How I manage chronic fatigue syndrome

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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 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.

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.

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
behaviour. 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. The 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.

**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 them 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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Their recovery. Rarely needed. No time limit should be set for cated hospital unit may be helpful, but these ing, both at home and later at colleges of environment to be in; and various exciting conceived, may be a quite inappropriate improve. But for some children and for variable be slow and gradually progressive as they retain residual handicaps for many years. children will not recover appreciably or will be in seclusion in a darkened one-to-one basis, for more than a few minutes, and cannot cope with a conversation, even on a 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.