

# DLAAB

Disability Living Allowance Advisory Board

## NEWS & UPDATE

Feedback from Decision Makers suggests that they experience difficulties with the assessment of claims from applicants whose disability is a consequence of...

- a) Conditions for which there is no apparent clinical causation, and for which there is no confirmatory diagnostic test, e.g. chronic fatigue syndrome.
- b) Conditions that show considerable natural variation in severity, e.g. multiple sclerosis.

The Education sub-group of DLAAB has therefore decided to focus on such conditions in the next few issues of the Update

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## DLAAB NEWS AND UPDATE

Hello Everyone,

Welcome to the new look Up-date and News from the Disability Living Allowance Advisory Board. The recently formed Editorial team have made a special effort to capture some of the areas where concerns have been expressed and where information and advice has been sought, so I hope you will enjoy the contents.

There is also a real opportunity for you all to participate in the questions and answers section, so please feel free to contact us with your queries. DLAAB really does want to help.

Anne Spaight  
Chair DLAAB

## FIBROMYALGIA

### David L Scott

Fibromyalgia is a common disorder. Its cause is unknown. The essential features are chronic widespread pain occurring together with multiple tender points. It is a disruptive condition that can greatly reduce physical function. Fibromyalgia is usually characterised as a type of soft tissue rheumatism. This classification implies that it does not involve inflammation of bones or joints. Its most characteristic feature is chronic, generalised pain, which involves joints, muscles and the spine.

Some years ago, a committee of the American College of Rheumatology produced a set of classification criteria. These are based on the presence of a history of widespread pain and pain in at least 11 tender points.

The first diagnostic criterion is a history of widespread pain. This pain has to involve all quadrants of the body. This means there has to be pain on the left side of the body, the right side of the body, above the waist and below the waist. In addition, there must be pain in the cervical spine, anterior chest, thoracic spine or low back. The pain has to have been present for at least three months.

The second diagnostic criterion is the presence of pain and multiple tender points. Pain on finger pressure needs to be present in at least 11 of 18 possible sites. These sites are present on both sides of the body. They consist of:

- Occipital region (back of the head)
- Low cervical spine (neck)
- Trapezius region (between the shoulder-blade and the spine)
- Supraspinatus (above the shoulder-blade)
- Second rib (below the collar-bone)
- Lateral epicondyle (outer side of elbow)
- Gluteal region (buttocks)
- Greater trochanter (uppermost outer prominence of thigh bone)
- Knee

Many patients with fibromyalgia also have fatigue and poor unrefreshing sleep. The triad of widespread pain, fatigue and poor sleep is highly suggestive of the diagnosis.

In fibromyalgia there are no useful diagnostic investigations. In the absence of other disorders, all investigations should be normal in fibromyalgia; this places a unique importance on the clinical assessment, although the clinical features themselves are relatively non-specific.

Patients with fibromyalgia often have one of several related disorders. These include chronic fatigue syndrome, irritable bowel syndrome, migraine and interstitial cystitis. These conditions are sometimes called "unexplained medical disorder". Alternative names are "burnout", and "multiple chemical sensitivity", and all share demographics and the presence of somatic symptoms that cannot be explained in terms of medical disease.

This group of unexplained medical disorders share symptoms such as fatigue and pain, disability out of proportion to physical examination findings, inconsistent demonstration of laboratory abnormalities and an association with 'stress' and psychosocial factors. The reason why these disorders occur together is not well understood.

One explanation for their development is the process of somatisation, which has been described as the expression of personal and social distress through physical symptoms.

Fibromyalgia can exist by itself. It is then called primary fibromyalgia. In addition, patients with other diseases can have features of fibromyalgia. Fibromyalgia is also seen in patients with arthritis, systemic lupus erythematosus and primary Sjogren's syndrome.

A widespread pattern of pain is considered to be the clinical hallmark of fibromyalgia. The prevalence of fibromyalgia, which means the number of people who have the disease at a given point in time, is about 3.5 % of the adult population. It is far more common in women. Chronic widespread pain may affect up to 10% of adults.

