

‘WHO WILL PROTECT THE CHILDREN?’

CHRISTINE HUNTER

**Consumer Advocate, Physiotherapist
Alison Hunter Memorial Foundation**

Abstract

Disease is very old and nothing about it has changed. It is we who change as we learn to recognise what was formerly imperceptible.

J M Charcot

Winston Churchill reminded us that if we do not learn from history we are doomed to repeat it.

Such observations were never more relevant to the position today facing young people with ill-defined illness, such as chronic fatigue syndrome (CFS). Medical history is littered with the tragedies of those whose diseases awaited scientific recognition – myasthenia gravis was attributed to somatoform disorder; autism was attributed to ‘refrigerator mothers’.

A philosophy of disbelief pervades the medical approach to conditions where the aetiology remains elusive. This shifts responsibility to the child and family to provide proof of illness.

Attributions such as school phobia, malingering, hypochondria, parental overprotection, Munchausen Syndrome by Proxy, somatoform disorder and conversion hysteria leave young people severely ill, at risk of enforced removal to state or psychiatric care. Appropriate medical treatment is denied.

Children who are sick have even fewer rights and even fewer advocates than adults. Children cannot make their own decisions. They are dependent upon their worried parents who are dependent upon a physician’s advice. And when that advice is wrong, the harm done to a still developing mind and body can be permanent.

David Bell¹, paediatrician, CFS researcher

Can we learn from past tragedies? Care today is seriously failing young people with complex illnesses. They face isolation, humiliation, contempt, hostility, torment and cruelty.

From whom? Loving family, good teachers, excellent doctors, compassionate nurses and physiotherapists and people with exemplary standards of care.

How can this happen? Then again, how can someone look so well and claim to feel so ill? But appearance belies many diseases. The difficulties are further compounded by ‘normal’ laboratory

test results. Or is it **no abnormality detected**, NAD? NAD does not necessarily mean normal, ie. no pathology to be found.

Absence of evidence is not evidence of absence. CFS is one of many diseases with no specific diagnostic test. Instead, distinct clinical criteria are used for diagnosis. Rather than the physician acknowledging the limitations of medical science, more frequently the young person is referred for psychiatric help, feeling disbelieved and dismissed.

U.S. psychiatrist, Dr Alan Gurwitt,² spoke recently of ‘*a major crisis in paediatrics*’, warning of ‘*the iatrogenic damage the psychiatric profession continues to cause young people with CFS*’.

Semmelweis, one of the earliest pioneers of asepsis was ridiculed for cautioning surgeons to handwash between dissections and confinements. Roy Porter’s³ text of medical history reminds us it took the profession 50 years to ‘believe’ in bacteria.

With the constant denial imposed upon the child and the assumption that the symptoms are imaginary, only confusion can result. A confusion that may colour judgement and self-image for the next 50 years. The child never understands the concept of normal health.

David Bell, paediatrician

The voices of young people and their carers provide poignant testimonies to the consequences when people don’t believe.

Amanda’s Story

Amanda who became sick following rubella immunisation, has had a severe progressive illness course with life threatening complications.

‘When I was hospitalised for 10 weeks because I could not stop vomiting I had lost 25 kgs. I was interviewed by a psychiatrist who suggested perhaps I was not wanted by my family because of the nine year break in age between my older brother and sister, and me. He also said because I was minded on occasions by my grandparents that my illness could have been caused because I was interfered with by my grandfather, which is very untrue’.

This young girl was transferred to an eating disorders unit without prior discussion. She discharged herself after three days. Outpatient motility studies requested by her GP showed severe gastroparesis. Rehospitalised, considerable remission of gastrointestinal symptoms was achieved after 12 weeks of jejunal feeding.

With illnesses which are poorly understood the dividing line between research and treatment is a grey area. Transparency and closer scrutiny of behavioural programs for young people may find some aspects of such programs rejected by Ethics Committees. Would adults tolerate the loss of “privileges” such as visitors, telephone contact, and television when unable to comply with prescriptive regimes?

Michelle's Story⁴

'When I was 12 I caught glandular fever and began to get worse and worse. Within two months I was bedridden, I was in great pain and my legs started to go numb. I got to the stage where I could no longer eat without being sick. I was to be tube-fed in the end. I became totally paralysed from the waist down. My hands and feet started to claw-up. The doctors and some of the nurses and physiotherapists kept on telling me that it was all in my mind. It got to the stage where my physiotherapist was told to put me in the swimming pool. This wasn't to help me, it was to harm me for the rest of my life. The psychiatrist was there too. He took off all my clothes except my underpants and they both lifted me up to put me in the pool. I was helpless I had only my right arm so I couldn't defend myself. They were watching me sink to bottom of the pool. I was too tired to struggle. I was going to die if they left me. I was at the bottom of the pool. I was on my back staring up. They said if I needed air then I would come to the top on my own. My mum came in to see what was happening. I couldn't hear very much but my mum climbed into the pool with her clothes on and got me out while they were still trying to defend what they had done.'

