

Jordanian Patient Support Group

(Empowerment)

Dr.Yusef Sarhan, FACRM

Kuala Lumpur

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الجمعية الأردنية لتلازمة الألم العضلات الليفيّة



JFEA

Jordanian Fibromyalgia Association

Introduction

- Widespread pain
- Fatigue
- Sleep Disturbance
- Cognitive Difficulty
- Morning Stiffness
- Comorbid Conditions

Fatigue

Irritability

Brain Fog

Restless Legs

Overlapping Syndromes

Muscle & Joint Pain

You Never Feel Good

Anxiety & Depression

Loss of Control

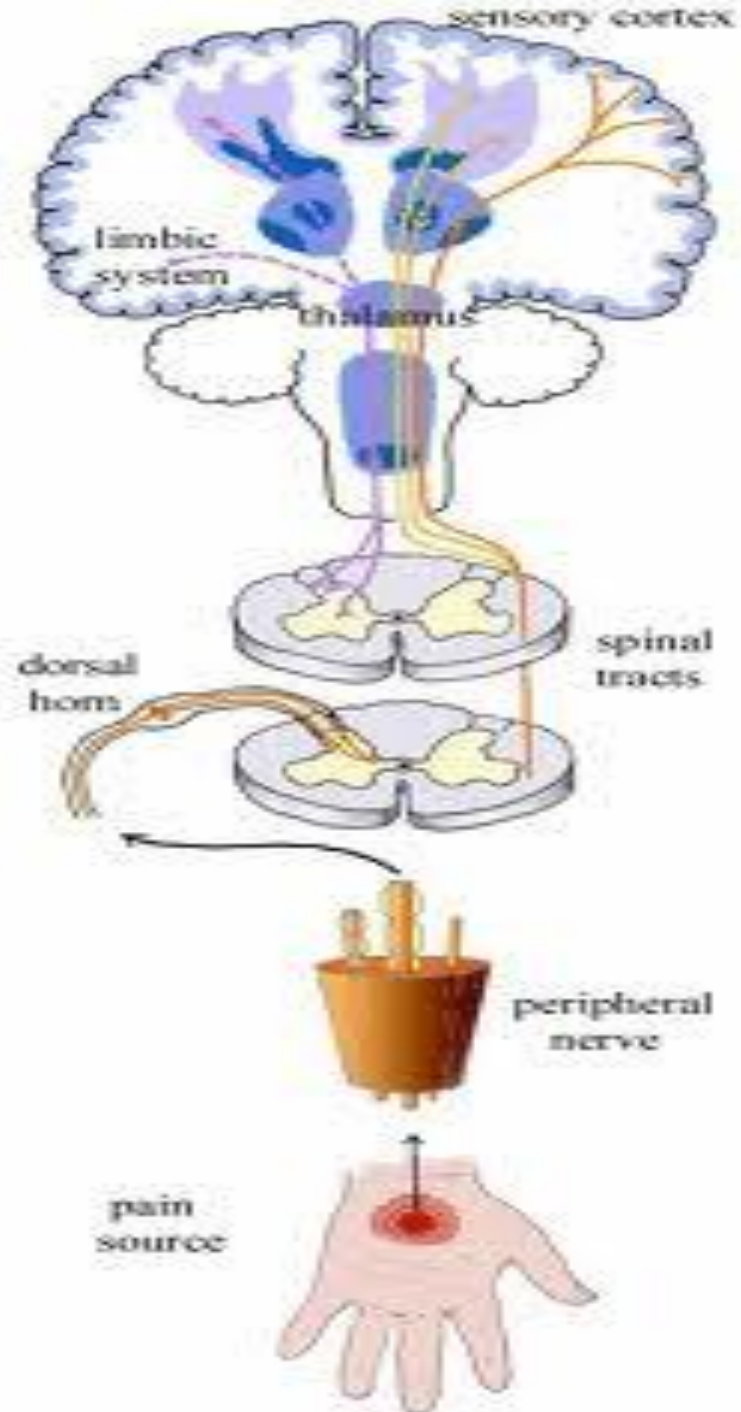
Grief & Worry

Immune Dysfunction

A Lifetime Fight

Introduction

- Affects 2 % _ 5 % of the adult population.
(May reach 5 % _ 12 %)
- Females account for 80 % _ 90 % of cases.
- Under diagnosed
(3 out of 4 in 2009 report)
- Delayed diagnosis
 - _ time average 2.3 year (was 5)
 - _ Number of physician average 3.7 (was 15)



Importance of Improved recognition and diagnoses

- No negative effect on clinical outcomes.
- Improved satisfactions of health and health providers.
- Fewer long term symptoms.
- Decrease in utilization of medical resources and associated costs.
- Starting treatment earlier even as a trial if the diagnosis is only suspected.



foggy thinking

bad memory

**anxious
blue, moody**

**can't figure
things out**

Brain Fog

OUT OF
ORDER!



