



FIBROMYALGIA ASSOCIATION UK

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What to do if your Medical Professional refuses to accept Fibromyalgia as a 'REAL' illness

What are the facts?

Fibromyalgia is accepted by the Department of Health and is included on the NHS Direct Website www.nhsdirect.nhs.uk. The following has been extracted from that site:

Introduction

Fibromyalgia is a complex chronic condition. 80-90% of people affected are women and, whilst frequency increases with age, it can affect people of all ages.

The condition name comes from Latin: 'Fibro' meaning fibrous tissues (ie tendons, ligaments), 'my' meaning muscles, and 'algia' meaning pain. It used to be known as fibrositis, which literally meant inflammation of the muscles and soft tissue. However this was thought to be inaccurate since recent studies have found there is no inflammation or nerve injury so it was renamed fibromyalgia in the 1980s.

Full recovery is uncommon and the likelihood of recurrence is high, but the condition is not necessarily physically debilitating, and may not severely impair quality of life.

Fibromyalgia does not reduce life span.

Symptoms

Pain can vary in severity from day to day and change location, becoming more severe in parts of the body that are used the most (i.e., neck, shoulders, and feet). In some people, it can be so intense that it interferes with the performance of even simple tasks, while in others it may cause only moderate discomfort. Likewise, the fatigue of FM also varies from person to person ranging from a mild, tired feeling to the exhaustion of a flu-like illness.

The most common symptoms are:

- fatigue, severe tiredness and lack of stamina
- headaches and facial pain often as a result of neck, shoulder and jaw muscle stiffness
- disturbed sleep, tiredness upon waking, may feel more awake later in the day
- general pain and stiffness especially trunk, abdomen, around joints, skin and organs throughout the body and specific soreness and tenderness in multiple points eg elbows, shoulders, knees, etc
- itching or burning pain, sometimes accompanied by muscle spasm

- irritable bowels or bladder, increased need and urgency to pass urine, bloated feeling, difficulty swallowing anxiety and depression
- varying poor concentration, memory lapses, feeling of spaciness
- sensation of poor circulation and swollen hands and feet tingling, numbness, prickling or burning sensations in hands and feet (paresthesia)
- restlessness in the legs, particularly at night.

Causes

There are a number of potential theories about what causes fibromyalgia such as change in sleep patterns leading to lack of deep sleep, serotonin deficiency, viral infection, psychological disturbances or trauma, altered pain perception, lack of growth hormone, lack of exercise, and others.

There may be multiple factors involved in the onset of the condition and no one trigger* has been identified. Recent US studies suggest there may be a strong genetic pattern within families.

Diagnosis

There are no specific tests for fibromyalgia and diagnosis can be difficult. Referral to a specialist in connective tissue disorders (rheumatologist) may be advised to rule out arthritis and get more information.

Routine laboratory and x-ray testing may be conducted along with a complete medical history and physical examination to rule out those conditions with fibromyalgia-like symptoms such as Lupus, Underactive thyroid, Multiple sclerosis, Myositis, Rheumatoid arthritis, and Sjogren's syndrome.

Treatment

Treatment is focused on managing fibromyalgia symptoms to the greatest extent possible. Because symptoms vary so much what works for one person may not work for another.

The following medicines may be prescribed to help relieve symptoms:

- Low dose tricyclic antidepressants such as Amitriptyline, Doxepin, or Trazodone to address serotonin deficiency, help control pain, and promote better sleep.
- Selective serotonin re-uptake inhibitors (SSRI's) such as Fluoxetine (eg Prozac), Sertraline, or Paroxetine for people with depression to address serotonin deficiency. SSRIs should not generally be prescribed to under 18s, although Fluoxetine can be prescribed if specialist advice is sought.
- Local anaesthetic injection mixed with corticosteroids for localised pain relief.
- Non-steroidal anti-inflammatory drugs (NSAIDs) such as Aspirin or Ibuprofen for reducing the level of pain.
- Opioid analgesics or in severe cases stronger narcotic analgesics (ie codeine, methadone, morphine)
- Mild tranquillizers like diazepam (eg Valium) to treat anxiety and muscle spasms

Self-help measures include:

- Increasing exercise and improving general fitness, low impact aerobic exercise
- Regular stretching, yoga
- Avoiding nasal decongestants, excess alcohol and caffeine
- Controlling emotions, behaviour and thinking (eg by cognitive behavioural therapy)

A number of complementary therapies may be useful in the management of fibromyalgia including acupuncture, relaxation therapy, postural training, chiropractic and osteopathy.

Government promise

In the NHS publication "Assuring the Quality of Medical Practice: Implementing Supporting doctors protecting patients", published January 2001, John Denham, Minister of State for Health says, '*Patients have a right to expect high quality care and treatment from the NHS, whichever part of the NHS they use and wherever in the country they use it*'. He goes on to say, '*We recognise the need to provide support to NHS staff, to keep their skills up to date in their demanding and pressured jobs*'..... '*The National Services Framework is committed to 'raise national standards of care and reduce unacceptable variations*'.

The full text of this publication can be found at www.nhs.uk/nhsplan.

What to do if your Medical Professional refuses to accept Fibromyalgia as a diagnosis

If your medical professional refuses to believe that fibromyalgia is a 'real*' condition, you can gently point them in the direction of their own NHS Direct website www.nhsdirect.nhs.uk. From this site, click on 'health encyclopaedia', click on 'Alphabetical Index', choose letter 'F', then select Fibromyalgia.

What to do if your Medical Professional still refuses to accept FM as a real illness

The following complaints process can be found at www.nhs.uk/patientsvoice/local_resolution.asp

All NHS trusts, primary care trusts, GPs, dentists, opticians and pharmacists have a complaints procedure.

It is important for you to contact someone in the organisation about the cause of a complaint as soon as possible. This helps them to investigate the complaint properly.

Complaints manager

All NHS trusts and primary care trusts (PCTs) will have a complaints manager who can advise you on your complaint. GPs, dentists, opticians and pharmacies should also have someone who oversees their complaints procedure. If you are not sure who to contact, get in touch with your local PCT.

Advice and support

You can ask the Patient Advice and Liaison Services (PALs) office at the hospital trust or PCT for information and help on using their complaints procedure. You can telephone NHS Direct on 0845 4647 for information on how to complain.

You can expect a full and prompt reply to any complaint made against a trust or PCT, normally within 20 working days. Family health service providers - GPs, dentists, pharmacists or opticians - should reply within 10 working days.

Conclusion

We hope this information will enable you to discuss the problems you are facing, as a result of suffering from fibromyalgia, with your doctor. We appreciate that our medical professionals have very few 'tools' in their possession with which to help us, all we are asking is for a little understanding and support until such time as a 'cure' is found.

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