

## Beth ydy ME?

Mae Enseffalomyelitis Myalgig yn gyflwr niwrolegol sydd â'r potensial i achosi analluogrwydd ac i fod yn gronig. Mae'n effeithio ar bobl o bob oed ac o'r ddeuryw.

Mae'n effeithio ar yr ymennydd ar lefel gorfforol, meddyliol ac emosïynol. Mae ymchwil wedi dod o hyd i dystiolaeth o ddiffyg genynnol sy'n effeithio ar nifer o systemau, yn cynnwys y system imiwneidd, yr hypothalamws, y gyfundrefn nerfol awtonomig a'r cyhyrau.

Does yna ddim un achos amlwg, er, gyda llawer o gleifion, mae'n ymddangos mai firws sy'n ei gychwyn, gan weithiau olygu bod y diagnosis cychwynnol yn un o Syndrom Lludded Ôl-Firol (Post Viral Fatigue Syndrome, PVFS). Defnyddir y term ymbarél Syndrom Lludded Cronig gan feddygon ar gyfer salwch sydd â lludded yn brif symptom, yn cynnwys ME.

Ar y cychwyn, mae oedolion yn tueddu i gwyno o salwch tebyg i fflw trwm, sy'n waeth ac yn para'n hwy na dos o fflw, gyda dolur gwddw a chwarennau chwyddedig, poenau yn y cyhyrau a'r cymalau, a lludded. Gall plant hefyd ddirodded o gur pen a phoen yn y stumog. Dros amser, gall patrwm y salwch newid ac efallai y bydd yn cynnwys amrywiaeth eang o symptomau – yn rhai corfforol a gwybyddol.

Prif nodwedd y salwch, fodd bynnag, ydy bod symptomau'n gwaethygu ar ôl ymdrech gorfforol neu feddyliol, er y gall yr adwaith fod yn hwyr yn ymddangos. Mae symptomau'n anwadal, a gellir cael cyfnodau o wella ac ailwaelu, gan achosi dryswch a rwystrdigaeth i'r cleifion a'u teuluoedd fel ei gilydd.

Mae cynnydd yn anodd ei ddarogan. Gall rhai wella, bydd y mwyafrif yn amrywio yn eu cynnydd a gall rhai gymraedd 70-80% o'u lefel iechyd flaenorol. Mae tua 25% yn aros yn ddirffifol anabl.

## ME yng Nghymru

- Amcangyfrifir bod tua 13,000 o bobl yng Nghymru ag ME ac CFS.
- Does gan Gymru ddim arbenigwyr meddygol ME.

- Ychydig iawn o hyfforddiant, neu hyd yn oedd ddim o gwbl, mae meddygon a gweithwyr proffesiynol eraill yn ei dderbyn am yr afiechyd.
- Dydy natur niwrolegol a chronig ME ddim yn cael ei gydnabod yn eang.
- Mae'n anodd dod o hyd i ddiagnosis manwl gywir.
- Mae'n anodd dod o hyd i gymorth i lunio cynllun datblygu.
- Mae'n anodd cael budd-daliadau, gofal cymdeithasol ac addysg addas.
- Gall y triniaethau a gynigir (e.e. rhai cyffuriau, therapïau ymddygiad ac ymarfer) fod yn anaddas.
- Mae yna angen am ymchwil o safon dda i bob agwedd ar ME yng Nghymru, yn arbennig epidemioleg a darpariaeth gwasanaethau.

## Ellwch chi helpu?

- Ymunwch fel gwirfoddolwr – mae yna nifer o ffyrdd, yn fach a mawr, y gellwch ein helpu i wella'r gwasanaethau a'r gefnogaeth i bobl ag ME.
- Byddwch yn gefnogwr:
  - ◆ rhowch wybodaeth i ni am eich profiad o ME a gwasanaethau ynddo Nghymru
  - ◆ cofrestrwch ar gyfer ein cylchgraw, newyddion a chyfryngau cymdeithasol
  - ◆ lledaenwch wybodaeth – gofynnwch i ni am bosteri, erthyglau a phamffledi
- Rhowch help llaw i ni i godi arian – holwch am y nifer fawr o brojectau sydd angen eu hariannu. Gallwn awgrymu gweithgareddau codi arian.
- Cyfrannwch arian neu offer.



