

# ***Local Education Authorities Fail Sick Children***

***ME Awareness Week 2007: May 7-13, 2007***

Education chiefs are being accused of flouting the law by not providing sick children with the learning support they are entitled to.

The UK's largest children's ME/CFS charity says some Local Education Authorities are pleading poverty, saying they cannot afford to provide sick children with a suitable education.

In a survey by the Association of Young People with ME (AYME, pronounced 'aim'), one third of children and young people with ME/CFS said they received no education for a period of time, 18 percent were in school part-time, 19 percent were receiving home tuition, 17 per cent were in college and others were participating in correspondence courses.

AYME's Chief Executive Officer, Mary-Jane Willows, says there are some great examples of good schools supporting pupils with ME/CFS, but there are also some heartbreaking stories of Local Education Authorities acting unreasonably, inflexibly and, in some cases, illegally, by not providing the support they are obliged to in law.

"It is every LEA's duty to provide suitable education for children with medical needs and it's no defence to say they can't afford it," says AYME's education advisor, Hilary Tandy.

Section 19 of the 1996 Education Act says that LEAs have to provide a 'suitable' education for sick students. The court case East Sussex County Council ex parte Tandy says that LEAs cannot take money into account when deciding on what constitutes a suitable education.

Additionally, under the national guidelines every LEA must have a written policy statement explaining how it will provide education for children and young people who are unable to attend school because of their medical needs. This policy should be freely accessible to all, yet LEAs fail to inform parents about these policies and the child's legal right to a suitable education. When AYME put this to the test by writing to all 151 LEAs in England requesting a copy of their policy, 83% failed to respond.

This year's ME Awareness Week campaign focuses on raising awareness and understanding of ME/CFS amongst school staff and students. Certificates of Excellence are being awarded to schools and home tutors nominated by young people for making their lives easier.

## **Editor's Notes:**

For further information or, to request interviews with young people with ME/CFS contact the press officers: **Katie James, Tel: 01908 379737 mobile: 07816 989 067 or email: [katie@ayme.org.uk](mailto:katie@ayme.org.uk). Also see our website [www.ayme.org.uk](http://www.ayme.org.uk) for more background on ME/CFS and education issues.**

On March 28, 2007, AYME wrote to 151 LEAs requesting a copy of their policies as outlined under Section 19 of the Education Act 1996 and the DfES guidance 'Access to Education for Children and Young People with Medical Needs'.

In paragraph 2.2, the DfES guidelines states that each LEA should have "a written policy statement on the implementation of its legal duty to provide education for children and young people who are unable to attend school because of their medical needs..." and that "the policy should be freely accessible to all."

LEAs that have sent in their policy are: Bath and NE Somerset, Birmingham, Bolton, Bury, Calderdale, Camden, Cambridge, Coventry, Derbyshire, Dudley Metropolitan Borough Council, Durham, East Riding, East Sussex, Kent, Lincolnshire, Norfolk, Northamptonshire, Northumberland, North Yorks, Rutland, Sheffield, Staffordshire, Somerset, Suffolk, Tameside, West Sussex.

