



Registered Charity 1080985

*Advancing
the care
of people
with ME*

*Report of the UK Government Chief
Medical Officer's
Working Group on CFS/ME*

*Children and Young People
The Key Points*

“The Department of Health welcomes the publication of this report as the start of a process of improving awareness and understanding that we hope will lead to improved diagnosis, management and treatment.”

**From the Government Response to the publication of the Report,
January 2002**

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Report of the Chief Medical Officer's Working Group on CFS/ME

Background to the Report

In 1994, the first National Task Force produced a report on ME. Its Focus Group on Children included Jane Colby, former Headteacher, specialist in the education of children with ME and later to become Chief Adviser to Tymes Trust, and Dr Alan Franklin, Consultant Paediatrician and current Medical Adviser to the Trust.

Recommendations included home tuition and/or distance learning for most children, and/or a reduced school timetable. It also stated that attendance at school was only appropriate if it did not make the illness worse or disadvantage the child's achievement.

In 1996 the three Royal Colleges of Physicians, General Practitioners and Psychiatrists produced a conflicting report, emphasising school

attendance and discouraging home tuition. Doctors and Local Education Authorities have tended to follow these recommendations, possibly unaware that, as the Royal College of Physicians stated, although the group met in their building, "the lead was taken by the Royal College of Psychiatrists".

In 1998 the Government Chief Medical Officer set up a Working Group to report on the various treatments for the illness. Representation was this time more balanced, with clinicians drawn from all medical fields and featuring the inclusion of patients and patient organisations.

This is the Report that was published on 11 January 2002 by the Department of Health and is endorsed by the Dept for Education and Skills.

Tymes Trust's Involvement in the Working Group

On the Key Group

Dr Nigel Hunt, GP; Medical Adviser to the Trust.

On the Children's Group

Jane Colby, Then Chief Adviser to Tymes Trust; presently the Trust's Executive Director
Dr Alan Franklin, Consultant Paediatrician; Medical Adviser to the Trust
Anna Grace Lidstone, Young Person with ME; then Co-Ordinator and Editor to the Trust
Alec Western, Trustee and Carer, represented Anna Grace at meetings

On the Reference Group

Gleyns Thomas, Carer; then Advice Line Contact for Tymes Trust

Special projects for the Children's Group

Sally Player, Trustee, Carer and Advice Line Contact and *Jane Colby* co-organised and co-presented the children's Sounding Board Event for the Department of Health, attended by a group of our young members and their families.

Jane Colby presented an educational analysis to the Children's Group attended by representatives of the Department for Education. She was invited to draft the Children's Group response to the Government's Consultation on Sick Children, leading to the Department for Education and Skills statutory guidance *Access to Education for children and young people with medical needs*. As a former Headteacher, her educational recommendations have been incorporated with those of doctors in Chapter 5 of the Report. She also contributed key statements to other chapters of the Report.

Anna Grace Lidstone was consulted at distance by the Department of Health at many stages of the three year process, drew up the outreach project proposal and produced *Whispered Words* to document problems faced by severely affected children and young people. *Young members* contributed messages and experiences to a "Thank You" book for the Children's Group.

Key Quotes

All the statements below are contained in the text of the Report; they are not our interpretation of the Report, but direct quotes from it. Taken together they comprise key information on the illness, on how it affects children, and on how it should be managed, including educational management.

Nature of the Illness and Symptoms

- Chronic Fatigue Syndrome (CFS/ME) is a genuine illness and imposes a substantial burden on the health of the UK population. CFS/ME affects many people and their families in the UK and elsewhere in the world.
- Many of the symptoms of CFS/ME suggest dysfunction of the central nervous system.
- Characteristic or common symptoms include: persistent/excessive tiredness or fatigue; cognitive impairment; postexertional malaise; pain; sleep disturbance; recurrent sore throat; digestive disturbances; intolerances eg of certain foods, medications and alcohol; other symptoms apparently related to the neurological and/or endocrine systems.
- Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms.
- Early recognition with an authoritative, positive diagnosis is key to improving outcomes.