Ethicist, Peter Singer,⁵ has written, *'The difficult question we should be asking ourselves is: What is it that we think ourselves justified in doing today that will create scandals for the next generation, to look back on with shock and horror?'*

'First do no harm'

Anne's Story by her mother⁶

'Nurses who knew little or nothing about the illness would time and time again try to make her do things she was not able to do. Anne was unable to swallow and a nasogastric tube was inserted... she was strapped into an upright chair and left in a semiconscious state while the nurses laughed and ridiculed her for pretending to be ill. Her clock was taken away. Nurses' lied to her about the time of day to try and confuse her because the consultant had decided she was staging attacks at a determined time. She lost sensation in her legs and could not move the top half of her body. She could only speak in a whisper. Still the nurses kept on saying "when Anne stops pretending...." She was laid on the floor until she was freezing in an attempt to make her get up and put herself back to bed. Anne was informed the reason she was there was because her parents did not want her at home.'

Premature enthusiastic rehabilitation may lead to 'apparent' improvements in activity as the powerless child struggles to comply. But these improvements may be unsustainable, at a cost of worsening symptoms, and may in fact jeopardise the long term prognosis.

Complaints and attempts by parents to intervene as the child's advocate can have dire consequences as demonstrated by UK paediatrician, Nigel Speight⁷.

'Families have been referred by their paediatricians to social services as cases of emotional abuse and neglect, non school attendance and Munchausen Syndrome by Proxy... These actions have been inappropriate and have constituted "child abuse by professionals" '.

Amy's Story

The following testimony (excerpt) was presented to the CFS Interagency Coordinating Committee appointed by the U.S. Congress to oversight CFS: Jill McLaughlin 29 April 1998.

Amy who just turned 15 has been sick since she was 8 or 9. It took us a year to get a diagnosis during which time we went to numerous Boston specialists.

We were told repeatedly that there was nothing wrong with her to which we replied "yes there is something wrong you just can't happen to find out what it is". She had missed 45 days of school in fifth grade. We finally found a doctor at Children's Hospital who made the diagnosis. We were very relieved at the time thinking she would take the summer off to recuperate and she would be fine.

By the sixth grade she was not fine and was unable to attend school even part time. Mid-year we were notified that the school had contacted the Department of Social Services and threatened to file a 51A – child abuse and neglect. We were not neglecting her medical condition, and indeed there were no treatments, we contacted a lawyer.

Later that year there were suspicions that we were "encouraging illness behaviour" and the school system demanded a full psychiatric evaluation, which came back that there was no evidence of depression or family dysfunction. If this is what happened to us – my husband is a doctor and I have a degree in biology, as well as our having some local political connections, what must happen to others.

*It is unconscionable that patients who are very ill have to search for information and potential treatments and try to educate the very people whose job it is to protect them. **We've been subjected to deceit, denial and dissembling. Patients are still suffering, mainly due to their inability to access adequate medical care and social support. Others are dying or committing suicide – not from fatigue or stress or depression or deconditioning, but from negligence and apathy.***

Faced with the difficulties presented by such complex medical cases/conditions, sometimes the response reveals more about the practitioner's prejudice than the patient's condition.

Thomas' Story

'I was a student and champion athletic at national level. I went trekking the Kokoda Trail having been chosen to take part in a leadership program in August 1996. I had the routine vaccinations before leaving home, but part way through the trek I collapsed with vomiting and diarrhoea.

Being too ill to go on I was left in a native village to be air-lifted out but was still there three days later because cloud cover make it impossible for a plane to get in, when a runner brought the news the trek leader had fallen and a plane was coming in to collect him. The runner helped me to stumble/run for one and a half days to the airstrip. The gastric, and other symptoms were then by far worse and I was having spasms of being quite unaware.

On return to Sydney I had lost 25kgs and our G.P. said I has the symptoms of typhoid fever. I was admitted to hospital where the diagnosis differed. After four days of I.V. therapy I was discharged. The gastric symptoms had subsided but other symptoms remained and I was sent home to rest.

Until August 1998, although I saw many medical and natural health practitioners I remained ill and was in varying states of debilitation, mostly wretched. I collapsed again and was admitted to hospital where various examinations, (all of which were negative) were done. I was put on an I.V. and discharged six days later still vomiting.

I collapsed again twelve days later and was re-admitted for another five days. During this admission the endocrinologist who had met members of our family during my prior hospitalisation decided that I needed to see a psychiatrist because my problems were being caused by the effect up on me of having adopted sisters with coloured skin.

She labelled me as suffering from anorexia. She was correct. By this time I was 28kgs lighter than before I went to New Guinea. She ordered the I.V. down and I went home directly after its removal still vomiting. It was frightening to realise there seemed to be nothing I could do about my hopeless situation.

