



The Brief

I was recently asked: ‘If you are a sick child you do have special educational needs, don’t you?’

Well no, not officially! It’s a different system. There were always two systems, with sick children assumed to have short-term needs ie sick in bed (in hospital or at home), then back to school, with maybe some home tuition or a hospital teacher as a stop-gap in between.

‘Special Educational Needs’ (SEN) on the other hand, was a phrase coined to replace other labels that people didn’t like. It referred to children with intellectual limitations of one sort or another. The most seriously affected would have been in special schools in the past, and some still are. Their needs are considered long term or permanent. You might get children with certain medical conditions in the special schools too. It was always a more protective environment. My mother was a specialist teacher in this field and became a lecturer at the Institute of Education, training already experienced teachers for such work.

When SEN was coined and the Statement of Special Educational Need was invented by Baroness Warnock (who has since expressed regret at the system it spawned) children thought to have intellectual limitations went through a process of assessment, typically taking years, during which nothing much might be done for them. Meanwhile, special schools were closing as they became unpopular with government. Integration into mainstream became the new black. It has recently been recognised that special schools have a vital role to play for some children after all. I covered this in the journal *Special Children* in 2005.

A Statement of Special Educational Need protects a child’s needs legally up to age

19 and there is an annual review to see if provision is

adequate. For sick children, however, there is no automatic long term help. A parallel system sees hospital schools and units as an alternative to home tuition, based on the ‘short-term’ model. Re-integration to school is a prime aim of such units.

The Code of Practice for the Identification and Assessment of Special Educational Needs omitted to list illnesses that might *cause* Special Educational Needs by affecting brain function. I argued against this, but it was policy to provide for the needs of sick children separately.

It has now been recognised that some children fall into both categories, as I had always argued, which is where ME sits. Because of the neurological dysfunction it causes in the brain, children with ME typically do have Special Educational Needs, as well as requiring access to suitable education under the Statutory guidance *Access to Education for Children and Young People with Medical Needs*.

Where children with ME have Statements, the review can seem like a test of their achievements rather than whether provision is adequate, so any goals need to be carefully set. Government has cut back on Statements but if you wish to ask for a formal assessment, the educational psychologist can consult the helpful *ME/CFS Guidelines for Educational Psychologists* by Chartered Educational Psychologist Naomi Burgess and myself at www.tymestrust.org/tymespublications.htm. Some families may find the questionnaire within it helpful to demonstrate their needs, whether or not they are asking for formal assessment.

Quotes : The Nightingale ME Definition

Byron Hyde MD (of the Nightingale Research Foundation) separates ME from CFS and demonstrates that ME is an early diagnosable and provable disease:

ME is a clearly defined disease process. CFS by definition has always been a syndrome. At one of the meetings held to determine the 1994 CDC definition of CFS [...] Dr. K Fukuda stated that numerous ME epidemics - he cited the Los Angeles County Hospital epidemic of 1934, the Akureyri outbreak of 1947-48 and the 1955-58 Royal Free Hospitals epidemics - were definitely not CFS epidemics. Dr. Fukuda was correct. [...]

Primary ME is an acute onset biphasic infectious disease process, where there is always a measurable and persistent diffuse vascular injury of the CNS [Central Nervous System] in both the acute and chronic phases. Primary ME is associated with immune and other pathologies. [...]

Primary ME is a chronic disabling, acute onset biphasic infectious disease process affecting both children and adults. There are both central and peripheral aspects to this illness. [...]

***Primary Infection Phase:** The first phase is an epidemic or endemic infectious disease generally with an incubation period of 3 to 7 days; in most, but not all cases, an infection or infectious process is evident. (See *Clinical and Scientific Basis of ME/CFS*, Hyde B, pps.124-126)*

***Secondary Chronic Phase:** The second and chronic phase follows closely on the first phase, usually within two to seven days; it is characterized by a measurable diffuse change in the function of the Central Nervous System. This second phase is the persisting disease that most characterizes ME [...]*

Extent of Injury

***Type 1:** One side of the cortex is involved [...]*

***Type 2:** Both sides of the cortex are involved [...]*

***Type 3:** Both sides of the cortex, and either one or all of the following: posterior chamber organs (the pons and cerebellum), limbic system, the sub-cortical and brainstem structures are involved. Type 3B are the most severely affected patients [...]*

Degree of Injury

***Type A:** Anatomical integrity is largely maintained in the Brain SPECT scan.*

***Type B:** Anatomical integrity is not visible in the CNS SPECT scan.*

Over time, new areas of the brain can take over functions of injured areas.

What is new and different about the Nightingale ME Definition is the following:

A Testable Definition:

The definition is set out in both a clinical diagnostic and scientifically testable fashion. This will allow the physician both an early diagnostic bedside or office understanding of the illness and a scientific and technological method to investigate and confirm the diagnosis.

The Nightingale Definition lists the following:

Testable Neuropsychological Changes

Testable Major Sleep Dysfunction

Testable Muscle Dysfunction

Testable Vascular Dysfunction. POTS; Cardiac Irregularity; Raynaud's Disease; Circulating Blood Volume Decrease; Bowel Dysfunction; Ehlers-Danlos Syndromes Group; Persantine Effect in ME Patients; ME Associated Clotting Defects

Testable Endocrine Dysfunction: This feature is common and tends to be a late appearance. It is most obvious in: Pituitary-Thyroid Axis; Pituitary-Adrenal Axis Changes; Pituitary-Ovarian Axis Changes; Bladder Dysfunction Changes

Read the full Definition at
www.tymestrust.org/pdfs/nightingaledefinition.pdf

Ten Points on the Education of Children with ME

In my recent feature for the ME Association's *ME Essential* I mentioned my first article for the educational journal *Special Children*.

