

Cox, Diane ORCID: <https://orcid.org/0000-0003-2691-6423> (1999) Chronic fatigue syndrome: an occupational therapy programme. *Occupational Therapy International*, 6 (1). pp. 52-64.

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# Chronic Fatigue Syndrome – An occupational therapy programme

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*ABSTRACT: The cause of Chronic Fatigue Syndrome (CFS) is as yet undetermined; therefore, precise definitions for diagnosis and research have been developed. The most accepted diagnostic criteria are detailed below. It has been suggested that there are 150 000 cases of CFS in the UK, with a 2:1 predominance of females to males, and that prognosis without treatment is poor. The patterns of illness seen in CFS are identified and the development of an occupational therapy programme for the management of CFS is described.*

**Key words:** Chronic Fatigue Syndrome, occupational therapy, rehabilitation.

## Introduction

There is no one theory on the cause of Chronic Fatigue Syndrome. The current thinking is that different causes or triggers start the illness that results in CFS (Wessely et al., 1989; Surawy et al., 1995; Cox and Findley, 1998). Many researchers have explored a number of possible causative agents: infection, central nervous system abnormalities, chronic immune activation, and neuromuscular and psychiatric factors. Patients frequently cite an acute 'infection' or 'viral' illness at onset, which is not confirmed on laboratory testing (Lloyd et al., 1990; Wessely et al., 1995), often stating that their chronic illness 'all started with that virus that never went away' (Komaroff and Buchwald, 1998: 3). Two primary care studies have been carried out in the UK, with the aim of determining the relationship between viral illness and the onset of chronic fatigue 6 months later (Cope et al., 1994; Wessely et al., 1995). In the large

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cohort study carried out by Wessely and colleagues (1995) the researchers were unable to show that common viral infections were aetiological factors. In contrast, Cope and colleagues (1994) found that at 6 months follow-up from general practitioner-reported acute viral infections, 17.5% of patients remained chronically fatigued.

Historically, many chronic illnesses have been difficult to define. Specific causative agents are often unknown and diagnostic laboratory tests often have poor sensitivity and specificity (Holmes et al., 1988; Holmes, 1991). Because of these problems case definitions have been developed by the consensus of expert committees for illnesses such as rheumatoid arthritis, systemic lupus erythematosus and various psychiatric diseases (Holmes, 1991). Because of the illness's unknown aetiology, specific definition and diagnostic criteria for CFS were essential to ensure understanding and accurate study of the illness and to determine subgroups (Holmes, 1991). Laboratory tests in CFS have been shown to contribute little to the illness's assessment, diagnosis and treatment owing to insufficient sensitivity and explicitness (Valdini et al., 1989; Vercoulen et al., 1994; Bates et al., 1995). Fulfilment of specific criteria would also ensure that other diagnoses such as fibromyalgia were not missed (Goldenberg et al., 1990).

CFS was originally defined in 1988 by a group of US clinicians and researchers working with CFS who met at the Center for Disease Control (CDC) in Atlanta, Georgia (Holmes et al., 1988). Before publication of the definition, the illness in the USA had been known as Chronic Epstein-Barr Virus syndrome, although doubt had been cast on the relationship between Epstein-Barr and the development of a fatigue state (Buchwald et al., 1987). A new name was therefore proposed – Chronic Fatigue Syndrome (Holmes et al., 1988). CFS described the most noticeable characteristic of the syndrome without implying a causal relationship.

The definition became known as the CDC 1988 criteria, although the definition proved difficult to use in practice (Komaroff and Geiger, 1989). It was found that the definition was frequently modified in practice owing to difficulty in compliance and interpretation of the criteria (Straus, 1992). The inconsistency in application and interpretation of the CDC definition was confirmed by Schluederberg and colleagues (1992). An Australian definition published by Lloyd and colleagues (1988) was also unsatisfactory in practice and was not widely accepted (Sharpe et al., 1991).

In an attempt to resolve difficulties in using the 1988 CDC criteria (Holmes et al., 1988) a group of UK clinicians and scientists who were involved in CFS research met in Oxford, UK, to redefine CFS (Sharpe et al., 1991). It was agreed that CFS was the best name as it was descriptive and free from unproven aetiological implications. The main difference between the definitions was the statement that illness should not be lifelong and certain exclusions of schizophrenia, manic-depressive illness, substance abuse, eating disorder or organic brain disorder were cited. In addition a subtype of CFS was

defined and named Post Infectious Fatigue Syndrome (PIFS) (Sharpe et al., 1991). PIFS was defined as fatigue following an infection or associated with a current infection, with the infection being corroborated by laboratory evidence. This definition did not, however, gain wide recognition.