## Further Notes for the Editor:

### ME/CFS: The Hard Facts

1. Myalgic Encephalopathy (or Encephalomyelitis) ('ME') is also known as Chronic Fatigue Syndrome ('CFS') and sometimes, in its early stages, Post Viral Fatigue Syndrome ('PVFS'). There is debate about the most appropriate terminology so the composite term ME/CFS or CFS/ME is usually adopted.
2. ME/CFS is classified by the **World Health Organisation ICD-10** as a **neurological condition**.
3. ME/CFS is a chronic disabling illness with many complex symptoms. The cause is unknown. As yet, there is no cure.
4. It is estimated that as many as **25,000 young people and children** have ME/CFS. That's one in every secondary school in the UK. The commonest age of onset is 13-15, but cases can occur as young as five-years-old.
5. ME/CFS has also been recorded as the **most common cause of long term absence** among school children: 51% compared to 23% cancer and leukaemia, 13% general medical or surgical conditions, 12% musculo-skeletal problems, 5% psychiatric disturbance and 5% virus infections. *(Dowsett EG, Colby J. Long term Sickness Absence due to ME/CFS in UK School. An Epidemiological study with medical and Educational Implications. Journal of Chronic Fatigue Syndrome, 1997; 3 (2): 29:42)*
6. The illness can last for years. Symptoms vary from person-to-person. They fluctuate, sometimes daily, and can be severely disabling. The most common are:
  - **Fatigue:** Utter exhaustion, often to the point of collapse.
  - **Pain:** Particularly headaches and intense muscle and joint pain, which is difficult to relieve with normal painkillers. Skin sensations such as skin crawling and pains and needles may be felt.
  - **Cognitive impairment:** Poor short- and medium-term memory, mental confusion and mental fatigue. Difficulty concentrating, word-finding and thinking. Collectively known as 'brain fog'.
  - **Other symptoms:**
    - Body temperature disturbance
    - Dizziness
    - Vertigo
    - Postural hypotension
    - Sensitivity to light and noise
    - Sleep disturbance
    - Nausea, loss of appetite, gastrointestinal disturbance
    - Mood swings, panic, anxiety
    - Sensitivity to food, medication, alcohol, chemicals
  - **Severe symptoms:** 25% of patients are severely affected and in addition to the above, may experience blackouts, temporary partial paralysis, loss of speech, loss of swallowing function.
7. In total, in the UK ME/CFS affects around **240,000 men, women and children of all ages and social and ethnic backgrounds**. That is **1 in 250 people**.
8. Up to **25% of people with ME/CFS are severely affected**, either house or bedbound and unable to look after themselves.

9. The impact of ME/CFS is huge. A study by the adult ME/CFS charity *Action for ME* indicated that the cost to the nation is approximately £6.4 billion per year. The cost to the individual cannot be calculated.
10. **Early diagnosis** improves chances of recovery. Although there is no specific diagnostic test for ME/CFS, it can be diagnosed by taking a full clinical history of the patient, identifying the typical symptom pattern and ruling out other conditions.
11. In **2002 the UK Government gave formal recognition of the illness** and provided:
  - **£8.5m to develop new NHS services** in England
  - A national **research strategy** led by the Medical Research Council giving ME/CFS priority status
  - Referral to the **National Institute for Health and Clinical Excellence ('NICE')** to produce guidelines on diagnosis and management.

### **Estimated prevalence of ME/CFS by region**

Estimates of incidence OF ME/CFS are based on a research paper by Gallagher et al in the Journal of the Royal Society of Medicine, December 2004. The ME Alliance of charities believes that incidence is twice as high.

<b>Region#</b>	<b>Population</b>	<b>PREVALENCE</b>	<b>INCIDENCE</b>
North East	2,515,442	10,266	1,069
North West	6,729,764	27,465	2,861
Yorkshire and the Humber	4,964,983	20,263	2,111
East Midlands	4,172,174	17,027	1,774
West Midlands	5,267,308	21,497	2,239
East	5,388,140	21,990	2,291
London	7,172,091	29,271	3,049
South East	8,000,645	32,652	3,401
South West	4,928,434	20,114	2,095
Wales	2,903,085	11,848	1,234
Scotland*	5,062,011	20,659	2,152
Northern Ireland	1,702,628	6,949	724

Source: *Mid 2003 Population Estimates, Office for National Statistics; General Register Office for Scotland; Northern Ireland Statistics and Research Agency*  
 \* 2001 census

**# Standard Regions:**

- **South East:** Kent, Surrey, Sussex, Hampshire & Isle of Wight, Berkshire, Buckinghamshire, Oxfordshire
- **South West:** Bristol (and former County of Avon), Cornwall & Isles of Scilly, Devon, Dorset, Gloucestershire, Somerset, Wiltshire
- **North East:** Durham, Northumberland, Former County of Cleveland
- **North West:** Cheshire, Cumbria, Lancashire, Liverpool, Greater Manchester
- **Eastern:** Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk, Suffolk

- **East Midlands:** Derbyshire, Leicestershire, Lincolnshire, Rutland, Northamptonshire, Nottinghamshire
- **West Midlands:** Herefordshire, Shropshire, Staffordshire, Warwickshire, Worcestershire, Former County of West Midlands
- **Yorkshire & The Humber:** Yorkshire (except for former county of Cleveland), Former South Humberside (North East Lincolnshire & North Lincolnshire Unitary Authorities)
- **London:** City of London, and all London Boroughs