How I manage chronic fatigue syndrome

A Franklin

About 12 years ago, I was asked to do a domiciliary visit to see a 10 year old girl who in the spring had taken her secondary school entrance examination; caught a heavy cold with a persistent sore throat, which was taking a long time to clear; had a perpetual headache; dizziness on standing; extreme tiredness, which became worse if she tried to do anything; paraesthesia of the hands and feet intermittently; and disturbed sleep. Her general practitioner suggested postural hypotension, but I could find little abnormal except for some unsteadiness when she tried to walk. Routine haematological and biochemical tests were normal, as was computed tomography of her head. The physiotherapist that I referred her to reported that their attempts to mobilise her were actually making her worse, and wondered if she had a neuromuscular disease.

Diagnosis
This illness, which I did not then recognise, has since been described in various publications, but the best summary was issued in 1996 by the US National Institute of Allergy and Infectious Diseases, using the International Centre for Disease Control criteria published by Fukuda et al, which gives a clear research definition. In children, the symptoms change little after three months, and I accept symptoms stable at three months as the time to apply these criteria as a working definition. Although there is a common pattern of symptoms in all age groups, there may be several subgroupings of the illness with either a predominant pattern of muscular pain and physical weakness for which treatment using cognitive behavioural therapy (CBT) may be less appropriate, or predominantly neurocognitive symptoms for which CBT may be helpful, but an early return to school inappropriate. Bell describes common complaints in children and adolescents of fatigue, headaches, sleep disturbance, and cognitive disturbance; anorexia is also frequent in this group, but not anorexia nervosa because there is a realistic appreciation of loss of weight and the importance of food.

A good discussion of possible aetiology has been given by Dickinson, who suggests evidence of organic lesions of the central nervous system seen as small localised defects of the reticular formation of the upper brain stem caused by previous viral infection. It would be inappropriate to discuss this further in this article. In adults, up to two thirds of patients with chronic fatigue syndrome (CFS) are alleged to show symptoms of major depression at some time, whereas in adolescents with CFS seen early in the illness there was no difference in this respect from a normal control group, the prevalence being nearer to 15%.

Management
Because CFS may not be a single disease process, but a compendium, there is no specific remedy that can be applied effectively in all cases. As a starting point it is important to recognise the illness, make a definite diagnosis, and arrange tests to exclude possible confounding with other conditions. The onset may be rapid or slow and intermittent.

It is important to engage the family for a management plan that is realistic and hopeful, and to establish an attitude of trust and confidence in both child and carers. As in any illness with children, it is important to listen to the parents, accepting their descriptions of the cause of the illness, modifying extreme or incorrect ideas with an open mind. Management should be directed on two fronts: (1) medical to improve physical and mental well being and (2) educational to optimise conditions to allow suitable learning to continue. On each front, the severity of the illness will suggest the strategy. A carefully paced lifestyle is encouraged in all cases.

Minor illness
Children continue to walk about and play briefly, but need to rest or stop after a short period of activity. Sometimes more noticeable is a rapid decline in their academic ability in school. For such children, a good balanced diet given as regular or frequent small meals with vitamin and mineral supplements and essential fatty acids; planned rest periods of 15–45 minutes after one hour’s activity (physical and mental), preferably in a quiet room apart from noise and other stimulation; and freedom from the necessity to participate in games, physical education, and sports activities except when they feel able to do so without undue tiring, are all that are required. They can maintain social and peer group interaction during and after school, but may need some encouragement to do so without “loss of face” from having to stop early. The diagnosis may well be missed in this group or it may be fairly short lived, and as children adjust to their pace of living, they may merge back into the normal range of childhood.
behave. These children may require some relief from academic pressure in school—dropping some subjects or homework and other expectations, and also will need help with transport to and from school. They will probably recover and be back to normal activities within two years, but will need to be careful not to over exert themselves physically or become stressed mentally, or they may relapse.

