



Child Protection Issues: A Presentation to the All Party Parliamentary Group on ME

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Abstract

On 2nd July 2008, Jane Colby and Joanna Smith gave presentations by invitation of the All Party Parliamentary Group on ME on Child Protection Issues, covering Child Protection procedures and recommendations, misunderstandings over parental or carer influence, and the personal experiences of a parent of a Tymes Trust member.

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Introduction

On 2nd July 2008, Jane Colby and Joanna Smith gave presentations by invitation of the All Party Parliamentary Group on ME on Child Protection Issues.

Jane was a Headteacher for nine years, a member of the government Chief Medical Officer's Working Group on CFS/ME and co-authored ME/CFS In UK Schools, the largest epidemiological study of ME to date. She is a member of the National Association of Educational

Inspectors, Advisers and Consultants (now ASPECT), a life member of the National Association of Head Teachers and a Fellow of the Royal Society of Arts.

Joanna Smith is the parent of two children with ME (members of the Trust) and a Welfare Rights Advisor to Brunel University.

The presentation was divided into three parts.

1 Presentation by Jane Colby

Jane first laid out the situation regarding Child Protection procedure and gave the Trust's recommendations to help stop their misapplication to the families of children with ME. She said: 'We cannot just discuss this problem and wring our hands over these injustices. I have been fighting this problem since the 1990s and I did the survey for the BBC Panorama programme which revealed the statistics of the problem at that time. Now these cases seem to be escalating again. The Trust is today making practical suggestions that we believe would go some way to improving the situation.'

Jane explained that the Trust was continually dealing with these cases, which were frequently reopened after they had previously been resolved without action. She had reopened her discussions with Dr John Sentamu, Archbishop of York, where cases had taken place. He had asked Jane to keep him apprised of developments and report to him the outcome of the APPG meeting.

Sick children and innocent families are being caught up in a web of professional misunderstanding about ME. It seems to these families that the presumption of innocence that is enshrined in British law does not apply to them.

Proceedings are held in the Family Courts, which do not demand the same level of evidence as the criminal courts. Secrecy adds to the difficulties in these cases.

The children's chapter of the Department of Health report of 2002, which was not widely circulated to professionals, stated:

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

It would appear that child care professionals often do not proceed in this way; one professional's suspicions typically have a ripple effect, influencing all the other professionals who come into contact with the child.

A great deal has been written about Munchausens Syndrome By Proxy (now called Factitious Induced Illness) in the child protection context. In Australia, the Queensland Appeal Court judgment of R v LM QCA 192 (2004) ruled that the term was inadmissible

evidence. Holmes noted that MSBP/FII was ‘circular reasoning’ that ‘explained nothing’. That legal reasoning was adopted by the UK High Court in the Family Division (*A County Council v A Mother and A Father and X,Y,Z children* (2005) EWHC 31 Fam). In the case, Ryder stated that he hoped MSBP would be ‘consigned to the history books’. However, the term FII is still in use in its stead.

If a family is suspected of child abuse, the following procedure is initiated:

- Within 24 hours: an initial decision is made about whether to pursue a child protection Section 47 investigation.
- Within 7 days: an initial assessment must be done which involves seeing the family.
- Within 30 days: a core assessment must be done.

Thus the process moves swiftly and parents are unprepared as to how to fight it.

The Social Services Manager who advises the Trust feels that ideally, if anyone becomes the subject of a Child Protection investigation and it is not clear if the child’s symptoms are due to ME, the family should be informed of organisations that can advise and assist them.

The Department of Children Schools and Families has published ‘Working Together to Safeguard Children’, which is the statutory guidance in relation to child protection.

2 Misunderstandings over Parental or Carer Influence

Jane presented the Trust publication ‘ME - The Illness’, which the Official Solicitor had asked her to write for a court case to provide the judge with an overview. She read out the section on parental and carer influence since this was clearly at the heart of the Child Protection issues under discussion.

Large-scale misunderstandings about parental influence exist amongst physicians, teachers and social workers with a poor understanding of classic ME, as professionals are not trained in this illness. The Trust’s caseload of families seeking help would suggest that these misunderstandings are on the increase.

