Adolescents should be the age group who are fittest, healthiest and least likely to trouble their doctors. When they do not fit this stereotype they may find it difficult to obtain access to the health care they need. This may reflect their embarrassment, inability to communicate, gaucheness or scepticism about adult authority. It can also reflect the confusion of doctors, both in primary and secondary care: demarcation lines between paediatricians and general physicians, and between child, adolescent and general psychiatrists may leave 14–19 year olds languishing in limbo. Doctors must never forget that behind the façade of bravado or aggressive experiments with sex, drugs and rock and roll there is still a vulnerable and uncertain child.

Prevalence of symptoms

Population studies, usually from self-completed questionnaires, suggest that the prevalence of frequent or persistent somatic symptoms in secondary school children is 4–10%\(^2\). Probably the most common chronic unexplained symptom is that of fatigue. Estimates of prevalence vary, largely because of different criteria used by investigators. Simply asking parents whether their 12 year olds complain of feeling tired and lacking in energy produces an affirmative answer for 19% of boys and 29% of girls\(^3\) – little different from findings in primary care of adults who are ‘tired all the time’. What really matters is how many youngsters suffer such debilitating fatigue that their normal daily living is significantly adversely affected. Such patients are generally classified as having chronic fatigue syndrome (CFS) by doctors and myalgic encephalomyelopathy (ME) by themselves, their families, self-help groups and the media. A UK study using school attendance registers proposed a prevalence of 0.07% for CFS/ME\(^4\). The methodology has been criticised\(^5\), but one finding is likely to be correct – namely, that CFS is the commonest reason given to school authorities for long-term absence: for example, it is cited twice as frequently as leukaemia and other cancers. Reliable prevalence figures should eventually be available from the collaborative study by the Royal College of Paediatrics and Child Health Research Division and a network of over 900 general practices (L Haines; personal communication).

One reason for confusion about prevalence is uncertainty over diagnostic criteria (Tables 1 and 2). Two major definitions are commonly used: the US Centers for Disease Control (CDC) definition and the Oxford criteria\(^6,7\), neither of which is strictly appropriate for adolescents because:

- there are ambiguities
- the demand for illness of at least six months’ duration is probably too long
- the CDC criteria do not exclude all those who may have another diagnosable reason for their fatigue state.

Chronic fatigue

Not all symptoms will be present in any one patient, and they may vary in severity and nature from time to time. Illness duration varies from several months to years, although the prognosis appears to be better in children than in adults\(^8\). Even though the worst affected may be bedridden, physical signs are minimal, non-existent or secondary to disuse. This can frustrate those doctors who depend upon physical signs for confident diagnosis.

Obviously, not all these conditions must be worked through in every patient. However, it is reasonable to exclude a cerebral space occupying lesion in those with suspicious headache and fall off in school performance as major features. Similarly, a combination of tiredness from anaemia with even minor gastroenterological symptoms may point to the need to rule out Crohn’s disease.

Investigations

Investigations should include:

- basic screening by full blood count, C reactive protein or erythrocyte sedimentation rate
- blood creatinine, electrolytes, acid-base status, liver enzymes and thyroid studies
- selective use of creatinine phosphokinase (males)
- immunoglobulins, endomysial and anti-gliadin antibodies
- serology for chronic infecting agents such as Epstein-Barr virus, cytomegalovirus, toxoplasmosis, etc

Key Points

1. Chronic fatigue syndrome is the commonest reason for long-term sickness absence from school
2. Diagnosis is based on a clinical history conforming with published diagnostic criteria
3. Patients state that what they most desire from their doctor is affirmation of the reality of the symptoms and reassurance that they will recover eventually
4. Liaison with school and education authorities is vital
5. There is no shame in admitting uncertainty as to diagnosis, pathogenesis, treatment and prognosis
Management

Accept the patient’s distress. Do not dismiss it as unworthy of further attention because you have been unable to diagnose a more glamorous, more easily treatable or less time-consuming problem.

Describe in language appropriate to the young person’s level of vocabulary and comprehension how doctors, society and patients variously view the illness. Do your best not to potentiate the myth of separation of the physical and emotional. Written information helps, provided that it does not contradict what you have told the family.

State your uncertainty over how long the young person will be unwell, but be optimistic. Stress that, contrary to what they might read or hear, most people get better.

When you consider psychiatric referral would help, discuss with the family why this might be so. Try to make the decision a shared one.

If a physiotherapist with knowledge and skills in CFS is available, offer a graded exercise programme, but be prepared to justify it to the sceptical. Remember that there is no published trial in this age group.

Learn what cognitive behaviour therapy involves, and suggest the patient may wish to explore this with the psychiatrist to whom you make a referral.

Run through the medications that have been used and their disappointing results. Nevertheless, consider prescribing simple analgesics for pain, mild hypnotics for sleep disturbance (e.g., chloral hydrate, low-dose tricycles) and (rarely) tricycles or a selective serotonin reuptake inhibitor for depression.