2.Diagnosis

- a) The ACR Criteria (1990).
- b) The ACR Revised Criteria (2010).

A. The ACR Criteria

1. Widespread pain
2. Duration of 3 months or longer
3. Tender points of at least 11 of 18 pre designated sites.

* Specificity of 81.1 %.

* Sensitivity of 88.4 %.



B. The ACR Revised Criteria

1. Widespread pain index (WPI) ≥ 7 and Symptoms severity (SS) scale score ≥ 5 or WPI = 3-6 and SS > 9 .
2. Symptoms have been present at similar level for at least 3 months.
3. The patient does not have a disorder that would otherwise explain the pain.

Treatment (Evidence _ Based)

A. Pharmacological Therapies

B. Non – pharmacological Management.

B- Non pharmacologic Management

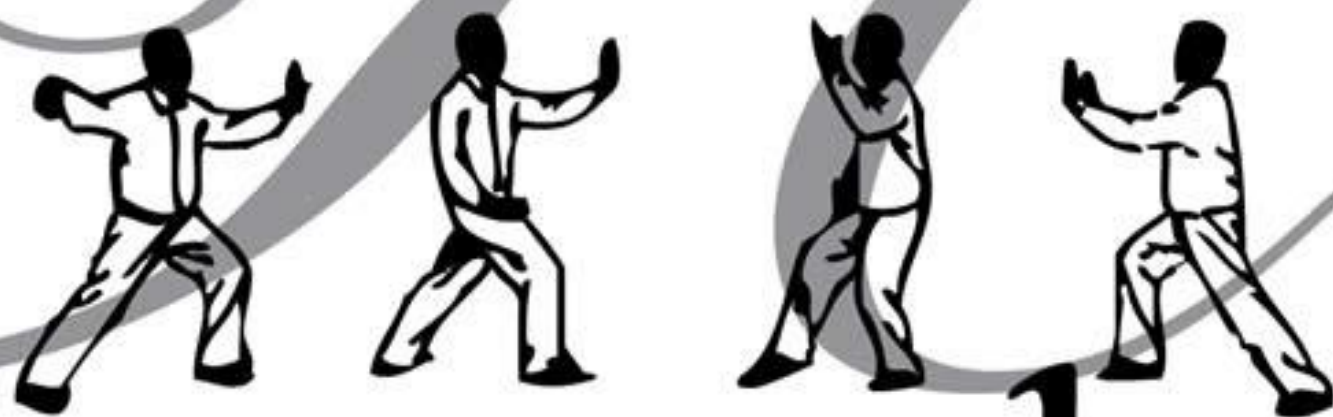
- Strong Evidence

1. Exercises (hydrotherapy and aerobics).
2. Cognitive – behavioral therapy.
3. Patient education / Self management.
4. Combination (multidisciplinary therapy)
(Bio psychosocial).



balance your life





tai chi

Moving for Better Balance







3. Patient education / Self management

- Knowledge
- Activity management
- Stress management
- Exercise

Promoting Self – efficacy

- Efficacy expectation
- Efficacy outcome
- Ways to achieve
 - Mastery
 - Symptom reduction
 - Modeling
 - Verbal persuasion

