

## Managing chronic fatigue syndrome in children

Liaise with family and teachers to keep morale high and minimise disability

See pp 1647, 1700

ast month the British press made much of a study purporting to show that chronic fatigue syndrome was the single commonest cause of long term absence from school in Britain. The authors claimed to have calculated prevalence figures for both pupils (0.07%) and teachers (0.5%) similar to previously reported figures for the general population.2-4 Dowsett and Colby make much of "clusters" of cases, defined as three or more cases in a school. The press release distributed by one of the authors states that 39% of cases occurred in such clusters, saying that this "suggests that ME results from an infection." It refers to one cluster extending over several schools in an area where there was "recreational water heavily polluted by sewage." The published paper contains no reference to pollution by sewage or anything else, but only to several cases in "schools near two new towns in a rural environment alongside recreational water."

Unfortunately, the data from this questionnaire survey are heavily overinterpreted. The response rate was only 37% of schools contacted, no attempt was made to define whether non-responders differed from responders, and the local educational authority districts surveyed were chosen on the basis of social and geographical diversity but also "their interest in the project." It is not clear on what criteria diagnoses were based except for "using reports originating from primary care physicians who may have referred cases to specialists for diagnosis." No consideration was given to possible subjectivity of diagnosis except to suggest underdiagnosis in the areas of lowest prevalence. The possibility of overdiagnosis in the areas of highest prevalence was not mentioned.

Considering all of this, should the report be dismissed as special pleading? I believe not. While Dowsett and Colby's paper does not help elucidate the true prevalence or aetiology of the condition, it serves two useful purposes. It points out that there is a small number of seriously incapacitated children whose education is imperilled and for whom help is needed. It also provides some confirmation of the common belief of doctors treating adults with chronic fatigue syndrome that teachers are over-represented in their caseload.

Faced with a child with chronic fatigue syndrome, general practitioners and paediatricians have several tasks (see box).<sup>6</sup> Firstly, to consider and rule out an extensive differential diagnosis of both physical and emotional disorders. Secondly, to hesitate before diagnosing chronic fatigue syndrome unless the criteria set

# Chronic fatigue syndrome in children (adapted from the royal colleges' report<sup>5</sup>)

#### Diagnosis

- New onset of severe disabling physical and mental fatigue for more than three months

  \*Investigation\*\*
- Full history and examination
- One stop tests to exclude other diagnoses *Management*
- · Intervene early
- Acknowledge the reality of the child's symptoms
- Insist on inseparability of the physical and psychological
- · Explore family and psychosocial issues
- · Liaise closely with school
- Agree with family a daily life activity and educational programme
- Consider home tuition only when even part time school attendance proves impossible

by the United States Centers for Disease Control or the Oxford consensus criteria are met.<sup>7 8</sup> Thirdly, to try to gain the family's acceptance from the outset that physical and psychiatric diagnosis and management are not mutually exclusive.<sup>6</sup> And, finally, to liaise with a physiotherapist, child psychiatrist or psychologist,<sup>9</sup> representatives of the local education authority and the child's school, and anyone else from any discipline who has something to offer, in devising and carrying out a plan of physical, emotional, social, and educational care to keep morale high and minimise disability.

Differing views on the value of rest as opposed to graded exercise cause anxiety for families.<sup>10</sup> Evidence for the effectiveness of graded exercise comes from a randomised trial in adults published in this week's *BMJ* (p 1647).<sup>11</sup> Experience suggests that a similar result would be likely with children.

Teachers play a pivotal role. As Dowsett and Colby imply, there can be scarcely a school where no member of staff has suffered from chronic fatigue. They may have firm views on the subject, which may sit uneasily with the doctor's acceptance of uncertainty or even scepticism, preferably kept in reserve. One result can be conflict on how best to continue a child's education. In particular, there will be those, like Dowsett and Colby, who strongly favour home tuition. Some paediatricians and educational psychologists are concerned that providing this may increase secondary gain in those children whose chronic fatigue includes elements of depression, school phobia, or unreason-

able overattachment to home or family. Education authorities may be concerned about cost.

