

### Lupus and Co-existing Fibromyalgia

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#### Why talk about it?

- In my practice as a life skills/health coach and holistic nutrition professional, about 80% of my lupus clients have co-existing fibromyalgia.
- Since the OFA the Ontario Fibromyalgia
   Association closed a couple of decades ago,
   many people have not had ready access to
   accurate, current information on fibromyalgia.
- Increased symptoms, including pain and fatigue, new diagnosis.

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#### **Abbreviations**

- · FM: fibromyalgia
- CMP: chronic myofascial pain
- · CNS: central nervous system
- TrP: trigger point (tender point)
- ME: myalgic encephalomyelitis also known as
- CFS: chronic fatigue syndrome
- · Dx: diagnosis
- · Rx: prescription

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### What is FM?

- Central sensitization condition where the CNS is hypersensitized.
- "Patients with FM have enhanced sensitivity to a number of stimuli; not just pressure and pain." (Geisser ME, Glass JM, Rajcevska LD et al. 2008)
- Often called "irritable everything"
- CNS dysfunction causing systemic not local symptoms, a pain amplifier.

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#### What is FM?

 When the central nervous system is sensitized, hormones and other informational substances lose their balanced states. In the brain and spinal cord there are neurons. Those nerve cells have been studied longest and received the most attention, and many medications available act on them. There are also glial cells. Once considered only scaffolding for neurons, we now know those glial cells are what affect the spinal neuron sensitivity. (Wieseler-Frank J, Maier SF, Watkins LR. 2005.)

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#### What is FM?

 Central sensitization results when the glial cells become irritated. When the CNS is hypersensitized, any pain sensation is amplified (hypersensitivity), and normally non-painful sensations such as touch, sound, light, and even smell can be translated by the CNS as pain (allodynia). Too much stimulation creates what I call "sensory overload." The CNS is "pre-occupied" with processing stimuli and can't handle anything else. (Starlanyl DJ, 2014.)

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### **Symptoms**

- · Pain.
- · Overwhelming Fatigue.
- · Cognitive deficits such as memory, word finding, way finding, "fog", inability to concentrate or to recognize familiar objects.
- Non restorative sleep.
- New or increased anxiety and/or depression since FM symptoms started.

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#### What causes FM?

- · Sometimes unknown.
- · Infections.
- · Trauma either physical or emotional.
- Sustained grief.
- · Toxic exposure.
- Genetics.
- Stress if left untreated and unresolved.

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### What does FM mean for me?

- Severity of symptoms is individual ⇒ so treatment plans must be individual.
- · Compliance with treatment plans.
- Critical to decide to have a positive attitude. Symptoms are not optional, suffering is.
- Accept your reality, limitations, responsibility for what you can do to help yourself.

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#### Your Treatment Team

- · Family doctor, rheumatologist, neurologist, nurse practitioner, pharmacist.
- Kinesiologist, physiotherapist, osteopath, fitness coach, massage therapist.
- · Occupational therapist.
- Naturopath, homeopath, holistic nutrition professional.
- Energy therapists, reiki, therapeutic touch, qi gong, acupuncture, reflexology, tai chi, etc.

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#### Your Treatment Team

- The bare minimum treatment team I suggest is family doctor, rheumatologist specializing in lupus and in FM, registered holistic nutritionist or dietician, physiotherapist or kinesiologist.
- Helpful to have: naturopath, acupuncturist, massage therapist, osteopath, chiropodist, nurse, laser therapist, occupational therapist, chronic pain specialist.

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#### **Your Support Team**

- The bare minimum support team I suggest is lupus peer support group, FM peer support group, qualified therapist, true friends, family members who care enough to educate themselves about lupus, spiritual director.
- · Helpful to have: life coach, volunteer drivers, prayer partners, babysitter or eldercare respite.

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## Communicating With Your Teams

- Respect is key to any relationship.
- This applies to conversation, email, fax, texting, facebook, instagram, telephone calls and regular mail.
- This includes telemedicine, online audio/video appointments.
- It also means not gossiping or bashing anyone to a third party.

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## Communicating With Your Team

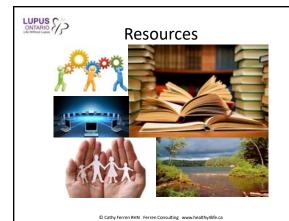
- You might be shocked by how often I hear people with FM being totally rude, aggressive and offensive when communicating with their treatment or support team members.
- It does not help you get what you need and can even get you fired/discharged as a patient.



#### Ask for Help

- You also need to ask for and accept help when you need it. Be grateful and polite.
- · This is part of having respect for yourself and taking care of your self.
- You may need help for physical, psychological or spiritual symptoms or a combination of these.
- · You have choices.

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#### Resources

- Links to FM related organizations https://www.healthy4life.ca/fibromyalgia---mecfs-1.html
- · Links to FM books that I recommend https://www.healthy4life.ca/fibromyalgia.html





# Living Well with SLE & FM

- Sharing, caring, listening, self education and support - with honesty and integrity are within your control.
- Diet and movement/exercise are within your control.
- The choice is yours, suffer or thrive.
- · Live well with Lupus and FM.
- You are worth it!

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