Fibromyalgia Syndrome (FMS) or Chronic Widespread Pain (CWP)

http://www.fenixstopspain.com/fibromyalgia_syndrome.html

"Aching all over and too tired to think"

Fibromyalgia Syndrome (FMS) is a condition where the affected person experiences some-or-all of the following symptoms;

1. **Widespread pain:** (pain all over, 'aching like a dose of the flu'), especially the spine, neck and shoulders. Often the lightest touch feels painful.

2. **Chronic fatigue and sleep problems** (no energy-hard to get out of bed).

3. **Sensory sensitivity:** light ('fluoro' tubes), sound, temperature changes, smells, chemicals, medications.

4. **Pain and other symptoms:** headaches, restless legs, irritable bowel or bladder, jaw pain (TMJ), chest pain or indigestion, sinus problems, swelling, rashes, pins and needles, numbness, ringing in ears or dizziness.

5. **Changes in mood:** anxiety, depression, poor appetite, libido.

6. **'Fibro fog':** difficulties with memory, concentration and thinking.

- **'Fibromyalgia'** literally means 'aching muscles', however there's actually nothing wrong with the muscles. There is no 'disease' or 'damage' of muscles, or any other tissues for that matter.

- Some doctors use the term, *'Chronic Widespread Pain'* (CWP).

- FMS is very common, affecting 3% of the population.

© E.J Visser 2016

Patient information sheet

Generic information only-all due care taken to ensure accuracy of information; not specific clinical direction.

- Females are affected 3 x more often than men.
- FMS can occur at any age, but is more common between 30 and 60 years of age.
- FMS is more common in patients with a family history of widespread pain.
- FMS is more common in patients with anxiety, post traumatic stress disorder (PTSD), panic disorder, obsessive-compulsive disorder (OCD), depression or bipolar (this does not mean it is 'imaginary pain' or 'all in the mind').
- FMS is more common in patients who already have chronic pain, such as whiplash-associated neck pain, irritable bowel syndrome, 'restless legs', TMJ (jaw) pain, rheumatoid arthritis or low back pain.
- About 30% of patients with chronic pain in one part of their body may go on to develop FMS.

FMS is part of a 'spectrum' of similar conditions including *chronic fatigue syndrome (CFS), myalgic encephalitis (ME)* and *chemical sensitivity syndrome*.

In FMS, chronic pain and other symptoms develop as part of the body's response to **stress.** This is called the **'Sickness Response.'**

Exposure to 'stresses' that 'threaten' the body, such as **injuries** (eg. whiplash, broken bones), **illness** (eg. glandular fever virus, cancer, arthritis) or **'life-events'** (eg. depression, anxiety, work or relationships problems) cause changes in the whole-body's nervous, immune and hormone systems, producing a **'sickness response'** (exactly like a dose of the 'flu'), which sometimes doesn't 'switch-off' as expected, but continues over the long-term (especially if the 'stresses' continue).

This **'sickness response'** not only produces chronic pain in various parts of the body (like the aching muscles you feel when you're sick in bed with flu), but many of the other symptoms that go hand-in-hand with pain, like chronic fatigue, poor sleep, lack of energy and motivation, difficulty thinking, poor memory, depression, anxiety, sensitivity to various sensations (cold or bright lights), poor appetite and libido.

© E.J Visser 2016

Generic information only-all due care taken to ensure accuracy of information; not specific clinical direction.

In FMS, the immune system is in 'overdrive', producing chemicals that promote the 'sickness response' (interleukins, substance P). The pain control system becomes super-sensitive (the pain 'volume' is turned up, just like an amplifier). There are changes in hormones (growth hormone, cortisone) and brain chemicals such as serotonin and dopamine which control pain, mood and sleep.

The 'sickness response' is the body's way of 'shutting down' for a few days to help recovery. By staying in bed and sleeping, the body has a chance to build up the energy it needs to overcome the stress it's dealing with, such as a 'flu' virus. This is a good thing if we are fighting an infection and it only lasts a few days.

However, the 'sickness response' can go on for weeks, months or even years if we are 'overloaded' by stresses such as injury, illness or 'worries'. It then becomes a hindrance rather than a help, and we develop FMS.

The 'sickness response' (and FMS) is a kind of *hibernation* (bears deal with the 'stress' of a cold winter by 'going to sleep' in a cave for months).

FMS may be triggered by the following 'stresses';

- **Injuries:** eg. 'whiplash', back injury, surgery, major trauma (eg. MVA).
- **Viruses & infections**: eg. Ross River virus, glandular fever.
- **Illnesses:** eg. rheumatoid arthritis, cancer.
- **Environmental factors:** eg. chemicals, toxins.
- **Psychological & social stressors:** eg. childhood abuse or illness, anxiety, post traumatic stress, military service.

The more **stresses** a person is exposed to over time, the greater the risk of developing FMS.

Example: FMS develops in a 45 year old woman after a motor vehicle accident, with whiplash-associated neck pain and post traumatic stress disorder, followed by a court case and family breakdown.

Investigating FMS

There is no 'gold standard' test for FMS; it's diagnosed on history and examination. There are special criteria (American College of Rheumatology, 2010) for the diagnosis of FMS.

Your doctor will have to rule out other conditions that 'look like' FMS;

© E.J Visser 2016

Generic information only-all due care taken to ensure accuracy of information; not specific clinical direction.

-Endocrine problems (hypothyroidism, hypogonadism, hypocortisolism).
-Iron deficiency or overload (anaemia, haemochromatosis).
-Osteomalacia (vitamin D deficiency).
-Rheumatological/auto-immune disorders (polymyalgia rheumatica).
-Sleep disorders (sleep apnoea, restless legs syndrome).
-Cancer, HIV, hepatitis B or C.
-Psychiatric disorders.
-Opioid induced hyperalgesia (strong morphine-based pain medications can actually produce pain 'all over').

