

Management of chronic (post-viral) fatigue syndrome

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SUMMARY. *Simple rehabilitative strategies are proposed to help patients with the chronic fatigue syndrome. A model is outlined of an acute illness giving way to a chronic fatigue state in which symptoms are perpetuated by a cycle of inactivity, deterioration in exercise tolerance and further symptoms. This is compounded by the depressive illness that is often part of the syndrome. The result is a self-perpetuating cycle of exercise avoidance. Effective treatment depends upon an understanding of the interaction between physical and psychological factors. Cognitive behavioural therapy is suggested. Cognitive therapy helps the patient understand how genuine symptoms arise from the frequent combination of physical inactivity and depression, rather than continuing infection, while a behavioural approach enables the treatment of avoidance behaviour and a gradual return to normal physical activity.*

Introduction

GENERAL practitioners are increasingly being called upon to manage a group of patients with an illness whose predominant characteristics are: severe physical and mental fatigue induced by physical or mental effort, emotional symptoms and an absence of abnormalities on conventional neurological investigations.

There can be no doubt that these patients suffer a high degree of physical and psychological morbidity,^{1,3} but there is more doubt about the correct name for the condition. Various labels have been used, of which the most common are myalgic encephalomyelitis and post-viral fatigue syndrome. Although the most accurate term is probably chronic fatigue syndrome,⁴ and this is now gaining international acceptance,⁵ most practising doctors will be more familiar with the term post-viral fatigue syndrome.

So far little has been written in the medical literature on the treatment of such patients and this paper is an attempt to rectify this. No *a priori* assumption as to aetiology is made, and indeed it is the contention of the authors⁶ that although several risk factors have been suggested, both organic⁷ and psychological,⁸ the precise aetiology of the illness is unknown. This paper is not a review of the subject,^{6,9} but is intended to offer treatment guidelines to general practitioners, neurologists, physicians and psychiatrists, all of whom may be faced with people with the chronic fatigue syndrome.

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Acknowledgement and validation of distress

There is a difference between establishing the nosological validity and subsequently the aetiology of a specific disease and establishing that the patient is suffering from something. Not to do the latter because convincing evidence of the former is available is a fundamental error.¹⁰

At the initial interview it may be necessary to discuss with patients their previous, often unsatisfactory, medical experiences in a non-critical fashion. It is almost certain that by the time patients are referred to a specialist centre with an unusual illness they will have suffered difficulties with the medical profession. It is important not to join the patient in criticizing medical colleagues, especially from the hospital setting. The general practitioner is likely to be responsible for the continued care of what may be a long-term condition, and he is entitled to the support of specialist colleagues.

By the time many of these patients reach specialist care they have made their own diagnosis of chronic fatigue syndrome. Regardless of the personal views of the physician there is little point in challenging this, except when there is evidence of a different disease which requires specific treatment. Instead, the diagnosis should be seen as only the beginning, and the patient should be encouraged not to view the syndrome as a chronic and incurable disease. With the lack of precise knowledge as to prognosis or treatment, diagnostic decisions and treatment decisions must be clearly separated. There is convincing evidence that in psychiatry, diagnosis does not strongly predict treatment, and that instead such decisions are based on symptoms — the problem oriented approach.¹¹ This is equally applicable to any chronic physical illness without an obvious cure. A similar eclectic approach should be taken to the problem of chronic fatigue syndrome.

Beginning treatment

Many patients referred to a specialized hospital with chronic fatigue syndrome have embarked on a struggle. This may take the form of trying to find an acceptable diagnosis, or indeed any diagnosis, and may involve reading the scientific literature concerned with the condition — health professionals appear to be over-represented among those seen in hospital practice with this condition. One of the principal functions of therapy at this stage is to allow the patient to call a halt without loss of face. This is most likely to be achieved if the doctor is perceived as open-minded and enquiring. It is necessary to share with the patient the uncertainty surrounding the topic, to admit that there are many conditions for which medicine does not possess all the answers, and to help the patient accept that there will never be an 'ultimate opinion' or 'final specialist'.

The patient should be told that there is no life threatening illness left, although the doctor must be aware of the potential risks of depression, and that it is now time to 'pick up the pieces'. A useful analogy may be the recovery of someone involved in a hit-and-run accident, emphasizing that pursuing the car at this stage will bring no benefit. The process is therefore a transfer of responsibility from the doctor, in terms of his duty to diagnose, to the patient, confirming his or her duty to participate in the process of rehabilitation in collaboration with the doctor, physiotherapist, family and others.

It is essential to agree jointly on an acceptable model, because people need to understand their illness. The cognitive-behavioural model described in the next section can explain the continuation of symptoms in many patients.

