

# Revisiting the 2002 Department of Health Report on CFS/ME



*For three years Jane Colby, Executive Director of The Young ME Sufferers Trust, worked on the children and young people's panel of the Chief Medical Officer's Working Group on CFS/ME.*

*Staunchly supported by consultant paediatricians Dr Alan Franklin and Dr Nigel Speight, who is a member of the Trust's Professionals Referral Panel, Jane ensured that proper recommendations were made for the educational needs of children with ME. As a former headteacher and severe ME sufferer, she was in a unique position to make such recommendations, only to find that NICE chose not to incorporate those detailed arguments in its Guidance, issued in 2007. The Trust is now fighting the same battles again.*

Our advice is to insist on your child's legal rights to suitable education and avoid being pressurized into accepting unsuitable arrangements, including subject options, examination arrangements, school attendance or any other matter.

The Working Group report was not perfect, and did on occasion use rather unfortunate and controlling language about managing the child (rather than the illness). Nevertheless, there is much that is good about the Children's Chapter, particularly the sections on Education and Child Protection, and we bring some of it to you here, since the Dept of Health failed to circulate the published Report. We hope this information will assist you, your doctors and teachers.

## **Children and Young People**

*From the report published by the Dept of Health, January 2002*

***‘It is important to believe the child and listen to their views’***

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. However, there are important differences as well as similarities between children and adults both in the nature and impact of the disease and in its management. [...]

The principles of care of children and young people with chronic illness are well established. Management of such conditions in England is guided by principles laid down by the Dept of Health for England. Children’s rights are safeguarded by UN convention and need to be respected at all times by professionals and parents/carers. The rights to be heard, to have their views taken into account, to access quality medical treatment, and to be protected

from abuse both by individuals and by systems need particular attention. [...]

### ***5.1 Nature and impact of CFS/ME in children and young people***

Ill health imposes great demands on children and young people, so it is remarkable how many meet the challenges positively. Isolation from peer groups and loss of schooling cause a young person concern even if for short periods and for a well-known disorder. When their condition is less well known, or when the young person meets disbelief or perceives professional hostility or criticism of his or her parents/carers, the impact of the illness is compounded. No more is known about CFS/ME in children and young people than in adults, but this should not prompt professional indifference - quite the opposite. [...]

The potential influence of any chronic disorder on education is of particular concern, as is the broader effect of the illness on parents/carers and family life. [...]

### **5.1.1 Epidemiology**

CFS/ME has become more commonly diagnosed among school-age children and even in children as young as 5, although evidence suggests increased onset at secondary school age and around 14-15 years. Information on the disease burden in young people is scanty. Two studies have suggested a prevalence rate of 0.07% for children and young people. Dowsett and Colby found that 51% of all long term sickness absence in a studied school population of 333,000 was due to CFS/ME. Regardless of whether these figures are more widely applicable, CFS/ME clearly represents a substantial and widespread problem in the young.

### **5.1.2 Clinical profile**

In general, CFS/ME that develops in a child or young person is recognisably the same clinical entity that develops in adults, with some differences. Children usually have a symptom pattern similar to adults, but they are particularly prone to abdominal pain, nausea, and variations in appetite, leading to weight gain or loss. Younger patients [...] have a prolonged recovery period after activity. Even in those with a mild form of the illness, physical activity is

usually limited and loss of schooling occurs.

As with adults, symptoms wax and wane over time and in severity, and are affected by the individual's circumstances, previous healthy functioning, and responses to the illness. Aetiological and pathological considerations [...] seem similar to those in adults, but children seem to be more vulnerable to the [adult] misconception that the disease is 'all in the mind' or worse, that it does not exist. In addition, children do not always listen to caution from adults, teenagers may deny they have the illness, and very young children are often not able to understand the fluctuating nature of the condition. The expected duration of the illness in younger people is unknown because, as in adults, it is unique to the individual. However, most studies suggest that prognosis is better for children and young people than for adults, and many children recover even after long illnesses.