MIGRAINS

FIBROMYALGIA

PAIN

★ *ANXIETY*

CONFUSION

**LACK OF SUPPORT FROM
FAMILY OR FRIENDS, LOSS
OF RELATIONSHIPS DUE TO
LACK OF KNOWLEDGE AND
UNDERSTANDING.**

*LOSS OF
IDENTITY*

ALONE

**SARCASTIC AND HURTFUL
WORDS FROM THOSE WE
TRUST OR COMPLETE
STANGERS.**

PANIC

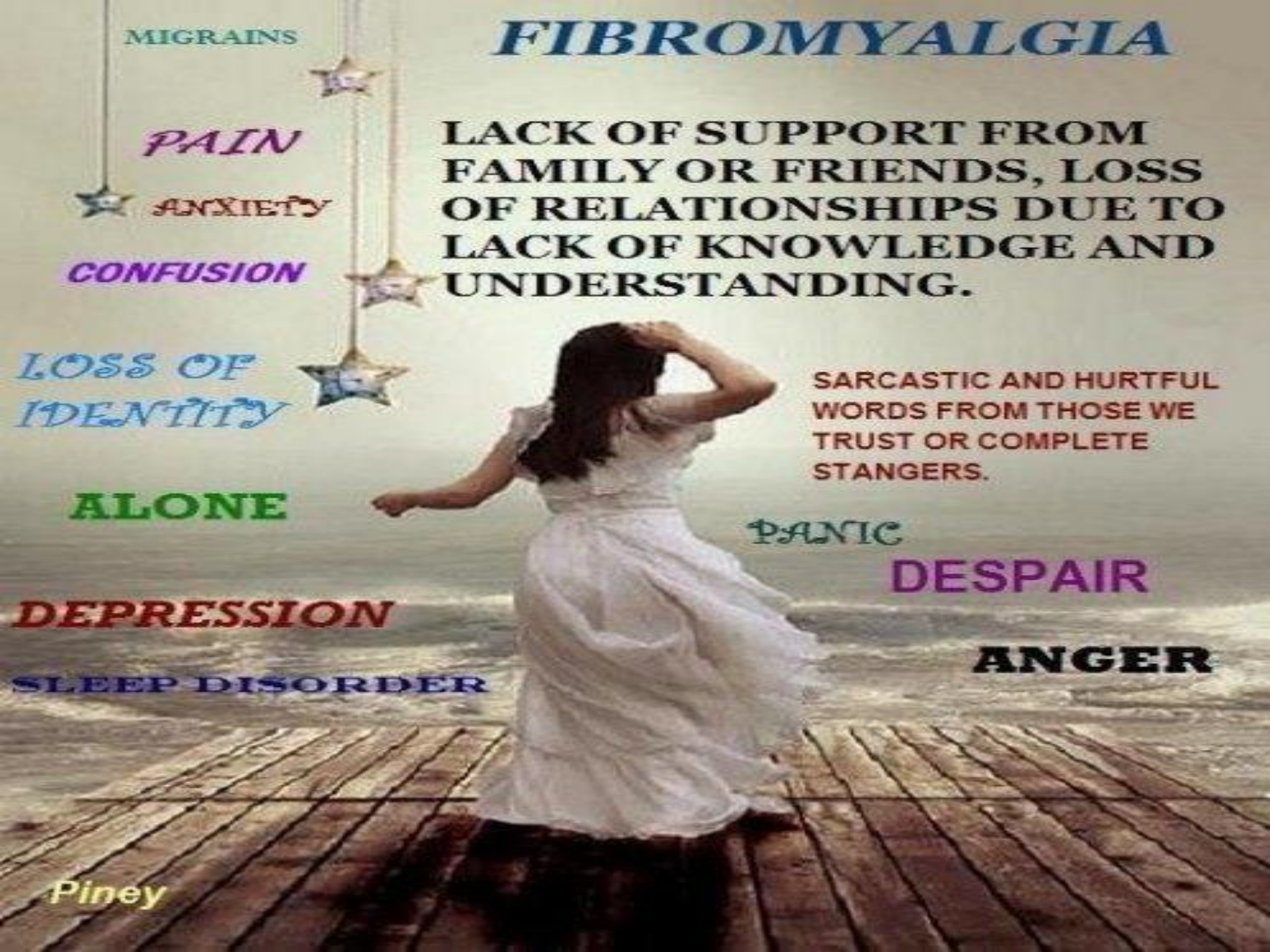
DESPAIR

DEPRESSION

ANGER

SLEEP DISORDER

Piney





Fibromyalgia
hurts all the time.

But your indifference
hurts more.



Affective Self - Awareness

- Central messages :
 - Experience of pain in FM is real.
 - Pain is processed in the central Nervous system.
 - Unresolved emotional experiences can initiate and increase physical symptoms.
 - Mind – body link can be used to empower individuals with FM to more effectively diminish pain and associated symptoms.

