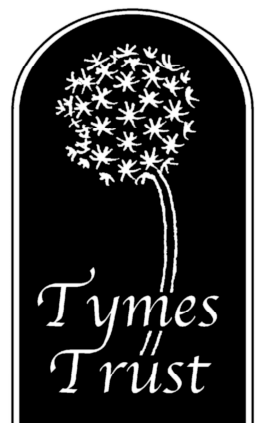


The Essex ME Companion



General Information for families of children with ME/CFS
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
World Health Organisation classification ICD10 G93.3

Living with ME/CFS

ME is a neurological illness that can affect any age, but it is the biggest cause of long term sickness absence from school. Evidence shows the involvement of viruses. Young people are resilient; most get much better over time and may lose their symptoms completely. However, it is possible that they may not be so strong as before, even if they appear well, so it is important to guard against relapse. Healing is a very individual thing and a bout of ME can go on for a long time. For a list of symptoms please see *The Quick Tour of ME Symptoms, Management and Tymes Trust Services* at www.tymestrust.org.

We advise families to adapt life to cope with how things are at the moment and we suggest that you 'Don't put your life on hold'. Live as well as possible now, and adapt life sufficiently to suit the child's present needs. This helps to alleviate symptoms, to promote recovery and to keep their spirits up.

It's good to be hopeful about the future, but try not to put all the emphasis on future recovery. People may become frustrated or depressed waiting for that day to come.

Parents

- Try not to talk about your child returning to full health as if it is the only thing that matters to you; a child can feel as if they are not loved as much as when they were well.
- Do ask for home tuition or online learning if needed. It is best not to leave it too long. Your child may become worse through doing too much. Remember to ask for Special Arrangements for examinations. It is more constructive than hoping the child will be well again by the time the exams arrive. We get a number of last minute calls for advice, just before the exam takes place.
- It's always best to put adaptations in place in advance, just in case. Try not to 'wait for a healthy future' – try to actively promote it, by concentrating on managing the present as well as possible, putting something into each day that your child enjoys, giving lots of love and care and adapting the child's lifestyle as much as you can to promote healing.
- It may, by these means, be possible for you to influence how bad the illness gets, and also to ward off relapses, by adapting things now. But do not blame yourself if your child is ill for longer than you were expecting. Other things which may influence the illness may not be within your control, for example, other infections or challenges to the immune system.
- Manage the output of energy very carefully, to keep enough in reserve for the healing process. Good old-fashioned convalescence is a good basis from which to start. Try to get your GP's and/or your consultant's support in asking for any services that you need.

Delayed effect of effort

- This is a classic – and a diagnostic – sign of ME. Up to 72 hours after an activity there can be a deterioration in health.
- Look back a couple of days to see what might have caused the deterioration. For example, if the child is always unwell on Thursday, what do they normally do on Tuesday?
- Don't forget that intellectual effort can have the same after-effects as physical effort. At exam time it's best to reduce physical effort to avoid overload.
- Graded exercise therapy, hydrotherapy or physiotherapy all entail making an effort of some kind, and therefore can produce a deleterious after-effect if this is too much for the patient. Avoid being persuaded to do more than is helpful.

Alternative remedies

As there is no absolute cure or effective medication to make the child well, many families get tempted to try alternative remedies or therapies in order to help symptoms.

Our advice is that if you do feel tempted to take this route, be very careful. Check with a pharmacist that any remedies you try are safe, and take care that they do not cost you too much, and are not touted as 'cures'.

Remember:

- 'Natural' substances are not always safe – many plants are poisonous.
- When people recommend things to you and claim that certain remedies make them better, it is hard to prove that this really *is* what made them feel better. There could have been other factors involved.
- A person may start taking an alternative remedy at the same time as quitting their job, or a child may start a remedy when school broke up or they began home-based education, thus saving energy. In both these examples, it was quite likely to be the reduction in effort and stress that made the improvement.
- Ask a doctor's advice before taking a remedy; some may interact with other medication. Pharmacists can give information about drugs and remedies.
- People with ME are more sensitive to substances, such as certain foods, remedies, medication, perfume, solvents (*eg* in glue or paint). People with ME may need a lower than normal dose of medications.
- When someone reports a noticeable improvement after taking a remedy or starting a particular therapy, we often find that they have had ME for quite some time already. Notable improvements often occur over time, in the normal course of ME.
- Taking a remedy or starting a therapy sometimes gives confidence to try doing more than before. The person may find that they can now do more than

they thought, but may interpret it as if the therapy itself caused the improvement.

- Sometimes when a person recommends a remedy, they are also selling it or acting as an agent. They can therefore not be considered impartial.

Sleep

Sleep patterns may be reversed with the person being wakeful by night and vice versa. This generally resolves over time as the brain heals. Taking naps during the day is discouraged by some doctors but many people with ME find them helpful, especially as a sick brain needs more sleep for the healing process.

Melatonin is sometimes tried for controlling sleep, for example, in treating jet-lag. There are problems with inappropriate use and it has been withdrawn from over-the-counter sale.

Sleep disturbance in ME comes from a malfunctioning hypothalamus gland in the brain, whereas melatonin is produced by the brain's pineal gland. Our information is that giving extra melatonin is therefore unlikely to produce improvements, except the placebo effect, which can be very strong, with approximately 30% of patients in drug trials reporting some improvement from a placebo. Side-effects of melatonin may include interference with the sex hormones.