A lot of attention has been paid to the potential role of psychological risk factors. Between 10-20% of patients with fibromyalgia have evidence of one or more psychiatric diagnoses. Patients with fibromyalgia have high life time rates of major depression, panic disorder and mood disorder. There is no conclusive evidence that fibromyalgia causes depression or vice versa. In any event only a minority of patients with fibromyalgia are depressed and the disorder is clearly not just a psychological disease.

Patients with fibromyalgia can benefit from a variety of treatments, though none are ideal. These include simple analgesics, anti-inflammatory drugs, anti-depressants, exercise and cognitive behavioural therapy.

Different studies have found considerable variations in the impact of fibromyalgia on patients' lives and the course of their disease. This partly depends on the severity of their disease. It is also influenced by cultural and clinical circumstances. Most prospective studies suggest between 40% and 60% of patients have persisting symptoms, which can last 10 to 15 years or longer. On the other hand, most cases will experience some improvement in symptoms after the onset of their disease. Although poor functional outcomes in fibromyalgia are often associated with high levels of anxiety and depression, most patients do not have significant psychiatric disorders. Overall, research indicates that the symptoms of fibromyalgia are remarkably persistent and pervasive over many years, despite many patients being reassured that this is not a crippling condition.

In common with most rheumatic diseases, there are ongoing debates about the nature, treatment and outcome of fibromyalgia. As the disease has no diagnostic tests, it lacks clear-cut "gold standards" to judge whether it is present. Some argue that it is merely one end of the spectrum of chronic pain. There are also obvious limitations with the diagnostic criteria. For instance do patients with chronic widespread pain who have less than 11 tender points have a different disease? Almost certainly they do not, but the shortcomings of the diagnostic

criteria are no different in fibromyalgia than in other rheumatic diseases.

A second and related area of controversy lies in the absence of objective findings in fibromyalgia. Pain, tender points, fatigue and disability are highly dependent on patient's perceptions and are subjective. In a disorder without objective findings and laboratory abnormalities it is inevitable a patient's subjective views will be critically appraised and may not inevitably be acceptable at face value. This lack of objective findings is not such a marked problem in clinical practice. Objective findings may be difficult to reproduce in other disorders. In addition, anatomical abnormalities on imaging or abnormal blood tests are often unrelated to any clinical features.

The final area of marked debate is how best to treat fibromyalgia. Most available treatments are relatively ineffective. Analgesics, anti-inflammatory drugs, anti-depressants and hypnotics are usually of only marginal benefit.

There is a substantial amount of evidence that indicates exercise, especially aerobic exercise may help patients but is not curative. Patients with fibromyalgia are 20-30% weaker than their healthy counterparts.

Most centres do not have access to psychological treatments. The majority of patients with fibromyalgia, who are not very disabled, can probably be given modest support and left to cope with their disease. The real problem is how to help those patients who are severely affected, who have marked pain and are not working. At present, there is no easy answer, and this is clearly an area where further knowledge is needed.

## **CHRONIC FATIGUE SYNDROME (MYALGIC ENCEPHALOMYELITIS)**

### **Christine Whitehead**

Widespread controversy continues to surround the nature of Chronic Fatigue Syndrome (CFS), also known as or Myalgic Encephalomyelitis (ME), and Post viral Fatigue Syndrome.

A feeling of fatigue is a normal response to prolonged mental or physical exertion, and chronic fatigue is not uncommon. To distinguish CFS, an international consensus definition has been agreed. The diagnosis is dependent upon:

1. Principal complaint of fatigue
2. At least four of the following additional symptoms:
  - Subjective memory impairment
  - Persistent sore throat
  - Persistent tender lymph nodes
  - Muscle pain and/or joint pain
  - Headache
  - Unrefreshing sleep
  - Post-exertional malaise lasting more than 24 hours
3. Impairment of function (disability)
4. Duration of at least six months
5. Other conditions excluded.

It follows that the diagnosis can only be established after a doctor has investigated for diagnoses that are known to be associated with chronic fatigue, such as thyroid disease.

In 1998, the then Chief Medical Officer, Sir Kenneth Calman stated, "I recognise that the Chronic Fatigue Syndrome is a real entity. It is distressing, debilitating, and affects a very large number of people. It poses a significant challenge to the medical profession."

## **PREVALENCE**

The Chronic Fatigue Syndrome affects 0.5% to 1% of the population, the actual numbers of people with the condition being hard to come by due to difficulty in defining the condition precisely. The most common age of onset is early twenties to mid-forties. CFS is about twice as common in women as in men.

