of tests, established by the CDC and followed by the AMA. The first of test to be done, the ELISA, is known to miss the organism in the samples tested. Only when this less-than-accurate ELISA is positive is a second test, the Western blot, ordered. Since these labs use the Centers for Disease Control & Prevention's epidemiological criteria, which even the CDC says is not to be used for diagnostic purposes, thousands of people each year who get negative ELISA and

Western Blots are told by their doctors that they do not have Lyme, when in fact they do. Many of those who go on to develop chronic Lyme do so because of not getting properly diagnosed right away, or not getting the appropriate treatment (too many doctors still prescribe too-short a period of antibiotics). Others keep testing negative for the disease because the tests used do not detect the strain they have, or the *Bb* is in one of its many presently undetectable morphs.

Over the past several years, as independent labs such as IgeneX and MDL have developed more sensitive tests for *Borrelia* and other tickborne diseases, an increasing number of people who were originally diagnosed with CFS and FM are turning up positive for *Borrelia* and, frequently, one or more of the other tickborne diseases. Others who are seronegative for *Bb* (getting false negatives on tests) respond to appropriately aggressive antibiotic therapy, and may later show positive on the Western blot IgM (early or reactivated infection) and/or IgG (chronic or ongoing infection) tests, despite negative ELISAs and earlier Western blots.

*Note on Symptoms:* Many of these are symptoms common to other diseases. Getting a proper diagnosis for CFS, FM, and CMP is as much ruling out other diseases (including proper testing *and* assessment for Lyme and other tickborne diseases) as it is looking at the clues in dozens of tests and the actual physical exam.

For more on Lyme Disease, please see [www.anapsid.org/lyme](http://www.anapsid.org/lyme).

## **AUTONOMIC NERVOUS SYSTEM/ENDOCRINE/IMMUNE/HORMONE**

Abnormal sensitivity to hot or cold

Allergies (nasal, other; new, increased or worsening)

Canker sores (frequent)

Chills and/or shakes when hungry (may occur instead of feeling hungry)

Cold hands and feet

Extreme fatigue after minimal exertion

Feeling hot or cold often

Flu-like symptoms, on-going or recurrent after initial gradual or acute onset; includes mild fever (99.5-101.5 F / 37.5-38.6 C), chills

Hair loss (alopecia)

Herpes simplex or shingles rash

Increased susceptibility to infections

Low-grade fevers

Low blood pressure (below 110/70)

Low body temperature (below 97.5)

Lymph nodes painful, swollen (in neck; under arms)

Night sweats (not related to menopause or fever)

Orthostatic Intolerance (neurally mediated hypotension)

Reactive hypoglycemia and insulin resistance

Thirst, increased

Temperature irregularities; often feeling hot or cold irrespective of actual ambient temperature and body temperature; low body temperature (below 97.6 F / 36.4 C)

Thyroid inflammation (acute thyroiditis; hypothyroidism; Hashimoto's thyroiditis)

## **CARDIOPULMONARY/RESPIRATORY/CIRCULATORY**

Cardiac abnormalities (mitral valve prolapse; myocarditis; tachycardia; palpitations; dysrhythmia)

Cough

Dyspnea (out of breath) or shortness of breath (air hunger) after minimal or no exertion

Heart attack

Heart palpitations  
Heart pounds so hard it shakes body, bed  
Pulse skips  
Serious rhythm disturbances of heart  
Sighing, frequent, not related to mental/emotional state  
Stroke  
Vasculitis

### **CENTRAL NERVOUS SYSTEM/NEUROLOGICAL/NEUROPATHIC/OTOLOGIC**

Abnormal CAT, MRI and/or SPECT scans  
Alcohol intolerance  
Aseptic meningitis  
"Brainfog"; inability to think clearly  
Difficulty moving tongue to speak  
Diminished or absent reflexes  
Fainting or blackouts; feeling like you might faint  
Headaches (frequent, severe, recurring)  
Hearing fluctuations (sounds fade then return)  
Hearing changes, often from day to day (need to turn up, then down, volume of radio, TV)  
Joint or arthritic pain not relieved by NSAIDs (ie, ibuprofen)  
Libido (decreased)  
Light-headedness, feeling spaced-out  
Migraine headaches  
Muscle twitching  
Noise intolerance  
Paralysis or severe weakness of limb  
Parasthesias (numbness, tingling, crawling, itching sensations) in face, head, torso, extremities  
Photosensitivity  
Radiculitis  
Seizures; seizure-like episodes

Sensory alterations (hyper- or hyposensitivity) - smell, taste, hearing (noise intolerance)

Severe muscle weakness

Syncope (fainting)

Tinnitus (ringing/noises in one or both ears)