Children and CFS/ME

- Children and young people (defined as being of school age) do get and are profoundly affected by CFS/ME, contrary to some professional and public perceptions.
- In children, the commonest age of onset is 13-15, but cases can occur as young as 5.
- A diagnosis in the young must be especially prompt, accurate and authoritative, and second opinions are needed if doubt exists.

Time-Scale for Diagnosis in Children

- When a child or young person has symptoms affecting school attendance for at least four weeks, active steps should be undertaken to identify the cause from a list that includes CFS/ME.

Spectrum of Severity

- Some children and young people with CFS/ME are so severely affected by the disease that they become bed-bound, with a similar degree of cognitive and physical impairment to that experienced by patients with severe neurological conditions.

What clinicians can do

- Listen to the patient, recognise and believe his or her individual experience.
- Acknowledge uncertainty and the impact that this has on the patient, family and carers.
- Provide information on and discuss: the nature of the condition, approaches to self-management, helpful therapies, and how to access other agencies for support and services.
- Agree a name for the condition. [The Report suggests CFS/ME.]
- Give advice on symptomatic treatment.

Note: The Report recommends that patient organisations be contacted for support. Tymes Trust recommends that families read the Report itself; for those online, an easy way is via youngactiononline.com where there is a link to the Department of Health website. As you can see, the style is clear and most information is in lay terms. Chapter 4 (Management of CFS/ME) and Chapter 5 (Children and young people) are likely to be especially relevant to readers of this document. Find more Key Quotes on Treatment and Education overleaf.

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Treatment/Management

- No management approach to CFS/ME has been found universally beneficial, and none can be considered a “cure”. Patient responses suggest that [...] all can cause harm if applied incorrectly.
- As with many chronic conditions, the emphasis should be on improvement and adjustment rather than “cure”. The goal of rehabilitation or re-enablement will often be adjustment to the illness.
- Experience suggests that provision of a wheelchair or other mobility aid does not stop patients working towards mobility without the equipment in the long term; indeed, such aids probably assist remobilisation, with suitable supervision.
- The notion of “once in a wheelchair, never out” is prejudicial: each case must be assessed according to clinical and functional need.
- Although there is no cure for CFS/ME, the condition has been found to improve in most patients both with and without* treatment; it is good practice to encourage patients to become experts in self-management and to choose between treatment options.[*Patients may therefore decline active treatment.]
- Most children who are missing school can be cared for and managed in their homes, with follow-up in primary care or by a specialist such as a community paediatrician.
- Careful listening and respect for parents/carers' opinions are important factors.

Educational Management

- Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. Some young people will be too severely affected by their illness to participate in any form of education, even at home.
- An educational plan is not an optional extra but an integral part of therapy.
- A young person who is likely to have special needs, including home tuition, should be identified early in the diagnostic process, preferably by a GP or paediatrician.
- Specifically, a young person with CFS/ME should never be forced to study but instead should be encouraged to set a pace that is likely to be sustainable, then have their progress regularly reviewed.
- Some more severely disabled children may need home tuition and/or distance learning on a longer-term basis. In addition to the time of a tutor or therapist, this may require information and communications technology, which can also help improve social contact.

Child Protection

- In cases of CFS/ME, evidence clearly suggestive 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.

Prognosis

- Overall, there is wide variation in the duration of the illness, with some people recovering in less than two years, while others remain ill after several decades.
- A minority of those with CFS/ME remain permanently severely disabled and dependent on others.
- Most people with CFS/ME can expect some degree of improvement with time and treatment, so a positive attitude towards recovery needs always to be encouraged.

Further Reading

Children and Young People with ME produced by Tymes Trust with Medical Adviser and Working Group member Dr Alan Franklin; a practical booklet of diagnostic and management advice for physicians, families and schools.

The ME Library at youngactiononline.com or by post. Re treatments and therapies: *Graded Exercise - Does it really work?*; *Polling your New Consultant (discusses different methods)*; *Diet in ME*; *Herbal Remedies - Are they really safe?* *Zoe's Win* by Jane Colby. Child-friendly book, also for families and professionals. “A little gem.” Dr Anne Macintyre.