## WAMES - Working towards ME awareness in Wales

The Welsh Association of ME & CFS Support is a voluntary organisation which aims to give a national voice to people with ME & CFS, and their carers and families in order to improve services, awareness and support.

### We do this by:

- campaigning for recognition of ME as a neurological illness in line with the WHO classification and the results of biomedical research
- campaigning for health, education, social care services, benefits and research.
- raising awareness of ME
- offering support to young people with ME
- providing information in Welsh and English for patients & professionals
- aiding local support groups.

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**Patron:** Lord Barry Jones

**Advisor:** Dr Nigel Speight

## What is ME?

Myalgic Encephalomyelitis is a potentially disabling and chronic neurological condition which affects people of all ages and both sexes.

It affects the brain at a physical, mental and emotional level. Research has found evidence of gene dysfunction affecting many systems including the immune system, hypothalamus, autonomic nervous system and muscles.

There is no single identifiable cause although for many the trigger appears to be a virus, sometimes leading to an initial diagnosis of Post Viral Fatigue Syndrome (PVFS). The umbrella term Chronic Fatigue Syndrome (CFS) is used by doctors for illnesses with fatigue as a major symptom, including ME.

Initially adult patients tend to complain of a severe 'flu-like' malaise, which is worse and longer lasting than a bout of flu, with sore throats and swollen glands, muscle and joint pain, and exhaustion. Children can also experience headaches and stomach aches. Over time the pattern of the illness can change and may include a wide range of symptoms – both physical and cognitive.

The major characteristic of the illness however, is that symptoms become worse after physical and mental exertion, although the reaction may be delayed. Symptoms fluctuate and there can be periods of remission and relapse leaving patients and families alike, confused and frustrated.

Progress is difficult to predict. A few may recover, the majority will make variable progress and some may reach 70-80% of previous level of health. About 25% remain severely disabled.

## ME in Wales

- There are an estimated 13,000 people in Wales with ME and CFS
- Wales has no ME medical specialists
- Doctors & other health workers receive little or no training in the illness
- The neurological and chronic nature of ME is not widely recognised
- It is difficult to find an accurate diagnosis
- It is difficult to find help with devising a management plan
- It is difficult to access benefits, social care and appropriate education
- The treatments offered (e.g. drugs, behavioural and exercise therapies) can be inappropriate
- There is a need for good quality research into all aspects of ME in Wales, including epidemiology and service provision.

## Can you help?

- Join us as a volunteer - There are many ways both large and small that you can help us to improve services and support for people with ME
- Become a supporter:-
  - ◆ give us information about your experience of ME and services in Wales
  - ◆ sign up for our magazine, news and social media
  - ◆ spread the word – ask us for posters, articles and leaflets
- Help us to fundraise – ask about the many projects that need funding. We can suggest fundraising activities
- Donate money or equipment.



## WAMES – Gweithio tuag at ymwybyddiaeth o ME yng Nghymru

Mae Cymdeithas Cefnogi ME ac CFS Cymru yn gymdeithas wirfoddol sy'n amcanu at roi llais cenedlaethol i bobl ag ME ac CFS, ynghyd â'u gofalwyr a'u teuluoedd, er mwyn gwella gwasanaethau, ymwybyddiaeth a chefnogaeth.

### Byddwn yn gwneud hyn trwy:

- ymgyrchu dros gydnabyddiaeth i ME fel salwch niwrolegol yn unol â dosbarthiad WHO a chanlyniadau ymchwil biofeddygol
- ymgyrchu dros iechyd, addysg, gwasanaethau gofal cymdeithasol, buddaliadau ac ymchwil
- codi ymwybyddiaeth o ME
- cynnig cefnogaeth i bobl ifanc ag ME
- darparu gwybodaeth yn y Gymraeg a'r Saesneg ar gyfer cleifion a gweithwyr proffesiynol
- rhoi cymorth i grwpiau cefnogi lleol

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