A case discussion, held at school with parents present, can do a great deal to ensure that all parties work together even if they have differing perceptions of the underlying problem. Each family needs an individual plan. Until we have evidence from research into the education of these children, polarised positions on the value of part time school attendance or provision of home tutoring are as pointless as those on the post-viral or psychosomatic hypotheses of pathogenesis.

In the meantime, simple practical measures may help; for example, persuading the local educational authority to pay for transport to and from school at other than standard times. Pressing the authority to provide home tuition sometimes proves the best option, but only when school phobia has been definitely ruled out<sup>12</sup> and the benefits of home tuition will outweigh potential social isolation. In my experience there is great satisfaction and pleasure for all concerned when a child finally returns to a full and lively school life after months or years of disability. Optimism is not out of place, even though reliable follow up studies are unavailable for a large series of children with proper entry criteria. Experience suggests that children are likely to recover more rapidly than adults

Perhaps the most important implication of this study is one not mentioned by the authors. Most long term absences from school were ascribed in this survey to chronic fatigue syndrome, which reflects the fact that other serious childhood diseases no longer automatically result in this added disability. Many children who are successfully treated for malignancies and serious rheumatological disorders miss little school. Children with cystic fibrosis are unlikely to miss more than a few weeks in any year.<sup>13</sup>

The report on chronic fatigue syndrome by the joint working group of the royal colleges of physicians, psychiatrists, and general practitioners concluded that research should be directed in three areas: one was the management of the condition in children.<sup>5</sup> Dowsett and Colby echo this and deserve support in their plea for research into the educational needs of these children

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## Why healthcare systems need medical managers

Doctor managers have distinct advantages

This can happen only if doctors become more involved in management and increase their management skills. Experience in many health systems has shown that doctor managers have distinct advantages over their non-medical counterparts, including greater credibility, a deeper knowledge of how health care works, and a less trammelled ability to speak out. But these advantages will count for little unless doctors who become managers are well trained and work to develop the intellectual base of medical management. Various initiatives are under way to develop medical managers, including the relaunch in February 1998 by the BMJ Publishing Group of the journal Clinician in Management.

Doctor managers put patient care and clinical outcome ahead of the financial imperative, and this ultimately is the only way to develop the business of healthcare systems—looking after patients. Businesses prosper not because they try to make profits but

because they do something important well. The British healthcare system, the NHS, like many systems has two lines of management. One is a bureaucracy characterised by a hierarchical, top down management inescapably bound up with politics. Alongside this system sit the professionals, often working in teams with members whose status is essentially equal. This coexistence inevitably generates tension between the professionals, who organise through peer review, and managers, whose survival is dependent on achieving targets set from above.

Clinicians who are well trained in management have a unique power base. They have an intimate knowledge of how the service works, and their views are thus often accepted more readily than those of non-clinicians. Furthermore, medical managers have a clinical career to develop or return to. They can thus afford to adopt high risk strategies with far greater comfort than their non-clinical colleagues. And they can speak out. Consider the trust that faces a health

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<sup>2</sup> Bates D, Schmitt W, Lee J, Ware NC, Lee J, Thoyer E, et al. Prevalence of fatigue and chronic fatigue syndrome in a primary care practice. Arch Intern Med 1993;153:2759-65.

<sup>3</sup> Buchwald D, Umali P, Umali J, Kith P, Pearlman T, Komaroff AL. Chronic fatigue and the chronic fatigue syndrome prevalence in a Pacific Northwest Healthcare System. Ann Intern Med 1995;123:81-8.

<sup>4</sup> Lawrie S, Pelosi A. Chronic fatigue syndrome in the community: prevalence and associations. Br J Psychiatry 1995;166:793-7.

<sup>5</sup> Chronic fatigue syndrome. Report of the joint working group of the royal colleges of physicians, psychiatrists and general practitioners. London: RCP, 1996. (CR 54.)

<sup>6</sup> Marcovitch H. Chronic fatigue states in children. In: Jenkins R, Mowbray J, eds. Post viral fatigue syndrome. Chichester: John Wiley, 1991:335-44.

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<sup>8</sup> Sharpe M, Archard L, Banatvala J, Borysiewicz LK, Clare AW, David A, et al. Chronic fatigue syndrome: guidelines for research. J R Soc Med 1991;84:118-21.

