CFS: A suitable case for treatment

The controversy surrounding Chronic Fatigue Syndrome has overshadowed one very important issue — how can psychologists help patients with CFS? **Peter Spencer**, *a former sufferer himself, recalls how cognitive behavioural techniques helped put him on the road to recovery.*

IN the Summer of 1994 I was struck by the illness known as Chronic Fatigue Syndrome (a.k.a. Post Viral Fatigue Syndrome (PVFS) or Myalgic Encephalomyelitis — ME). It was only 18 months later that I considered myself fully recovered from it. Having now completed two swim marathons and having been back at work full-time for over two years, I feel I can look back on the event with a mixture of personal experience and objective assessment that I think can make a worthwhile contribution to the often acrimonious debate on this topic.

As well as the usual challenges presented by a long illness there was an added ingredient in my case. I am a Chartered Psychologist whose primary job is to teach health and biological psychology to undergraduate students. Thus the assessment of therapeutic procedures took on at once a personal as well as a professional dimension.

Chronic Fatigue Syndrome (CFS) is not a new illness. Perhaps its most famous precursor was neurasthenia, described as a modern illness at the end of the 19th century (Wessely, 1996*a*). Illnesses such as Effort Syndrome and Da Costa's Syndrome also bear a striking similarity to CFS. The cardinal symptom is disabling physical and mental fatigue, but other symptoms include muscle, joint and chest pain, headache and sleep disorders often accompanied by anxiety and depression. My symptoms began with chest pains followed by extreme mental and physical exhaustion as well as headache, dizziness, nausea, excessive sweating, difficulty sleeping and emotional lability. Blood tests and an electrocardiograph all showed normal values although my lymph glands were swollen.

The first important point to make is that a very great many people with CFS (I would suggest the majority) make a complete recovery (Royal Colleges of Physicians, Psychiatrists and General Practitioners, 1996; Wessely, 1996*b*).

Yvette Cooper, someone else who has made a complete recovery from the illness, makes the point: 'Lots of people get CFS for months or for years, and get better … we recover enough to be as bouncy and boisterous as ever we were before we got ill … the most dispiriting thing I did when I first fell ill was to open a self-help book on ME. Within three pages I was convinced that my illness would last forever … Now I climb mountains, canoe rivers, swim regularly, and work long hours without ever thinking about my health.' (Cooper, 1996, p.19)

The problem is that for a long time two views have become polarized. One is that the illness is 'not real' and the other that it is the most devastating medical crisis since the great plague. This polarization splits itself along the line of psychological versus physical. ME groups have resisted any attempt to use what they consider psychological methods to tackle CFS. Quite often, as soon as a new paper is published showing positive effects of psychological interventions, the ME organizations produce a hostile reaction (Stepney, 1996).

Simon Wessely summarizes the situation thus: 'Although the arrival of CFS or ME has generated a considerable amount of heat, it has not always generated much light. The often intense controversy surrounding the subject shows us that our pious hopes that psychological distress is treated as seriously as physical illness is just that — a pious hope … One consequence has been the neglect of perhaps the most important aspect of chronic fatigue and chronic fatigue syndrome — what to do about it.' (Wessely, 1995, p.ix)

This state of affairs has led to almost three separate literatures of CFS — scientific papers using psychological techniques, much anecdotal evidence

