# COGNITIVE-BEHAVIOURAL TREATMENT OF CHRONIC FATIGUE SYNDROME: AN IN-DEPTH CASE STUDY

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# ABSTRACT

Chronic Fatigue Syndrome (CFS) is a chronic disabling condition characterised by persistent physical and mental fatigue, and a variety of somatic, psychological and neurological The aetiology of CFS is unknown and the cause of the illness remains symptoms. Cognitive-behavioural therapy (CBT) is a non-pharmacological treatment controversial. approach that has been shown to be effective in treating patients with CFS. It is based on a model that hypothesises that certain maladaptive thoughts and dysfunctional beliefs may contribute to self-defeating behaviour that perpetuates symptoms and disability, and thereby impedes recovery. The main aim of this study was to critically examine the cognitivebehavioural approach of CFS outlined by Sharpe, Chalder, Palmer & Wessely (1997) by conducting three in-depth case studies. An additional aim was to present a full cognitive developmental case conceptualisation of CFS based on the theories of Leahy (1996) and Young (1994). This case study evaluated the effectiveness of a CBT treatment programme in a 48-year-old Caucasian woman diagnosed with CFS for three years. The treatment consisted of sixteen sessions of CBT and was evaluated both quantitatively and qualitatively. On the basis of this study, a set of core maladaptive schema in the area of disconnection and rejection was identified. In addition, it was found that specific compensatory schemas had developed to offset the core maladaptive schemas and that this compensatory strategy played an important role in maintaining the condition. The results also showed a significant decline in fatigue coupled with a moderate decline in functional disability and depression. A one-month follow-up interview revealed evidence of a substantial consolidation of therapeutic gains in that the improvements observed at the end of the treatment were sustained. Finally, the feasibility of incorporating a cognitive-developmental and/or schema-focused model into the standard CBT treatment model is discussed and the case study method as a research toll is evaluated in light of the findings.

#### TABLE OF CONTENTS

# ACKNOWLEDGEMENTS TABLE OF CONTENTS ABSTRACT

			р
1.	INTRODUCTION		
	1.1 Historical Overview of CFS		
	1.1.1	Neurasthenia and Chronic Fatigue	10
	1.1.2	Infectious Illness, Prolonged Recovery and Chronic Fatigue	11
	1.1.3	Epidemic Illness and Chronic Fatigue	11
	1.2 Diagn	osis	13
	1.2.1	Diagnosis and Medical Care	15
	1.3 Psych	obiological Investigation into CFS	18
	1.3.1	Viral Infection	18
	1.3.2	Immunological Dysfunction	19
	1.3.3	Neuroendocrine Abnormalities	19
	1.3.4	Sleep Disturbances	20
	1.3.5	Neuroimaging Studies	21
	1.3.6	Conclusions	22
	1.4 Psychological Investigations into CFS		
	1.4.1	Psychiatric Symptomatology in CFS	23
	1.4.2	Psychiatric Diagnostic Overlap in CFS	24
	1.4.3	Problems in Assessing CFS Patients	24
	1.4.4	Models of the Relationship between CFS and Depression	25
	1.5 An Integrative Cognitive-Behavioural Approach to CFS		26
	1.6 Rationale for the Application of CBT to CFS		27
	1.6.1	A Schema-Focused Cognitive Therapy	28
	1.6.2	A Cognitive Developmental Perspective	30

	1.7.1	1.7.1 Predisposing Factors to CFS		
		1.7.1.a	Perfectionistic Beliefs and the Role of Compensatory Coping	31
		1.7.1.b	Personality Variables and Lifestyle Factors	33
	1.7.2	Precipita	ating Factors of CFS	34
		1.7.2.a	Infectious Illnesses and Psychosocial Stressors	34
	1.7.3	Maintair	ning Factors of CFS	35
		1.7.3.a	External versus Internal Attributional Style	35
		1.7.3.b	Specific Illness Beliefs and the Avoidance of Activity	39
		1.7.3.c	Oscillation between Activity and Inactivity	40
		1.7.3.d	Inactivity and Physical Deconditioning	41
		1.7.3.e	The Development of Self-Defeating Coping Strategies	43
	1.7.4	A Cogni	itive-Behavioural Model of CFS	45
	1.8 The C	ognitive-l	Behavioural Treatment of CFS	45
	1.8.1	Evidenc	e for the Efficacy of CBT for CFS Patients	46
	1.8.2	Summar	ry of Findings on CBT for CFS	56
2.	METHOE			58
	2.1 Rationale for the Aims of the Study			58
	2.2 The Case Study Research Method			58
	2.3 The Selection of Participants		61	
	2.4 Data Collection Phase One		61	
	2.4.1	Quantita	ative Assessment Measures	62
		2.4.1.a	Fatigue Questionnaire	62
		2.4.1.b	Work and Social Adjustment Scale	62
		2.4.1.c	The Beck Depression Inventory-II	62
		2.4.1.d	The Beck Anxiety Inventory	63
	2.4.2	Qualitat	ive Assessment Measure	63
		2.4.2.a	The Schema Questionnaire	63
	2.4.3	The Pre-	-Assessment Meeting	65