<sup>9</sup> Vereker MI. Chronic fatigue syndrome: a joint paediatric-psychiatric approach. Arch Dis Child 1992;67:550-5.

<sup>10</sup> Report from the national task force on chronic fatigue syndrome (CFS), postviral fatigue syndrome (PVFS), myalgic encephalomyelitis (ME). Bristol: Westcare, 1994.

<sup>11</sup> Fulcher KY, White PD. Randomised controlled trial of graded exercise in patients with the chronic fatigue syndrome. BMJ 1997;314:1647-52.

<sup>12</sup> Berg I. School refusal and truancy. Arch Dis Child 1997;76:90-1.

<sup>13</sup> Walford GA, Nelson WMcC, McCluskey DR. Fatigue, depression and social adjustment in chronic fatigue syndrome. Arch Dis Child 1993;68:384-99

authority making irrational decisions. A medical director can argue against it and is likely to be believed. It is much harder for chief executives to make similar statements, not least because their average length of time in post is currently running at two years and eight months. No matter how much a chief executive's values may coincide with that of the clinicians, he or she is vulnerable if there is direct conflict between what is right for patient care and what is demanded from above.

Senior strategic roles in management now attract the brightest and best doctors, and this must be encouraged if doctor managers are going to make real improvements in healthcare systems. Management should no longer be seen as an eccentric hobby for the bored or inept doctor. All clinicians must know something about management, even if it is to be able followers rather than leaders. Doctors have a duty not only to play their part in management but also to ensure they have the knowledge and skill to do it well. There is an art and a science to the management of servicesmaking them work, developing contingency systems, motivating, managing colleagues' performance, and understanding service operations. It is time for doctors who have taken a lead in management to share their knowledge and enthusiasm with the medical profession as a whole. The next generation of doctors must not only be able clinicians but must also know how to run an effective clinical service, from understanding the budget to improving clinical outcomes.

The maturity of medical management is signalled by the increasing contribution of medical managers to major national committees; the emerging interest from the royal colleges; the development of the Scottish Intercollegiate Initiative in Medical Management; the growth in the British Association of Medical Managers (BAMM), which now has 800 members; and the appearance of the new journal. Clinician in Management was originally BAMM's in house publication, but it will now become a quarterly peer reviewed journal with an international circulation. It will publish research, air controversial issues, share good practice, and examine every aspect of healthcare delivery and the role of professionals. One way in which doctors can contribute to management is to bring their research based scientific tradition to the discipline This will be one of the aims of Clinician in Management.

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Jenny Simpson is editor of *Clinician in Management*: see advertisement in this issue (except compact edition).

# Health priorities for the European intergovernmental conference

Long term, multisectoral issues rather than knee jerk political responses

ast month, Britain's new prime minister, Tony Blair, called on the European Community to become less obsessed with itself and its institutions and to focus instead on the issues that matter to people. These included, he said, public health, fraud, and the environment. From the start, public health has held only a tenuous foothold within the community, and there had been reports that the community's remit in public health, set out in article 129 of the Maastricht treaty in 1993, would be abandoned. But as a result of the crisis about bovine spongiform encephalopathy (BSE), article 129 is now safe, at least in some form, and it will figure on the agenda of the intergovernmental conference on treaty reform this month in Amsterdam.

Unfortunately, the outcome of any review of the community's role in health may be only a short term response to the problem of BSE. Such knee jerk action is already evident in the European Commission's proposal earlier this year to revise article 129, which tacked on a highly visible reference to actions in the veterinary and phytosanitary fields, even though this duplicated powers existing elsewhere in the treaty. Instead, the community needs to fundamentally change the way it deals with health matters.

The community's current role has been based on a limited definition of public health, restricted to specific areas such as "prevention," "major health scourges," and "drug dependence." This disease based approach was outlined immediately after Maastricht in the commission's framework document.<sup>2</sup> While it may have proved politically successful, such an approach has reduced the community's ability to make a substantial contribution to the health of European citizens.