Published in 2000 and now available on the Trust's website, it is a practical 'How To' setting out principles that really do enable a child with ME to achieve educationally whilst preserving health as much as possible. I developed these principles through years of personal experience and study of the illness, and they have proven consistently effective where applied. They represent energy-efficient education.

A parent recently emailed me about 'Ten Points':

I am so glad to say that your staggered educational plan has worked - and is working - for my daughter. Though we still have many years ahead of us, I believe your plan is the only way forward for young people in her situation. I also believe that it protects health and generally ensures a balanced lifestyle despite illness.

At last we are seeing some of the principles I drew up in the 1990s being regularly recommended by doctors.

One was revolutionary at the time - instead of the sick child studying a little of many subjects, only a few are studied at once, to aid achievement and fulfil a child's right to 'suitable education'. It was revolutionary because the National Curriculum aimed to provide 'a broad, balanced curriculum'. But this 'entitlement' proved, for many children with ME, to be an entitlement to fail at all subjects rather than succeed in a few.

Another principle is that, just like studying an instrument, children with ME should take exams when ready. That way, a portfolio of qualifications can be amassed and further subjects studied. The principle of taking exams when ready has now been put forward by government in certain circumstances.

www.tymestrust.org/pdfs/tenpoints.pdf

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

In the Spotlight : The Tymes Trust View

Self-Help

ME ~ and My Friends (*a leaflet for your friends*)

The Tymes Trustcard (*a pass card for school*)

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

Reports

ME Diagnosis : Delay Harms Health †

Children and Young People : The Key Points

The Forgotten Children : A Dossier of Shame †

Succeeding with ME (*the Virtual Classroom*) †

Our Needs Our Lives (*on CFS/ME clinics*) †

† presentation copies available

Experiences

Mummies Aren't Supposed To Cry

Whispered Words (*the severely affected*)

For Professionals

The Nightingale Definition of Myalgic Encephalomyelitis (ME)

Professionals Referral Service

Teacher Information on CFS/ME

Back to School?

Pushing the Boundaries in ME/CFS

Ten Points on the Education of Children with ME

The SENCO's Key Role in Supporting Pupils with CFS/ME

The Doctor's Guide to ME in Children and Young People

GPs Good Practice Guide to Education for Children with ME

Physios Urged to Go Cautiously

Implications for Schools of the Chief Medical Officer's Working Group Report on CFS/ME

ME/CFS Guidelines for Educational Psychologists

Care of CFS/ME in Children

Everyone wants to protect children, but this system can go wrong. I was recently asked to provide evidence for the Parliamentary Group calling for the withdrawal of the present guidelines on Munchausen's Syndrome by Proxy / Fabricated Induced Illness (MSBP/FII). These terms label parents as deliberately harming their children. Misunderstandings can occur where the child has ME, and child protection procedures may once again be on the rise. Do seek legal advice if this happens to you, and contact the Trust for assistance.

Here are some documents available online that you can print out to assist your case.

Special problems of children with ME/CFS and the enteroviral link

Journal of Clinical Pathology
www.cfids-cab.org/rc/Colby.pdf

This includes the following quote: *ME has not uncommonly been mistaken for school phobia, anorexia nervosa, neglect, child abuse, MSBP/FII, or Pervasive Refusal Syndrome (PRS). The common factor is often the perception of the illness as not capable of causing profound physical disability over a long period of time, with Cognitive Behaviour Therapy mistakenly employed as a 'cure'.*

The Key Points of the Chief Medical Officer's Working Group Report, 2002

www.tymestrust.org/pdfs/keypoints.pdf

A 4-side summary of the main conclusions from the Chief Medical Officer's Working Group on CFS/ME (Dept of Health 2002). The most relevant quotes are probably these:

a) In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection conferences or initiating care proceedings in a family court

b) Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse

Another quote explains that as there is no 'cure' for ME: *It is good practice to encourage patients to become experts in self-management and to choose between treatment options.*

Professionals Referral Service

www.tymestrust.org/pdfs/referralservice.pdf

How social services and others can access experts in their own professions who are also experienced in ME through the Trust, plus a page from *The Key Points*.

Our Needs Our Lives

www.tymestrust.org/pdfs/ourneedsourlives.pdf

The relevant pages are 32/33, revealing that statistics about young people's families being suspected of MSBP are not consistent with National Statistics.

The SENCO's Key Role in Supporting Pupils with CFS/ME.

www.tymestrust.org/pdfs/senco.pdf

This explains the interrupted pattern of school attendance that typically occurs in ME. It was written for Birmingham University School of Education.

The Quick Tour of ME

www.tymestrust.org/pdfs/quicktour.pdf

Explains the symptoms and tells people about the Trust, with a commendation from the Prime Minister.

To my knowledge, and that of the Trust to date, no suspicions of our members being thought to have MSBP have been confirmed.