Preview...

The Young ME Sufferers Trust

The Human Factor

A preview of The Colby Report 2008

by Jane Colby

Updated passages from ME - The New Plague

Why did No-one Believe that ME was a Persistent Viral Infection?
from an exclusive interview with John Chia MD

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No-one to Turn to

Early in 1996, the phone rang at the home of Mary, one of many local group volunteers throughout the country who have ME themselves and are willing to be a ‘listening ear’ for others with the condition.

When she answered, there was a silence, broken only by the sound of a child crying. This was particularly distressing because, without knowing the problem which triggered off the call for help, Mary was powerless to do anything about it.

For some time she kept contact with the caller. At one point the girl tried to speak, but what followed were simply sobs which turned into a paroxysm of tears. Mary reassured her. ‘Don’t put the phone down. I’ll wait until you feel ready to speak.’ But in the end the receiver was replaced without any words being exchanged.

Dialling 1471, Mary discovered that the source of the call was a nearby school. It was a sobering thought to realise that this child, surrounded by friends, teachers, welfare and class assistants, had no-one to whom she could turn but a stranger.

In the process of researching ME in schools, Dr Elizabeth Dowsett and I observed that many schools where there were known cases (some, indeed, with a number of cases) declined to take part in our study, although it was entirely confidential.

It is a sad fact that the disbelief which originally surrounded ME and which still persists in less well informed medical and educational circles has seemed to be particularly common in those who deal with children, where suspicions that it is the parents who are actually causing the illness are all too frequent.

Children are not easily able to speak for themselves. When things go wrong with their bodies, their difficulty in getting someone to listen is even more acute than that which adults face. All too often, adults in positions of authority expect children to listen to them, but only make token attempts to reciprocate.

In addition, children may not even realise that what they are feeling is abnormal, and then it is truly up to adults to do their realising for them.

One paediatrician who was especially concerned to find out direct from children themselves how they felt and what they could manage to do was allergy and ME specialist, the late Dr Alan Franklin.

> ***Jane*** The children who’ve been mistakenly diagnosed as school phobic or with anorexia nervosa or some other emotional disorder? What is the after-effect of trying to force them back to school?

Alan The majority effect is a total rebellion on the part of the family. The family usually say, ‘We’ve had enough of this and we’re not going to see you any more.’

Jane Do you feel that’s a healthy reaction?

Alan On the whole, yes. I think parents are pretty good at recognising what’s going on.

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If the Hat Fits…

Tommy Cooper was master of that old music hall turn - reciting a dialogue while you act out all the parts. To show who is speaking, you take a different hat out of the box and place it on your head. In dialogues, this leads to some quick changes!

But when one of the hats sticks - like the mask of comedy sticking on the face of that famous mime artist Marcel Marceau, while the rest of his body went through agonies trying to remove it - the end effect is not at all funny.

The profession a person a follows (the hat that is worn during work hours) is not the sum total of that person’s identity. A doctor or a teacher or a social worker is not merely a professional, he or she is a person with a personal life. This personal life has often been seen as a total irrelevance, if not an active hindrance, when the professional hat is being worn. But is it really a source of distraction, or is it rather a source of wisdom, to allow both hats to remain in place at once?

Parents are often seen by professionals as somehow different from them in the course of their work with children; perhaps even without realising it, they come from a position of ‘I’m the doctor, you’re the parent’, or ‘I’m the teacher, you’re the parent.’ Yet how many professionals are parents themselves?

When an educational problem besets a teacher’s child, suddenly that teacher has to don a different hat and deal with their own child’s school in the role of a parent. But the teachers at that school may regard this outsider - even though a teacher - as just another of the parents they have to deal with. And so the spiral goes on.

When the child of a medical consultant fell ill with ME and he was faced not only with the role of parent rather than doctor, but with a disease he had hitherto not believed in, he was forced into taking up a completely new position.

Trying to get help, especially educational help, many parents of children with ME feel like Arthur Clennam in Dickens’ *Little Dorrit*, who went to the Circumlocution Office in order to ‘get something done'.