Blood tests and x-rays such as a bone scan may be required.

MANAGEMENT OF FIBROMYALGIA SYNDROME

We talk about 'management' rather than treatment or 'cure'. Unfortunately, there is no magic cure for FMS.

Management is based medications that reduce pain sensitivity (without causing side effects), dealing with stress, anxiety and depression, and steadily building-up physical fitness and activities in a 'paced fashion'.

We need the help of a number of health care professionals to treat the 'whole person' with FMS, including physiotherapists, clinical psychologists and occupational therapists.

The following information is what we suggest to health care professionals.

"Treat the whole person and the 'components' of FMS".

- Pain relief for widespread pain is based on the use of simple analgesics (paracetamol), antidepressants (amitriptyline, duloxetine, venlafaxine), tramadol or gabapentinoids (pregabalin 'Lyrica', or gabapentin), occasionally non steroidal anti inflammatory drugs (eg. ibuprofen, celecoxib). These medications vary in their effectiveness; usually improves sleep and pain in about 1 in 6 patients.

- The use of strong opioids (eg. codeine, oxycodone, morphine or patches) is **not helpful** in FMS and can make widespread pain worse (opioid induced hyperalgesia).

© E.J Visser 2016

Generic information only-all due care taken to ensure accuracy of information; not specific clinical direction.

- Many patients with FMS are sensitive to the side effects of medications ('pharmaco-sensitive'); therefore 'start low and go slow' when first starting medications.

- Gradually building up muscle strength and endurance with the help of a physiotherapist is the most effective way of managing FMS. People with FMS have muscle (and generalised) physical deconditioning because they've done less exercise than usual for quite a while. The difficulty is that people with FMS are chronically fatigued (a 'catch-22' situation), so exercise may be hard to do.

- Helpful activities include walking, hydrotherapy, muscle strengthening, swimming and tasks of daily living.

- 'Pacing' your activities is vitally important (keep an activity diary and use a timer and pedometer to measure progress).

- 'Pacing' means building-up your activities *slowly* (by 10% per week, so as not to overdo it -'start low and go slow').

- You will experience 'good and bad days' (with 'flare-ups' of pain and fatigue); this *will improve* over time so don't be disheartened if this happens.

- Clinical psychology-behavioural pain management is very important.

- A multidisciplinary pain management programme like STEPS or PUMP at Fremantle Hospital is **very helpful** and based on good scientific evidence.

- 'Specific' FMS treatments include;
    - -Managing sleep problems.
    - -Treating mood and anxiety problems.
    - -Myofascial trigger-point therapies (eg. neck and shoulders).
    - -Headache management.
    - -Occupational therapy review (work, home).

Alternative therapies: There are many medical and complementary therapies for FMS, including mineral or vitamin treatments, ketamine or lignocaine drips, muscle therapies, herbal remedies etc. The effectiveness of these treatments may not have been scientifically proven.

© E.J Visser 2016

Generic information only-all due care taken to ensure accuracy of information; not specific clinical direction.

Be careful not to get 'swept up' in all sorts of 'promising' treatments, especially if they are expensive!

PAIN MANAGEMENT PROGRAMMES:

Effective pain programmes (such as STEPS) include;

- Education and information (which promotes self-management and the ability to make informed choices about pain management strategies; promotes an understanding of pain and its mechanisms, thereby taking away some of the 'mystery', fear and threat associated with pain).
- Psychological techniques (stress management, relaxation, 'mindfulness', hypnosis).
- Physical therapy techniques (activity pacing, fitness, spinal core stability).
- 'Brain power training techniques' (mirror box, virtual reality, placebo).
- Lifestyle management (sleep, medication use, workplace and home, relationships).
- Medical treatments (procedures and medications).
- Strategies to deal with pain 'flare-ups' (the bad days).

Modern pain management focuses on helping **you** take control and using your whole-body's resources to deal with your pain.

The treatment approach is to manage your pain so you can improve your ability to function in areas of your life that are important. Although this may not sound easy, with help and support it is possible.

Everyone's pain experience is unique. That is why **you** are the most important person in successfully managing **your** pain.

Realistic expectations:

There's no magic cure for FMS. **Realistic** aims (over several *months*) include;

- Steadily building-up muscle and whole-body fitness in a 'paced fashion'.
- Improving your ability to perform every day activities, work and recreation, with less pain.
- Improving your mental function and mood.

© E.J Visser 2016

Generic information only-all due care taken to ensure accuracy of information; not specific clinical direction.

- Reducing fatigue and improving sleep.

Websites:

Arthritis Australia Fibromyalgia information sheet:
http://www.arthritisaustralia.com.au/images/stories/documents/info_sheets/2011/2011_updates/Condition_specific/Fibromyalgia.pdf

American college of Rheumatology site:
http://www.rheumatology.org./practice/clinical/patients/diseases_and_conditions/fibromyalgia.asp

UK Fibromyalgia:
http://www.ukfibromyalgia.com/

American Fibromyalgia Syndrome Association:
http://www.afsafund.org/

Medical review article: Fibromyalgia: A Clinical Update: June 2010 (Volume XVIII, Issue 4) Author: Claudia Sommer [accessed 20 September 2011]
http://www.iasp-pain.org/AM/Template.cfm?Section=Clinical_Updates&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=5&ContentID=1566

Handout on principles of physical reactivation (Dr E Visser)

Generic information only-all due care taken to ensure accuracy of information;
not specific clinical direction.