NAME	PERSONAL DETAILS (M=Male F=Female)	STATED REASON FOR RECOVERY	REFERENCES
Sue Head	F	Acupuncture, polarity therapy, diet, immunoglobulin injections, care, love and positive outlook	*Interaction* (1994)
Sue Taplin	F	Early diagnosis, acupuncture	*Interaction* (1994)
Flavia Boyd	F (13 years)	Colonic irrigation	*Reader's Digest Family Guide to Alternative Medicine* (1991)
Pauline	F (37 years)	Cognitive behaviour therapy	Chalder (1995), pp.35-37
Sarah	F (42 years)	Cognitive behaviour therapy	Stepney (1996)
Susan Flynn	F (23 years)	Graded activity and cognitive behaviour modification	Deale & Wessely (1994)
Mark	M (20 years)	Graduated exercise	Smith (1989), pp.14-16
Sarah Smith	F (19 years)	A programme of activity... I just increased my activity levels and built up my fitness	Mihill (1996)
Jackie Chappell	F	Running	*Today's Runner* (1996)
13 British Airways employees	M–8 F–5 Median age 29 years Range 20–57	Total rest in the early stages, followed by a gradual build-up in the hours and type of work	Peel (1988)
Andrew Oldcorn	M (32 years)	'I had to push myself to the limit and think positively'	Henderson (1993)
Michael Mayne	M (55 years)	'Deeply ingrained belief that God would heal me... Power of my body to renew itself... Increased walking'	Mayne (1990), p.18, p. 25
Sally May	F	Prozac, amitriptyline, counselling	*Interaction* (1994)
Anna Konas	F (21 years)	Avoiding food sensitivities	*Daily Mail* (1995)
Catherine Howard	F	Initial complete rest and absence of stress, anti-candida diet and nystatin	*Interaction* (1994)
Peter Foster	M	Anti-candida diet, vitamin supplements, transcendental meditation	*Interaction* (1994)
Christine Gould	F	Kinesiology, anti-candida diet, hypnotherapy	*Interaction* (1995)
Clare Fleming	F	Diet, progress charts, acceptance and encouragement	Fleming (1994)
Angela Kilmartin	F	Propolis	Chapman (1994)
Ailsa Whitham	F	Oestrogen patches	*Interaction* (1995)
Sheila Redpath	F	Reflexology, hypnotherapy, healing	*Interaction* (1994)
Brian Hunt	M (60 years)	Spiritual healing	*Interaction* (1994)
Sylvia Rose	F	Kinesiology and spiritual healing	*Interaction* (1994)
Jo-Anne Wilkinson	F	Spiritual healing	*Interaction* (1995)
Jo Gerzimbke	F	Spiritual healing	Fane (1994)
Vivien Duffy	F	Transcendental meditation, Chinese medicine and homeopathy	*Interaction* (1994)
Sheila Mansergh	F	Kinesiology, Chinese medicine and yoga	*Interaction* (1994)
Total number 39 persons (13 males, 26 females) Age range 13–60 (median 29 years)			

Table 1: Personal details and stated reasons for recovery of 39 persons

from the ME charities, and newspaper reports. I have attempted to sample all three areas to try to find common ground amongst these often conflicting groups.

Table 1 shows patients' reports of their route to recovery from all three of the above areas, and Table 2 lists the therapeutic intervention they considered to have produced the effect. Of the 39 people sampled there are no less than 26 methods cited! I am quite certain (seeing that many people cite more than one treatment as being effective) that if these individuals had been probed more closely the number of effective treatments would have expanded even more.

As well as cognitive behaviour therapy (CBT), graded exercise, counselling, positive thinking, hypnotherapy and meditation, all of which psychologists might well be able to make a contribution to, there is the full gamut of complementary therapies, diets and medicines, and anti-depressants.

Acupuncture	**Homeopathy**	**Prozac**
Amitriptyline	**Hypnotherapy**	**Reflexology**
Chinese medicine	**Immunoglobulin injections**	**Running**
Cognitive behaviour therapy	**Kinesiology**	**Spiritual healing**
Colonic irrigation	**Nystatin**	**Total rest in the early stage**
Counselling	**Oestrogen patches**	**Transcendental meditation**
Diet	**Polarity therapy**	**Vitamin supplements**
Early diagnosis	**Positive thinking**	**Yoga**
Graded activity	**Propolis**	

Table 2: Different types of beneficial interventions given by 39 persons

My own road to recovery mirrors this diversity. Primarily, I used cognitive behavioural techniques combined with increasing aerobic activity. I set myself realistic targets, wasn't down-hearted when occasionally I couldn't meet these, told myself all the time I was getting better and avoided a perfectionist attitude. I was encouraged by an excellent general practitioner who encouraged me to believe, in my more negative moods, that I would undoubtedly recover. This doctor was also capable enough to make the diagnosis relatively early, thus avoiding the anxiety and stress of an undiagnosed illness.

