

SUMMARY REPORT

ENFA

European Network of Fibromyalgia Associations

European Network of Fibromyalgia Associations (ENFA) Annual Conference and General Assembly 2019

Saturday 18 May 2019

Heraklion, Crete, Greece

A holistic approach to the management of fibromyalgia across the life course

The European Network of Fibromyalgia Associations (ENFA) Conference 2019, with support from The Arthritis Foundation of Crete, took place on Saturday 18 May 2019 in Heraklion, Crete, Greece. Titled 'A holistic approach to the management of fibromyalgia across the life course', the conference enabled delegates from across Europe to discuss strategies for individualising the management of fibromyalgia by focusing on the physical, psychological and social wellbeing of people living with fibromyalgia.

Recent activities of ENFA

Souzi Makri, President of ENFA, delivered an overview of activities carried out by ENFA since 2018. At the time of the meeting, ENFA had 18 member organisations. Souzi highlighted current challenges in obtaining funding within the area of fibromyalgia, given a lack of targeted treatments approved for fibromyalgia management within Europe. Souzi then went on to mention the 11th revision of the ICD (ICD-11), where fibromyalgia is classified under MG30.01 Chronic widespread pain. At this moment in time, it is difficult to predict the practical implications of this change.

The clinician's perspective

Consultant Rheumatologist, **Nikolaos Kougkas**, admitted that people with fibromyalgia often have complex health problems and there are few effective treatments to offer with sufficient evidence behind them. Importantly, he felt that people with fibromyalgia require a lot of patience and time to navigate from symptom-onset to appropriate management of their disease, which is often scarce in the doctor's office.

He felt that after a prompt diagnosis, a structured programme of patient education should be offered at the earliest opportunity. Any treatment plan should be individualised according to the needs of the patient, with decision-making shared between the patient, their carer if appropriate, and healthcare professionals.

Any treatment plan should be preceded by a comprehensive assessment followed by a multidisciplinary approach offering both non-pharmacological and pharmacological treatment. Nikolaos emphasised that in order to find the optimal pharmacological treatment, one may have to try different combinations. The first choice should always be the non-pharmacological options, including exercise where possible, following the updated **European League Against Rheumatism (EULAR) recommendations for the management of fibromyalgia**. A clear concluding message was that input from multiple healthcare professionals across a range of disciplines, in a timely and co-ordinated manner, is needed.

Social media engagement

On Facebook, Instagram and Twitter, using the hashtag **#ENFA2019**.

Psychosocial factors in fibromyalgia

Health Psychologist, **Georgia Dimitraki** facilitated a workshop looking at the role of psychosocial factors in fibromyalgia. Georgia began by presenting the most important techniques for pain management-based cognitive behavioural therapy (CBT). Georgia explained the vicious cycle of pain which affects people's work, relationships, social activities and self-esteem. This can result in avoiding activities, the person withdrawing and becoming less active, which leads to a decline in physical functioning. Pacing and cognitive restructuring were outlined as two steps in helping people to break the cycle.



Georgia Dimitraki facilitating a workshop exploring psychosocial factors in fibromyalgia.

Pacing is the skill that enables you to be more active without feeling pain. Time-based pacing is a process where activity breaks are based on time intervals, rather than how much of a task you have completed. The goal of CBT was introduced, as a way of modifying maladaptive automatic thoughts and behaviours with the aim of improving levels of pain. This is also known as cognitive restructuring. It works by identifying automatic thoughts and consequences such as negative, automatic thoughts about pain.

Georgia concluded with some relaxation techniques to help people gain control over many bodily functions. Three relaxation techniques were demonstrated: Diaphragmatic breathing, progressive muscle relaxation, and visual imagery. **An example of a progressive muscle relaxation training can be accessed here.**

Self-management and fibromyalgia

Souzi Makri shared highlights from a self-management programme organised in Cyprus, which consists of five weekly meetings, each lasting 2.5 hours. Delivered by patient trainers, psychologists and trained staff, the programme aims to educate and inform people living with fibromyalgia and other RMDs about techniques and tools to help them to manage their pain more effectively. Through the sharing of experiences alongside structured content, the programme helps to build confidence, positive thinking and better communication. One of the main benefits of the programme is the group dynamic which evolves through meeting people going through similar experiences.