Six weeks ago I completed an eight month course of antibiotic therapy under another medical practitioner. I have gradually improved with this treatment and now feel I am well on the way to recovery.'

Through the prism of disbelief all signs and symptoms and behaviour of the young person and parents will be misattributed. Documentation may be at best scant or at worst seriously flawed.

Misattributions:

- expanding file of normal results
- a vast symptom complex
- worried attentive parents
- lethargic, requesting pain relief
- normal looking child with marked loss of function – paresis, paralysis
- nausea, anorexia, gastrointestinal dysmotility, pain and weight loss
- too ill to attend school
- impaired cognition affecting new memory and sequential learning
- requests for further investigation
- venepuncture sites by pathology
- photophobia/darkened room - sunglasses
- prolonged course/failure to recover
- ▷ over-investigation/thick file syndrome
- ▷ too many symptoms to be real
- ▷ over-protective, encouraging invalidism
- ▷ depressed, withdrawn, anxious
- ▷ hysteria, abnormal illness behaviour, pervasive refusal syndrome
- ▷ anorexia nervosa, bulimia
- ▷ school phobia
- ▷ lack of motivation/lazy
- ▷ keen to submit to painful unnecessary tests
- ▷ evidence of drug abuse
- ▷ social withdrawal, Miss Haversham Syndrome
- ▷ maintained by belief in illness

The profile of Munchausen Syndrome by Proxy (MSBP) is reinforced by such labelling and can lead to court proceedings for removal of the child. An authoritative study published May 1999⁸ revealed, *The overwhelming majority of judges indicated that the failure to make expert witnesses accountable constituted a significant problem for the fact finding process.* The implications for MSBP cases are grave.

Through the prism of belief such signs and symptoms would be acknowledged as manifestations of serious disease which eludes standard investigations. Specialised tests are required and a well-informed practitioner determined to trust and support his patient and seek new avenues of help. A true partnership in care will encourage and value the young person's input in decision making. Parents should be respected for the expertise they develop in their child's condition.

'If you disbelieve a mother you do so at your peril and the peril of their child. They're very acute observers.'

Professor John Beveridge
Former Professor of Paediatrics, Prince of Wales Children's Hospital

There are time lags between occurrence, recognition, finding a label, acceptance and scientifically proven treatment. There is also stigma... When a disease is not fully accepted a number of important things happen. Self help groups become extremely important. Things they learn become part of medical knowledge and enable us as doctors to care for our patients better and often they lead us to look back and realise how we didn't do it well and we could perhaps do it better next time.

New Zealand Doctor, 29 April 1993 Dr Malcolm Fisher

Where do the new advances lie?

- Emerging illnesses demand meticulous documentation to reveal their natural course and long term outcome.
- Molecular medicine will shed light on inborn errors of metabolism, defects in the antiviral defence pathways.
- Forensic polymerase chain reaction PCR techniques will lead to identification of complex infections – mycoplasma, Rickettsia, Lyme and Q fever agents, retrovirus and prions.

Such infectious agents can remain undetected within the cells and evade the immune system.

*'These silent survivors could be causing chronic illnesses, we presently don't think of as having a viral origin'*⁹ stressed Professor Michael Oldstone at the recent International Congress of Virology, Sydney.

- QEEG; SPECT and PET scans will better identify mechanisms of brain dysfunction.
- Genetic variability may be linked to susceptibility to toxic chemicals¹⁰.

Such advances clearly demonstrate current limitations of testing.

In conclusion it is imperative those entrusted with responsibility – the health professionals, peak advocacy bodies, family service officers, legal counsel and judiciary – to advocate for children’s health care, protect their rights and **hear their voices**.

A man should never be ashamed to own he has been in the wrong, which is but saying, in other words, that he is wiser today than he was yesterday.

Jonathan Swift

References

David Bell, MD Paediatrician, Harvard CFS Researcher - Author *The Doctor's Guide to Chronic Fatigue Syndrome*

American Association for Chronic Fatigue Syndrome Scientific Meeting Boston, USA October 1998. Address: The Greatest Benefit to Mankind: A Medical History of Humanity from Antiquity to the Present - Ray Porter, Harper Collins

Interaction: the *Journal of Action for ME*: No. 20, Spring 1996

Peter Singer, Professor, Centre for Human Bioethics, Monash University Victoria – Essay, Sydney Morning Herald

Interaction: the *Journal of Action for ME*: No. 20, Spring 1996

International CFS Conference April 1999 London – Essex Neuro Sciences Unit, Southbank University. Address: Australian Judicial Perspectives on Expert Evidence – Dr Ian Freckelton Australian Institute of Judicial Administration Inc.

11th International Congress of Virology Sydney, August 1999 – keynote address

New Scientist 19 June 1999