The Circumlocution Office was Dickens' own invention; it was the nineteenth century equivalent of Jim Hacker's Department of Administrative Affairs in *Yes Minister*. It existed precisely to make sure that nothing was ever done about anything. Papers and people were shifted and shunted from office to office until they 'wore out'.

Dickens, of course, used such humorous tricks to throw into relief the injustices that were committed in his day, as people's problems were allowed to fester even as they sought help, while the various authorities imposed the procedures that suited them.

Despite grand words and recommendations in official documents, injustices are still being committed and tragically, many of them happen purely because of this headgear problem. People get categorised and trapped under a particular hat.

Hats off to those professionals who can simply remain human.

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Once Upon a Time in a Small American town…

By a strange twist of fate, it was only the emergence of new technology in the 1940s that made doctors first consider the ME syndrome as *different* from poliomyelitis.

Polio is the terrible illness that attacked so many children before vaccination was brought in, and it could strike in mild or severe ways, just like ME. The two conditions are, of course, similar in many other ways. By another twist of fate, it is even newer technology that has shown up the links between them again.

In 1948, a polio-type illness in New York State prompted scientists to use tissue culture to grow the virus. But with their new technology, what grew looked to them like a *new* virus.

The technology we have today shows that what was then thought to be a new virus was simply one of a family - the enteroviruses, or *bowel viruses*. Polio itself also belongs to that family.

But - being human - they called this 'new' virus Coxsackie, after the small town up the Hudson river where it was found. And they called the disease *atypical polio* because its symptoms identified it as a kind of polio.

This kind of polio, atypical polio, was only afterwards named ME, and even more recently it got dragged into the so-called ‘Chronic Fatigue Syndrome’, with the UK Department of Health now using the term CFS/ME. The link with polio was forgotten.

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On the Trail of the Bug

A good detective investigation usually involves leg-work, digging around into old records, searching out long-forgotten pieces of information and slotting them together.

Seeking out the causes of ME is no different; it is not only a matter of new research and technology, but also of old records rediscovered.

If we look back at one particular epidemic of polio in Hawaii, described by Johnson in the *Annals of the New York Academy of Sciences* in 1995, we find that some of the enteroviruses (bowel viruses) which produced that polio epidemic were not the ones that had originally been given the name ‘polio’ at all.

Johnson says: ‘In the spring of 1957… we investigated an epidemic of poliomyelitis in Hawaii. Of the 39 cases of non-paralytic poliomyelitis, only 4 were related to type 1 poliovirus. There were 16 cases of echovirus 9, 7 cases of Coxsackie A9, and 4 to 5 other enteroviruses.’

So the very enteroviruses now *known* by doctors to be implicated in ME were shown in Hawaii, as long ago as 1957, to cause non-paralytic polio; ME has of course, often been diagnosed as non-paralytic polio, its symptoms are so similar.

Perhaps even more interestingly, two of the 38 cases of paralytic polio in that epidemic were not caused by the polio virus at all, but by another enterovirus, Coxsackie B2.

ME and polio are clearly inter-related.

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Human Achievement

‘It is a virus!’

‘No it isn’t. Give me my ball back, I’m going to play on my own.’

This might seem a simplistic view of the squabbles that have infiltrated some areas of the medical profession over ME. Unfortunately, in my work I have come across instances of reputable research being refused publication in respected medical journals, apparently on the basis of just such casual pique.

Until this nonsense and prejudice is cleared out of the way, progress is bound to be impeded at a time when it was never more needed.

There has been a strange paradox in the accusations levelled at ME sufferers. We have at one and the same time been seen as ‘over-achievers’ who push ourselves too much, and as people who like to sit back and enjoy the ‘sick role’. It is difficult to see quite how we can be both at the same time.

But the determined sceptic can always find an answer. One way out of this apparent logical impasse is to say that, being over-achievers, we have become so stressed out by our lifestyle that we need a respectable excuse to give it up. Physical illness is a respectable excuse.