#### **5.1.2.1 Severely affected children and young people**

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. Sensitivity to light, sound, and touch are characteristic

symptoms in this group, together with visual deficits, hypotonia, and myoclonic jerks. Other aspects of the condition, such as nutrition, may also be severely affected. Care of such children and young people presents particular challenges. Diagnosis may be difficult and require particular care. In general, such patients would benefit from mobilisation of full community support services. Additional support and services may be required (eg tube feeding). Where they exist, community children's nursing teams are ideal to co-ordinate care with these patients and their parents/carers. Such support may need to continue for months or years.

### ***5.1.3 Social impact***

Within a family, any individual affected with CFS/ME has a profound impact on family life, particularly when that individual is a young person. The family unit experiences increased stress, stopping of normal activities, and in some instances the inability of other family members to accept the illness. The need for ongoing care means that parent(s) may have to give up work. In turn, the young person's progress towards increasing independence is impeded, children become more reliant on their parents, and separation from them can cause distress. Many young people lose contact with friends and peers, which means that often the individual's only peer-group contact is with siblings. Other children in the

family can feel left out as attention is focused on the ill child. CFS/ME can cause social isolation and an end to 'normal' family life. Clinicians and other professionals caring for the child can play a valuable part in minimising the impact of the disease on the family. Referral to the Disability Social Work Team should also be considered, to assess the need for support to the child and to help the family access disability related services.

## ***5.2 Management***

CFS/ME needs to be managed and services developed in keeping with general principles applicable to any chronic disease in the young: around the needs of and in partnership with the young person and their family. The uncertainties that surround CFS/ME are particularly difficult for children and young people, in whom an incorrect diagnosis presents an additional risk. Clinicians face additional difficulties in supporting and managing younger patients and their families, including issues over off-licence or off-label prescribing, and obtaining consent to research or treatment in minors.

### ***5.2.1 Diagnosis***

A diagnosis of CFS/ME in the young must be especially prompt, accurate, and authoritative, and second opinions are needed if doubt exists. As with other medical conditions that lack a diagnostic test, the diagnostic

process for CFS/ME is the familiar one of assembling positive clues from the history and examination, while simultaneously ruling out other conditions, usually by laboratory and imaging investigations. During this process and throughout the illness, it is as important to consider symptoms in the context of the entire length and breadth of the illness as it is to focus on a single symptom for fear of overlooking an alternative condition (eg headache and brain tumour).

Other conditions that present with school absence are important differential diagnoses in the young, since they can mimic or complicate CFS/ME. Such disorders need to be considered early and excluded or treated. The possibilities include physical illness such as hypothyroidism, musculoskeletal, neurological or cardiac disorders and mental and social conditions [...]

Almost all healthy children and young people are in full-time education. Given the potential impact of illness on education, the timescale for establishing a working diagnosis and management plan needs to be minimal, whatever the cause. When a child or young person has suffered excessive tiredness and/or other symptoms leading to fragmentary school attendance or absence for at least 15 working days, active steps should be undertaken to identify the cause from a list of diagnoses that includes CFS/ME.

### **5.2.2 Approach to management**

An ideal approach to management is patient centred and involves early recognition of CFS/ME by primary care services, and confirmation by a specialist if appropriate. [...] Few chronic medical conditions in childhood are managed by a single discipline and many require specialist follow-up. The hallmark of successful chronic disease management in children is integrated multidisciplinary support, provided locally and usually co-ordinated by a paediatrician in partnership with family/carers and children. 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. Given the variability in professional expertise and education on CFS/ME, the speciality of the co-ordinating clinician is not as important as the need for someone to adopt that role. If needed, hospital follow-up can be with a general paediatrician or other specialist mutually agreed by the child, their family and GP.

In general, local services are preferred, although non-local services might be accessed for respite care and in specialist/hospital care for second opinions and for complicated cases.

### **5.2.3 Primary care**

The affected child's GP is pivotal to orchestrating an effective response to

the illness, and to alerting community paediatric services. The GP may also be the most appropriate clinician to co-ordinate care in some patients, although this would usually be done with input from a paediatrician. [...]

For severely affected young people, GPs can access the domiciliary visiting service by consultants. [...] Although many healthcare professionals have not had specific education on CFS/ME, all should follow general principles for care of children with chronic illness. Primary care workers need at least to be aware of ongoing liaison with the child's Local Education Authority, particularly over provision of services such as transport and home tuition.

