



# *The Young ME Sufferers Trust*

## **Explain Your Abilities**

### **Jane Colby**

Former Head Teacher

Member, National Association of Educational Inspectors, Advisers and Consultants

Member, Chief Medical Officer's Working Group on CFS/ME

Executive Director, The Young ME Sufferers Trust

### **Naomi Burgess**

Chartered Educational Psychologist

MSc Ed Psych C Psychol AfBPsS

## **Introduction**

The questionnaire in this document is a self-help tool designed for you to complete and give to teachers or other professionals.

Answering these questions is meant to help you convey how much you can do within the limits of your illness. It can be done in stages over a number of days if necessary. Always keep a copy.

The questionnaire also forms part of the Trust's *ME/CFS Guidelines for Educational Psychologists*, whose job includes assessing pupils' Special Educational Needs. If you are having your Special Educational Needs assessed, we recommend that you give the Guidelines to your Educational Psychologist if they don't have them already.

## **Completing the questionnaire**

You don't want to make yourself ill, so do it in short, bite-size pieces.

The idea is for you to take time to think about the questions.

You can get your parents to help.

You don't have to do it all. But do fill in what you can manage because it can help your teachers to understand.

Leave any questions that aren't relevant to you or that you would rather not answer.

If there are questions you find difficult, phone the Trust on 0845 003 9002.

## Questions for you to complete

### About you

Name:

Date of Birth:

How old you are now in years and months:

School year:

Key Stage:

School:

School address and telephone numbers:

Circle the name of the illness you have been diagnosed with:

Chronic Fatigue Syndrome

ME

Post Viral Fatigue Syndrome

CFS/ME

ME/CFS

Other (*write the name here*)

How long do you think that you have been affected?

Have any of your doctors given you any advice about education?

It is important to understand your mobility needs:

Do you use a wheelchair? (*if not, say if you think it would help*)

If you go to school sometimes, how do you feel after the journey? (*say how you get there and back*)

How do you feel if you have to get around the building? (*say how you get around*)

Do you need to use a lift?

Anything else you'd like to say about your mobility needs?

Your social needs are important as well. Do you think you might be able to manage visits to school to see friends, if you don't have to attend a lesson?

How often can you attend school (doing lessons as well as visiting the building) without feeling ill?

Do you have to take time off in order to get over it or can you maintain this pattern week after week?

What is your sleep pattern like?

Do you find some parts of the day where you feel better than others?

If you have any difficulties with the following, please write 'yes' or 'no' beside them. Don't give lots of details, but do indicate what the main problem is.

Vision/perception

Hearing

Feeling shaky and wobbly

Feeling breathless

Trembling hands or fingers

Feeling too hot or cold

Becoming distressed

Understanding what is said to you

Speaking

Feeling faint

If there are other difficulties you wish to note, list them briefly.

If you have lessons at home do these problems make it hard for you to learn? *(if yes, explain briefly)*

Note down some ways in which these problems have made it hard for you in school.

Does using a computer make you ill?

If yes, do you think it is just because you went on for too long?

Do you have a computer at home? (PC or Mac?)

Are you online? (Dial-up or Broadband?)

Would you like information about ‘virtual education’? (*learning at home via the internet with support - the Trust can provide information and contacts for this*)

What aspects of your learning were difficult for you before you were ill? Explain briefly.

Can you tell when you have done enough and need to take a break?

Is there anything your parents notice about how you look just before you feel ill? (*please explain - it will help others to have this information*)

## **Friends and Feelings**

Are you able to be involved in any after school activities that you used to enjoy?

Are you able to see friends after school and/or weekends?

Do you have friends who come to see you or ring you up?

Do you find yourself getting irritable, moody or down?

If yes, has anyone tried to help you through this?

## **About School**

At the end of each of these questions you might like to ask yourself ‘what would need to change to make this manageable for me?’ (*this can help when you discuss your answers*)

Do you feel that any of your school staff understand your illness? (*do not write names*)

On the whole, is your school flexible about what you can and can’t manage?

Have you heard of/do you have a Tymes Trustcard? (*it is a passcard signed by your headteacher that you can show any member of staff if you need a break or other help*)

Has your school offered you a similar card?

Do you think a passcard might help?

Have you got examinations or SATs coming up?

If so, are they worrying you?

Have you got any deadlines that you have to meet for coursework?

Would you like help negotiating how much coursework you need to do?

Is there anything we haven't asked about that you would like to mention? *(it might be something about you, your illness or a suggestion as to how things could be made easier for you)*

## **About your doctors**

Name of your GP:

Name of your Consultant(s):

Name and position of any others:

## **Well done answering all these questions. How was it?**

*(this helps explain how much you can manage at one time)*

How many hours/days did it take?

Did you do it in short bursts?

Where did you do it? *(in bed, at a table, etc)*

How long did you spend on each occasion?

Did someone else have to help you?

Did you get symptoms (feel ill) as a result?

Do you feel you paced it about right?

## **What to add to the completed questionnaire**

You could write a letter to put in with your questionnaire, but try to keep it short (one page if possible). Don't repeat what's in the questionnaire. Use it to explain any special personal circumstances.

## **Other Trust publications to give professionals**

Find them all - and lots more - on the Publications page at [www.tymestrust.org](http://www.tymestrust.org).

### *Quick Tour of ME Symptoms, Management and Tymes Trust Services*

'Mum uses your leaflet to explain the illness to people, like my care manager. It's the best leaflet on ME we've seen!'

### *Professional Guides - Back to School?*

This Guide helps schools understand how relapses in children with ME are being caused by some programmes of reintegration to school. Demands on children with ME to get back to school too soon often come from misinterpretations of the government's statutory guidance called *Access to Education for Children and Young People with Medical Needs*. First published in *Special Children* magazine April/May 2003.

### *Professional Guides - The SENCO's Key Role in Supporting Pupils with Special Educational Needs*

All schools have a Special Educational Needs Coordinator. This Guide has been produced to assist SENCOs to manage educational demands on children with ME to preserve health and help them achieve. It incorporates some of the best ideas and practice to come out of years of work in this field. First published by Birmingham University School of Education.

### *ME - The Illness and Common Misconceptions*

This publication can help stop misunderstandings if they develop. Very simply contrasts Myalgic Encephalomyelitis with Chronic Fatigue Syndrome. Explains why the parents of young people with ME can be misunderstood as neglecting their children or making them ill. Also clarifies why young people with ME can be misunderstood as lacking mental capacity to make decisions affecting their lives. It was written at the request of the Official Solicitor as a Judge's briefing.

## **And for you**

### *The Tymes Trustcard*

This is a 'pass card' signed by your Head Teacher or college Principal. It says that you have permission to use the facilities you need, or to obtain assistance so you don't have to keep explaining. It also helps schools comply with the government statutory guidance *Access to Education for Children and Young People with Medical Needs*.

### *School Examinations and ME - Special Assessment Arrangements*

Special examination arrangements are intended to enable candidates who might not otherwise be able to do so to demonstrate their attainment. Special arrangements should be requested as a matter of course for young people with ME, well in advance if possible.