The 1988 CDC criteria were also criticized for not explicitly defining certain terms and not specifying the duration and quality of bed rest and the rigour of neurological and psychiatric evaluations (Armon and Kurland, 1991). As exclusion of other illness was a major criterion of CFS, in practice confusion centred around the role of depression (Bell, 1992). The UK definition (Sharpe et al., 1991) stated that depressive illness, anxiety and hyperventilation syndrome were not necessarily reasons for exclusion.

An international group of clinicians, scientists and researchers therefore met at the CDC to redefine and propose a conceptual framework to enable an integrated and comprehensive approach to the study of CFS (Fukuda et al., 1994). This definition has become the most accepted. It suggests three subdivisions: Chronic Fatigue Syndrome, Post Viral Fatigue Syndrome and Idiopathic Chronic Fatigue. All the case definitions (Holmes et al., 1988; Lloyd et al., 1988; Sharpe et al., 1991; Fukuda et al., 1994) required considerable morbidity from new fatigue in excess of 6 months with all other recognized causes of fatigue having been excluded by history, observation and clinical assessment. To comply with the CDC 1994 criteria the patient must fulfil both major points 1 and 2 below, and present with four or more of the symptoms listed in point 2 (Fukuda et al., 1994: 954–6).

1. New onset of self-reported persistent or relapsing, debilitating fatigue in a person who has no previous history of similar symptoms, which has lasted for 6 months or longer, is disabling and affects physical and mental functioning and:
  - a. is characterized by fatigue as the principal symptom
  - b. is of new or definite onset (has not been lifelong)
  - c. is not the result of ongoing exertion
  - d. is not substantially alleviated by rest
  - e. results in substantial reduction in previous levels of occupation, educational, social or personal activities.
2. Other clinical conditions that may produce similar symptoms, including pre-existing psychiatric diseases, must be excluded by thorough evaluation, based on history, physical examination and appropriate laboratory findings.

These conditions will include:

- a. any active medical condition
- b. any previously diagnosed medical condition whose continued activity may explain the illness, such as previously treated malignancies and unresolved cases of hepatitis B or C infection
- c. any past or current diagnosis of major depressive disorder, including

- bipolar affective disorder, schizophrenia, delusional disorders, dementia, anorexia nervosa or bulimia nervosa
- d. alcohol or substance abuse within the past 2 years
  - e. severe obesity
3. Four or more of the following symptoms must be concurrently present for 6 or more months:
- a. impaired concentration or memory
  - b. sore throat
  - c. tender cervical or axillary lymph nodes
  - d. muscle pain
  - e. multi-joint pain without joint swelling or redness
  - f. headaches of a new type, pattern or severity
  - g. unrefreshing sleep
  - h. post-exertional malaise lasting more than 24 hours.

To meet the criteria for Post Viral Fatigue Syndrome (PVFS) patients must:

1. fulfil the criteria for CFS as defined above
2. have definite evidence of infection at onset or presentation (a patient's self-report is unlikely to be sufficiently reliable).

They should also fulfil the following criteria:

- a. the syndrome is present for a minimum of 6 months after onset of infection
- b. the infection has been corroborated by laboratory evidence.

If the criteria for CFS or PVFS are not met, the fatigue is lifelong and no other cause for the fatigue is identified, a classification of *Idiopathic Chronic Fatigue* will be given (Fukuda et al., 1994).

From clinical experience, the most common presentation seems to occur as a result of chronic stressors in a vulnerable individual (Cox and Findley, 1998). The other primary contributing factor is the report of a 'flu-like' illness at the onset (Salit, 1997; Komaroff and Buchwald, 1998). The main complaint is persistent fatigue, which differs from normal tiredness. The extreme fatigue affects both mental and physical capacity, reducing a person's activity ability substantially below their previous level of functioning (Joyce and Wesley, 1996; Cox, 1998). It is accompanied by a range of other unpleasant symptoms, such as muscle or joint pain, daily headache, recurrent sore throats, fluctuations in mood, intolerance of alcohol, processing difficulties which result in poor concentration and memory problems, and autonomic changes such as temperature control problems, night sweats, digestive changes and

palpitations (Behan and Bakheit, 1991; Hickie et al., 1995; Cox, 1998; Komaroff and Buchwald, 1998). A 'triangle of pain' from the posterior base of the skull to below the scapulae is often described, affecting predominantly the upper part of the trapezius (Cox, 1998). Problems with sleep are common, and include sleeping longer than usual or having difficulty going to sleep and waking frequently (Morriss et al., 1993; Moldofsky, 1995). Whatever the problem, sleep is seldom refreshing (Sharpe et al., 1997). The overall symptoms vary in degree in each individual (Behan and Behan, 1988) and are exacerbated by minimal exertion and unexplained by conventional biomedical diagnosis (Sharpe et al., 1997).

