**Unrest – Facts about ME / Chronic Fatigue Syndrome**

The award-winning cinema documentary *Unrest* explores the stories of people living with ME / Chronic Fatigue Syndrome. Here are some facts about the disease.

**What is ME / CFS?**

* ME (Myalgic Encephalopathy or Myalgic Encephalomyelitis) is a medical condition characterised by reduced ability to function after exertion
* Other names used for ME may include:
  + Chronic Fatigue Syndrome (CFS)
  + Post-Viral Fatigue Syndrome (PVFS)
  + Chronic Fatigue Immune Dysfunction Syndrome (CFIDS)
  + Systemic Exertion Intolerance Disease (SEID)
* According to current estimates, over 250,000 people in the UK have ME / CFS[[1]](#footnote-1) (more than double the number of individuals with HIV or Multiple Sclerosis)
* 80% of people with ME go undiagnosed, due to a lack of education and awareness[[2]](#footnote-2)
* Lab findings for individuals with ME show:
  + Changes in immune function, including low natural killer cell function[[3]](#footnote-3), increased autoantibodies[[4]](#footnote-4), and significant elevation or depletion of inflammatory chemicals in the blood[[5]](#footnote-5)
  + Changes in cellular metabolism that limit energy availability for patients
  + Neuroinflammation and increased lactate in the brain, and MRI changes post-exercise
  + Alterations in the autonomic nervous system, including issues with temperature regulation, high variability in heart rate and blood pressure, and ability to maintain

**Severity and symptoms**

* The majority of patients tend to see a fluctuating pattern of symptoms including . Symptoms vary considerably over time.[[6]](#footnote-6)
* Symptoms can be mild, but in 25% of cases they are severe enough to leave patients housebound.[[7]](#footnote-7) Individuals may be confined to bed for months or years.
* Common symptoms of ME include:
  + Significant physical or mental fatigue
  + Profound loss of muscle power
  + Muscle pain that may include tenderness and swelling
  + Reduction in ability to function, after even minimal exertion
  + Debilitating pain
  + Difficulty sleeping
  + Cognitive dysfunction
  + POTS (postural orthostatic tachycardia), which prevents patients from maintaining an upright or seated position

**Causes**

* The cause of ME is unknown. However, it is confirmed that many patients contract ME after a viral infection, and some infections are more associated with onset than others.
* Other triggers may include an operation or an accident, although some people experience a slow, insidious onset.

**Who is affected?**

* Men and women, and people of all races, creeds and colors, can contract ME. Both children and adults can have ME.
* However, women are four times as likely to have ME than men[[8]](#footnote-8).
* The myth of “yuppie flu” has been discredited. Studies show that people of all socioeconomic classes have ME.[[9]](#footnote-9)

**Diagnosis and treatment**

* There is no single test that can diagnose ME and it often takes several years for patients to receive a diagnosis
* There is no cure for ME and no universally effective treatment. Treatments which help some patients are often ineffective or harmful in others.[[10]](#footnote-10)
* The aim of much care is to reduce symptoms, and treatment can include drugs and complementary therapies.
* Controversially, the official NHS treatment for ME involves a combination of CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy).
* However, the government funded PACE trial – the 2011 research that formed the main basis of the recommendation – has been featured on Retraction Watch and PLoS has placed a ‘Notice of Concern’ on the study.
* Patients have found that CBT is ineffective and graded exercise therapy can make their condition worse. Furthermore, the PACE trial methodology has been shown to be flawed by many clinicians and academics. The ME Association is calling for an independent review of the trial. [[11]](#footnote-11)

**UK Research and service provision**

* ME is a stated priority for the Medical Research Council, but research activity remains “chronically” low according to ME Research UK.[[12]](#footnote-12)
* Grants from the largest funders for ME / CFS are worth an estimated £17 million in the UK, a twentieth of the amount available for Multiple Sclerosis Research

**Economic and societal costs**

* In addition to the 250,000 people directly affected, ME has an impact on carers and family members. Family life, education, and ability to work can all be severely disrupted.
* At a societal level, ME has a major impact on health and social care services, as well as productivity in terms of working hours lost
* The economic cost of ME/CFS was estimated at £3.3 billion per year in the UK in 2004 and the cost is likely to have increased since then.[[13]](#footnote-13)

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