Touch or weight of clothing on or against body causes discomfort or pain

Tremors, trembling

## **COGNITIVE FUNCTION**

Becoming lost in familiar locations when driving

Difficulty with simple calculations (e.g., balancing checkbook)

Difficulty expressing ideas in words

Difficulty moving your mouth to speak

Difficulty making decisions

Difficulty following directions while driving

Difficulty remembering names of objects

Difficulty remembering names of people

Difficulty recognizing faces

Difficulty following simple written instructions

Difficulty following complicated written instructions

Difficulty following simple oral (spoken) instructions

Difficulty following complicated oral (spoken) instructions

Difficulty integrating information (putting ideas together to form a complete picture or concept)

Difficulty putting tasks or things in proper sequence

Difficulty paying attention

Difficulty following a conversation when background noise is present

Difficulty making and/or retrieving memories (long/short-term memory deficits)

Difficulty understanding what you read

Easily distracted during a task

Feeling too disoriented to drive

Forgetting how to do routine things

Forgetting the use of common objects (such as, what to do with the shampoo when you are standing in the shower)

Forgetting how to get to familiar places

Impaired ability to concentrate

Losing your train of thought in the middle of a sentence

Losing track in the middle of a task (remembering what to do next)

Poor judgment

Switching left and right

Slowed and/or slurred speech

Stuttering; stammering

Transposition (reversal) of numbers, words and/or letters when you speak and/or speak

Word-finding difficulty

Using the wrong word

## **DIGESTIVE/HEPATIC**

Bloating; intestinal gas

Decreased appetite

Digestive chemicals (acid, enzymes) reduced or absent

Esophageal reflux; heartburn

Frequent constipation

Frequent diarrhea

Food cravings (especially carbohydrates, sweets)

Food/Substance intolerance

IBS

Liver function impaired; mild abnormalities

Increased appetite

Nausea

Spleen tender or enlarged

Stomach ache, cramps

Vomiting

Weight gain or loss

## **EQUILIBRIUM/PERCEPTION**

Bite your cheeks or tongue frequently

Bump into things frequently

Difficulty discriminating printed matter despite proper vision correction

Distances (difficulty judging when driving; when putting things down on surfaces)

Dizziness or vertigo

Dropping things frequently

Dysequilibrium (balance problems)

Impaired coordination

Loss of balance when standing with eyes closed

Perception (not quite seeing what you are looking at)

Some patterns (stripes, checks) cause dizziness

Spatial disorientation

Staggering gait (clumsy walking)

Words on printed page appear to jump off page or disappear when staring at them

## **EYES/VISION**

Acuity changes not related to prescription changes

Blind spots

Blurred vision

Conjunctivitis

Diminished visual acuity in absence of actual vision change

Drooping eyelid

Double vision

Eye pain

Flashes of light perceived peripherally

Optic neuritis or atrophy

Oscillopsia (image jiggles)

Prescription changes more frequently

Pressure sensation behind eyes

Red and/or tearing eyes  
Retinal damage  
Slowed accommodation (switching focus from far to near, near to far)  
Spots or floaters not related to migraines  
Swelling around eyes  
Uveitis and/or iritis  
Wandering or lazy eye

### **HEAD/NECK/MOUTH**

Bell's palsy (facial paralysis, one or both sides)  
Bruxism (grinding/clenching teeth)  
Canker sores  
Dizziness when you turn your head or move  
Dry chronic cough  
Dry eyes, nose and mouth (sicca syndrome)  
Pain in ears, palate, gums  
Periodontal disease  
Prickling pain along skin of jaw  
Problems swallowing, chewing  
Runny nose in absence of cold, allergies  
Sinus infections  
Sore spot on the top of your head  
Temperomandibular Joint Syndrome (TMJ)  
Unexplained toothaches  
Xerostoma (dry mouth)

### **MUSCULOSKELETAL**

Arthritic pain that migrates from joint to joint  
Carpal tunnel syndrome

Frozen shoulder  
Intermittent joint swelling  
Joint aches (arthralgia)  
Joint pain, without redness or swelling  
Loss of tone  
"Lumpy, bumpy" long muscles  
Morning stiffness  
Muscle aches (myalgia)  
Muscle pain, stiffness, weakness  
Piriform muscle syndrome  
Reduced range of motion  
Stiff neck  
Writing causes pain in hand, arm shoulder

### **PAIN SYMPTOMS**

Abdominal pain  
Chest pain  
Generalized pain  
Shooting or stabbing pains  
Painful tender points (FMS: 11 out of 18 tender points)