Rather than this disease based strategy, we need greater focus on risk factors associated with diseases and determinants of health. This calls for a multisectoral approach that incorporates subjects such as poverty, unemployment, agriculture, transport, housing, and education. Such an approach has recently been highlighted by Tessa Jowell, Britain's new minister for public health, in her message to the World Health Assembly on 7 May. This longer term, risk based approach may be less politically appealing but is likely to be more effective in health terms.

Many other areas of European Community policy (such as agriculture and industry) can and do impact on health, and there is great potential for an integrated approach to health at community level. Since the Maastricht treaty, health protection must be integrated into other areas of community policy, but this has not happened effectively. The most substantial product has been an uncritical annual report by the commission's public health unit<sup>3</sup> instead of initiation and facilitation of policy changes and development.

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There is also an urgent need to define where the European Community can act in public health and which areas should remain the preserve of member states, as the present lack of clarity may lead to disputes over the community's role. A clear framework for setting priorities is needed: to define the criteria for community actions, where they can be performed more cost effectively for the community as a whole, where there is a need for the coordination of activities at European level, where other community policies have health implications, and where there are issues that cross national boundaries. Such areas include communicable disease surveillance, the free movement of people and goods including drugs and medical devices, the collection of comparative data, the standardisation of definitions, health technology assessment, environmental health policies, and exchanging information on best practice in health

Another fundamental definition that needs clarification is that of "added value." This is supposed to guide community action, but there is little understanding of what it actually means in practice. Given the differences between member states in the development of their public health policies, health systems, and socioeconomic status, what constitutes added value is not necessarily the same for all member states. Action by the European Union must take into account these different needs and levels of development.

Implementing a new framework for setting priorities must go hand in hand with reforms of European Community institutions and decision making to redress the relative weakness of those responsible for health, particularly in the commission. Currently, health related activities are scattered throughout the commission without any effective central focus for health. This was obvious in the BSE crisis, in which

agriculture and not health officials took the lead both in the commission and the Council of Ministers. Health related policies are also discussed by ministers of transport and industry at European level, for example, but omitted from the agenda of meetings of health ministers. This is not altogether a bad practice as it enhances a multisectoral approach, but there is currently no effective mechanism to bring together all health related discussions. The commission's public health unit does not have the resources to lead this integrated approach to public health policy, and the newly created directorate general for consumer policy and consumer health protection will mainly focus on food safety.

The intergovernmental conference provides an important starting point to overhaul the way the European Community deals with health. Government representatives at the conference must discuss in a comprehensive way the future of public health in the European Community rather than responding to short term political considerations arising from the BSE crisis. With its expertise in public health, Britain now has the opportunity to contribute meaningfully to the discussions on the future shape of public health in the European Community. This opportunity should not be missed.

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## Treating anal fissure

Glyceryl trinitrate ointment may remove the need for surgery

atients with chronic anal fissures make up about 10% of new attenders at colorectal outpatient clinics. The cause is known: traumatic or ischaemic damage to the anal mucosa produces a superficial tear, usually in the posterior midline. Subsequent spasm of the internal sphincter leads to the lesion becoming chronic. The clinical hallmarks are an external hypertrophic skin tag or "sentinel pile" and induration in the base.

In the past the surgical treatment was manual dilatation of the anus under a general anaesthetic, but this resulted in high rates of long term incontinence and recurrence. The surgical approach was, therefore, changed to a lateral anal sphincterotomy, but this was associated with incontinence (about 20-30% of patients were incontinent of flatus, 5-10% had soiling, and 2-5% had faecal incontinence), and a long term failure rate of about 5%.

