

## The Young ME Sufferers Trust

The Trust is a national ME charity specialising in children and young people. In 2010 we received the Queen's Award for Voluntary Service - the MBE for volunteer groups - for pursuing the educational rights and advancing the care of young ME sufferers.

### Our Ethos

We are the longest running national organisation supporting children with ME, inaugurated in 1989 by two young people with ME.

We realise that much distress is experienced when a young person is diagnosed with a serious and disabling illness. Members tell us that our friendly, personal approach, coupled with the provision of reputable information supplied by a professional and experienced team, makes us a 'lifeline' and a 'port in the storm' of controversy surrounding ME. We hope that we shall be able to help you too.

### The Trustcard

Carry the Young ME Sufferer's Trustcard at school or college to make sure you get the help you need. Endorsed by the Association of School and College Leaders and launched at the House of Lords by the Parliamentary Under-Secretary of State for Schools.

### Support the Trust

Let us together support this excellent charity that is providing so much practical help to children with ME. As you consider whether to donate, I urge you to remember that everyone at the Trust works free of charge. This is a cause they believe in.

*Lady Elizabeth Anson, Cousin to the Queen  
ME sufferer, Patron of the Trust*

Go to [www.tymestrust.org/donations.htm](http://www.tymestrust.org/donations.htm) to make your contribution, or just write in with your cheque. We will not contact you again unless requested.

Thank you.

## Incidence of ME

An estimated 25,000 of the 300,000 UK sufferers are children. ME is the biggest cause of long-term sickness absence in schools; a study of 333,000 pupils revealed that 51% of those on long-term sick leave had ME. This is the biggest category of pupils with medical needs requiring home tuition or distance learning on a long-term basis. Clusters of ME occur in schools, families and communities.

### Management

- ◆ There is no known cure. The body needs energy to heal, so personal energy management is a safe way to live with ME without provoking side-effects.
- ◆ Pacing life carefully, using physical aids and finding alternatives to energy-sapping activities are often effective in promoting recovery.
- ◆ Studies claiming the effectiveness of 'graded exercise' have generally been restricted to the less sick or the partially recovered, and to those without classic ME symptoms.
- ◆ Some treatments may be harmful, such as overzealous physiotherapy. The condition naturally fluctuates, and may improve despite, rather than because of, treatments.
- ◆ GPs may be able to assist with symptomatic relief but medication can cause side effects and may not always be of benefit eg for inducing sleep or relieving pain.
- ◆ The illness tends to resolve over an extended period but relapses can occur.
- ◆ If treated inappropriately, the patient can become much worse. In extreme cases, children can suffer fits or collapse. Some go through periods of partial paralysis and may have to be tube-fed.
- ◆ Good old-fashioned convalescence is a good start, followed by careful management of the young person's life and education to avoid the downturns associated with trying to force recovery.

# The Young ME Sufferers Trust



## Quick Tour of ME Symptoms, Management and Trust Services

Registered Charity 1080985



[www.tymestrust.org](http://www.tymestrust.org)

0845 003 9002

PO Box 4347  
Stock  
Ingatstone  
CM4 9TE

Founder Patron : Lord Clement-Jones CBE

## Myalgic Encephalomyelitis

ME (Myalgic Encephalomyelitis) is a potentially chronic (long-lasting) and severe neurological condition. It was formerly known as Atypical Polio. The term Chronic Fatigue Syndrome (CFS) is also used but may include other fatigue states. Viral infections are known triggers of ME.

### Symptoms of ME

#### *Brain and central nervous system*

- ◆ Loss of memory, concentration, balance, coordination and fine motor skills
- ◆ Difficulty sequencing words and numbers, speaking, thinking and absorbing information
- ◆ Abnormalities of sensation (eg pins and needles, numbness), vision, hearing, sleep rhythm, appetite, temperature control, digestion, blood pressure, circulation, hormone production, response to stress
- ◆ Development of sensitivities (eg to light, sound, touch, certain foods, chemical substances such as perfume, paint, medication and anaesthesia)
- ◆ Bouts of racing pulse (tachycardia) and breathlessness
- ◆ Mood swings, panic, anxiety or depression may result from brain dysfunction and the distress of misunderstood illness

#### *Generalised pain and weakness*

- ◆ Pain in muscles, joints, head, back, limbs, chest and stomach
- ◆ Muscular weakness and twitching is common

#### *Exhaustion, up to 72 hours after effort*

- ◆ Even minimal exertion (cognitive or physical) can trigger exhaustion and worsen symptoms. The delayed effect is a classic sign of ME, differentiating it from other types of fatigue.
- ◆ Temporary hyperactivity may be experienced due to brain dysfunction, resulting in exhaustion.

## Education in Young People

- ◆ Inappropriate educational demands impede recovery and are a key cause of relapse in children. Energy Efficient Education (home education, home tuition, distance or virtual learning) can maximise achievement whilst protecting health.
- ◆ Social contact can be preserved through visits from school and friends and through making new friends who understand the limitations imposed by the illness.
- ◆ Children with ME are legally entitled to education suited to their needs.

### Advice Line

The Trust provides an Advice Line manned by our own Advice Line Team. All have personal experience of ME. Many are parents and some have also had ME themselves. They have full information.

Leave your message at 0845 003 9002. One of our team will call you back with information to assist with your query - please speak clearly when leaving your number, and let us know the best times to call.

### Publications

Members receive our publications, with medical and educational articles, activities for and contributions from children and young people. We send little prizes and gifts to brighten their day.

### Professionals Referral Service

We can refer doctors, teachers, social workers and other professionals to an appropriate ME expert from our panel. Your doctor could talk with an ME specialist doctor, your teacher could talk with an ME specialist teacher and so on. We can also advise them directly if you arrange it.

### Parents and supporters

To hear from us regularly, and be invited to our events, register to join our 26+ group.

## www.tymestrust.org

Much more information (including this leaflet) is available free from the Trust's website, from a single sheet to give friends to show them how to help, to detailed guides for your doctor or your school.

You can find out about the *Young Hearts* book of poetry, watch the ITV Central News interview with Jane Colby which was aired when the book was launched by Terry Waite at Warwick Castle, and register for free email Alerts.

### To Register

To register for our services and receive your Welcome Pack, fill in the form online at [www.tymestrust.org](http://www.tymestrust.org), or post us the form below.

Do you want to discuss whether to register? Call and speak to one of our Advice Line Team. You do not have to be a member to obtain a Trustcard.

With love to all of you from all of us.

### Registration Form

We ask for a contribution of £10 when you register. From then on, services are free to young people with ME under 26 and their families (if you are over 26, we ask you to contribute each year).

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Telephone Number \_\_\_\_\_

Email Address \_\_\_\_\_

Date of Birth \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Send to The Young ME Sufferers Trust,  
PO Box 4347, Stock, Ingatstone, CM4 9TE