I also had nine acupuncture treatments, three aromatherapy visits and several spiritual healing sessions. I changed my diet, ate lots of fruit, vegetables and complex carbohydrates. I stopped drinking alcohol or caffeine and severely restricted dairy products and refined sugar. I am sure these helped, and I have three hypotheses concerning why. Firstly, they could have helped my body relax enough to give it the power to heal itself and recover, or it could have taken away any immediate stress and enabled me to take a more relaxed view on things. Certainly stress and personality appear to play a key role in the development and perpetuation of CFS (Lewis, 1996). Thirdly it might have given me, subconsciously, a rationale for recovery.

Elaine Showalter (1997) suggests that: 'Although sources of the fatigue may have disappeared, patients cannot easily discard their symptoms without some kind of face-saving intervention.' (p.129)

The three hypotheses are, of course, not mutually exclusive. To return to my original point, the central, superordinate idea is that recovery does happen, but the patient must believe this and want to recover. Michael Mayne, a vice-president of the ME Association who suffered for some time from the illness, makes this point: 'Do you want to recover? Many don't. It is not hard to recognize the professional invalid, who escapes from the demands life would otherwise make into the cosier, restricted world of the sick-bed. But there are infinite subtleties in the games we play and the ruses we adopt in our desire for sympathy and protection from the harsh reality of life, and our need to be valued and reassured.' (Mayne, 1990, p.75)

The substitution of negative, pessimistic thoughts by positive cognitions is, of course, a cornerstone of CBT (Chalder, 1995).

What, then, should be the role of the psychologist in CFS? Clearly cognitive behavioural approaches and exercise psychology are relevant as well as the use of various relaxation techniques. However, despite the increasing evidence of the efficacy of CBT and exercise there is quite often a relatively high refusal rate (Enright, 1997). Given the distaste for all things psychological of many CFS sufferers, this is hardly surprising.

It is important to be aware of any possible factors that might reinforce or maintain any illness behaviours and any (probably subconscious) gains that may accrue to the patient from remaining in the sick role (Williams, 1997). In cases where patients are convinced that a particular type of medicine or diet is going to be effective, then it may also (providing the substance is harmless) be a good idea to harness the effect of the placebo by reassuring the patient that they will recover. The Royal Colleges report suggests that whilst many diets and medicines are not effective *per se*, the role of the therapist in encouraging recovery is important.

Finally, the abandonment of the futile psychological versus physical debate and the adoption of a truly holistic approach is long overdue. My own bias is towards cognitive behavioural methods, but I also realize that the causes of CFS are multifactorial and the paths away from the illness need to be as individually tailored.

I was fortunate that I had the support of an excellent GP, a good friend who was also a clinical psychologist, and colleagues and friends at work. They never dwelt on the possible causes of my illness (my first sick note read *? viral illness* but then after that it was either PVFS, CFS, or ME) but rather focused on plans for me to regain normal functioning through increasing activity and a gradual return to work. Exercise has always been one of the points of conflict between patients' groups and therapists. My own experience tells me that exercise was crucial to my recovery, which appears to be supported by recent research (Fulcher & White, 1997; Marcovitch, 1997).

In a nutshell, the approach to management and recovery which I would suggest therapists should consider is summed up by Sharpe *et al.* (1996): 'During treatment patients were encouraged to question a simple disease explanation of the illness and to consider the role of psychological and social factors. They were also invited to evaluate the effect of gradual and consistent increases in activity and to try strategies other than avoidance. Additional components of the treatment included strategies to reduce excessive perfectionism and self-criticism and an active problem solving approach to interpersonal and occupational difficulties.' (p.23)

I changed from barely being able to walk downstairs to completing swim marathons while working full-time. Believe me, if this mid-forties man could do it (with a little help from my friends) then anyone can. I hope this article goes some way towards giving psychologists confidence in helping their patients. There is, increasingly, effective collaboration of psychologists with psychiatrists, physiotherapists and nurses. Perhaps we need to extend this to complementary therapists also.