Clearly, a new treatment was needed, and anal fissure has proved to be a good example of basic labo-

ratory research leading to worthwhile advances in treatment.<sup>2-4</sup> Nitric oxide has recently been identified as the chemical messenger of the intrinsic non-adrenergic, non-cholinergic pathway mediating relaxation of the internal anal sphincter.<sup>2-3</sup> The terminal branches of both inferior rectal arteries pass through the internal anal sphincter, and blood flow to the skin of the anus is related to anal pressure. Applying glyceryl trinitrate, which donates nitric oxide into the pathway that relaxes the anal sphincter, lowers the resting pressure in the anus in both normal people and in patients with various anal conditions.<sup>5</sup>

Several studies have recently examined the use of glyceryl trinitrate in patients with anal lesions. Gorfine used the treatment in a mixed group of 15 patients with anal ulcers and fissures for as long as two years in some cases. A daily dose of 0.5-1 g of a 0.5% preparation relieved pain, but some patients had a headache as an occasional side effect. The St Mark's Hospital group treated 19 patients with chronic anal fissures with oint-

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ments containing a range of concentrations of glyceryl trinitrate (0.2-0.8%). They found this reduced the maximum resting internal anal sphincter pressure by at least 25%.7 The minimum effective concentration was 0.3%, and the quantity of ointment applied was 200 mg. Local application twice daily for six weeks produced healing in nine out of 15 patients followed up: the other six needed a lateral anal sphincterotomy. The main side effect was headache, and tachyphylaxis (progressive decrease in the response to treatment) occurred in some cases. Another study, from Nottingham, reported improvement in 18 of 21 patients treated with a 0.2% ointment.8 Finally, a paper from the Netherlands reported that local application of 1% isosorbide dinitrate (ISDN) administered six times daily for six weeks lowered anal pressures and increased anodermal blood flow, resulting in healing of the fissure in 30 of 34 patients.9

All of these studies were, however, observational and uncontrolled. In the absence of any proper randomised controlled trials, treatment with nitrates should still be classed as of uncertain benefit. Additionally, headache and tachyphylaxis may result either in poor compliance or withdrawal from treatment. The optimum dose remains uncertain; most studies have found that 0.3% glyceryl trinitrate ointment gives the best results, but the actual quantity of the ointment used may be just as important.5

Another approach to chemical sphincterotomy is by an injection of botulinum toxin into the groove between internal and external sphincter muscles. The toxin paralyses the external sphincter. Again, this treatment should be regarded as experimental.<sup>10</sup>

For the time being, the management of patients with anal fissures should begin with conservative management-bran and bulk laxatives-which produces resolution in 40-50% of cases. Local anaesthetic gels may be helpful either with or without laxatives. 11 In the past anal dilators were used, but no benefits were shown in a randomised trial.<sup>12</sup> If these measures fail, the patient should be referred to a colorectal clinic, where a therapeutic trial of ointment may be attempted. Some refractory patients will still require surgery.11 Some will require an examination under anaesthesia to exclude other causes of anal pain and bleeding. Topical nitrates may prove to be an advance,<sup>13</sup> but further careful prospective randomised controlled trials of nitrates versus conventional conservative and operative treatments are now needed, paying particular attention to long term results and recurrence rates.

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### Why does acute back pain become chronic?

Chronic back pain is not the same as acute back pain lasting longer

cute episodes of back pain are remarkably common. There is a high natural remission rate, with about 90% of cases resolving within six weeks. For patients with simple backache—acute onset of pain in the back without nerve root symptoms or signs of serious spinal pathology-bed rest is indicated only if the patient is in great pain and unable to stand or walk, and should be only for a short period. Analgesia and early physical activation improve the rate of recovery and allow early return to work.2

Despite these optimistic findings the prevalence of chronic or recurrent back problems is high-present in up to 39% of adults.3 Much effort is expended searching for a specific organic diagnosis such as a herniated lumbar spine, annular tears, spinal stenosis, or spondylolisthesis. But in the vast majority of cases it is impossible to identify the source of the pain. Patients may show limitation of spine movements, radiological spondylosis, facet joint osteoarthritis, or signs of disc degeneration and protrusion on magnetic resonance imaging. However, these commonly identified features have only weak correlations with the presence of back pain.