In 1999, the Trust’s present Executive Director Jane Colby (a former Head Teacher) designed a questionnaire with the BBC which was sent to families whose children had ME. It received a 62% response and revealed that 7% of children from families questioned had been subject to child protection proceedings (court proceedings either threatened or carried out) and 4%

There is a general theme of giving information to families who are the subject of Child Protection enquiries except where to do so would place the child at further risk. This is subject to a fair degree of interpretation in individual cases.

In practice, it appears that families in this situation are not being adequately informed of their rights or of the procedures that are being followed.

There is another important theme of the guidance; the wishes and feelings of the child should always be sought, as should the child’s account of what has been happening to them.

In ME cases the child may not be well enough for a detailed discussion with someone they don’t know, especially where ME friendly procedures are not used, for example, short discussions with rest breaks. Where workers do communicate with the child they do not always attach great weight to what the child says.

Action

The Trust takes the view that The Department of Children Schools and Families should urgently alert Social Services professionals to the frequency of misunderstandings in cases of ME.

The Trust also recommends that a leaflet clarifying the procedures that should be adhered to by professionals in child protection investigations should be given to families under suspicion, and they should be informed of their rights.

had been labelled with Munchausen’s Syndrome by Proxy. National Statistics at that time showed that MSBP affected just one in 100,000 families so clearly this was a statistical anomaly. The Trust is not aware of any of these cases having, in the end, been shown to be due to parental interference with the child’s medical condition, recovery or treatment.

Several years after the BBC survey, the Trust carried out its own survey ‘Our Needs Our Lives’ in the county of Essex, with a grant from Essex Community Foundation Local Network Fund. It revealed that 25% of families involved had faced the suggestion that parents were causing the illness, and 79% reported that doctors had misunderstood their illness as psychological. The Trust is not aware of any of these cases eventually having been found to be due to parents or to psychological factors.

These common misunderstandings appear to occur mainly because physicians and social workers have found it difficult to appreciate that severe and chronic

disability could be due to a condition as benign sounding as Chronic Fatigue Syndrome. They often regard it as partly psychological, either in origin, in perpetuating factors, or both. CFS is often treated as if it were a mental health problem and professionals may propose that carers have in some way caused or exacerbated the illness or sabotaged recovery out of a personal need to keep the patient dependant. The Trust is not aware of any such suggestions having eventually been found to be the case in its own work.

The care and treatment of people with ME is greatly affected by the split in the medical profession between those who have knowledge of classic ME and the

existence of subgroups of CFS, and those who do not.

It is therefore a misperception that the divide is between the medical establishment and the patient support fraternity. When the government Chief Medical Officer set up a Working Group to report on what the DoH now terms CFS/ME, the Trust's present Executive Director was an invited member of the Group and assisted specialist paediatricians to produce its Children's Chapter (Dept of Health 2002).

The full publication, 'ME - The Illness and Common Misconceptions: Abuse, Neglect, Mental Incapacity' is at www.tymestrust.org/pdfs/metheillness.pdf

3 Presentation by Joanna Smith

Ladies and Gentlemen

My name is Joanna Smith and I am a mum of 2 teenagers who are suffering from ME.

I work as a Senior Adviser for Brunel University Students' Union and am an experienced legal adviser of many years.

I am here to tell you my story about how having children who are ill with ME can lead to the nightmare of Child Protection proceedings.

My older daughter, Patricia fell ill in 2001. It took 6 years for the diagnosis to arrive. Our GP said he doesn't know anything about ME. As there are no local ME specialists, Patricia was referred to the Adolescent Health Clinic at Great Ormond Street. I was so happy - it is a world famous hospital, I assumed they'll be able to offer proper help and support.

I was bitterly disappointed. Not only the consultant there referred to ME as a "fatigue" which is an entirely different thing, he proceeded to conduct a battery of psychological tests, spending less than 15 minutes of our 3 hour long visit on physical symptoms and needs. My daughter was struggling to sit up, answer his questions, was getting confused and had to continue without being offered a rest break and losing her ability to participate - as a consequence she has suffered a very bad relapse.

Great Ormond Street Hospital's physiotherapist ignored Patricia's pleas that she'd rather not get on the exercise bike because she was really exhausted and nauseous and was worried that she'd fall.