The emotional aspect of chronic pain

Lizy Zommer from Roots for Generations in Israel went on to describe her personal experience of fibromyalgia. Lizy discussed the value of emotional intelligence, which includes self-awareness, the ability to manage emotions, internal personal motivation, empathy and an ability to deal with relationships. She went on to explain how people define emotions in different ways, but how emotions control our thinking, behaviour and actions – including the intensity of pain felt by people.

The importance of water exercise

Andreas Iacovou, an experienced physical education trainer from Cyprus, explained the benefits of warm water exercise and stretching. Andreas told delegates how the density of water makes it easier to do exercises, without adding unnecessarily loads onto joints. The warmth also helps to dilate blood vessels and reduce pain, by reducing the sensitivity of sensory nerve endings. He said that the goal of exercise should be to improve general physical conditioning, leading to better activities of daily living. Since water exercise increases flexibility, endurance and strength, it is suitable. The optimal training frequency is around three times per week at a low-to-intermediate intensity.

During the last part of his talk, Andreas emphasised how stretching is vital for maintaining flexibility. He reminded delegates that most people will stretch to some extent at the start of each day. He stated that there are essentially two types of muscle stretching - static and dynamic, which are used for different purposes. Static stretching means a stretch is held in a challenging but comfortable position for a short period of time. Dynamic stretching means a stretch is performed by moving through a challenging but comfortable range of motion repeatedly.

Andreas focused on static muscle stretching, recommending three sets holding at 30 seconds, several times a day, using a maximum range of motion at a very slow and steady speed to have the desired effect. Such stretching can be done practically anywhere - whether in the office, stood in the kitchen, or in bed. Learning to embed such stretching exercises as part of your daily routine could be beneficial.

ENFA General Assembly

The ENFA General Assembly took place shortly after the formal conference session on Saturday 18 May 2019. Twelve European countries were represented at the General Assembly, including: Belgium, Cyprus, Denmark, Greece, Israel, Italy, Norway, Portugal, Serbia, Slovenia, Sweden and the United Kingdom. During the General Assembly, **Souzi Makri** stepped down as President, and a Board Member. Souzi was thanked for her outstanding contributions to ENFA, and the wider fibromyalgia community.



ENFA Members at the General Assembly held on Saturday 18 May 2019 in Heraklion, Greece.

Mateja Kržan also stepped down as Vice President, but wished to remain a Board Member. Prior to the General Assembly, Joana Vicente stepped down from the Board due to existing commitments. Joana was thanked for her contributions over the past year.

ENFA members unanimously agreed to elect **Simon Stones** as President, **Gunilla Göran** as Vice President, and **Ricardo Fonseca** as Treasurer.

Three new members were also elected:

- **Eva Deurloo** (Sweden), elected Secretary representing Fibromalgiförbundet
- **Judi Olsen** (Denmark) representing Dansk Fibromyalgi-Forening
- **Egidio Riva** (Italy) representing Associazione Italiana Sindrome Fibromialgica



The newly elected ENFA Board.

From left to right: Gunilla Göran (Vice President), Simon Stones (President), Mateja Kržan, Egidio Riva, Judi Olsen, Ricardo Fonseca (Treasurer) and Eva Deurloo (Secretary).

Activities for the 2019/2020 year were discussed at length among all members, and will include:

- ▶ Formulating a refreshed, and ambitious strategy.
- ▶ Exploring the needs and expectations of member organisations.
- ▶ Enhancing communication, learning and collaboration among member organisations and external partners.
- ▶ Increasing ENFA's visibility through the website, social media platforms and participation in external events.

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