There is evidence that some factors act as 'triggers' for CFS. The disease may follow glandular fever, meningitis or hepatitis, and the profusion of symptoms may delay diagnosis. If CFS continues for about eighteen months or more, it may then persist indefinitely, and, without treatment; individuals may remain unwell for years. However, the majority of sufferers show some improvement within eighteen months.

## **TREATMENT**

Three approaches have been found to be of benefit:

- Graded Exercise, a form of structured and supervised activity that aims for gradual but progressive increases in activity. It is

based on the principle that inactivity and subsequent physical deconditioning can be reversed by gradual, supervised progressive increases in exercise.

- Cognitive behavioural therapy, the aim being to help individuals adopt more effective coping strategies.
- 'Pacing', an energy management strategy, which aims to achieve an appropriate balance between rest and activity.

Cognitive behavioural therapy and graded exercise have both been shown in randomised trials to be effective therapies for CFS. A balance needs to be struck between supporting individuals when they are disabled and encouraging independence as they improve, particularly in response to treatment.

There is no specific drug treatment. Anti-depressants are helpful for clinical depression and may be used as symptomatic treatment for muscle pain and sleep disturbances.

## **CARE NEEDS.**

The level of disability varies from mild to severe. At one end of the spectrum some may be able to continue in full time employment, while at the other end individuals may become confined to bed or wheelchair dependant. Difficulty in walking may be as a result of fatigue, muscle pain or weakness, or loss of balance. The level of disability and energy levels may fluctuate considerably, even from day to day.

## **FURTHER EVIDENCE**

In many cases an EMP report is often the most useful source of evidence. GP factual reports can provide information on diagnosis, clinical findings and treatment and should be able to provide details of the severity of symptoms. As defined, CFS cannot be self-diagnosed.

Where there are significant and complex issues, a report from a consultant would be helpful, although currently there are few specialising in this area.

# **DLAAB NEWS**

## **MEETINGS WITH OUTSIDE ORGANISATIONS**

The Board meets regularly with outside organisations. At these meetings Board members with relevant skills, expertise or interest have discussions with representatives of various groups. The Board invites specific groups and also welcomes approaches from any group who feels it would benefit from meeting the Board.

Although we have a set remit there is a lot of positive action that could happen as a result of these discussions. The more we can learn the better we can advise. In the past many issues have been raised and groups who represent specific disabilities or conditions that result in disabilities are a source of knowledge and insight. In return the Board can offer a better service to all. Often it is an opportunity for groups to gain insight into the framework of DLA/AA and confirmation of changes being made or particular issues being studied is reassuring.

Meeting with outside organisations is a very important part of our work. It has been said by some of those whom we meet that they were a bit daunted by the idea of meeting the Board. In fact often there are 3 or 4 members present and our visitors sometimes outnumber us.

Please contact the Secretariat if your organisation would like to meet with us.

Since the last issue of Update the Board have met with:

- **ARTHRITIS CARE**
- **THE NATIONAL RHEUMATOID ARTHRITIS SOCIETY**
- **THE DISABILITY ALLIANCE AND ALLIED ORGANISATIONS**
- **THE MS SOCIETY**
- **MENCAP**
- **THE DOWN'S SYNDROME ASSOCIATION**
- **THE NATIONAL AUTISTIC SOCIETY**

## THE BOARD

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~Dr John Keen

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~Dr Audrey Oppenheim

~Ms Sarah Playforth

~Mr Douglas Ross

~Mrs Christine Whitehead

## THE REMIT

The Board has three main functions:

- To give advice to the Secretary of State on matters referred by him/her.
- To give advice to Department of Work and Pensions Medical Services doctors on cases referred for expert advice.
- To present an Annual Report on it's activities over the year to the Secretary of State.

### **INVITATION TO DM'S**

If you have any specific questions or general queries please contact us via the Secretariat.

We wish to use the News & Update as a forum for discussion.

### **HEALTH WARNING**

Please note- the articles contained in this news- sheet are written for the benefit of Decision Makers, to help them with their job.

The articles are **not to be quoted** in any decision or communication with members of the public or their representatives.

### **GETTING IN TOUCH**

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