

The Sussex & Kent ME/CFS Society is the registered charity that informs, supports and represents those affected by Myalgic Encephalopathy or Chronic Fatigue Syndrome across Sussex and Kent.

Recent research, commissioned by the Society, estimates that in Kent and Sussex there are over 12,000 adults and children that are affected by Myalgic Encephalopathy / Chronic Fatigue Syndrome and that 3,000 of these are virtually house-bound.

ME/CFS type illnesses have appeared in the medical literature since 1750 indeed Charles Darwin and Florence Nightingale are thought to have had the illness. The disease has been known by many names world-wide over the decades including Royal Free Disease when ME was reported in The Lancet after an outbreak at London's Royal Free Hospital in 1955 - these days the illness occurs more spasmodically.

In recent years ME/CFS has been classified by the World Health Organisation as a [neurological disorder](#) and the country's Chief Medical Officer (CMO) set up an expert panel to carry out a review ([Click here to see review](#)) . The Medical Research Council (MRC) have also formulated a [research strategy](#) and the National Institute of Clinical Excellence (NICE) have issued guidelines ([Click here to see guidelines](#)) . Locally, our society has been working with the Primary Care Trusts (PCTs) of both Kent and Sussex establishing specialist NHS services that are now operational.

ME/CFS can follow a viral infection or trauma. Symptoms include profound physical and mental fatigue, muscle pain, sleep and mood disturbances, alcohol sensitivity, difficulty with concentration and short term memory along with gastric and eyesight problems. The symptoms, which vary and fluctuate, can be exacerbated by over exertion. Overtime, most patients gradually improve significantly.

The role of the Sussex & Kent ME/CFS Society remains profoundly important informing, supporting and representing patients. Services include help-lines, newsletters, meetings, Egroup, library and special interest groups etc. The charity keeps in contact with support

agencies and medical professionals and has eminent doctors as advisors. We also enjoy the support of a number of patrons including MPs who are members of an All Party Parliamentary Group (APPG) that works in the interests of ME/CFS patients nationally.