Moderate illness

The majority of children referred to consultant paediatricians will fall into this category. Many of these will have spent a week or two at home after an acute illness and find it impossible to keep going when they return to school. They will probably have a reduced modified Karnofsky activity score of 40–70, and be unable to attend school full time. As well as a reduction in academic pressure and number of subjects, they should be relieved of competitive sports and tedious journeys, noisy activities, and long conversations. Part time school attendance backed up by home learning, with or without tutors or information technology computer programs, should be considered. One of their greatest losses, which is worse for children involved in sports, is separation from their peers and their common interests which they normally get in school. Children with CFS often find standing difficult and have to sit or lie down because of orthostatic hypotension and a possible reduction in blood volume. Inevitably, they become more dependent on their carers, and opportunities should be taken to encourage contact with peers through short visits, telephone conversations, and following their interests on television or videos with encouragement to keep those interests alive. Keeping a daily diary can be helpful to monitor encouragement to keep those interests alive. Cognitive problems, problem solving, and forward thought, problem solving, and forward planning. Time allocation should be made to allow completion of these tasks. Gross and fine motor problems, decreased spatial perception, and visual discrimination interfere with practical tasks and independence. These problems, together with natural impulsiveness and emotional lability in younger children, make children more irritable and less compliant, particularly when they are expected to comply with adult rules. Encouragement is more rewarding than compulsion. Individual and home tuition is much less stressful and can be geared to the child’s own pace.

Medical symptoms

Pain should be tackled symptomatically using mild medications (paracetamol) and alternative medications and treatments (for example, osteopathy) considered. I often prescribe a small dose (10 mg) of amitriptyline to help relaxation and sleep, but the herbal product St John’s Wort can be as effective.

For those with recurrent sore throats, vitamin C 1–3 g/day, and a mixed vitamin and mineral tablet (Biocare) plus two epogam capsules/day for those who may be poorly nourished. Small frequent low allergen and low sugar meals seem to help, and extra salt should be given to those who are light headed and dizzy. Amitriptyline can be increased by 10 mg/night at two weekly intervals, stopping when the symptoms of morning drowsiness become intrusive. I also encourage regular bedtimes and waking times in the mornings, trying gradually to adjust these to the “normal” working schooldays. Encouraging set waking times only applies to patients who are nearly recovered and are in the third stage of the illness. For those who have attention difficulties in the morning, I have tried a small dose of fluoxetine—starting with 1 ml of the liquid (4 mg) and increasing at one to two weekly intervals—or L-threo-diphenyl-ethylamine (selegiline) given after waking, but the side effects—for example, over stimulation before they are ready for it, or may be unacceptable. Directing the interests of children to activities possible for them to do easily will increase motivation and will distract from the frustration that most will experience as a result of their physical and mental limitations. Many of these children will keep going and will be functioning at about 90% of their capacity within two to four years, but may need special conditions—for example, an amanuensis, a special quiet room or rest breaks, and extra time to help them with their examinations. According to one American paediatrician, resolution is heralded by the voluntary resumption of activities without the consequence of exacerbation of symptoms.

Severe illness

The more severely ill are the most disabled, usually house bound and sometimes bedridden. It is possible that a few may arrive at this point through neglect; some as a result of a series of illness events, each one leaving them worse than before the previous event; and some as a result of over enthusiastic attempts to rehabilitate them too early. In most cases, however, it is part of the natural development of the illness. Several authors have suggested that undue pressure (stress) to stand on their feet again has a deleterious effect, which follows initial improvement. If there is genuine impairment of physiological mechanisms in various systems of the body, this result is not surprising. Psychologically, they may refuse or be too afraid to engage in suggested activities. These patients should be individually assessed, and specific attempts made through passive physiotherapy and some regular counselling to first support their physical needs—for example, food (including
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nasogastric tube feeding if necessary), sleep, relief of symptoms, movement, and gradual encouragement to return to manageable and acceptable activities in a relatively stress free environment, usually their own homes. Sensitive psychotherapy may be helpful here, provided that the therapist understands the physical limitations of the illness. This is likely to take a long time and efforts should be made to start treatment early in the illness to prevent the child from reaching the stage of losing interest in the progress of life. Some of these children will not recover appreciably or will retain residual handicaps for many years. Re-introduction to learning and school should be slow and gradually progressive as they improve. But for some children and for variable lengths of time, school, as it is usually conceived, may be a quite inappropriate environment to be in; and various exciting alternatives are available for individual learning, both at home and later at colleges of further education. A sympathetic and dedicated hospital unit may be helpful, but these are scarce, and residential inpatient care is rarely needed. No time limit should be set for their recovery.