Model of treatment

The development and persistence of chronic fatigue can be understood using a cognitive-behavioural model. This is used to explain the observed progression from the avoidance of most forms of activity during the initial acute illness, which is both necessary and adaptive, to chronic avoidance behaviours, which are maladaptive. This model has been successfully applied to chronic pain.^{12,13} Philips¹² has outlined how cognitive factors may result in symptom perpetuation, and has shown that 'avoiding stimulation plays an active part in reducing the sufferer's sense of control ... and increasing his or her expectation that exposure will increase pain. These cognitive changes encourage further withdrawal from normal activities and a growing intolerance of stimulation'. This appears to be clinically relevant to the analogous problem of chronic fatigue where avoidance, with the inevitable physiological and psychological consequences, may also lead to increased sensitivity and hence further fatigue. Our model does not require the original agent to remain active to explain the continuation of symptoms.

Treatment should therefore follow broadly cognitive-behavioural lines and both aspects must be emphasized. Patients are unlikely to attempt such a programme without a valid and convincing explanation of the mechanisms underlying the development and persistence of chronic fatigue. At the beginning of treatment patients should be presented with two hypotheses.

The conventional view

You are ill with a poorly understood disease. Physical and mental activity should be limited in an effort to prevent further deterioration in your condition. Work, housework, childcare and physical exercise need to be avoided or approached with caution. An upsurge in symptoms should lead to further rest. This approach may help limit your symptoms until they resolve or a treatment becomes available. This is the 'conventional' view (ME Action Campaign factsheet, 1988).

The new approach

You have had an acute illness, probably infectious in origin, which forced you to become inactive for a period of time. Subsequently you have begun to experience fatigue on exertion and as a result you have started to limit or avoid activity of all sorts. Thus, you begin to experience symptoms whenever you attempt activities but never pursue them long enough to allow the symptoms to subside. At the same time there is a loss of tolerance to everyday activity owing to your increasing unfitness and poor cardiovascular condition. This means that you develop symptoms at increasingly lower levels of exercise, and find activities previously undertaken extremely difficult, if not impossible.

When you experience these symptoms, you have also experienced associated thoughts, such as 'If I carry on I may become worse', or 'There must be something seriously wrong with me to make me feel like this'. These symptoms are real, but unaware of their origin, you may have incorrectly attributed them to a recurrence of the original infection. This is particularly likely because the symptoms of muscle pain, breathlessness, dizziness, fatigue and others are similar to those experienced initially. This has led to a vicious circle of increasing avoidance, inactivity and fatigue.

The evidence to support this second hypothesis should be

shared with the patient. Many sufferers have been told that 'physical and mental exertion is to be avoided' (ME Action Campaign factsheet, 1988). This may be correct in some cases, but there is as yet no way that these cases can be identified. In general such advice is counter-productive, and must be set against the following:

- the harmful effect of disuse and inactivity on muscle function, in addition to respiratory and cardiovascular performance;¹⁴
- the psychological benefits of exercise on emotional disorders;¹⁵
- the adverse psychological effects of lack of exercise;¹⁶
- the deleterious psychological effects of avoidance of feared situations, as in agoraphobia;¹⁷
- recent evidence that dynamic muscle function is normal in patients with chronic fatigue syndrome, muscles being neither weak nor fatiguable.¹⁸

Work of treatment

All patients should have an assessment to establish the rationale behind therapy, clear-cut realistic goals that they wish to work towards and whether they accept the offer of treatment.

In the initial session it is important for the therapist and patient to discuss openly the patient's doubts and reservations. For example, the patient may often speak of the terrible effect of exercise. This is almost certainly true, and should be pre-empted by a statement, such as 'I know you have tried to exercise and ended up feeling worse'. It will be necessary to explain how reduced exercise capacity secondary to inactivity normally leads to the earlier onset of symptoms when exercise is undertaken.¹⁹ Moreover, such symptoms will lower morale, and lead to further reduction in exercise, further reduction in exercise capacity, further symptoms and so on. It is often remarked that many sufferers from chronic fatigue syndrome are extremely fit prior to the illness — this group may be the most likely to have a substantial deterioration and to experience the most symptoms.

After the initial session patients should be able to accept the proposed model as one they can work with, even if they do not believe in it. They should also have a clear understanding of the loss of tolerance to activity and the fear-avoidance model.

Ideally a behavioural programme should be individually tailored, with agreed targets appropriate to the degree of initial disability. However, it is likely to involve the following features:

1. Regular exercise, with which the patient can feel comfortable.
2. A graded increase in exercise, involving walking, swimming and so on.
3. Encouragement of exercises such as yoga and callisthenics.
4. Gradual exposure to all avoided activity.
5. Cognitive work to break the association between increase in symptoms and stopping or avoiding the activity.
6. Further cognitive strategies involving alternative explanations for symptoms. For example, if the patient admitted to thinking 'I feel tired, I must have done too much', one might ask the patient to look for alternative explanations, such as 'I may be tired because I haven't been doing much lately'.
7. No further visits to specialists or hospitals unless agreed with therapist.
8. Involvement of a co-therapist.

Treatment is likely to involve six outpatient sessions. Behavioural and symptomatic measures should be made before and after treatment, and at follow-up.