2.4.4.a The Clinical Interviews			65
	(i)	Presenting Problem	66
	(ii)	History of the Illness	66
	(iii)	Current Situation	66
	(iv)	Background	66
	(v)	Treatment History	67
	2.4.4.b Diag	gnostic Evaluation and Mental State Examination	67
	(i)	Depression	67
	(ii)	Anxiety	68
	(iii)	Somatoform Disorders	68
2.5 Data Reduction Phase One			68
2.5.1	Presenting Pr	roblem	69
2.5.2	Family and P	ersonal History	69
2.5.3	Summary of	Treatment History and Medication Regimen	69
2.5.4	Diagnosis		69
2.5.5	Case Concep	tualisation	70
2.5.6	Problem List	and Treatment Plan	70
2.6 Treatment Contact		71	
2.7 The Design of the Treatment Intervention			72
2.7.1	Stage 2: Iden	tifying and Reviewing Behaviour and Thoughts	72
2.7.2	Stage 3: Re-e	evaluating Unhelpful, General Attitudes	74
2.7.3	Stage 4: Prob	blem Solving Practical Difficulties	74
2.7.4	Stage 5: Con	solidating Gains and Planning for the Future	74
2.8 Data Collection Phase Two			74
2.9 Data Reduction Phase Two 74			74
2.9.1	The Selection	n of a Single Patient	75
2.9.2	The Case Nat	rrative	75

# 3. THE PRESENTATION OF AMY'S CASE OF CFS

	3.1 The C	ase History	76
	3.1.1	Presenting Problem	76
	3.1.2	Family and Personal History	78
	3.1.3	Summary of Treatment History and Medication Regimen	81
	3.1.4	Diagnosis	82
	3.1.5	Case Conceptualisation	84
	3.1.6	Problem List and Treatment Plan	86
		3.1.6.a Difficulty in prioritising daily activities	86
		3.1.6.b Excessive engagement in activities	86
		3.1.6.c Unresolved feelings about early childhood experiences	87
		3.1.6.d Social Isolation	87
	3.2 The C	ase Narrative	88
	3.3 Quantitative Presentation of the Outcome Measures		102
	3.3.1	Commentary on the Outcome Measures	103
		3.3.1.a Fatigue Questionnaire	103
		3.3.1.b Work and Social Adjustment Questionnaire	103
		3.3.1.c The Beck Depression Inventory-II	104
		3.3.1.d The Beck Anxiety Inventory	104
	3.4 Qualit	ative Presentation of the Schema Questionnaire	105
	3.5 Summ	ary of Medication Usage During Treatment	106
4	DISCUSS	SION	107
		iscussion Outline	107
		BT Help the CFS Patient?	107
	4.2 General Issues Pertaining to CFS		
	4.3.1	The Relationship between Chronic Stress and Infectious Illness in CFS	111 111
	4.3.2	Different Attributional Styles in CFS	113
	4.3.3	The Relationship between CFS and Depression	114

115

	4.4.1	The Schema Dynamics of CFS	115
	4.4.2	The Role of Compensatory Scripts in CFS	117
	4.4.3	The Role if Specific Compensatory Schemas in CFS	118
	4.5 Evalua	ating the Efficacy of the CBT Model in Treating CFS Patients	123
	4.5.1	The Quality and Nature of the Therapeutic Relationship	123
	4.5.2	Sharing the Case Conceptualisation with the Patient	124
	4.5.3	The Role if the Therapeutic Relationship in Augmenting the	
		Cognitive-Behavioural Strategies	125
	4.5.4	The Specific Guidelines Regarding Treatment Delivery	127
	4.5.5	The Value of the Developmental Perspective	128
	4.5.6	The Importance of the Action Plan	129
	4.6 Recommendation for Medical Practitioners		130
	4.7 Evalua	ation of the Study and Implication for Future Research	136
5.	REFERENCES		136
(			1 4 7
6.	APPENDICES 145		

Appendix I	Participant Questionnaire	145
Appendix II	CFS: CBT Research Consent Form	147
Appendix III	Informational Guides	149
Appendix IV	Record of Dysfunctional Thoughts	150

# 1. INTRODUCTION

Fatigue is defined as "a subjective feeling of weariness, lack of energy and exhaustion, that is exacerbated by even minor exertion" (Berrios cited in Sharpe 1997a, p 382). The feeling of fatigue is a common complaint affecting between 10% to 40% of the general population, and is often due to life stresses, overwork or interrupted sleep (Wessely, Chalder, Hirsch, Wallace & Wright, 1997). If the fatigue is persistent, debilitating and cannot be ascribed to a known medical or psychological condition, then it may be associated with a syndromal diagnosis such as Chronic Fatigue Syndrome (CFS) previously known as Myalgic Encephalomyelitis (ME) (Friedberg, 1996). CFS is a chronic disorder which is characterised by continuous or recurring physical and mental fatigue, and a variety of somatic, psychological and neurological symptoms. The aetiology of CFS is unknown and the cause of the illness remains controversial. However, it seems likely that it is a heterogeneous condition, with various combinations of factors producing symptoms in individual cases (Jordan, 1994). This disorder also has marked similarities to the syndrome of fibromyalgia (Sharpe, Chalder, Palmer & Wessely, 1997).