**GENERAL MEASURES**

In addition to the supports mentioned earlier, sleep problems are important. If a young person feels deprived of sleep they cannot think clearly or behave rationally. Treatment should be started by encouraging regular times of going to bed and getting up the next morning and supplemented with a small dose (10 mg) of amitriptyline or a similar alternative. For some, short daytime naps may be helpful, but not appropriate for all. If children are bedridden, their muscles will deteriorate through weakness, but not atrophy significantly if the nerve supply is intact. These children run the risk of pulmonary embolism through circulatory stasis, and psychologically some may have shut off from the world around them and need to be gently encouraged to make contact again. Gentle physiotherapy taught to the carer at home will help prevent muscle atrophy and contractures and the feeling of physical incompetence. Many young people in this condition are hypersensitive to bright light and to sound and cannot cope with a conversation, even on a one-to-one basis, for more than a few minutes, spending their lives in seclusion in a darkened and quiet world. Gentle attempts should be made to gradually open up this environment.

Parental cooperation and agreement to treatment modality can be a problem unless understanding and trust are first established. Disagreement often arises when doctor and parent view the illness differently—a point that has been well argued in a paper in *American Psychologist* by Jason et al., but compulsion is hardly ever justified and may lead to failure and relapse (B Lask, personal communication, 1997). Parents often understand their child more completely than the doctor, whereas the doctor has a wider understanding of the range of illness behaviour. Thus, cooperative planning of management is needed. A partnership of equals between doctor and parents seems to work best, but manipulation on either side leaves the child bewildered and delays progress towards recovery. Friedberg and Koupp found that CBT showed significant reductions in symptoms of depression, stress, and fatigue severity in patients with CFS, but their fatigue severity remained abnormally high. Relieving depression does not cure fatigue symptoms. They also found that there was no evidence that exercise avoidance had become a phobically mediated behaviour. More often they had to encourage their patients to rest more. Much time, patience, ill feeling, and money can be wasted in desperately seeking second opinions on the one side and invoking legal restraints on the other. There is no definitive treatment for all cases.

**Doctor’s role**

My first duty as a doctor is to establish the diagnosis beyond a reasonable doubt, calling for sufficient investigations to rule out alternative diagnoses and for second opinions from colleagues or institutes that have a working experience of the illness in all of its forms, where doubts remain. My second duty is to establish a trust with the patient and their parents or guardian that will allow both parties to proceed with honour, and to avoid making rash promises about prognosis. Very rarely in severe cases this may require lengthy hospital admission, but the mobilisation of adequate community resources to support the patient in their own home is my preferred option. Over and above this, the doctor should become familiar with the illness to be confident about making decisions that will assist the patient’s rehabilitation without harming the trustful relationship already built up. I prefer an organic approach, remembering the brain is involved in cognition and emotional disorders, but others may prefer rehabilitation based on a psychiatry and distraction approach. There is no published follow up evidence to suggest that any one approach is more effective than any other. Clearly, CFS is not a wholly psychiatric disorder, but neither can we have brain disease without expecting some behavioural dysfunction, especially in young people. Organisations such as The National ME Task Force Young People’s Focus Group and the Association of Child Psychology and Psychiatry have been working on multidisciplinary guidelines which will be published separately in the near future. Little is to be gained by continuing to intervene when a trustful relationship has broken down, neither is it wise to invoke a spurious diagnosis of Munchausen’s syndrome by proxy, and one must be sure of the alternative diagnoses of anorexia nervosa and school phobia before evoking them as alternative diagnoses.

**Conclusion**

CFS is a real illness and currently affects a large number of children whose education is interrupted for long periods due to sickness. This illness is a genuine disability whether it is thought to be of biological, psychological, or mixed origin. The doctor may be called upon...
to advocate for the patient with CFS, and I believe that families need more empathy rather than criticism from the medical profession. Those young people who have recovered gradually feel more secure in their own ability than those who have been forced to submit to a regimen which they resent for years afterwards.

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