Liaison with schools

Many of the young people will be tormented by anxiety about public examinations, and their parents may be even more concerned. Even if they are not in a year preparing for such a trial, you must help them plan how to keep their education going. Some children are capable of some school attendance, but others are restricted by exhaustion, a disturbed sleep cycle that prevents them arriving on time, fear of noise and bustle, and inability to travel in comfort. There are various methods of liaising with schools:

- Write directly to the appropriate member of staff describing the young person’s medical problem and offer to attend a conference at the school with staff, parents and pupil
- Write to the consultant community paediatrician responsible for the local authority area in which the school is situated and ask him or her to take over the task
- Liaison with schools

- but be sure you know how to interpret the often confusing results (for an excellent summary of confusion surrounding serological investigations in CFS, see Ref 9)

- urine microscopy and culture
- psychological assessment, possibly including evaluation by standardised diagnostic questionnaires.

Abdominal ultrasound or brain imaging is merited in a few patients. There may be sufficient clues in others to consider more complex tests for endocrine or metabolic disorders (e.g., adrenal function tests), but these should not be carried out as a routine.

Table 1. Criteria for diagnosis of chronic fatigue syndrome (CFS)/myalgic encephalomyelopathy (ME).

<table>
<thead>
<tr>
<th>Fatigue</th>
<th>Mental and physical, separate from tiredness due to exertion, loss of motivation due to depression, and weakness from neuromuscular disease</th>
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<tbody>
<tr>
<td>Cognition</td>
<td>Reduced attention span, reported impairment of short-term memory, poor concentration, difficulty in finding the right word</td>
</tr>
<tr>
<td>Pain</td>
<td>Muscle, joint, abdominal and/or headache – often worse after exertion</td>
</tr>
<tr>
<td>Sleep dysfunction</td>
<td>Hypersomnia, altered sleep/wake pattern, unrefreshing sleep</td>
</tr>
<tr>
<td>Depression</td>
<td>Occurs as a secondary consequence Presenting as a major feature, it calls into question the diagnosis of CFS</td>
</tr>
<tr>
<td>Other</td>
<td>Dizziness, often most noted on standing, anorexia, nausea, weight gain. Increased sensitivity to light and sound</td>
</tr>
</tbody>
</table>

Table 2. Differential diagnosis.

| Chronic infection | eg Epstein-Barr virus, hepatitis, enterovirus, Lyme borreliosis, brucellosis |
| Endocrine disorders | Hypothyroidism, hypopituitarism, hypoadrenalism, myasthenia |
| Haematological disorders | Severe anaemia, lymphoreticular malignancy, immune deficiencies |
| Gastroenterological disorders | Crohn’s disease, gluten enteropathy |
| Psychiatric disorders | Depression, anxiety states, somatising disorder related to family pathology, anorexia nervosa, school phobia |
| Neurological disorders | Cerebral tumour, chronic subdural haematoma |
| Other | Sleep apnoeas |
Contact the educational psychologist responsible for the school and ask him or her to coordinate management.

When discussing a patient with teachers, explore their attitude towards such responses as timetable modifications, part-time attendance, facilities for the child to rest during the day, help with getting around school (even including wheelchair assistance), financial support towards transport, and exemption from some national curriculum requirements such as those for physical education.

Liaising with social security services

Children with CFS may qualify to receive disability living allowance. This has two components:

- a mobility payment for those virtually unable to walk or who require extra supervision outside the house
- a care payment, payable at various rates depending on what proportion of each 24 hours requires extra care.

Additionally, a parent who gives up work to care for a sick child may be entitled to carers’ allowance. It is kind to remind families of these benefits, explaining that details can be obtained at local social security offices or post offices. It is worth warning them that the procedure may not end up satisfying them because of arguments about the degree of disability.

Liaising with self-help groups

Many doctors are ambivalent about patient support groups. In the case of CFS, this may be partly because of the aggressive stance taken by some of these groups when dealing with doctors. We should not be surprised at this reaction, considering that the groups may be governed by the most severely ill, and that some doctors have been unsympathetic towards sufferers. It might also be because of the publication of studies suggesting that membership of such a group was one factor possibly associated with poor prognosis. Nothing will prevent your patient’s wish to contact such a group, so there is no point in adopting a confrontational attitude. My own experience is that young persons can obtain a great deal of support from contact with an organisation such as The Association of Youth with ME (AYME) (contactable at Box 605, Milton Keynes MK6 3BH).

CFS continues to be a conundrum wrapped in an enigma. So long as this remains the case, individual clinicians and public health physicians responsible for providing health services will encounter distrust or even hostility from those who believe they are not receiving the help they need and deserve. The doctor’s duty is not to turn his face away from such difficulties but to engage with patients, admit uncertainty, and do his best to explore with them how their lives can be made more tolerable.

References


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