The prevalence estimates of CFS are not entirely consistent due to the absence of reliable epidemiological studies. This problem is confounded by the fact that most of the studies conducted have been based on specialist clinic estimates or on physician identification. Such data is further influenced by psychological morbidity, selection bias and uncertain diagnostic boundaries. However, a recent prospective primary care study has estimated that in the United Kingdom the prevalence of CFS is 2.6%, falling to 0.5% if comorbid psychological disorders are excluded (Wessely et al., 1997). These estimates are reportedly between ten and a hundred times higher than most previous estimates of prevalence, and suggest a public health burden.

Investigators have indicated that many patients with CFS are Caucasians between the ages of 20-50, who are well-educated and employed in upper income jobs. However, recent studies have revealed that there is an overrepresentation of CFS in higher socio-economic groups largely due to selection bias (Lloyd 1998; Wessely et al., 1997). Previously, a preponderance of documented cases were white women but current research suggests that there is a modest excess of female patients suffering from CFS, once adjustments are made for psychological disorder Wessely et al., 1997).

The duration of CFS varies considerably in that some patients can be ill for a few months while

others are afflicted for many years. Friedberg (1996) refers to research that reveals that 60% to 65% of CFS patients show slight to significant improvements in their illness over time whereas 25% to 35% remain ill or report a worsening of symptoms. Only a minority of patients between 2% and 8%, experience a complete recovery. The extent to which CFS is progressive or degenerative has not been established, but it is not known to be fatal (Jordan, 1994). However, suicidality is the one lethal complication of CFS (Abbey & Demitrack, 1996).

#### 1.1 Historical Overview of CFS

Demitrack & Abbey (1996), provide a comprehensive historical review of CFS, and the present overview draws on various aspects of their work. The most frequent and significant observations to emerge from their review with respect to the development and clinical expression of CFS, are central nervous system dysfunction, and the role of stress and behavioural factors in regulating the illness.

# 1.1.1 Neurasthenia and Chronic Fatigue

Clinical syndromes characterised by the principal symptom of fatigue have been described in medical literature for more than a hundred years (Sharpe, 1997a). Demitrack & Abbey (1996) noted that Sir Richard Manningham, in 1750, provided one of the earliest descriptions when he wrote of the "febricula" or "little fever". The presentation of this illness consisted of profound feelings of weariness, coupled with various constitutional complaints but scant objective clinical data. In addition, Manningham observed the relationship between this condition and life stressors, and noted that the majority of cases were upper class, white females. In the 1860's, the American neurologist George Miller Beard described a clinical syndrome similar to that reported by Manningham, and identified it as neurasthenia. The term neurasthenia is a combination of the Greek words for "nerve" and "strength" which denotes the primary source of the debility being, "a lack of strength in the nervous substance of the individual". Despite the controversy surrounding Beard and his presentation of this syndrome, he highlighted the importance of taking a thorough history of the symptoms in order to identify any comorbid illnesses that may influence treatment of the illness (Demitrack & Abbey, 1996).

In 1871, an American physician, J.M. Da Costa described a clinical syndrome that he observed while treating soldiers during the American Civil War. He termed the entity "irritable heart" of the soldier. Demitrack & Abbey (1996) propose that this syndrome is of interest as it shared

many clinical and historical similarities to Beard's description of neurasthenia: (a) this entity was similar in symptomatic presentation to neurasthenia; (b) the pre-eminent role of stress in the emergence of the syndrome echoes the notion of central nervous system involvement in the pathophysiology of the illness, and (c) the fate of this entity followed a similar path as that of neurasthenia, namely the initial recognition of the role of psychological distress, and the subsequent dismissal of these clinical syndromes by the medical community as undeserving of further research.

# 1.1.2 Infectious Illness, Prolonged Recovery and Chronic Fatigue

By the early 20th century, the diagnosis of neurasthenia was becoming less acceptable due to a growing recognition of the role of psychological factors in the perpetuation of the illness (Sharpe, 1997a). Demitrack & Abbey (1996) cite a number of noteworthy studies of chronic brucellosis, influenza and infectious mononucleosis, which increasingly reveal the complex interplay of physiological stress and psychological stress. They contend that this interaction of stressors may occur at multiple levels within the psychobiology of the individual or at varying points during the life of the individual. Hence, a cyclical process is established whereby stressful life events have a formative influence on the personality in terms of determining how individuals go about acquiring the help they need and responding to such help. Personality factors, in turn, may determine how frequently the individuals expose themselves to stressful life events. They suggest that stress activates multiple physiological signals resulting in complex intercommunications along the central nervous system, endocrine system and immune system.

#### 1.1.3 Epidemic Illnesses and Chronic Fatigue

According to Demitrack & Abbey (1996), a number of contemporary epidemic illnesses were also described which closely resemble the infectious syndromes mentioned above. They discuss two specific epidemics in detail as these outbreaks highlight significant aspects of the illness, and provide a more comprehensive understanding of the problems encountered in defining and diagnosing contemporary chronic fatigue syndromes. The first epidemic occurred at the Los Angeles County General Hospital in 1934, in the midst of a legitimate poliomyelitis epidemic. Although it is probable that some true cases of poliomyelitis were present in the specific outbreak, the majority of patients presented with symptoms suggestive of a novel illness. The clinical presentation revealed a sudden onset, considerable variability in symptoms coupled with pain and headache. There were few physical signs, no laboratory abnormalities and prognosis was fair. A disproportionate degree of emotional lability and depressive symptomatology were noted. There was also a preponderance of young females, particularly health care providers among the afflicted. The diagnosis for the outbreak at the time was poliomyelitis. In perusing the report, Demitrack & Abbey (1996) observed a marked lack of objectivity due to the presumption of infectious illness despite evidence to the contrary, and inadequate clinical documentation of cases, which may have obscured the heterogeneity of the phenomenon under observation.