### **PSYCHOLOGICAL SYMPTOMS/MOOD/EMOTIONS**

Abrupt/Unpredictable mood swings  
Anxiety or fear for no obvious reason  
Appetite increase/decrease  
Decreased self-esteem  
Depression or depressed mood  
Feeling helpless and/or hopeless  
Feeling worthless

Frequent crying for no reason  
Helpless/Hopeless feelings  
Inability to enjoy previously enjoyed activities  
Irritability; over-reaction  
New phobias/irrational fears  
Panic attacks  
Personality changes (labile, irritable, anxious, confused, forgetful)  
Phobias (irrational fears)  
Rage attacks; anger outbursts for little or no reason  
Suicidal thoughts or suicide attempts

### **SENSITIVITIES**

Acute or abnormal reactions to medications  
Alteration in taste, smell, and/or hearing  
Chemicals (alcohol, medications; lower tolerance for)  
Food sensitivities  
Increased perception of and sensitivity to noise  
Light sensitivity  
Sensitivity to odors (able to detect and/or react in concentrations far lower than before and that healthy people cannot smell)

### **SKIN/NAILS**

Abnormal scarring  
Acrodermatitis Chronica Atrophicans  
Blotchy or mottled skin  
Bruise easily  
Bruises may take longer to appear, and/or longer to fade  
Bull's-eye (Erythema migrans) on light skin (resembles a bruise on dark skin)  
Dermographia (minor scratch pressure on skin leaves vivid red welts)  
Dry, itchy skin

Easily scar  
Eczema or psoriasis  
Fragile nails  
Frequent skin irritations  
Lymphadenosis benigna cutis  
Nails that curve under or downward  
Overgrowing connective tissue (ingrown hair, adhesions, thickened/split cuticles, cysts, fibroids)  
Painful skin (abnormal/excessive pain when scratched or rubbed)  
"Paper" skin (feels fragile, tissue-thin when rubbed)  
Rashes on body, face  
Vertical ridges or beads in nails

### **SLEEP SYMPTOMS**

Abnormal brain activity in stage 4 sleep  
Altered sleep/wake patterns (alert/energetic late at night, sleepy during day)  
Difficulty falling asleep  
Difficulty staying asleep (frequent and/or prolonged awakenings)  
Hypersomnia (excessive sleeping)  
Myclonus (restless leg syndrome; occasional jerking of entire body)  
Nightmares (frequent, extremely vivid and/or disturbing)  
Unrefreshing/Non-restorative sleep UROGENITAL/REPRODUCTIVE  
Decreased libido  
Discharge from breast or galactorrhea  
Endometriosis  
Frequent urination  
Incontinence  
Impotence  
Infant: premature; low birth weight; low muscle tone; failure to thrive  
Interstitial cystitis  
Miscarriage or stillbirth

Painful intercourse  
Painful urination or bladder  
Pelvic and/or rectal pain  
Prostate pain  
Swollen testicles  
Other symptoms worsen before start of menstruation  
Worsening of PMS

## **OTHER**

Abnormal or other changes in sweating  
Activity level reduced to less than 50% of pre-onset level  
Burning sensation (internal and/or external)  
Cancer  
Changed voice  
Changes in sweat odor/body odor  
Delayed reaction to overactivity/exertion (onset 24-48 hours after exertion)  
Electromagnetic (EM) sensitivity (electrical storms, full moon, affect function of electrical devices)  
Fatigue, prolonged, disabling, made worse by exertion or stress  
Fibrocystic breasts  
"Gallop" cholesterol and triglycerides  
Hair loss (not related to age, hormones, diet, medication)  
Hands hurt excessively when put in cold water  
Handwriting changes, altering signature and/or other writing  
Hoarseness  
Painful, weak grasp that gives way/lets go  
Periods of concentrated thinking causes physical and mental exhaustion, increases pain  
Sore throat  
Swelling/Idiopathic edema (fluid retention syndrome)  
Symptoms worsened by extremes of temperature (hot, cold), stress, and/or air travel  
Symptoms change focus from time to time, like infection is moving through the body

Thickened mucus secretions (nose, bowel, vaginal)

Thickened "sleep" around eyes in mornings

Very attractive to biting flies and mosquitoes

Weight changes (usually gain)

### **COMMON CO-INFECTIONS AND DISORDERS**

Babesiosis

Cytomegalovirus (CMV)

Epstein-Barr virus (EBV)

Ehrlichiosis

Herpesvirus

HHV6

Iron deficiency

Mercury or other metal toxicity

Mycoplasma

Systemic mold and/or mold sensitivities

## Sources

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Centers for Disease Control & Prevention:  
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Lyme [www.cdc.gov/ncidod/dvbid/lyme](http://www.cdc.gov/ncidod/dvbid/lyme)

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