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**THE BRIEF QUESTIONNAIRE 2010**

**Schools and Local Authorities  
Are they failing children with ME?**

*A pull-out for you to complete and send back*

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**The Brief**

**Question 1**

**Are you satisfied with the present education provision for your child?**

*Yes / No (circle as appropriate)*

*Now please read on; then complete the questions and  
continue on another sheet if you wish to give us more details  
(for example if you are not using State education).*

**Introduction**

Ever since, at the suggestion of Shirley Conran, I started writing *The Brief*, I have concentrated on bringing you new information. In this issue I'm asking you to supply me with new information. I would be very grateful if you would fill in this questionnaire and send it back as soon as possible.

In 2004 the Trust's report *The Forgotten Children* revealed how children with ME were being misunderstood and failed by the educational system. We found that:

- 87% had struggled for recognition of their needs
- 81% had moved school to get recognition of their needs
- 65% had paid for private or distance learning
- 63% had left state education

And 84% had felt threatened or bullied by attitudes from professionals.

The Young ME Sufferers Trust has always been a practical charity. We set about trying to help. We campaigned, we supplied lectures and

training. We teamed up with the Nisai Virtual Academy to provide virtual education as an alternative to school.

As well as receiving political support, we were backed by a number of knowledgeable and compassionate doctors, including Dr Elizabeth Dowsett, Dr Nigel Speight, Dr Alan Franklin, Dr Darrel Ho-Yen, Dr Nigel Hunt, Dr Byron Hyde, Dr Charles Shepherd. We began to feel optimistic that things were starting to look up.

I am extremely concerned, therefore, at recent developments. We are receiving disturbing accounts, as bad as ever they were, about uncaring attitudes, and about schools pressurising children to increase their attendance inappropriately.

The NICE Guideline on CFS/ME (2007) did not see fit to repeat the guidance on education which, as a former headteacher, I worked so hard to get included in the Report of the Chief Medical Officer's Working Group, published in 2002 by the Department of Health. (You can find key educational recommendations of that report on our website.)

As a result, the old-fashioned approach of ‘bums on seats’ appears to be still suppressing more enlightened, 21st century educational thought. Some paediatricians appear to be using school attendance as part of a graded activity programme (such as advocating an increase in attendance by 10% per week) rather than supporting the children’s legal rights to suitable education for their needs, whether that be at home or at school.

There are, of course, some Local Education Authorities providing a variety of strategies such as home tuition, or - at half the cost of home tuition - virtual education, which typically enables children with ME to achieve as well or better than those who are fit and well and attending school. Families report good results from such strategies. And we should none of us forget that there are kind, encouraging and supportive schools and teachers out there. They are like gold dust.

But sadly, this comment from a parent is more typical: *‘The school exams invigilator reprimanded Sophia for asking for a break soon after the start of her final history paper in a way that made her very upset. She was unable to write her paper properly due to weeping and feeling upset.’*

It is to her credit that Sophia gained an A despite what her parents describe as *‘this discriminatory invigilation’*. Calls to our Advice Line suggest that parents are increasingly needing to have recourse to formal complaints, whether about attitudes or about the reluctance to provide suitable education within the law.

It is important that you describe your own experiences for us. Thank you.

## Question 2

**Have you had to struggle for recognition of your child’s educational needs?**

*Yes / No (circle as appropriate)*

*Please give details*

## Question 3

**Have you or your child felt threatened or bullied by attitudes from the school or LEA?**

*Yes / No (circle as appropriate)*

*Please give details*

## Question 4

**Have doctors asked for a stepped or graded increase in your child’s school attendance (eg 10% per week)?**

*Yes / No (circle as appropriate)*

*Please give details*

**Question 5**

**Have you been offered education in the home (eg home tuition, virtual education)?**

*Yes / No (circle as appropriate)*

*Please give details*

**Question 6**

**Have you received kindness and understanding from your school/teachers?**

*Yes / No (circle as appropriate)*

*Please give details*

**Question 7**

**Do you feel that your difficulties with school or LEA are or were due to the following?**

*Circle one choice per line*

- |   |                              |
|---|------------------------------|
| <i>A their lack of understanding</i>              | <i>no / a little / a lot</i> |
| <i>B lack of sympathetic attitudes</i>            | <i>no / a little / a lot</i> |
| <i>C unwillingness to listen to child/parents</i> | <i>no / a little / a lot</i> |
| <i>D doctor's advice to school/LEA</i>            | <i>no / a little / a lot</i> |
| <i>E social services' advice to school/LEA</i>    | <i>no / a little / a lot</i> |
| <i>F school attendance worsens illness</i>        | <i>no / a little / a lot</i> |
| <i>G other (please give details)</i>              | <i>no / a little / a lot</i> |

Quick Tour of ME Symptoms, Management and Trust Services

Email Alerts and Trust Statements

Special Problems of Children with ME and the Enteroviral Link

**Self-Help**

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

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

Explain Your Abilities

School Examinations and ME - Special Assessment Arrangements

The Essex ME Companion

Diet in ME

**Reports**

Child Protection Issues

Long Term Sickness Absence due to ME/CFS in UK Schools

ME Diagnosis : Delay Harms Health

Revisiting the 2002 Department of Health Report on CFS/ME

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*)

**Experiences**

Speech to the Royal Society of Medicine

Mummies Aren't Supposed To Cry

Whispered Words (*the severely affected*)

**For Professionals**

ME - The Illness and Common Misconceptions: Abuse, Neglect, Mental Incapacity

The Nightingale Definition of Myalgic Encephalomyelitis

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

### Question 8

**Is there anything else you or your child would like to tell us?**

*If you have experienced both good and bad, tell us about both.*

*Continue on a separate sheet if necessary (please attach securely to this questionnaire).*

### Question 9

#### **Your Details**

*You may remain anonymous, but if you do I can't contact you if I have any questions.*

*Your Name*

*Your Child's Name*

*Address (and postcode please!)*

*Email*

*Telephone*

### Question 10

**Would you like to be quoted by name when the results of this survey are used by the Trust?**

*Yes / No (circle as appropriate)*

#### **Post to**

The Brief Questionnaire 2010, PO Box 4347, Stock, Essex, CM4 9TE

The Brief