Comprehensive non-pharmacological pain management (ExPRESS)

Ex = Exercise

P = Psychiatric Comorbidity

R = Regaining Function

E = Education

S = Sleep hygiene

S = Stress management

The Need

The Start

- One member support group



Early on

- Two-Member Support Group



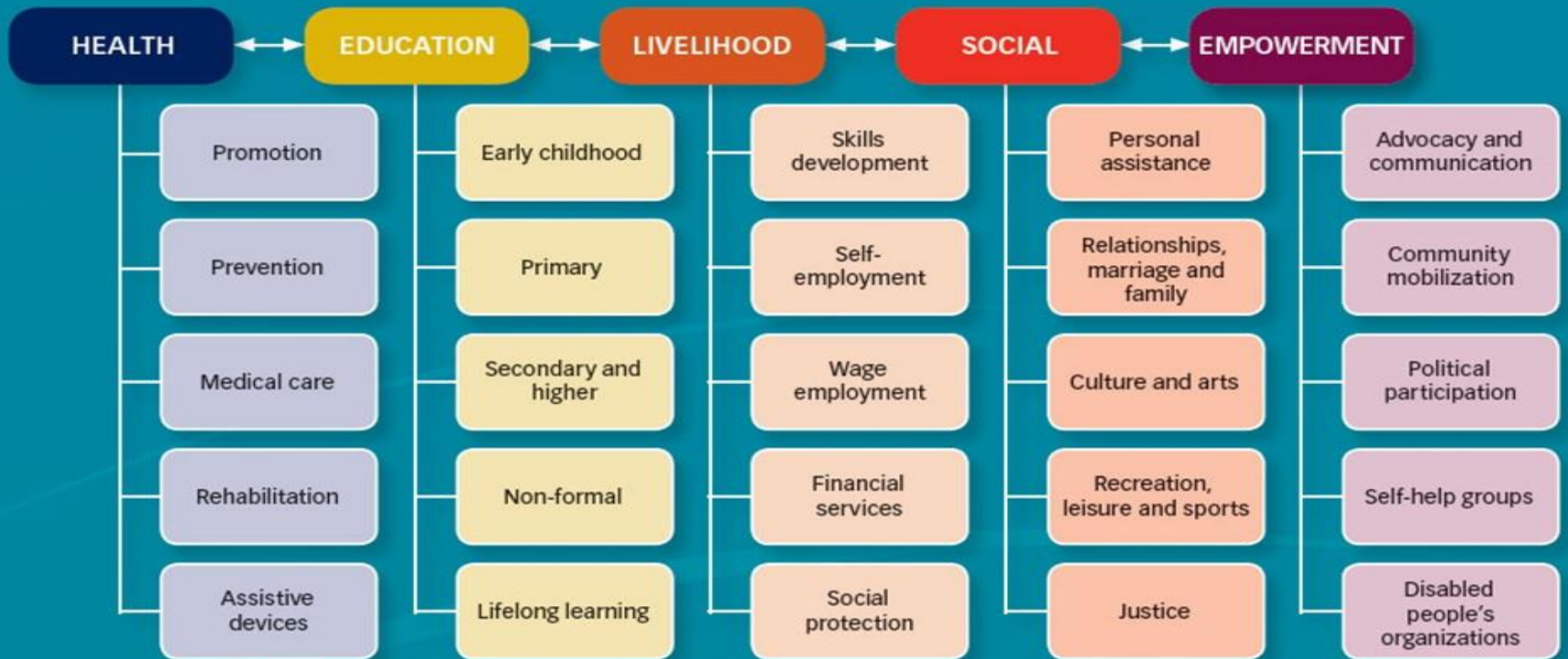
Growing Interest



Benefits of Support Group

- Hope
- Social Support
- Empowerment
- Knowledge and Education

CBR MATRIX



Preparation

1. Are we ready?

- Time
- Money
- Knowledge

2. Ask for Help

- Other Support Groups
- Experienced Personnel

3. Train ourselves

4. Official Measures

Officially Registered 2010

- Rules & Regulation
- Administrative Board
- Honorary Chairman
- Place
- Resources

Actions

- Flyers
- Contact Person
- Finding Members
 - Direct Contact
 - Professionals
 - Media
- Fees for Membership
- Donations