The degree of dysfunction can vary from mild to very severe (Behan and Behan, 1988). Mild dysfunction is where patients are still mobile for short distances, able to carry out some outdoor activities and continue to work part time. Very severe dysfunction is assessed as when the patient is totally dependent on the support of others and predominantly bedbound (Cox, 1998; Cox and Findley, 1998). In more severely affected individuals, late-stage anxiety is often seen (Cox, 1998).

### **Development of the CFS service**

Services for patients with CFS at Oldchurch Hospital, Romford (Havering Hospitals NHS Trust), developed because of the interest of the author, who was working on the then North East Thames Regional Neurosciences Unit. In 1990, one of the unit's neurologists started to admit patients to the unit with fatigue of unknown origin. Initially the patients were assessed alongside the general neurological caseload. The occupational therapist was asked to carry out comprehensive functional assessments to assist in deciding how much the fatigue disturbed the patients' daily life. It was soon apparent that the CFS patients did not respond like other neurological patients and often got worse following treatment – this was somewhat disconcerting for the therapist.

Between 1991 and 1994 an investigation was carried out into the types of treatments offered to these patients in the UK (Wessely, 1989, 1990, 1991 and 1992; Sharpe, 1991).

During the 2 years following 1990, there was a gradual increase in the number of people with CFS seen in the medical outpatient clinics of Havering Hospitals NHS Trust. At this time patients were admitted to:

1. confirm the diagnosis of CFS through history and clinical evaluation
2. commence appropriate medication
3. commence education for management of the illness.

During 1992 and 1993 a treatment and management approach was developed by the author as new ideas, techniques and theories were learned. In February 1993, the initial protocol for admission to the unit was written.

Interest and enthusiasm in treating the illness on the unit flourished as patients made consistent progress that continued on return home (Cox and Findley, 1994). Since July 1994, the service has been managed independently. There are now six dedicated inpatient beds and a comprehensive outpatient service. The team consists of four full-time occupational therapists, a senior physiotherapist and two part-time counsellors.

### **The current CFS service**

The occupational therapists attend the new patient and follow-up medical clinics to support the consultant in identifying the most appropriate course of action: that is, inpatient treatment, outpatient therapy, investigations only, monitoring through clinic, referral to other services or no action. Overall, only 20% of the patients seen need inpatient admission.

An inpatient admission enables:

- education, consolidation and reinforcement of management principles
- time for questions
- full access to a specialist team without travelling
- communication and discussion
- assessment, evaluation and investigation to confirm diagnosis
- a change of environment to limit adverse dynamics
- patients outside a reasonable travelling distance to be seen.

The minimum length of stay is 2 weeks for clinical evaluation and team assessment, and the maximum length of stay is 10 weeks. A review admission is occasionally required at 6 months post-discharge to review the patient's current level of ability, adapt the management and review medication.

Where possible, however, outpatient therapy education and management of the illness is recommended. One-to-one outpatient occupational therapy lifestyle management consultations are suggested for patients in the mild to moderate categories. The aim is to educate the patient in the principles of daily management. Follow up and review are offered as required by the patient for further adaptation and modification of the management approach. An occupational therapy outpatient group is offered to geographically regional patients, in the mild to moderate categories, who require in-depth information. The aim is to enable adaptation of lifestyle, management of lifestyle and improvement of daily functional ability. An occupational therapy outpatient support package is offered to patients who require further education and consolidation of techniques learned following either inpatient or outpatient past treatment with the team.

The same process of assessment and educational programme is carried out with each patient, regardless of whether they are seen as an inpatient or outpatient. The main difference is the depth of information covered.

### **The occupational therapy programme**

The occupational therapy programme has developed over the past 8 years based on patients' needs and clinical presentation. A recent pilot study of inpatients (Essame et al., 1998) indicated the importance of occupational therapy (OT) with this group of patients.

