

# ME Diagnosis: Delay Harms Health

## Early diagnosis: why is it so important?

A report from the ME Alliance

### Executive summary

Despite official government acceptance that ME/CFS is a genuine and disabling illness, and recommendations that the illness should be diagnosed within six months<sup>1</sup>, many people still experience a considerable delay in obtaining a firm diagnosis from a doctor. This has serious implications for health and wellbeing, employment and education, and access to welfare benefits.

An ME Alliance survey has found that:

- 53% of people with ME/CFS waited over a year for a diagnosis of their illness
- Only 25% of people were diagnosed within the recommended six months
- 45% of children and adolescents waited over a year for diagnosis, despite the recommended timeframe for diagnosis in this age group being three months

#### The importance of early diagnosis

- Establishing an early and accurate working diagnosis provides patients with a name for the problems they are experiencing and enables a plan of management to be developed. Recognising and accepting the illness early on maximises the potential for improvement and recovery.

*Preliminary findings from a study into risk factors for severe ME/CFS show that severity is linked to the length of time before a diagnosis was made: those who were ill for more than a year before receiving a diagnosis from a doctor were more likely to be severely ill than those who waited less than a year. Only 27% of severe cases were diagnosed within a year compared to 54% of those who were mild or moderately affected.*

#### Delayed diagnosis: the consequences

Lack of diagnosis causes frustration, even despair, and impacts on all areas of life:

- Patients can be given inappropriate and harmful recommendations on management, particularly in relation to striking the right balance between activity and rest
- Relations with family and friends can be strained and arrangements with employers or schools become very difficult
- State and private sickness benefits can be impossible to obtain, leaving people without financial help, home-based education, or practical care
- In the wider context, ME/CFS becomes an increased social and economic burden

#### The ME Alliance campaign

Urgent action needs to be taken to improve the diagnosis of people with ME/CFS. New guidelines from The National Institute for Clinical Excellence will not be available to doctors until 2007 at the earliest.

*In the next two years, the ME Alliance estimates that over 50,000 people will develop ME/CFS, and many will experience considerable delay in their diagnosis.*

#### Call for action

The ME Alliance believes that organisations and agencies responsible for patient care, undergraduate and postgraduate medical education, and medical research should take action:

- 1 **Recognition and Awareness:** GPs must consider the diagnosis of ME/CFS at an early stage
- 2 **Education:** the diagnosis of ME/CFS must be properly covered in medical training
- 3 **Research:** government must fund an epidemiological study, commissioned by the Medical Research Council, to investigate the true prevalence and natural history of ME/CFS. Further research is needed into the underlying cause of ME/CFS to try and identify a consistent abnormality that could act as a diagnostic marker

#### How the ME Alliance can help

The member charities are keen to work in partnership with health professionals and to assist agencies involved with patient care, medical education and research. We can provide evidence on the patient experience and information on all aspects of the diagnostic and management process.

**For a full copy of the report contact the charities listed below:**

**Action for M.E.** [www.afme.org.uk](http://www.afme.org.uk)

**Association of Young People with ME** [www.ayme.org.uk](http://www.ayme.org.uk)

**Case History Research on ME (CHROME)**  
[www.chromesw6.co.uk](http://www.chromesw6.co.uk)

**The ME Association** [www.meassociation.org.uk](http://www.meassociation.org.uk)

**The National ME Centre** [www.nmec.org.uk](http://www.nmec.org.uk)

**The Young ME Sufferers (Tymes) Trust**  
[www.tymestrust.org](http://www.tymestrust.org)



Reference 1

A report of the CFS/ME Working Group: Report to the Chief Medical Officer of an Independent Working Group. 2002. Available online at the Department of Health. website: [www.doh.gov.uk](http://www.doh.gov.uk) – search under CFS/ME