

“WHO WILL PROTECT THE CHILDREN?”

A report

by

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The Alison Hunter Memorial Foundation in Australia, was the sole convenor/organiser of the Third International Clinical and Scientific Conference on Myalgic Encephalopathy/Chronic Fatigue Syndrome which was held in Sydney in December, 2001.

Recently I received a copy of the video which covered the segment of the Conference that dealt specifically with children and I was asked to write a report on it.

"Who will protect the children?" is an apt title and as I watched the video, I thought of Gordon Thomas' book "Journey Into Madness - Medical Torture and the Mind Controllers" in which he said:

"Nothing I had researched before could have prepared me for the dark reality of doctors who set out deliberately to destroy minds and bodies they were trained to heal."

It occurred to me (as it has done on other occasions) that some of the doctors referred to by both of the speakers on the video, are not so very different from the subjects in Thomas' book.

The cold, hard deliberateness with which the extensive scientific evidence of the physical nature of ME/CFS is routinely dismissed or ignored, goes beyond abuse. It speaks of an agenda that is not concerned with patient welfare.

While families agonise helplessly over the suffering they are forced to witness, the sufferers themselves have to deal with the cruel physical and mental consequences of inappropriate attitudes and treatments for psychiatric disorders that did not and do not exist.

It is hard enough for sick adults to protect themselves against misdiagnoses and mistreatments, but this video highlighted that where children are concerned, some are even denied parental protection.

The two speakers were:

1. Nigel Speight, a UK Paediatrician with 20 years experience in the Paediatric Department of the University Hospital of North Durham, UK.
2. A father presented the medical nightmare which his family and in particular, his daughter who suffers ME, endured.

FIRST SECTION - presenter: Nigel Speight (hereafter referred to as NS)

NS based his observations upon his many years of experience and one of the first points he made, will hold a certain irony for ME patients and their carers - some doctors "*can't stand the patient being so ill*".

As a result of this intolerance, one of two courses of actions is typically taken: (1) if possible, the doctor will steer clear of severe cases or (b) he will embark upon what NS refers to as "furore therapeuticus" – by which he means, intensive psychiatric "therapy".

Where "furore therapeuticus" is employed and the rehabilitative measures and psychotropic drugs succeed only in making the patient worse, doctors often become angry. The patient's failure to respond positively is blamed upon his or her stubborn determination to remain "ill".

NS believes that total rejection is probably safer for the patient than the "*We have ways and means of getting you better*" approach.

Time constraints did not allow NS to go into many histories, but he did refer to nine of his most serious cases where:

- * all had been bed-ridden for over 6 months
- * all had severe total body pain
- * all had sleep problems
- * all had difficulty with nutrition and fluid intake - 6 needed prolonged tube feeding.

In his role as paediatrician, NS is often called upon to supply second opinions regarding the diagnosis and its severity. This includes cases where allegations of parental abuse raises the issue of child protection. The point was made that, even

where the condition is life threatening, many of the patients' regular doctors still do not acknowledge that ME/CFS is a physical condition let alone one that can be so severe.

Fourteen cases in which parents were accused of child abuse were outlined. *"Take my word for it,"* said NS, *"these were all false allegations."*

It should be noted that for every one of those 14 cases, 100 more families throughout the UK were being threatened.

Of the 14 cases:

- * 9 were girls and 5 were boys;
- * 6 were prepubertal
- * 3 had been removed from their homes by the police and Social Services.
- * Single mothers are particularly vulnerable to medical abuse and there were 9 of them.

Four of the mothers had health problems of their own and were accused of keeping the children out of school to care for them. As a result of the onslaught, two mothers became suicidal. The "diagnosis" Munchausen's Syndrome by Proxy was used, and in some instances, the ME/CFS diagnosis was replaced by the convenient new "disorder", Pervasive Refusal Syndrome.

After NS's involvement, 13 of the 14 cases were reversed:

- * 8 when social services withdrew their allegations of abuse (for which there was no evidence) and
- * 5 as a result of court decisions.

At the time of the Conference, several paediatricians were still being investigated by the General Medical Council.

It was emphasised that in each case, all the main principles of ethics had been breached.

Child X is an example of the lengths to which some medical personnel will go in order to obtain parental obedience.

Child X was a very active boy who was elected rugby player of the year, but at the age of 13, he was struck down with ME/CFS. Knowing their son's enthusiasm for

sports and life in general, the parents were in no doubt that his illness was physical and were horrified when told that he was to be admitted to a teaching hospital for care under a certain psychiatrist.

In an effort to protect the child from inappropriate treatment and medical harm, the father took him abroad. Once his son was safe, he returned to the UK where he was arrested and sentenced to two years in prison - a term he was happy to endure knowing that the authorities could not touch his son. Unfortunately that feeling of security was short lived for the mother was then targeted and also threatened with imprisonment if the boy was not handed over to the authorities for treatment.

During the 7 months that Child X was in hospital, his condition deteriorated considerably and his safety was not assured until the matter was finally raised in the House of Lords.

Child X remains severely ill and is terrified of health professionals. When asked by NS what position he played in rugby, the boy looked at him as if he was mad. Child X could not remember that he had had a childhood and that he had played rugby.

SECOND SECTION - presenter: a father.

That the situation is no better in Australia, was highlighted by the father of Jenny who suffers ME.

Jenny loved school. She was outgoing, active, sporty and an academic achiever but at the age of 13, she contracted glandular fever. This led to a later diagnosis of CFS and her admittance to hospital where she was entered into a rehabilitation programme. She collapsed two weeks later.

Thereafter she spent her time between two hospitals and a pattern emerged.