The second epidemic occurred at the Royal Free Hospital, in London, in 1955 and the initial diagnosis was also poliomyelitis. The clinical presentation of patients described was remarkably similar to those of the Los Angeles epidemic, but with a more acute onset. The outbreak of the Royal Free epidemic sparked many of the earlier controversial issues raised resulting in these concerns being revisited. In two follow-up reports on the Royal Free Hospital disease researchers contended that the diagnosis of mass hysteria was applicable for the majority of illnesses previously described due to several supporting features observed. In reviewing these reports Demitrack & Abbey (1996) noted, on the one hand, that there was a more detailed behavioural analysis of the patients under study, yet, on the other, that the dichotomous approach adopted to diagnosis precluded any new, meaningful observations from being made. Hence, they contend that these earlier studies highlight two important lessons for future research and clinical practice. First, the need to refrain from premature conclusions regarding illness attribution and the meaning of physiological and psychological symptoms, and second, the need to adopt a broad-based, interdisciplinary approach to assessment and management of CFS (Demitrack & Abbey, 1996).

# 1.2 Diagnosis

Since the early 1980's there has been a resurgence of interest in fatigue as a clinical syndrome, and a plethora of alternative names have emerged in the professional and popular literature to describe this entity (Demitrack & Abbey, 1996; Sharpe, 1997). Two alternative names which continue to persist and are descriptive of the supposed underlying medical aetiology, include "Chronic Fatigue Immune Dysfunction Syndrome" abbreviated to "CFIDS" (Demitrack & Abbey, 1996) and "Myalgic Encephalomyelitis" or "ME" (Cleare & Wessely, 1996). Owing to the confusion of names and operational definitions, the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia outlined the symptoms characteristic of CFS in a consensus case definition designed for research purposes (Demitrack & Abbey, 1996). Three noteworthy issues in this original definition were identified by Demitrack & Abbey (1996): (a) the exclusion of known entities that could mimic the presentation of CFS, such as systemic lupus erythematosus, rheumatoid arthritis, multiple sclerosis, depression and certain occult malignancies; (b) an emphasis on the absence of discrete laboratory testing to support the diagnosis of CFS, and (c) a heterogeneous group of individuals with a variety of infectious and noninfectious antecedents were targeted by the definition.

However, the CDC definition attracted specific criticism for including multiple somatic symptoms as it reportedly led to an overrepresentation of psychiatric illnesses in studies of CFS. Demitrack & Abbey (1996) contend that it is difficult to establish if a psychiatric illness is explanatory of the clinical presentation of CFS or a secondary phenomenon of a primary disease process or perhaps a concurrent disease that modulates the presentation and course of the syndrome. Subsequently, there were two revisions of the initial case definition which made provision for excluding all physical signs due to inconsistency in documentation and presentation, and reducing the number of unexplained medical symptoms needed for a diagnosis to a minimum of four. However, the most controversial aspect of the second revision was the establishment of a category of idiopathic chronic fatigue for those patients who experience chronic fatigue without any additional physical symptoms.

During this same period, two separate revisions of the American case definition were published

by Australian and British researchers, respectively. The modifications in case definition arose due to a perceived lack of methodological validity and reliability in conducting research into CFS. A noteworthy feature of the Australian definition was the inclusion of neuropsychological impairment and/or abnormal cell-mediated immunity in the diagnosis of CFS. Major criticism was levelled at the inclusion of laboratory criteria in this definition as it was considered premature, given the lack of replicability of laboratory testing in relation to CFS (Demitrack & Abbey, 1996).

The British case definition was developed by Sharpe and several others at an interdisciplinary consensus meeting at Green College, Oxford. The Oxford criteria are distinct from the previous American and Australian definitions in their proposal of two broad categories for study, namely Chronic Fatigue Syndrome and Postinfectious Fatigue Syndrome (Demitrack & Abbey, 1996). This division of categories helps to distinguish a group of patients in whom an identifiable infectious agent clearly played a role in the onset of CFS, and influenced the course of the syndrome. In addition, the revision improved the terminology used in CFS research by introducing greater coherence into this area of study. The Oxford criteria are presented in Table 1. They are used by medical practitioners in diagnosing CFS and by researchers studying CFS, and specifically by a core group of British researchers (Chalder, Butler, Wessely, 1996; Chalder, Wallace & Wessely, 1997; Deale, Chalder, Marks & Wessely, 1997; Sharpe, et al., 1997; Wessely, et al., 1996, 1997). The current study is based on the work of this core group of researchers; therefore, the Oxford criteria are employed as the definition of CFS for the purposes of this study.