Extensive epidemiological studies have demonstrated little or no correlation between back problems and inherited factors, height, weight, deformity (unless gross), spinal movements, muscle strength, or radiological signs of disc degeneration. Much more important are cardiorespiratory disease, smoking, psychological morbidity, poor work conditions, social class, education, and income.4 In particular, studies in people not suffering from back pain show that potent predictors of future episodes of back pain include previous back pain, neck pain and other musculoskeletal pain, numbers of children (in men as well as women), work dissatisfaction, and psychiatric morbidity.5

There is increasing evidence that vascular damage plays a fundamental role in the pathogenesis of mechanical back pain. Degenerative disc disease is associated with atherosclerosis and spinal artery stenosis, and the degrees of disc degeneration and obliteration of the anastomotic arteries surrounding the disc are associated with increased vascularity in the annulus fibrosus.<sup>6</sup> The correlations between back pain and cardiovascular disease and smoking support a possible role for arterial disease. Disc degeneration and protrusion are associated with pressure on the epidural venous plexus, leading to venous dilatation, oedema of the nerve root, perineural and intraneural fibrosis, and neuronal atrophy.<sup>7</sup> Venous compression can occur at two or more levels in the spine, leading to isolated segments of poor perfusion.8 An inflammatory response is often observed in relation to mechanical spine damage.9 Pathological studies show that the local tissue reaction to herniated nuclear material seems to be due to endothelial proliferation, vascular dilatation and activation, and collagen proliferation,10 with pain fibres within this proliferating vascular tissue. These changes are not readily identifiable in life but, nevertheless, clearly offer the potential for pain production and also relate to the epidemiological associations with vascular disorders.

Some patients develop back and lower limb pain associated with hyperaesthesia, hyperpathia (excessive pain experienced from a minor noxious stimulus), allodynia (pain generated by minor stimulation of the skin), and vasomotor changes in the lower limbs with sensitivity to cold. The clinical features suggest sympathetically maintained pain, otherwise known as reflex sympathetic dystrophy. The sympathetic chains run down the sides of the vertebral columns, anastomosing with sympathetic fibres around and within the spine and intervertebral disc.

Involvement of the sympathetic system has long been recognised in patients with back problems and particularly in patients who have undergone failed spinal surgery. Altered vascular perfusion in the lower limbs, thought to be due to sympathetic dysfunction, is found in 80% of patients with sciatica and 69% of patients with low back pain.11 Sympathetic blocks with local anaesthetic may provide temporary relief of symptoms, and this technique is often used as a diagnostic test for sympathetically maintained pain. Unfortunately, surgical sympathectomy seems to provide only short term relief. Recent work suggests that sympathetically maintained pain may arise from altered central neuromodulation within the spinal cord, and sympathetic syndromes of this sort form part of the complex regional pain syndrome.

Peripheral injury increases excitability of the central nervous system. Within the dorsal horn, stimulation of peripheral pain fibres causes increased activity with prolonged periods of discharge, so that patients continue to feel pain long after the physical cause of the pain has healed. The dorsal horn cells develop increased sensitivity to afferent impulses. As a result, the patient experiences pain and tenderness that is disproportionate to the evidence of peripheral tissue damage, giving rise to the phenomena of hyperpathia and allodynia. The dorsal horn receptor fields may expand so that pain is felt over a much wider area than the damage to pain fibres would predict.<sup>12</sup>

This mechanism within the dorsal horn helps to explain why many people experience increased sensitivity to minor stimulation and pain that is persistent, disproportionate to the degree of tissue damage, and widespread. This type of pain is usually identified by comparison with the normal contralateral limb. However, if the syndrome affects both lower limbs, the diagnosis is difficult and clinical acumen is paramount.

We are now beginning to study central perception of back pain within the brain itself. Studies of patients with atypical facial pain in whom no specific cause or abnormality can be identified have shown abnormal activation of the cingulate region of the brain, and similar studies are currently ongoing in patients with chronic back problems. Altered central neuromodulation within the brain and spinal cord provide a mechanism for integrating physical and psychological influences and are likely to be directly relevant to the altered prognosis associated with psychological disorders.

The assessment of chronic back problems is changing rapidly. Patients should have a careful assessment for specific lesions causing pain. In some this may include intravenous enhanced computerised tomography or magnetic resonance imaging to identify vascular problems. A careful clinical history and examination, supplemented by psychological screens for depression and abnormal somatic perception as well as a pain drawing, will identify the patients in whom psychological influences and central neuromodulation should be considered. We now realise that, for many patients, chronic back pain is not the same as acute back pain lasting longer.

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