I was in despair to find that Great Ormond Street Hospital is not a good place for kids with ME. The consultant there would not even support our disability benefit application because, as he stated, Patricia "may recover in future" and that describing her as "incapable" would be bad for her chances of recovery.

He wrote to me to say that it is not helpful if she is thinking herself ill!

So medical side: a nightmare.

On the educational side things were not faring much better. Patricia was granted a place in one of the best High Schools in this country. Her attendance was falling, yet she has managed to stay in top sets in all core subjects. We were reduced to writing pitiful begging letters to her Head of Year, asking for assistance. I still want to cry when I think about those days.

In year 11 we realised that she will not be able to attend at all. It was like we have disappeared from the school and the LEA's horizon. For the school- Patricia has stopped being a useful league table statistic, for the LEA- I was a nuisance. My calls went unanswered.

Throughout that year I received one call from the LEA and a few emails from the Head of Year; none offering practical support.

Patricia by then was suicidal from pain, insomnia and distress. And when I say suicidal, I don't mean she vaguely thought about it - she actually attempted to take her life.

It took a year-long complaint, and the assistance of an educational specialist solicitor, for the Local Authority to admit to serious shortcomings in provision of education for my ill child. At first they denied any wrongdoing, prolonging my anxiety needlessly. Then they wanted to offer a few hundred pounds. Finally, they wrote to the Local Government Ombudsman to say they'd offer £3040. (That was in May- they still haven't paid.)

Then, in February of this year, my younger daughter Emily fell ill and our Child Protection nightmare began.

After a few months of slowly deteriorating, I could not pretend otherwise - it looked like she too had ME.

Emily's school, where I am a Governor, was not happy about her attendance, which slowed down to a halt, when she started to come home shaking and throwing up from exhaustion. They requested a diagnosis. I understood this perfectly- the school has a right to ask for it in light of a prolonged absence.

So the vicious circle started again - a GP who refused to acknowledge ME, a long wait for a paediatrician's appointment, and the school pressuring me for medical evidence.

The school would not believe me that there is a tendency for clusters of ME in families - even when I sent scientific papers.

The letters from the school started to arrive - terse, harsh letters about deregistration and penalties.

I knew I must keep the dialogue with the school. I sent publications, which consisted of brilliant guides by Jane Colby for education professionals, I explained how these are relevant to us, I explained that, by now, I have considerable experience of ME and that Emily is definitely not well. My requests for a meeting were ignored, and when I got to speak to someone at school, I was met with barely masked scepticism.

We were visited by a Social Worker, on referral from the school - without the school notifying me about it (the lack of notification being typical in child protection procedures). The school wrote to the Social Worker - and I have seen this letter - that Emily is copying her older sister, that she does not look unwell and that she is not reporting health problems to the school nurse.

The Social Worker knew nothing about ME. I gave her a lot of information and explained that ME kids may not always look unwell (of which I have already informed the school) and that Emily, previously very active and sporty, had 6 years to copy her older sister, so why now?

The Social Worker called me a few days later to explain that there is no case to answer, the file is closed, she is

happy that there is no need to continue the assessment.

Yet the worst came recently, when I was informed that, on the advice of a Child Protection Nominated Nurse the school is requesting Social Services to re-open the case. No explanation why, no information about allegations, no advice where to seek support. I was ill with shock.

The school has requested that the file is re-opened, on child protection grounds, clearly due to their lack of knowledge and understanding of ME and despite a Social Worker's assertion that there is no need for further assessment.

The irony of it all is that one of my responsibilities as a Governor is child protection issues. Also, please note that I am talking about the same Local Authority which already admitted inadequate support in the case of my first daughter.

The school, it seems, is now prepared to ruin my professional reputation; the Principal has written to my employer and other, outside parties, and invited my employer to instigate gross misconduct procedures as I used post franking facilities - which my employer allows anyway, upon reimbursement - to send one letter to her. She also circulated my email with all its confidential details about my daughter.

The overall picture shows two children with complex neurological disease, in London, in the 21st century, without access to adequate medical assistance and without access to education. Furthermore, the level of ignorance is so shocking, that despite the wealth of knowledge about ME, Child Protection measures are still brought against families like mine.

I am sure you will agree: it is an appalling situation.

NB

I would just like to add that without the support of The Young ME Sufferers Trust I don't know how we would have coped so far.