# Table 1. The Green College, Oxford Definition of Chronic Fatigue Syndrome

#### Broad Clinical Syndromes

- \* Chronic Fatigue Syndrome (CFS)
- (1). Principal symptom is fatigue with definite onset and not lifelong
- (2). Fatigue is severe, disabling, and affects physical and mental functioning
- (3). Fatigue for at least 6 months, during which it is present at least 50% of the time
- (4). Other symptoms may be included, such as: myalgia, mood disturbance and sleep irregularity
- (5). Definite medical and psychiatric exclusions: schizophrenia; manic depressive illness; substance abuse; eating disorder and organic brain disease
- \* Postinfectious fatigue syndrome (PIFS)

- (1). A subtype of CFS which follows or is associated with an infectious illness
- (2). Patients must fulfil criteria for CFS as specified above, and, in addition, have:
  - (a) Definite evidence, including laboratory corroboration, of infectious illness at onset
  - (b) Full syndrome is present for at least 6 months after onset of infection.

Elements considered essential to specify in reporting these syndromes

- \* State which syndrome is being reported
- \* Measure degree of disability
- \* Specify criteria for inclusion and exclusion
- \* Indicate extent of clinical examination and investigation
- \* Specify method of assessment for associated psychiatric disorder

In terms of the Oxford criteria, a patient can either be reported as having Chronic Fatigue Syndrome (CFS) or Postinfectious Fatigue Syndrome (PIFS), a subtype of CFS which follows or is associated with an infectious illness. In both cases, in order to meet the respective criteria, a patient must fulfil (1), (2) and (3) of the Chronic fatigue clinical syndrome, and the degree of disability must be measured. In addition, other symptoms such as muscular pain, mood lability and poor sleep may be included, while a number of definite medical and psychiatric exclusion criteria must be assessed. In addition to fulfilling the CFS criteria, patients with PIFS must have definite laboratory evidence of infectious illness at onset, which lasts for at least 6 months after infectious onset. Finally, the extent of the clinical investigation together with the specific method of associated psychiatric assessment must be indicated for both syndromes.

# 1.2.1 Diagnosis and Medical Care

A diagnosis of CFS has certain social and political implications that separate it from medical conditions such as cancer and cardiac disease (Wessely, 1996). This is primarily due to the lack of physical evidence or confirmation by laboratory testing coupled with the fact that patients often do not appear ill. These issues pose a dilemma for the physician in terms of conceptualising the diverse symptoms reported and diagnosing the condition (Sharpe, 1998b).

Woodward, Broom & Legge (1995) reported that 70% of general practitioners interviewed were reluctant to offer a diagnosis of CFS as they felt constrained by the controversy surrounding the

syndrome, and expressed reservations that a symptomatic diagnosis might become a disabling self-fulfilling prophecy. In contrast, 90% of patients interviewed found a diagnosis to be of paramount importance in terms of moderating the course of their illness. In general patients believed that a diagnosis provided a structure for understanding distressing symptoms and changes in functional ability, resulting in the adoption of positive coping strategies. It also served to alleviate feelings of fear, anxiety and self-doubt about whether or not they were suffering from an undiagnosed terminal illness. Although the diagnosis was valued by most patients, certain factors such as length and severity of illness and the extent of disruption caused, altered the personal meaning attributed to it. Woodward et al. (1995) noted that early diagnosis often provided social legitimacy and enabled patients to view their illness as less traumatic. Those without a diagnosis for many years eventually benefited from receiving a diagnosis in terms of finding meaning in their protracted suffering. They also observed that prior to diagnosis patients reported deteriorating health but that after receiving a diagnosis few complained of this problem.

Sharpe (1998b) observed considerable conflict between doctors and patients in terms of the types of diagnoses available to label medically unexplained chronic fatigue. He pointed out that medical diagnoses for chronic fatigue, such as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) or Postinfectious fatigue syndrome (PIFS) were more readily accepted by patients for various psychological, social and financial reasons. He noted that physicians felt disempowered in offering such diagnoses due to the scientific uncertainty of the condition. They also feared losing credibility in relation to medical colleagues, and were concerned about negatively influencing patients' perceptions of their symptoms. Sharpe contended that many psychiatric diagnoses such as depression, anxiety and the somatoform disorders were potential alternatives to a medical label, and that some patients did meet the criteria for such diagnoses. However, patients tended to reject this diagnostic option due to the perceived implication of fault, weakness or malingering, and also because it offered fewer financial benefits.

Sharpe (1998b) presents an alternative approach to the controversial issue of diagnosis. The

approach takes into account the importance of identifying patients' key beliefs and attitudes in relation to health. It also focuses on an acceptance of the patient's experience of the illness, which in turn encourages them to reveal their views about potential diagnoses. Sharpe suggests that by establishing common ground patients may be more willing to consider alternative diagnoses, but that if this is problematic then a descriptive diagnosis like CFS may be useful.

Such a diagnosis acknowledges the suffering of the patient yet does not imply a definite disease process. The efficacy of a collaborative approach is that it offers patients a flexible framework for interpreting their illness, and enables the physician to assist patients in altering unhelpful fears and beliefs about the illness.