برعاية



Kholoud Al-Khalili :079-6550223
Hiba Murad : 077-7731159



fibroasso.jo@gmail.com



Jordanian Fibromyalgia Association



Jordanian fibromyalgia supporting group



@JFASG



FIBROMYALGIA FREEDOM FROM PAIN

Dr. Yusef Sakhari
Mrs. Randa Abdelrahman
Dr. Sameh Abu Alkhair
Mrs. Khouloud Al Khairi
Designed by Hani' Abdelrahman

Imagine... You wake up in the morning feeling all beaten up like you didn't sleep at all, though you've slept early, your muscles are all stiff, you're in pain, what might come to your head in that moment? Well, you don't have to imagine that just ask someone with Fibromyalgia. People with Fibromyalgia lives through that in a daily basis, all what they need is support and understanding, because life is just too hard with pain. So take the first step and know about Fibromyalgia and read all along.



So, what is Fibromyalgia?

Fibromyalgia (pronounced: fib-ro-my-AL-ja) is a complex chronic pain disorder that affects people physically, mentally and socially. The pain is biological, psychological, and social. It affects all parameters, including even a spiritual or religious component. We call it biopsychosocial. We cannot separate these three because the brain will not separate those. The disorder affects an estimated 30 million people in the U.S. and an estimated 1-6% of the world population. While it is most prevalent in women, it also occurs in men and children of all ethnic groups. The diagnosis is usually made between the ages of 20 to 50 years, but the incidence rises with age so that by age 80, approximately 8% of adults meet the American College of Rheumatology classification of fibromyalgia.

What are the Symptoms?

- Pain: The pain of fibromyalgia is profound, chronic and widespread. FM pain has been described as stabbing and shooting pain and deep muscular aching, throbbing, and twitching.
- Fatigue: Fatigue of FM is an all-encompassing exhaustion that can interfere with occupational, personal, social or educational activities.
- Sleep problems: During sleep, individuals with FM are constantly interrupted by bursts of awake-like brain activity, limiting the amount of time they spend in deep sleep.
- Other symptoms: overlapping conditions, irritable bowel and bladder, headaches and migraines, restless legs syndrome, impaired memory and concentration, skin sensitivities and rashes, dry eyes, and mouth, anxiety, depression, ringing in the ears, dizziness, vision problems, neurological symptoms, and impaired coordination.

How it is Diagnosed?

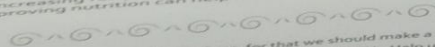
The FM diagnostic criteria, established by the American College of Rheumatology (ACR) in 1990, includes a history of widespread pain in all four quadrants of the body for a minimum duration of three months, and pain in at least 11 of the 38 designated tender points when a specified amount of pressure is applied. Since people with FM tend to look healthy and conventional tests are typically normal, a physician knowledgeable about the disorder is necessary to make a diagnosis. Remember, some doctors don't believe in it. Physicians should rule out other causes of the symptoms before making a diagnosis of fibromyalgia.

What are the Causes?

Recent research has suggested a genetic component. The disorder is often seen in families, among siblings or mothers and their children. Fibromyalgia often occurs following a physical trauma, such as an acute illness or injury, which may act as a trigger in the development of the disorder.

And the Treatments are?

A variety of prescription medications are often used to reduce pain levels and improve sleep. On June 24, 2007, the U.S. Food and Drug Administration approved Lyrica (pregabalin), the first drug to treat fibromyalgia. Cymbalta (duloxetine HCl) was approved in June 2006, and Savella (milnacipran HCl) was approved in January 2009. Physical therapy and Occupational therapy (Eduloxetine HCl) approved in January 2009. Alternative therapies such as massage, myofascial release, acupuncture, herbal supplements and yoga, can be effective tools in managing FM symptoms. Increasing rest, pacing activities, reducing stress, practicing relaxation and improving nutrition can help minimize symptoms and improve quality of life.



People with Fibromyalgia no longer have to be alone, for that we should make a support group to help them and cope with this syndrome, let's start by believing that it is REAL. Help us raise the aware about it, join us to make Jordanian Society for Fibromyalgia and become the first in Jordan and Middle East. If you want to help, please take a look at our brochure. Thank you for your time.



