



# South & South East Essex Fibromyalgia Support Group

Working With the Fibromyalgia Association UK (registered charity 1042682), We offer support and information, via our website and by holding regular meetings for those effected by Fibromyalgia in the South & South East of Essex

For Further information on the Group visit our Website [www.fibrofox.co.uk](http://www.fibrofox.co.uk)

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## SO YOU'VE GOT FIBROMYALGIA – WHAT NOW !

So you have just found out that you have Fibromyalgia (FM) and realized that there is 'no infinitive cure' so what now.

Are you feeling that your GP/Consultant has just left you to get with it, do you need support and advice ? You probably have so many questions and are feeling confused and neglected.

This guide is set out to try and help you understand how to live with this condition.

### 12 'Self Help' initiatives for the newly diagnosed.

#### **FMA UK Information Pack**

Fibromyalgia Association UK will send a free information pack upon receipt of a SAE. You may have already received the contents of that pack from us, or seen it online. The main content of the pack is the pale blue 12 page AS "**information Booklet for people with Fibromyalgia**". If you have not already received a copy of this then send a CS envelope, addressed to yourself and with a standard 'large letter' stamp on it to **FMA UK (Info Pack), PO Box 206, Stourbridge, DY9 E1YL.**

#### **Local Support Group**

Meeting together not only adds an element of social interaction but encourages you to get out of the house, become less isolated, more proactive, and positive. A support group can be a wonderful place to make new and understanding friends as well as providing a facility that allows you to voice your fears and frustrations in a confidential, safe and non judgmental environment.

Our group covers the area across South and south East Essex please contact us, and consider becoming a member also.

#### **Fibromyalgia support websites**

Our own website at [www.fibrofox.co.uk](http://www.fibrofox.co.uk) has lots of information about fibromyalgia, FM Support, local activities and more. We also try to include major news and updates from other key fibromyalgia websites on our site where copyright allows.

We try to give you all the information you require, as well as taking a light hearted look at things to help keep your spirits up.

We also link to the major National Support Sites

### **Family and friends**

They probably don't understand what is going on with you/your body (any more than you do). Talk to them and try to explain that you are still the same person you have always been. Encourage them to come to meetings with you, read the leaflets etc., and read the website information. There is a section on our website specifically for carers, family and friends.

### **FaMily magazine**

Published monthly, FaMily Magazine features the latest news from the world of research, proactive tips for pain management, complementary solutions, articles from leading authors and specialists from the UK and the world, practical treatment advice, local support group news, personal stories, parliamentary updates and more. An annual subscription is normally £21.50, but for members is just £18 through the support group. Contact us for more details.

**Educate yourself** –It is good to read all that you can about fibromyalgia, but scare yourself with too much information.

There are many books available about fibromyalgia. Some are very technical/medical, some very American, many rather expensive? Also many books available from local libraries.

Recommend Books are :

- Craggs-Hinton. C. **Living With Fibromyalgia** 0859698313
- Chaitovv, L. **Fibromyalgia and muscle pain** 0007115024
- Pellegrino, M. **Fibromyalgia Up Close and Personal** 1890018503
- Teitelbaum, J. **From fatigued to fantastic** 1583330975

### **Expert Patient Programme**

This is a 6 week course for 2 hours per week for anyone dealing with a chronic condition. We are hoping to be kept informed of when and where they are running in the South Essex area, but you **should** be able to find out more from your Practice Nurse or **Primary Care Trust**.

### **Exercise**

As hard as it may be at times, it is really important to get at least gentle exercise. There is a section on our website and we will be shortly producing leaflets as well.

### **Try not to stress about financial issues.**

You may be **entitled to benefits** whilst you continue to work, retrain, or if you have to relinquish your job. It's a complex - often changing - area but please feel **free** to contact us for more info. Alternatively contact your local CAB or DIAL office, the DWP's Benefit Enquiry Line (0800 882 200) or FMAUK's benefit helpline (0845 345 2343, Monday & Fridays 10am-12noon).

### **Establish a daily routine and learn to relax**

Do what your body feels comfortable doing but **try** to remember the **golden rule of not doing any activity for more than 20 minutes**. Try to incorporate time for relaxation in to your day, especially in the evening. Each day try to do something that you are interested in and enjoy, and remember that too much OR too little activity can make you worse.

### **Work with your medical professionals**

Every person reacts differently to the treatments that they are given, and many people with fibromyalgia are sensitive to medications. It is important to work with your healthcare professionals to evaluate the success of treatment. It is a good idea to keep a diary - What sort of day have you had? Have you had to take extra pain relief? Rate your pain on a scale of 0-10 and look for any common factors **or** patterns. Make a list of any questions that you want to ask your doctor or nurse when you see them. Take your diary with you when you go, and have patience: you **may** need to try several times.

### **Appreciate successes**

Try to go to bed each night happy that you have achieved at least one thing during your day. Even taking a short walk with a friend is an achievement. Try not to be too hard on yourself, but set realistic, manageable goals and celebrate the success of achieving them.

Always remember that you can and will have improvement in your fibromyalgia symptoms by implementing your own personalized self-management plan. Continuing to learn all that you can about fibromyalgia will help the light at the end of the tunnel become bigger and brighter.

### **Good luck with putting your self management plan together!**

You're not alone. It is estimated that 296 of the population are like 1k) to develop fibromyalgia, which accounts for **1** in every 5 referrals to rheumatology in Basildon Thurrock and Southend Hospitals. FMSupport is here to help.