In terms of medical care received, Ax, Gregg & Jones (1997) found a significant association between patient satisfaction and beliefs about the aetiology and management of CFS. Although the majority of patients experienced considerable relief after receiving a diagnosis of CFS, they expressed dissatisfaction with the informational and emotional support offered by medical professionals. Ax et al. noted that when doctors diagnosed CFS and gave advice pertaining to possible changes in lifestyle or suggested additional psychiatric/psychological support, patients rejected it as it contradicted their beliefs about CFS being a physical, uncontrollable illness. Consequently, patients harboured feelings of anger toward the medical fraternity resulting in an attitude of greater self-reliance, and a move toward alternative forms of treatment in conjunction with support from self-help groups. Ax et al., however, contend that self-help organisations tend to dismiss the important role of psychosocial factors which together with the uncertainty surrounding CFS lead patients to believe that it is largely a physical illness for which rest is the most appropriate treatment. They point out the paradoxical relationship in which patients need relevant information about the aetiology and management of CFS yet may reject this information if it contradicts their illness beliefs.

Twemlow, Bradshaw, Coyne & Lerma (1997) also observed that CFS patients were generally

satisfied with medical care if the system was congruent with their expectations. Those CFS patients who expected supportive, parental concern or who valued autonomy and wanted to discuss issues pertaining to the illness, were more dissatisfied with the system. In contrast patients who expected impersonal, dismissive treatment were more accepting of the medical support. They contend that although both CFS patients and general medical patients seem to have the same motivation and expertise to cope with their problems psychologically, CFS patients have a more negative attitude toward the medical fraternity. They found that the CFS group believed that doctors entered medicine for financial reasons or due to a need to control others. The group also felt less accepted as people and less understood by their doctors. Subsequently, they were more oriented towards suing medical professionals than the control group. Twemlow et al. also point out that both CFS patients and general medical patients expressed greater satisfaction with medical care if doctors used their first names in the consultation. They suggest that doctors need to acknowledge the importance of the relationship between doctor and patient, especially in the case of a controversial syndrome like CFS where there is little certainty about aetiology and treatment. In addition, they recommend that doctors need to note the idealised expectations of CFS patients in order to anticipate and deal effectively with later misunderstandings.

#### 1.3 Psychobiological Investigations into CFS

Demitrack (1996) identifies and reviews five main psychobiological factors that are frequently investigated with respect to the aetiology of CFS, namely: viral infection, immunological dysfunction, neuroendocrine abnormalities, sleep disturbances and brain abnormalities.

#### 1.3.1 Viral Infection

The infectious model of CFS is still one of the most popular frameworks for conceptualising the illness as it posits an identifiable, external cause for the symptoms which is readily accepted by both physician and patient. Among the various infectious agents examined in relation to their possible aetiological role in CFS, the Epstein-Barr Virus (EBV) a member of the herpes family has received the most attention in contemporary medical practice (Demitrack, 1996). Demitrack points out that EBV is the most common cause of infectious mononucleosis in humans and has been linked with a protracted period of recuperation in a significant number of people. He refers to several other studies that have investigated the EBV and have been unable to convincingly

demonstrate that a persistent, primary infection like EBV is the definitive cause of CFS. In addition, it has yet to be proved that reactivated viral infections play a role in the clinical presentation of CFS. He nevertheless contends that the role of physiological changes following an acute viral infection has not been completely excluded as a possible genesis of CFS.

#### 1.3.2 Immunological Dysfunction

Immunological abnormalities that could result in an aberrant response to physiological stress, have been associated with CFS. Demitrack (1996) contends that although subtle immunological dysfunction is evident in CFS patients across a number of functional measures, no specific immunological abnormality has been shown to exist in all cases, and in all studies. A noteworthy feature of the multiple studies cited is the considerable range and diversity of immune disturbances. A complicating factor is the fact that psychological factors can have a profound influence on the immune system, and may play an important role in the pathogenesis of these immune abnormalities (Jordan, 1994). Demitrack (1996) points out that the behavioural characteristics of patients with CFS are considered to be as complex as the immune findings, and demographic and non-specific characteristics, including age, gender, activity and sleep patterns also have an effect on immune function. He proposes that a more broad-based, interactive framework of the immune dysfunction evidenced in CFS, is necessary as it would facilitate a greater understanding of the complex interrelationships between the immune, endocrine and central nervous systems.

#### 1.3.3 Neuroendocrine Abnormalities

Cleare & Wessely (1996) reviewed recent evidence that the hypothalamo-pituitary-adrenal (HPA) axis was dysfunctional in CFS patients, although the aetiology of this was unknown. According to these researchers the HPA axis co-ordinates the body's response to stress through a complex network of biochemical signals. Further, Demitrack (1996) contends that the body's ability to regulate the HPA axis can vary during the course of the day, and that any physical or psychological change in functioning may result in HPA axis disturbance.

Demitrack & Greden (1991) propose two main lines of evidence consistent with HPA axis

disturbance in patients with CFS. First, there is a noteworthy overlap in symptom presentation of CFS and patients with a glucocorticoid deficiency. The primary symptom of glucocorticoid insufficiency is an abrupt onset of debilitating fatigue, precipitated by a stressor, joint and muscle pain, postexertional fatigue and disturbances in mood and sleep. Furthermore, glucocorticoids act as potent endogenous immunosuppressive agents which may suggest that the wide spectrum of immunological dysfunction evidenced in CFS patients could be due to a mild glucocorticoid deficiency. The second line of evidence focuses on the effects of a deficit of corticotropin-releasing hormone (CRH) on the HPA axis. In contrast to classical, melancholic depression, many alternative depression-like syndromes such as "atypical depression" are characterised by lack of energy, mood instability and the reversal of the vegetative features observed in melancholic depression. Demitrack contends that these alternative syndromes, similar in presentation to CFS, all show evidence of a deficit in the release of CRH resulting either through the direct effects upon the central nervous system or indirectly by causing glucocorticoid deficiency.

