Disability awareness

Chronic Fatigue Syndrome

What is it?

Chronic Fatigue Syndrome (CFS) is also known as ME (Myalgic Encephalomyelitis) but can also be diagnosed as Post Viral Fatigue Syndrome (PVFS).

It is a chronic fluctuating illness affecting many parts of the body such as the nervous and immune systems. The most common symptoms are severe fatigue or exhaustion, problems with memory, concentration and muscle pain. The physical symptoms can be as disabling as multiple sclerosis, rheumatoid arthritis, congestive heart failure and other chronic conditions.

CFS affects people differently. Health professionals may use the following terms:

- Mild: you are able to care for yourself, but may need days off work to rest.
- Moderate: you may have reduced mobility, and your symptoms can vary. You may also have disturbed sleep patterns, and need to sleep in the afternoon.
- Severe: you are able to carry out some simple daily tasks, such as brushing your teeth, but you may have significantly reduced mobility. You may also have difficulty concentrating.

Most cases of CFS are mild or moderate, but up to one in four people with CFS have severe symptoms.

CFS is estimated to affect up to 250,000 people in the UK. You are more likely to develop the condition if you are female, have a family member with the condition, or have other health conditions such as irritable bowel syndrome, fibromyalgia, depression or anxiety. However, there is a usually a trigger to the development of fatigue symptoms such as an infection (eg. viral infections and glandular fever), a stressful life event, accident, operation or even physical injuries or excessive physical exertion.

Symptoms

The symptoms of CFS vary from person to person, and generally an individual will have good and bad periods. When symptoms improve, they will be able to do many normal everyday activities but when symptoms flare up and get worse it can have a profound effect on both their physical and mental functioning.

Fatigue

- Look out for signs of distress or symptoms worsening
- Be supportive and positive give loads of praise
- Agree plans and goals together
- Set small achievable goals and celebrate successes
- Offer continuity where possible.

Disturbed sleep

- Difficulty getting to sleep or early wakening
- Excessive sleeping
- Disrupted sleep/wake cycle
- Unrefreshing sleep.

Pain

- O Unexplained muscle or joint pain
- Possibly with tingling and numbness
- Pain that moves from one joint to another without swelling or redness
- Headache of a new type, pattern or severity (often migraine-like).

Impaired cognitive functioning

- Reduced attention span and concentration
- Poor short-term memory
- Difficulty finding the right words
- Struggling to plan or organise thoughts.

Psychological difficulties

O Depression, irritability or anxiety.

Other physical symptoms

- Recurring sore throats
- Enlarged lymph nodes in your neck or armpits
- Nausea
- Loss of appetite
- Indigestion, bloating, cramps and bowel problems (similar to IBS)

- Intolerance to alcohol, some foods or medications
- Sensitivity to noise or light
- Dizziness on standing or balance problems
- Poor coordination
- Difficulty controlling body temperature or excessive sweating.

Other useful information

Factors that can make the symptoms worse:

- O Poor sleep or excessive sleeping
- Overdoing activity or too much inactivity
- Lack of relaxation time
- Stressful situations
- Large meals
- Any food and drink you're sensitive to
- Alcohol, caffeine, sugar and sweeteners
- Mood disorders, such as depression
- Beliefs and attitudes, including negative thinking.

Treatment strategies:

- O Cognitive Behavioural Therapy (CBT)
- Graded exercise therapy (a programme of increasing activity)
- Activity management (increasing activity to allow management of fatigue)
- Medication to control certain symptoms
- Advice on diet, sleep management, rest and pacing, relaxation techniques and/or useful equipment.

Self-help

Many people with CFS find pacing to be useful to help them manage day-to-day activities. This involves balancing periods of activity with periods of rest and not overdoing it or pushing themselves beyond their limits. Over time, they can gradually increase their periods of activity, as long as they are balanced with periods of rest. This technique helps people learn how to make the most of their limited energy and increase the amount they can do.

Contact us:

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