

Paediatric ME, CFS, SEID for Families and their GPs

In commemoration of Dr Alan Franklin FRCPCH DCH



I was a GP's wife, taking calls for the practice at evenings and weekends. I know that GPs need practical ways to help patients where there is no curative treatment. I was also a headteacher; I know how education can be modified for sick children. And I developed severe ME (diagnosed by that name) from a coxsackie B virus. All these experiences inform and guide my work with ME. The

late Dr Alan Franklin was one of the foremost experts in paediatric ME, and it was my privilege to work with him on many occasions, including the Chief Medical Officer's Working Group on CFS/ME.
Tymes Trust Executive Director Jane Colby

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The Queen's Award
for Voluntary Service

The MBE for volunteer groups

In 2010 Tymes Trust 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.

Free publications:
www.tymestrust.org

Advice Line:
0845 003 9002

Paediatric ME, CFS, SEID

The late Dr Alan Franklin was one of the foremost experts in paediatric ME. Based in Essex, in his long clinical experience he saw the whole spectrum of cases, from the least to the most severe, from all corners of the UK. He stated that the so-called 'fatigue' in ME:

is better described as exhaustion, asthenia or weakness, which is usually post-exertional, developing up to 3 days following moderate effort, and is not relieved by rest/sleep. [...] It may be physical or mental, can be severe and often fluctuating, and leads to significant reduction in normal activities.

Interviewed by Jane, he said: "I actually use the term *chronic fatigue syndrome* because it's more acceptable in medical circles. I usually explain to parents that there are different forms of chronic fatigue and that the severe form is also called ME." That was how he simplified for parents an umbrella term dominated by one symptom, 'fatigue'. In

severe cases, symptoms are relentless; there is deterioration with any effort. Dr Franklin informed child protection authorities that this is not a psychiatric condition, and not caused by parental neglect or abuse. He was in the Chief Medical Officer's Working Group on CFS/ME (children's section) which reported in 2002.

In 2011 an International Consensus Panel of clinicians, researchers and medical faculty representing thirteen countries and an extensive range of specialities, who together had diagnosed or treated approximately 50,000 patients with ME, stated [1]:

In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term 'myalgic encephalomyelitis' (ME) because it indicates an underlying pathophysiology. It is also consistent with the

neurological classification of ME in the World Health Organisation's International Classification of Diseases (ICD G93.3) [...]

Using 'fatigue' as a name of a disease gives it exclusive emphasis and has been the most confusing and misused criterion. No other fatiguing disease has 'chronic fatigue' attached to its name eg cancer/chronic fatigue, multiple sclerosis/chronic fatigue - except ME/CFS.

In 2015 the American Institute of Medicine produced a Guide for Clinicians, derived from its report [2], "intended to help primary and specialty care clinicians better understand this complex, debilitating and often-misunderstood illness." They recommended a new name: *systemic exertion intolerance disease* (SEID), explaining: "This name captures a central characteristic of the disease - the fact that exertion of any sort (physical, cognitive, or emotional) - can adversely affect patients in multiple organ systems."

Are there risks with Graded Exercise Therapy for ME and CFS?

The composite ME/CFS (or CFS/ME - see NICE) can imply that CFS and ME are synonymous. They are not. A Melvin Ramsay MA MD's original definition of ME differs markedly from widely used CFS criteria. **Ramsay cited fatiguability in contrast to fatigue.** Any patients diagnosed with 'CFS' who exhibit the fatiguability he describes will deteriorate following exertion, unless substantially recovered. Patient surveys consistently report this. As CFS is heterogeneous, are there risks to patients from graded exercise therapy? In ME, Ramsay cited diurnal variability and fluctuation of symptoms and physical findings, and "an alarming tendency to become chronic".

Professor Mark Van Ness has confirmed deterioration after effort by measuring gases exhaled during exercise; a fall in oxygen uptake occurs on a repeat test (two day Workwell protocol). Observations of *deviant physiological responses to exercise* reviewed by Twisk and

Geraghty [4] include *muscle weakness and myalgia, a substantial fall of oxygen uptake after exercise, an increase in metabolite-detecting (pain) receptors, increased acidosis, abnormal immune responses, and orthostatic intolerance.*

They conclude: *While we acknowledge the importance of physical activity in illness rehabilitation, our findings cast doubt on the efficacy of exercise protocols as a therapeutic approach* noting that, since these abnormalities are not observed in sedentary healthy controls, *the physiological abnormalities induced by ME/CFS cannot be simply explained by a sedentary life style and deconditioning or psychogenic factors.*

Ramsay wrote: "The clinical course of the Myalgic Encephalomyelitis syndrome is consistent with a virus type of infection." Extensive and ongoing work by virologists Chia and Chia [3] reveals chronic enterovirus infection of the stomach.



Jill Belch, Professor of Vascular Medicine at Dundee University

Research co-funded by Tymes Trust and ME Research UK and conducted at Dundee University [5] *showed for the first time, to our knowledge, that oxidative stress [...] and increased WBC apoptosis occur in children with ME. The data are also consistent with a reactivating or persistent viral infection.*

This is as predicted (published in 1997) by the largest epidemiological study on this condition to date by Consultant Microbiologist Dr Elizabeth Dowsett and Jane Colby [6] which also showed that **ME is the biggest cause of long-term sickness absence from school in both staff and pupils.**

NICE Guidance (CG53 2007)

Management

1.4.5.2: Healthcare professionals should proactively advise about fitness for work and education, and recommend flexible adjustments or adaptations to work or studies to help people with CFS/ME to return to them when they are ready and fit enough. [The words “education” and “studies”, not “school” or “college” are used. NICE accepted our recommendation on this.]

The venue for study may be the home until the young person is well enough to attend an educational institution without it undermining the doctor’s aim of helping their young patient improve. The doctor’s support for the child is invaluable, even though there is no specific cure that s/he can prescribe.

Virtual education, which can include interaction with tutors and other students, has been found very successful. It is energy efficient and allows a sick child to achieve and gain qualifications, just like other children. It also

restores self-esteem and can be very enjoyable. There is frequently too little enjoyment in the life of a child suffering with this painful and potentially chronic illness.

Education

1.4.5.4: Healthcare professionals should follow the guidance from the Department for Children, Schools and Families [now Department for Education] on education for children and young people with medical needs, or equivalent statutory guidance.

1.4.5.5: Healthcare professionals should work closely with social care and education services to ensure a common understanding of the goals of the person with CFS/ME. The use of a flexible approach should be discussed, including home tuition and use of equipment that allows a gradual reintegration into education. [Again, “education” is used, not “school” or “college”.]

The state must provide education suitable for a child’s needs, but some families may home educate.

No parent undertakes this lightly. We think it important to put on record that no parents with whom we have come in contact have told us they regretted their decision. Rather the reverse, since it has helped the child’s health and wellbeing to improve so markedly. That in turn enables more social contact with others.



The support that you provide children and their parents is both practically helpful and deeply thoughtful. I find it particularly touching that each member of your advice line has personal experience of ME. All of those involved with the Young ME Sufferers Trust should be incredibly proud of the brilliant work that they do.

**Rt Hon Nicky Morgan MP,
Secretary of State
for Education**