A programme of cognitive behavioural therapy (CBT) and rehabilitation was enforced. The parents were told that activities with other children would distract her from her “*intrusive symptoms*” – amongst which, were light and noise sensitivity. Rewards were offered for carrying out the required activities, but since they were beyond her capabilities, she was punished instead. This usually meant a cut back in family visits. Jenny’s health deteriorated.

When Jenny complained, her symptoms were invalidated. When her parents advocated on her behalf, they were told that they were undermining the hospital.

Some typical words of “encouragement” made by the hospital staff:

“You’re doing this so you don’t have to go to school..” (She loved school.)

“When are you going to get a life?”

“I don’t believe you have CFS!”

“Ninety percent is in your head. You’re not trying! You’re not pushing!”

“I’d like to give you a kick up the bum!”

Jenny had difficulty with eating and comments such as the following were made:

“Don’t take any notice of her. She’ll be sensible one day and start eating.”

“I’m the doctor and you’re the patient. I can con your parents into keeping you here.”

“You’ve regressed to a five year old.” This judgement was based on the soft toys that had been given to her.

When quiet and passive due to weakness, she was told she should be angry at her illness. When she demonstrated anger and/or distress at the manner in which she was treated, she was ignored.

If she cried she was told she was depressed. If she smiled, she was told that there was such a thing as smiling depression.

Some recorded medical opinions while in hospital:

At 6 weeks the diagnosis was changed to Pervasive Refusal Syndrome.

At 5 months, the mother was deemed to be an “*illness model*”.

At 9 months it was considered that Jenny had become “*adapted to her invalidism*” because the family had “*personalised*” her room with soft toys and mementoes.

At 10 months Jenny’s parents were blamed for her “*excessive invalidism*” and she showed “*a steely resistance to staff encouragement*”. (The father commented that Jenny was so weak, she was like a rag doll.)

Conflict between the parents and medical staff over psychiatric treatment was recorded.

Jenny’s struggle with the medical staff was “*an end in itself*” and that inpatient treatment “*encourages her to prove how ill she is.*”

At 12 months instructions were recorded that if the parents requested a referral, the only option to be offered was re-admittance to the first hospital for more psychiatric treatment.

At 20 months a new diagnosis was made - psychosomatic disorder. Jenny was discharged but contact with the hospital continued, presumably on instruction.

At home, she showed some improvement. She was certainly happier and even gaining weight but after five months the parents and Jenny were summoned to a meeting with personnel from both hospitals.

There the specialist told them that Jenny had not made any progress and that home care was no longer acceptable. The diagnosis, they were told, was not CFS, but deconditioning and psychosomatic disorder.

In front of a terrified Jenny, the parents were also informed that they had 48 hours in which to either agree to have her readmitted to hospital for re-evaluation and intensive rehabilitation or face the consequences of a child protection order.

That Jenny and her parents felt confusion, frustration, humiliation, anger, pain and fear, is hardly surprising. The lack of ethics and professionalism was plain, and one could not argue with the father's belief that those dealing with his daughter had abused their power.

THIRD SECTION – presenter: Nigel Speight

NS highlighted the following political issue:

Psychiatrists “have been allowed to hijack this condition for 30 years too long...they are emperors prancing around in the nude admiring each others non-existent clothes. Someone should break the news and persuade them to get back to their genuinely mentally ill patients who could benefit from their attention.”

Another political issue is terminology. A large section of the medical community attempted to do away with the title myalgic encephalomyelitis (ME) in favour of chronic fatigue syndrome (CFS). Patients refused to budge on this, and while support charities stuck to ME, the medical profession adopted CFS. In some quarters “*a strategic retreat to the more defensible position of encephalopathy*” was adopted.

During the first 5 years of NS's 20 years in the Durham area, there were few cases of ME. Since then the incidence has been rising and currently, there are 120 cases in Durham alone.

In this section, NS detailed 49 consecutive cases (covering the whole spectrum of severity), between 1988 and 1996.

Past histories showed the following:

Family history of ME/CFS in first degree relatives = 7 (14%)

Past history of migraine = 33 (67%)

Family history of migraine in first degree relatives = 28 (57%)

According to the CDC diagnostic criteria, a diagnosis of ME/CFS can only be made if the level of activity has been reduced to 50% or less. NS felt that left a number of patients with no diagnosis. He uses the following table when making a diagnosis.

Disability

Mild 70 – 90% activity level

Moderate 40 – 70% activity level

Severe 5 – 40% activity level

During the worst 6 month period

6 (12%) were mild (these would have been excluded by the CDC criteria)

19 (39%) were moderate

24 (49%) were severe

Social class

Of the 5 class categories, 27 cases (55%) came from Social Classes III, IV, V which negates the claim made by psychiatrists that this is a disease of middle class children i.e. Social Classes I and II.

The indications are that children have a better recovery rate than adults.

The follow-up revealed:

15 cases (31%) made a full recovery. However, it should be noted that the mean duration of the illness was 5.1 years.

27 cases (55%) had improved significantly.

7 cases (14%) remained severe and static.

The claim made by one prestigious hospital in London, that most children get better in 12 months, is “*a damaging myth*”.

School loss

ME/CFS accounts for the loss of 89 academic years which represents 1.8 years per child. This is the highest school loss for medical reasons in the UK.

Progress charts over the follow-up period, show that the illness follows no fixed pattern.

Conclusions

1. In North Durham, paediatric ME/CFS is a significant problem which appears to be increasing.
2. ME/CFS constitutes a major cause of chronic ill health and school loss.
3. The disease is not confined to social classes I and II.
4. There appears to be an association with migraine headaches.
5. Prognosis guarded - cautious optimism in most cases.
6. There is a need for further research on incidence, aetiology and treatment.

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The video, “Who Will Protect the Children” is available from:

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