Another argument is that some of us would like to be over-achievers but, being not quite competent enough, we can’t achieve what an over-achiever ought to. (This is getting like one of those tongue-twisters - how much achievement can an over-achiever achieve if an over-achiever can’t achieve enough achievement?) So once again, we turn to the sick role as an excuse to opt out.

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What does Society Really Think about Achievement?

On the one hand, over-achieving is obviously not a Good Thing and we are told that we risk making ourselves bodily ill through such inappropriate behaviour.

On the other hand, society worships international sportsmen and women, surely the best examples of all of over-achievement. And it worships their ‘perfect’ bodies. Bodies which are generally in pain from some injury or other, and which are put through the most appalling stresses. Yet the desirability of sporting success has penetrated even our National Curriculum.

Either achievement is healthy and good and psychologically sound, or it isn’t. Society can’t have it both ways.

Mankind’s nature has always been curiosity, coupled with a will to overcome obstacles. On balance, I find this urge uplifting, and it is only through this urge that the solutions to dealing with such problems as the ME conundrum are going to be found.

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Why did No-one Believe that ME was a Persistent Viral Infection?

In *ME The New Plague* in 1996, I argued that ME was a persistent viral infection related to poliomyelitis. My book was placed in the libraries of both Houses of Parliament and was quoted in parliamentary debates (see Hansard). People started to take notice.

Then, in 1997 - when I was on his programme after the *Journal of Chronic Fatigue Syndrome* published the Dowsett/Colby study - *Sky News* presenter and political journalist Adam Boulton described ME as ‘attacking schoolchildren now’. Indeed.

Yet the British scientists’ laboratory work that underpinned my work was widely doubted and generally dismissed. This tragically led to misunderstandings and even to the mistreatment of children and young people in the UK.

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Why did it Happen?

In late 2007 I was granted an interview with California infectious disease specialist John Chia MD, whose son contracted CFS/ME in 1997 at age 14.

Jane To me your work is the Holy Grail really!

As you know, I wrote a book back in 1996 about the link between enteroviruses and what at that point, we would have called ‘ME’, which got called ‘Chronic Fatigue Syndrome’ and then ‘CFS/ME’.

Looking at your latest work, to me the most significant sentence in it - if I were to pick out just one - is where it says in the conclusion to your Abstract ‘a significant subset of CFS patients may have a chronic disseminated non-cytolitic form of enterovirus infection which could be diagnosed by stomach biopsy’.

That means you’re looking at a proper diagnostic test, doesn’t it?

Dr Chia Yes. But before I comment on that I want to first say that I have learned a great deal from the British investigators. You, obviously, have written a lot about that.

Before I read the papers from the British investigators, I can tell you I had absolutely no clue as to the association of enteroviruses with this, so I learned a great deal from them and I quoted their work in my paper.

When I read those papers I was very objective. I know some of the American investigators who were involved in the early work about

CFS and one of them was my teacher, Stephen Strauss. I know what he was kinda like, he's a very dogmatic guy, very smart, but his expertise was not on enteroviruses but rather on Epstein Barr virus.

So when I saw the comments from him regarding the British work, then I read the British work, I thought, my gosh, I'm a reviewer for papers, I'm an objective guy, I said, how can this work be false? Or be wrong? There's very clear-cut evidence.

Unless they've blatantly lied about their results [Jane laughs] these are valid results, and you can't dismiss it.

Just the fact that we Americans could not reproduce it, I don't think there was then any effort for our people to go to your laboratories - British laboratories - to see how these tests were done.

And the reason I investigated this? I remember one of my friends, my dear friend who was the Man of the Year on the *Time Magazine* cover of 1996 - he's an AIDS researcher - David Ho.

I remember, I was in his research laboratory for about two years, I was helping him with some of the work on making antibodies against HIV so I remember all the things going on in the laboratory.

At that time, he was able to find the HIV virus in asymptomatic, HIV positive individuals, whereas other laboratories could not find it. And eventually, obviously he was right. So finding HIV virus in the blood is a routine thing now.

But the interesting thing was, when he was trying to do the RNA test for HIV, he had tremendous difficulties. So he asked the laboratory people to go to UCLA [University of California, Los Angeles] to the AIDS Research Institute to learn how to do some of the RNA tests. And lo and behold, we were able to do it in our laboratory.