References

Chalder, T. (1995). *Coping with Chronic Fatigue*. London: Sheldon Press.

Chapman, P. (1994). Bee-line to health. *Yorkshire on Sunday*, 23 October, p.8.

Cooper, Y. (1996). Tired of all this miserable ME stuff. *The Independent*, 4 October, p.19.

Daily Mail (1995). Do diet drinks make you fat? 22 August, p.36.

Deale, A. & Wessely, S. (1994). A cognitive behavioural approach to Chronic Fatigue Syndrome. *The Therapist*, **Spring**, 11-14.

Enright, S.J. (1997). Cognitive behaviour therapy — clinical applications. *British Medical Journal*, **314**, 21 June, 1811-1816.

Fane, O. (1994). He said: You can walk. And she could. *The Independent*, 4 April, p.18.

Fleming, C. (1994). The glass cage. *British Medical Journal*, **308**, 797.

Fulcher, K.Y. & White, P.D. (1997). Randomized controlled trial of graded exercise in patients with the chronic fatigue syndrome. *British Medical Journal*, **314**, 1647-1652.

Henderson, D. (1993). One for the ME generation.

The Guardian, 1 March, p.16.

Interaction (1994). *The Journal of Action for ME,* **No. 17**, 35-36.

Interaction (1995). *The Journal of Action for ME,* **No.19**, 50-57.

Lewis, S. (1996). Personality, stress and Chronic Fatigue Syndrome. In C.L. Cooper (Ed.), *Handbook of Stress, Medicine, and Health*, pp.233-253. London: CRC Press.

Marcovitch, H. (1997). Managing chronic fatigue syndrome in children. *British Medical Journal*, **314**, 1635-1636.

Mayne, M. (1990). *A Year Lost and Found*. London: Darton, Longman and Todd.

Mihill, C. (1996). Doctors drop confusing label. *The Guardian*, 3 October, p.6.

Peel, M. (1988). Rehabilitation in Postviral Syndrome. *Journal of the Society of Occupational Medicine*, **38**, 44-45.

Reader's Digest Family Guide to Alternative Medicine (1991). 251-252. New York: Reader's Digest Association.

Royal Colleges of Physicians, Psychiatrists and General Practitioners (1996). *Chronic Fatigue Syndrome*. London: Royal Colleges of Physicians, Psychiatrists and General Practitioners.

Sharpe, M.C., Hawton, K., Simkin, S., Surawy, C., Hackmann, A., Klines, I., Peto, T., Warrell, D. & Seagroatt, V. (1996). Cognitive behaviour therapy for the chronic fatigue syndrome: A randomized controlled trial. *British Medical Journal*, **312**, 22-26.

Showalter, E. (1997). *Hystories.* London: Picador.

Smith, D.G. (1989). *Understanding ME.* London: Robinson.

Stepney, R.A. (1996). A treatment for Chronic Fatigue Syndrome has provoked a hostile reaction from sufferers. *The Independent*, Section 2, 26 March, pp.6-7.

Today's Runner (1996). Letters, Road to Recovery, p.66.

Wessely, S. (1995). Preface in Chalder, T. (1995). *Coping with Chronic Fatigue.* London: Sheldon Press.

Wessely, S. (1996*a*). Sickness of the century. *The Guardian*, 28 May, p.13.

Wessely, S. (1996*b*). Summary of a report of a joint committee of the Royal Colleges of Physicians, Psychiatrists and General Practitioners. *Journal of the Royal College of Physicians*, **30**, 497-504.

Williams, C. (1997). A cognitive model of dysfunctional illness behaviour. *British Journal of Health Psychology*, **2**, 153-165.

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