Group Meetings

- Small Numbers
- Encourage exchange of ideas
- Future Plans

First Event

- Welcoming Speech
- Lecture
- Social Activities



FIBROMYALGIA

(Invisible but Present)

Dr. Yusef Sarhan

For
Jordanian Fibromyalgia Supporting Group

Regular Meetings

- Self-Help Group Discussion
- Scientific events



Yearly Events

- In May each Year



- Periodic Evaluations
- Building confidence
- Shared Leadership

Along the Road

- Frustration



Rewards and Joys Success Stories



Family Feelings



The Great Event

- May 2014



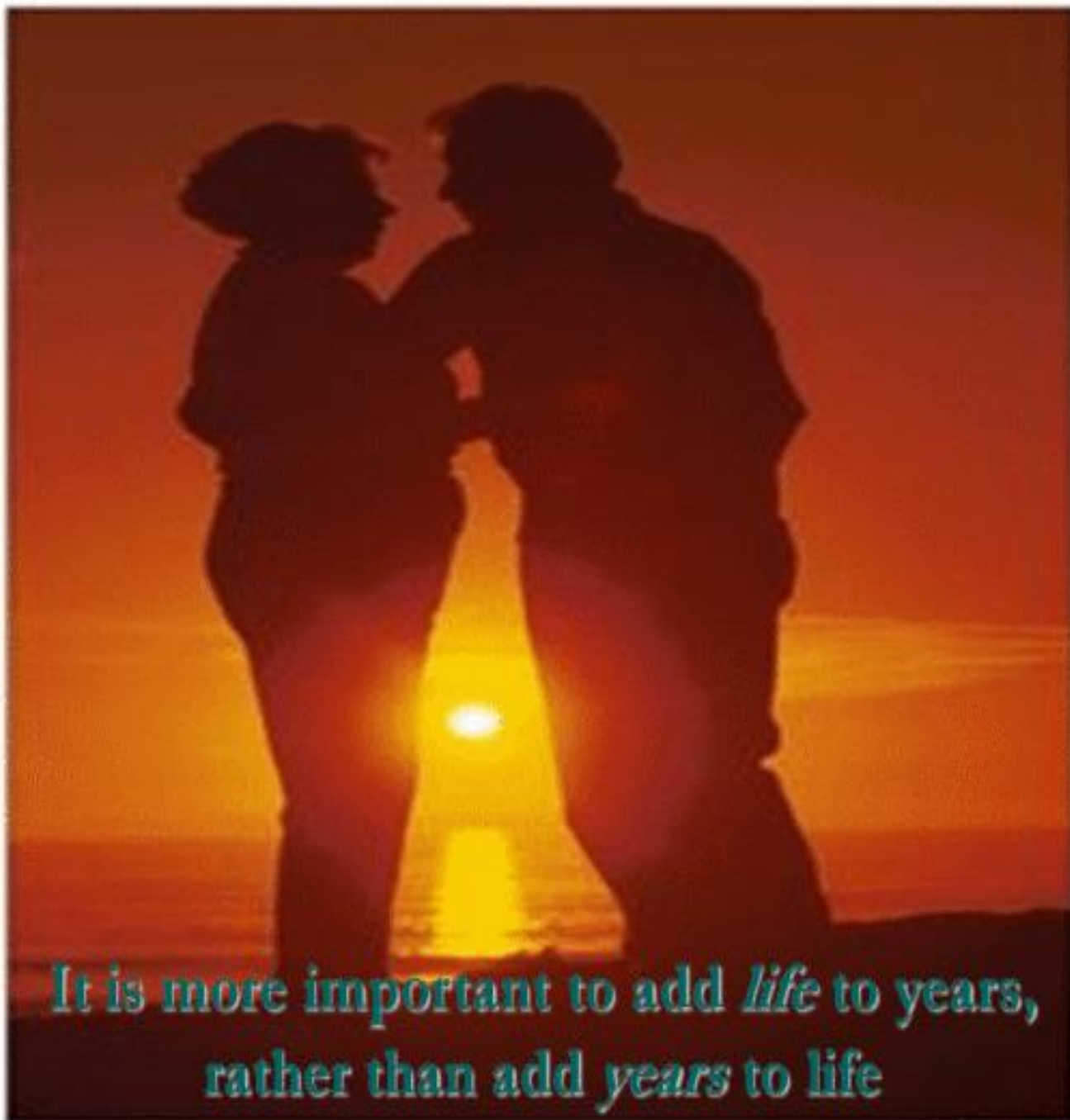


Contribution

- Arab Fibromyalgia Group
- Moroccan Fibromyalgia Support Group
- International Fibromyalgia Association

Future Plan

- Group Promotion
- A Patron



It is more important to add *life* to years,
rather than add *years* to life