Many children and young people with CFS/ME have unpleasant symptoms, just as adults do. Pharmacological and other treatment can be needed to relieve such symptoms.

#### **5.2.4 Further care**

Advice from physiotherapy or occupational therapy services may be sought for general energy/activity management, and particularly for sympathetic consideration of equipment needs. Provision of a wheelchair to a child can be perceived as a dramatic step to take, but wheelchairs can increase independence and allow families to regain a sense of normality in their social life. The notion of 'once in a wheelchair, never out' is

prejudicial: each case must be assessed according to clinical and functional need.

All services need to be audited and opportunities taken to create service networks to maintain standards, promote research, and share good practice. So-called 'postcode provision of services', when access to services is limited by the patient's residence, is unacceptable.

(NB Due to continued lack of appropriate training in ME for medical staff in such networks, the Trust recommends that families use their own judgement as to whether treatment recommended is in fact helpful to their child. One helpful statement by NICE was a reminder that there is no obligation to accept treatment.)

#### **5.2.5 Follow-up**

Most children with chronic medical conditions need specialist follow-up, with the frequency and scope dictated by the condition and its progress. [...] In keeping with the principle of locally accessible services, primary care should bear prime responsibility for follow-up where possible. However, more complex cases will need follow-up by clinicians more experienced in their management. [...] Children with chronic medical conditions can develop new medical conditions, which could be physical, psychological, or social,

and may require treatment in their own right.

### **5.2.6 Education**

Nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning. A critical element of the child's management is assessment and provision of educational needs. [...] 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. [...] Adequate provision of continuing education needs close liaison between GP, community paediatric services, education services, the young person, and their family.

Some young people will be too severely affected by their illness to participate in any form of education, even at home. [...] 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. [...] This may require information and communications technology, which can also help improve social contact.

(NB In the years since this report was compiled, interactive virtual education

in the home has been developed and is producing high level educational achievements from children with ME.)

### **5.2.7 Transition to adulthood**

[...] This is a unique period of a person's life. Services for young people with CFS/ME should be tailored to their progress to adulthood: in particular, arrangements for transition from paediatric secondary care to adult medical services need to be put in place well before it happens.

### **5.2.8 Child Protection**

On occasions, families of child sufferers with more severe CFS/ME have been the subject of child protection concerns. The Working Group notes that neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education for such a patient by the parent/carers and/or the young person constitutes evidence of abuse. [...] It is important to listen to the child, as well as to family members and parents/carers, to respect their experiences, and to give due weight to their views, especially the child's. The young person should be given the opportunity to speak with the clinician, with or without their parents/carers.

In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection procedures or initiating care proceedings in a family court – Social

Services should be made aware that medical opinion in this area is divided, and consideration should be given to obtaining a further opinion from an expert medical practitioner with a specialist knowledge of CFS/ME.

### ***5.3 Managing the impact on family/carers***

All professional involvement with family and carers requires a clear awareness of the implications for parents/carers of uncertainty over their child's illness. Clinicians who are sympathetic and responsive to the increased parental anxiety engendered by diagnostic uncertainty and other specific fears are likely to minimise additional impact on the child. A background of disbelief and misattribution can pave the way for parents/carers experiencing a sense that their parenting is under scrutiny and liable to criticism [...]. As with other chronic childhood illness, professional work needs to be founded on a clear awareness of the crucial role

of parents/carers in undertaking the main care of the child, and aim to equip them adequately to support the child's progress. [...]

It may be difficult for parents/carers to ask for help if it is not offered, since it is the child who is the patient. Risks for the main carer mirror those for the child (social isolation, work difficulties, loss of leisure, coping with the misperceptions of others, perceived blame, loss of confidence, depression, anxiety, etc.).[...] It is important that parental confidence is actively protected, since it may be made vulnerable by both lay and professional responses to the illness. Careful listening and respect for parents/carers' opinions are important factors. Although a family environment will inevitably impact on the course of any chronic childhood illness, the lack of blame needs to be specifically stated, and this is the key message that can open doors to achieving necessary support for the child and family.

You can find helpful quotes from other sections of the Department of Health Report in *Children and Young People - The Key Points*, available at [www.tymestrust.org/pdfs/keypoints.pdf](http://www.tymestrust.org/pdfs/keypoints.pdf).