Headache and pain

- ME is centred in the brain. Severe headache, particularly in children, is a common. The headache is often an indication that the brain must be given more rest, in order to try and heal itself. Pain throughout the body is also common.
- It is wise to check that headaches are not due to something else that can and should be treated. A neurologist may be needed for this. Ask your GP.
- Painkillers are not very effective in ME, even strong ones. It is safer to use 'ordinary' painkillers eg paracetamol to help take the edge off pain.
- Certain foods may aggravate headaches, as people with ME tend to become sensitive to foods that did not bother them in the past.
- Too much mental or physical effort makes ME headache worse. 'Too much' effort can, in some cases, actually mean very little effort.
- Taking life more easily can have more effect than painkillers but is unlikely to 'work' immediately. Patience is needed, care, love, and lifting of pressures.

Using computers

- The main problem with over-long use of computers, whether for games, email, surfing or school work, is over-expenditure of mental energy and concentration. Energy management should include management of time on the computer, with frequent rest breaks.

- Another problem can be light sensitivity, together with sensitivity to flicker on some computer screens – flicker is typically less of a problem with LCD displays (eg laptop displays). The solution is to turn down the brightness and contrast, adjust screen colours and make sure that conventional (CRT) monitors are run at a high refresh rate. Advice may need to be sought over this.

School attendance and home-based education – the law

- The 2002 Dept for Education and Skills statutory guidance *Access to Education for Children and Young People with Medical Needs* states that children off school sick for more than 15 days should be offered other education eg in the home.
- The 2002 Report of the Chief Medical Officer's Working Group, published by the Dept of Health states that most children with ME require home tuition and/or distance learning and some may need it in the longer term. This Dept of Health Report, and therefore its recommendations, is endorsed by the Dept for Education and Skills. It is summarised at www.tymestrust.org.
- Parents believing their child needs education in the home should seek the written support of their GP. Later confirmation from a consultant is helpful. These can both be sent to the school or Local Education Authority (LEA). Parents are advised to keep a copy. If the doctor writes to the school or LEA direct, parents are advised to ask for a copy.
- By law, a child is entitled to be educated at home if needed. The Tymes Trust/Nisai Education Partnership offers interactive online learning.
- The LEA may insist on a consultant's report before granting home tuition. Since a report could not be obtained within 15 days (see above) we are informed that this is not legally enforceable. The GP's letter is sufficient.
- A GP is a fully qualified doctor and can diagnose and treat ME. Any school that ignores medical advice may be failing in its Duty of Care and could be legally liable for deterioration in your child's health as a result.

Information for your school's SENCO (Special Educational Needs Co-Ordinator) is in *Professional Guides – The SENCO's Key Role in Supporting Pupils with CFS/ME*.

All schools have a Special Educational Needs Co-ordinator. This SENCO's guide has been produced to assist SENCOs to manage educational demands on children with ME to preserve health and help them achieve. It incorporates some of the best ideas and practice to come out of years of work in this field. First published by Birmingham University School of Education.

For further information on ME, see www.tymestrust.org or contact The Young ME Sufferers Trust on 0845 003 9002

Your Essex ME Companion and three issues of Vision from 2005/2006 have been produced and sent to you with the kind support of Essex Community Foundation's Millennium Fund.

Some Useful Contacts

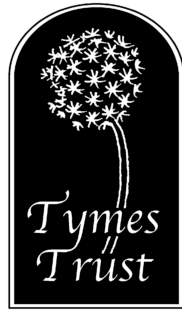
Websites

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| Citizens Advice Bureau | www.nacab.org.uk |
| The Department of Health | www.dh.gov.uk |
| The Department for Education and Skills | www.dfes.gov.uk |
| Disability Rights Commission | www.drc-gb.org |
| Essex County Council | www.essexcc.gov.uk |
| Legal website for disabled people | www.thesolicitorsroom.com |
| RADAR (Royal Ass for Disability and Rehab) | www.radar.org.uk |
| The United Kingdom Parliament | www.parliament.uk |
| The Young ME Sufferers Trust (Tymes Trust) | www.tymestrust.org |

Telephone

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| Benefits: Advice and information on benefits for people with disabilities | 0800 882200 (freephone) |
| Carers Line : Support and advice for carers | 0808 808 7777 (freephone) |
| Carers National Association | 080 8080 7777 |
| Free phone helpline on raising a disabled child including benefits and education. Welfare rights specialist. | |
| Citizens Advice Bureau | 020 7833 2181 |
| DIAL: Disability information and advice | 01302 310123, 01268 294400 |
| Disability Living Allowance helpline | 0345 123456 |
| Disability Rights Commission | 08457 622 633 |
| Essex Social Care Direct | |
| Adult (over 18): | 0845 603 7630 |
| Children (under 18): | 0845 603 7627 |
| Emergency service available if there is a risk of abuse or harm | |
| Primary Care Trusts | |
| Barking and Dagenham | 01708 465 000 |
| Basildon | 01268 705 000 |
| Billericay, Brentwood and Wickford | 01277 302 516 |
| Epping Forest | 01992 902010 |
| Harlow | 01279 694 747 |
| Havering | 0800 328 2556 (freephone) |
| Maldon and South Chelmsford | 01621 727 300 |
| Redbridge | 020 8478 5151 |
| Southend On Sea | 01702 224 600 |
| Tendring | 01255 206 060 |
| Thurrock | 01375 406 400 |
| Uttlesford | 01371 767 007 |
| Waltham Forest | 020 8928 2300 |
| RADAR (Royal Ass for Disability and Rehab) | 0207 2503222 |
| Samaritans (24 hour service) | 08457 909090 |
| The Young ME Sufferers Trust (Tymes Trust) | 0845 003 9002 |

Add any others you wish here



www.tymestrust.org