My point about this is that sometimes laboratories can find viruses because they're good at it, they've spent years doing it. But the nitty gritty stuff is never really clearly written in a paper. There's no way in the world you can write out every single experimental detail.

The two sides of the Atlantic - it's like there's almost competition. The Americans have never really gone to the British laboratory and learned how to do this, and to make sure to do everything the same.

If, then, the same samples cannot be reproduced...?

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The Human Factor

So the reason that people did not believe that ME was caused by a persistent enteroviral infection was simply that the British laboratory results were not reproduced.

You can read the entire interview, in which Dr Chia explains how he and his son found enteroviruses persisting for many years in the stomach, and how antiviral drugs are being developed that could eliminate them, in *The Colby Report 2008*.

I believe we owe these two scientists a great debt.

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Epilogue

What of those diagnosed under the name Chronic Fatigue Syndrome?

There is no Chronic Fatigue Syndrome as a separate and discrete illness. Evidence is accumulating that there are different conditions under the CFS umbrella, which each need their own diagnosis, management and treatment.

After all the official denials, one of these is emerging as a persistent enteroviral disease, the Ramsay-defined ‘Myalgic Encephalomyelitis’, or ME (see *Vision 2007-2*).

In my opinion, each case of CFS needs to be properly diagnosed for what it really is, and the whole Chronic Fatigue Syndrome edifice needs to come crashing down. I firmly believe that, one day, it will. And no-one will bemoan the demise of such an inappropriate tag for the devastating disease of ME.

Thanks to the work of John Chia in California and his son, we can at last hope for an effective treatment for ME itself in the not too distant future, with the further possibility for the prevention of future cases.

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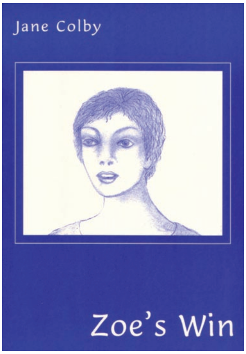
Register Your Interest

If you would like advance notification of the publication of The Colby Report, or if you would like to contribute to it by completing an anonymous questionnaire, please complete and return the form on page 11.

Zoe's Win



Just how does Zoe win? A great story, fun to read, good for reading aloud. Easy, clear print.

Also contains detailed practical advice for teachers.

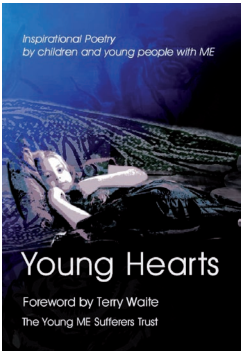
From a review by teacher Joanne, for Sheffield ME Group:

Zoe is a star pupil in Physical Education and when she starts to lose her abilities, no-one understands. The reader knows why and cringes when Zoe's is told to 'Pull yourself together girl! You can't win if you don't try.'

As a teacher I would have found this book beneficial if I had a child in my class with ME. Any professional dealing with children and their needs has to understand as much as possible about the health, welfare and education of children, and what can go wrong.

£7.95 inc p&p. Send a cheque made out to Dome Vision and we will process your order.

Young Hearts



A beautiful book of poetry and thoughts from children and young people with ME, fully illustrated throughout, was published for Christmas 2004 by The Young ME Sufferers Trust. Already into its fourth reprint.

The Young Hearts project was the dream of 14-year-old ME sufferer Jade Louise Scarrott, one of our young members who was tragically taken from us in a random accident on our roads. Jade wanted to raise awareness of ME and of the thoughts and feelings of young people with ME. No-one with a heart will fail to respond to these children's words.

We are honoured that Terry Waite, former Special Envoy to the Archbishop of Canterbury, agreed to launch the book on 29th November in Warwick Castle.

£7.95 inc p&p. See a review at www.tymestrust.org. Send a cheque or use the website donations button.

The Young ME Sufferers Trust, PO Box 4347, Stock, Essex, CM4 9TE

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