The programme is based on OT theory and encompasses the bio-psycho-social model (Wessely, 1992; Hagedorn, 1995; Sharpe et al., 1997) using the principles of cognitive behaviour therapy (Wessely et al., 1989; Sharpe, 1991; Cox and Findley, 1998) and graded activity (Butler et al., 1991; Sharpe et al., 1997; Cox and Findley, 1998). Randomized controlled trials have suggested that cognitive behaviour therapy (Sharpe et al., 1996; Deale et al., 1997) and graded exercise therapy (Fulcher and White, 1997) may be useful treatments in the outpatient management of CFS. The cognitive-behavioural applied frame of reference is based on the assumption that thoughts, behaviour and feelings are linked (Wessely et al., 1989; Sharpe, 1991). The OT programme therefore uses a combination of physiological and psychological frames of reference (Hagedorn, 1997).

As the programme has developed it is now apparent that it falls within the Canadian Occupational Performance Model guidelines for client-centred practice (Canadian Association of Occupational Therapists, 1991), although when it was developed this model was unknown. The client-centred approach encourages patients to direct their own therapy, to accept personal responsibility and to make decisions. The therapist acts as a facilitator, offering opportunities and education, enabling patients to explore thoughts and feelings in a safe therapeutic environment (CAOT, 1991; Cox and Findley, 1994, 1998). This is the basis of cognitive behavioural therapy (Sharpe et al., 1997; Cox and Findley, 1998). The main emphasis of the CFS OT programme is on dealing with problems identified by the patient, using activities that are meaningful to the individual. The aim following intervention is for the patient to have an increase in their level of ability, reduced symptoms and a positive change in thinking style and management of the illness.

### **The process of assessment**

Assessment for patients with CFS, as with any patient group, is essential. The most important aspect of assessment of a person with CFS is taking a full history, to identify the predisposing, precipitating and perpetuating factors and the patient's understanding of the illness (Sharpe, 1991; Sharpe et al., 1997). The predisposing factors may include stress, physical and mental overwork, and recurrent infections, building up over a 2- to 3-year period (Salit, 1997). The final trigger or precipitator may be any of the above. The perpetuators are the development of patterns of illness in response to the symptoms, stress and/or recurrent infection (Butler et al., 1991; Sharpe, 1991) and are discussed in more detail below.



Information on the patient's employment and domestic situation and history also needs to be explored to realize the full impact the illness has had on the patient and their life. An observational assessment of current activity levels is carried out to create a picture of daily functioning and, finally, the patient is asked to define his or her specific aims, and identify his or her purpose in attending therapy (Sharpe et al., 1997; Cox and Findley, 1998).

### **Description of daily patterns of activity**

Following assessments and observations of patients with CFS over time, daily activity in response to the symptoms experienced appeared to have a common pattern across all patients (Cox and Findley, 1994). A pattern of 'peaks and troughs' has been identified, meaning that patients do more when they feel able (peak), then often do too much, which pushes them into exhaustion so they have to rest (trough) until they feel more able again. Thus the pattern of peaks and troughs is established. This pattern occurs not only on a weekly or monthly basis but also on a daily basis, with patients often sleeping in the afternoon to regain energy. This pattern not only assists in perpetuating the illness but increases the sleep disturbance often described (Sharpe et al., 1997).

The focus of the OT programme is to break this pattern, to balance rest and effort in a more effective way (Cox and Findley, 1998). Although rest is an effective way of reducing tiredness and brings symptom relief in the short term, in the long term it is not helpful as it reduces exercise tolerance and can produce increased weakness, muscle wasting, and cardiac and respiratory difficulties, together with increased sensitivity to activity (Greenleaf and Kozolowski, 1982). Following an extended period of rest (days, weeks or months), any activity produces a range of associated symptoms. Therefore, prolonged rest can bring about short-term symptom reduction but a long-term increase in disability (Butler et al., 1991; Sharpe, 1991; Sharpe et al., 1997). This results in the vicious circle of the fluctuating bursts of activity (peak) and rest (trough) as people try to control and manage the illness by responding to the symptoms (Wessely et al., 1989; Cox and Findley, 1998).

### **The importance of scheduling activity and rest**

Rest can mean different things to different people. Some people with CFS may feel that rest means sleeping or perhaps just sitting down and 'not doing anything'. Others may feel that rest simply means being able to relax. Before becoming ill, patients may have found reading, watching television, or talking to friends on the telephone a good way to unwind. However, because of the 'overactive brain' or 'sensory overload' experienced in CFS, the concept of relaxation needs to be redefined. When the term rest is used in the CFS occupational therapy programme it means relaxation. Management of the sensory

overload is just as important as physical management, and for some people it is the most important aspect of the daily management of CFS. Relaxation should not focus solely on resting the body, but also on resting the mind. The point of relaxation is to achieve a state of minimal neurological (brain) activity.