Demitrack (1996) refers to a study he conducted together with other colleagues which confirmed the existence of this particular hypothalamic deficit in patients with CFS. Such a deficiency is suggestive of an aberrant stress response, and in particular mild hypocortisolism of central nervous system origin (Cleare et al., 1996). This could account for the debilitating fatigue experienced by patients with depression-like syndromes and of CFS. Although the validity of this hypothesis is yet to be conclusively proved, Demitrack points out the notable difference between the mild hypocortisolism evidenced in CFS patients, and the sustained hypercortisolism observed and documented in certain cases of melancholic depression.

### 1.3.4 <u>Sleep Disturbances</u>

Sleep abnormalities such as daytime tiredness, unrefreshing or fragmented sleep, insomnia and hypersomnia are frequently reported by CFS patients and could be linked to daytime fatigue. Although a number of studies have been conducted in this area, the findings are somewhat inconclusive regarding the nature of the relationship between sleep difficulties and CFS. However, Demitrack (1996) identifies several reasons why clinical sleep physiology is of importance in CFS. One noteworthy reason involves the interaction of several physiological systems closely associated with normal sleep, such as the immune and neuroendocrine systems.

More specifically, any disruptions of the HPA axis are likely to have notable effects on nocturnal sleep.

Demitrack (1996) refers to various studies in addition to that of his own research group which have found certain abnormalities in the sleeping patterns of CFS patients. Some of the more frequently reported disturbances include: a high prevalence of diagnosable sleep disorders, such as periodic limb movement disorder, sleep apnea or narcolepsy; an overall reduction in sleep efficiency despite increased time in bed; greater time spent in stage 4 and in delta sleep coupled with an increase in sleep latency; no reduction in rapid eye movement (REM) latency or any increase in REM activity and density; changes in cortisol output when sleep is denied or deliberately fragmented and finally, reductions in cortisol secretion partly attributable to the effects of glucocorticoid inhibition on the HPA axis functioning. He concludes by saying that research in the area of sleep disturbances and CFS is preliminary, and that findings should not be interpreted in isolation from immune abnormalities and neuroendocrine dysfunction.

#### 1.3.5 <u>Neuroimaging Studies</u>

Brain imaging studies are another source of evidence that functional and structural abnormalities are present in CFS patients, suggestive of central nervous system involvement. Although this research is considered preliminary, Demitrack (1996) refers to several studies that have found that blood flow patterns are abnormal in CFS patients. In one of the first published reports on neuroimaging in CFS, single photon emission computed tomography (SPECT), which measures the flow of blood to the brain, revealed a significant decrease in regional cerebral blood flow in CFS patients. However, the researchers were unable to identify a unique anatomical profile of involvement in CFS. Moreover, a later study found multiple areas of high signal intensity in the white matter of the central nervous system, using magnetic resonance imaging (MRI) (Demitrack, 1996).

Demitrack (1996) reports on a study that compared SPECT and MRI scanning in a group of 16

patients with CFS. The findings of the study showed that the SPECT scans revealed more evidence of abnormality than the MRI scanning technique. In addition, there was little anatomic correspondence between the SPECT and MRI scans in relation to the principal areas of cerebral involvement. In a six-month follow-up study, the SPECT scans showed some resolution of the abnormalities while the MRI scans revealed no evidence of improvement. An explanation for the striking contrast in the test results of these two brain imaging techniques was not offered.

Moreover, Demitrack (1996) refers to a companion report by the same research group which compared the SPECT scans of a group of CFS patients with three other participant groups namely, AIDS dementia patients, depressed patients and healthy controls. The findings showed comparable numbers of defects in the CFS and depressed groups while the AIDS dementia group had the greatest number of abnormalities. In addition, a lowered midcerebral uptake index was noted in chronic fatigue and AIDS dementia patients when compared to depressed patients and normal controls. The significance of these scan results in relation to clinicial symptomatology was not elucidated. The most recent neuroimaging study cited in Demitrack (1996) found reduced regional cerebral blood flow, and brain perfusion defects in the frontal and temporal lobes of both chronic fatigue and depressed patients, using SPECT images. These results were more evident in the right hemisphere for the CFS sample, while left hemisphere involvement was implicated in the depressed group of patients.

#### 1.3.6 Conclusions

In sum, Demitrack (1996) suggests that CFS is a complex syndrome that emerges due to a variety of disparate yet interrelated factors. The possibility exists that life stressors, personality variables, psychiatric illness and/or an innate deficit in HPA axis functioning could result in an inadequate response to an acute infectious or non-infectious stressor. Consequently, a reduction in any of the primary biochemical agents, such as hypothalamic CRH or adrenal glucocorticoids may lead to a deterioration in the patients' response to stress. As a result, continual activation of the immune response or an increase in delta sleep develops secondary to the primary central nervous system dysfunction.