Self-help groups

Self-help groups can provide considerable emotional and practical support. The best self-help group is the family, and the

spouse or partner should be involved as a co-therapist. Self-help manuals are also useful, and an informative handout should accompany the initial interview. The appendix to Edwards' article¹⁹ is helpful, while a fuller guide, describing the therapeutic effects of exercise, is given in *Women and fatigue*.²⁰

Psychological management

In addition to fatigue, emotional symptoms are a central feature of chronic fatigue syndrome, being variously described as 'cardinal'²¹ or 'characteristic'.²² Thus, a psychological assessment is mandatory. Patients are often wary of this, seeing it as suggesting that their illness is all in the mind. If depression is a major factor, then adequate treatment may be needed before patients can embark on the programme outlined above. Stephens has stated 'Good mental health is not a sufficient condition for initiating exercise but may well be a necessary one'.²³

An important way of gathering information and helping the patient to understand his or her symptoms is to introduce the concept of stress. Any stresses occurring prior to, and during the onset of the illness should be specifically noted. This is not just a way of obtaining background details but provides useful information that may be incorporated into management.²⁴

Any patient with a severe and potentially chronic illness, whether rheumatoid arthritis, multiple sclerosis or chronic fatigue syndrome, requires a psychotherapeutic approach. The basic features common to all supportive psychotherapies, such as appropriate reassurance, regard, ventilation of distress and acceptance of feelings, are especially applicable to chronic fatigue syndrome.

As regards formal psychotherapy, there is some rationale for avoiding insight-directed therapy, as sufferers are often already highly introspective.²⁵ Certainly, a deeper examination of earlier history may be welcomed, but can wait until the patient is able to give such details without feeling challenged.

Antidepressant treatment

Many people with chronic fatigue syndrome become severely depressed to the point of suicide² and may benefit from antidepressants. However, some patients need to be educated about the benefits of antidepressant therapy, especially in view of the often fragile self-esteem of the patient by the time of referral. Depending on the degree of psychological insight of the patient, this may be presented in different ways. For example, secondary depression may be seen as an almost inevitable consequence of severe disability and demoralization. It is often worth stating that depression is not a sign of weakness, but a human response to stress.

Occasionally patients may say that they cannot take drugs. Again, the problem needs to be redefined. One analogy, for example, is the claim that one can no longer eat certain foods after once getting food poisoning. However, sensitivity to side effects must be remembered, as many, such as postural hypotension, tiredness and poor concentration, are also the symptoms of the syndrome. The use of symptom checklists prior to treatment may be useful. The current adverse publicity being accorded to minor tranquillizers should be specifically mentioned to emphasize the differences between these drugs and antidepressants.

Other psychological symptoms

Anxiety is often part of the syndrome. Conventional treatments such as relaxation and anxiety management may all prove successful.²⁶ Sexual problems occur in the majority of patients referred to hospital (unpublished data). They may be due to fatigue or pain affecting performance, or a diminution in libido

following emotional changes. These should be inquired into, and treated as appropriate.

Sickness benefits

Problems have arisen regarding the status of chronic fatigue syndrome as grounds for a variety of Department of Health and Social Security payments.²⁷ Although the diagnosis is recognized by the DHSS for attendance allowances and disability payments, not all individual inspectors appear to interpret the situation similarly, once again reflecting current confusion over case definition. At present individual cases should be treated on their merits, but it is reasonable to expect a patient to cooperate with treatment before being labelled as chronically disabled. The advice contained in the current factsheet of the ME Association, which tells sufferers that if they cannot walk more than 50 yards they should apply for a wheelchair, a mobility allowance and an invalid's parking permit may not be of long-term benefit to all patients.

Alternative therapies

Almost all patients referred to hospital with chronic fatigue syndrome will have tried a variety of 'alternative' therapies (unpublished data). The clinician may be asked for advice, or even for further addresses. The patients' faith in treatments which may be beneficial to specific individuals should not be undermined but not all such therapies can be given approval. For example, a recent newsletter of the ME Association stated that 'The notion of allergies further alienates the patient from the illness, which exacerbates and extends it. Such ideas reinforce the view that the sufferer is merely under attack from outside elements which have nothing to do with himself or herself. There is no clinical evidence that allergies exist in anything but a small number of sufferers, and their existence may be coincidental'.²⁸ Patients may be subjected to such methods as total exclusion diets, colonic lavages, chronic antibiotic therapy and removal of dental fillings. Some of these are potentially dangerous, such as severe purgation which can lead to hypokalaemia. It is a doctor's duty to protect the patient from such exploitation, which may be medically and financially harmful. The willingness to try such untested treatments should be viewed as a reflection of the patients desperate need for help.

Conclusion

The chronic fatigue syndrome is a complex heterogeneous syndrome about which there are few unambiguous facts regarding aetiology, and for which there is as yet no proven treatment. This paper has attempted to offer guidelines for management which take account of both the physical and psychological consequences of the condition as well as the patient's previous experience. All of these are open to empirical evaluation.

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The dates for the next examination are as follows:

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