Rest therefore needs to be scheduled into each day regardless of the severity of symptoms so that it becomes consistent and part of the daily routine rather than varying depending on symptoms (Cox and Findley, 1998). For some people it helps initially to structure each day to gain an understanding of the balance required between rest and effort. Figure 1 shows an example of a daily timetable designed for a specific patient at the moderate level.

Chronic Fatigue Syndrome	Daily programme chart
date:	name:
time	activity
9:00 am	wake up/activity session
10:00 am	rest period
10:30 am	activity session
12:00 noon	rest period
12:30 pm	activity session
2:30 pm	rest period
3:30 pm	activity session
5:30 pm	rest period
6:00 pm	activity session
8:00 pm	rest period
8:30 pm	activity session
9:30 pm	1/2 hour wind-down
10:00 pm	bed

FIGURE 1: Example of a daily activity schedule

This amount of structure will not be required for all people, although rest and activity need to be scheduled into each day, regardless of symptoms being present or not.

### The use of graded activity

Prior to reintroducing further activity into their day, a patient is introduced to the concept of an activity baseline; a foundation from which to build. The activity baseline is defined as 'a comfortable level of activity that can be managed on a regular basis without experiencing an increase in symptoms'. Patients usually need to work out their daily and weekly baseline over a number of weeks or even months. It is important that the patient's baseline is established before further activity is introduced, to ensure that they have reduced the peaks and troughs pattern and are therefore starting to build up activity again, from a firm foundation.

Activity is defined as anything that stimulates or overstimulates the brain in terms of physical, cognitive or emotional effort. Thus, talking, watching television, reading and even eating are regarded as activities and different activities use different amounts of energy. A patient needs to be clear about how much energy each activity uses, such as high, medium or low. The purpose of energy-grading the patient's activities is to enable sustained and consistent activity on a daily and weekly basis. The idea is that they do not have all their high-energy activity together (peak) but that those activities are spread throughout the day and week, interspersed with medium- and low-level activities, enabling a more paced use of their energy and therefore reduction in fatigue.

Goals or steps are established that focus on each person's major difficulties. Their purpose is to facilitate: (a) a gradual increase in tolerance to activity, (b) an increase in previously avoided behaviours and activities, and (c) a reduction in symptoms. The goals need to be clear and specific, and set at a manageable level. They are increased gradually so that the amount of activity carried out each day builds up slowly. Examples of goals people have set themselves include:

1. to get up at 9.00 am every day
2. to walk for 15 minutes three times a day
3. to have a friend visit twice a week
4. to go to the supermarket once a week.

The most common trap patients fall into is attempting a rapid return to high levels of activity to which the body cannot respond because of its physical lack of condition. Activity has to be paced and gradual. This is particularly a problem for those who were previously very fit and active. Another temptation is for patients in a good phase to do all the activities they have not been able to do in a bad phase in an attempt to catch up. Activity must be paced and gradual.

Performing tasks in stages (graded activity) and slowly building up how much individuals can do takes time. However, if balanced, this approach will help patients to achieve more in the long run and sustain that level of activity, reduce fatigue levels and shorten the recovery time required following activity (Cox and Findley, 1994, 1998).

### Considerations and conclusion

Occupational therapists have the skills and training to assist in the management of people with CFS. The holistic nature of our approach is well suited to this pervasive and devastating syndrome. However, there are some considerations to bear in mind when treating this patient group:

- The programme takes time. Modification of the programme is usually needed as activity increases and patients encounter setbacks

- Patients need ongoing support, ranging from months to years
- Education of the family or significant others in the management of CFS is essential to ensure that there is a consistent approach in the home setting
- Effective verbal and written communication between all parties, both professionals and family, is vital, to ensure not only that everyone approaches the intervention programme with the same philosophy and that treatment methods are clarified, but that professionals and family are supported and that patients are referred on where necessary.

Using the client-centred approach, the OT acts as a facilitator encouraging the patient to take back the control they often feel they have lost. Success to date has been encouraging, 82% of past inpatients stating an increase in their overall activity level 6 months following discharge from the programme (Cox and Findley, 1998).

To conclude, the OT CFS programme's balanced and paced concept in the management of activity and fatigue is summed up succinctly by a quote from one of our past patients: 'I used to take two steps forward and three steps back, and now I take one step at a time.'

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