Although the hypothesis advocated by Demitrack (1996) is contentious, it is useful for two main

reasons. First, it becomes relevant to examine the psychological and social milieu in which the illness develops and the specific disease model adopted by the patient to conceptualise the multiple symptoms experienced. Second, it allows patient and clinician the opportunity to consider how symptoms are influenced by the maladaptive coping strategies employed by the patient and the response of significant others in their environment.

#### 1.4 Psychological Investigations into CFS

According to Abbey (1996b) investigators have postulated that psychiatric symptoms are common in the general population and often occur transiently. These symptoms are also part of a wide variety of medical conditions, and manifest in approximately one-third of physically ill patients. Specific studies suggest that some associations between psychiatric symptoms and medical disorders are more frequently encountered, for example depression with pancreatic cancer or following cerebrovascular accidents or anxiety in relation to hyperthyroidism. However, the presence of prominent psychiatric symptoms in conditions of uncertain aetiology, such as CFS, fibromyalgia and irritable bowel syndrome still raise questions regarding the legitimacy of these syndromes especially in the medical community.

## 1.4.1 Psychiatric Symptomatology in CFS

Abbey (1996b) refers to two studies that suggest that CFS is an organic illness in psychologically susceptible individuals, as psychiatric disturbance has frequently been noted in association with CFS. Several investigators have drawn attention to the high rates of psychiatric morbidity evidenced in patients with CFS (Cope, Mann, Pelosi & David, 1996; Salit, 1997; Wessely, 1996). Estimates of the prevalence of depression in particular are variable yet high with reported figures of between 46% and 67% (Powell, Dolan & Wessely, 1990), 67% (Chalder, Power & Wessely, 1996) and 73% (Bertagnolli & Morris, 1997). Other studies have consistently cited high rates of depressive illness in CFS patients in comparison to other chronic physical conditions (Friedberg, 1996; Howlett & Lindegger, 1996; Wessely et al., 1996). It has even been suggested that severe CFS and depression are indistinguishable (Chalder et al., 1996).

#### 1.4.2 Psychiatric Diagnostic Overlap in CFS

Various studies of CFS sufferers have noted a high prevalence of premorbid and current psychiatric disorders, primarily major depression followed by anxiety disorders and somatoform disorders (Cope et al., 1996; Salit, 1997; Wessely, 1996). Wessely et al. (1996) found that the majority of CFS patients also had a current psychiatric disorder when assessed by interview (75%) or questionnaire (78%). In addition, CFS was associated with previous psychiatric disorder. These findings were consistent with previous community, primary care and specialist reports of the strong association between CFS and psychiatric disorders. However, Abbey (1996b) describes a study by Hickie and colleagues which found that the rate of lifetime psychiatric disorder in CFS patients was no higher than general community estimates. Salit (1997) refers to research conducted by MacDonald and co-workers which also found no increase in psychiatric disorders prior to the onset of CFS, and noted that depression was more likely to be diagnosed subsequent to a diagnosis of CFS. Friedberg (1996) reviewed several studies that indicated that a substantial proportion of CFS patients (22%-76%) had no previous psychiatric disorder. He also referred to data that indicated differences between symptoms of depression and those of CFS. He reported that the debilitating fatigue described by CFS patients did not assume such prominence in the symptom presentation of depressive patients, and that several somatic symptoms experienced by the former (e.g. joint pain, recurrent sore throats, headaches and postexertion malaise) were not commonly found in the latter. Hence, these differences in symptom presentation may suggest that CFS is not just a somatic presentation of an underlying psychological disorder but that the psychological symptoms are an intrinsic part of the illness.

#### 1.4.3 Problems in Assessing CFS Patients

Since there are noteworthy differences among psychodiagnostic studies as to the proportion and nature of CFS patients with comorbid psychiatric diagnoses, a major debate has arisen as to why such discrepancies exist and what they could mean. Friedberg (1996) argues that the differences could reflect a variety of methodological problems such as differences in the types of psychodiagnostic methods used by researchers; differences in the decision rules applied to classification of symptoms shared by CFS and psychiatric disorders, and the heterogeneity between and within study samples in terms of symptom presentation and severity, and functional impairment. The association between CFS and depression is further complicated by four interrelated factors that emerge during the assessment of patients with CFS (Demitrack &

Abbey, 1996). First, CFS patients tend to under-report psychological symptoms pertaining to the sociocultural context in which they live. Second, they seem to have difficulty providing a detailed and accurate sequence of symptoms related to the retrospective nature of symptom reports. Third, they often engage in incomplete symptom reporting because of personal illness attributions (e.g. belief that CFS is a physical illness). Lastly, there is a potential for a mismatch between the patients' subjective symptoms or lack thereof and the clinicians' objective assessment.

Another problem in assessing the relation between CFS and depression is the heterogeneity of both diagnostic conditions (Abbey, 1996b). The biological and psychological features of depression often vary depending on illness duration, severity, subtype and possible comorbid diagnoses. Similarly, there is considerable diversity among CFS patients in terms of degree of disability, severity and duration of illness. Wessely et al. (1996) propose that there is no specific symptom profile to distinguish CFS from other conditions, although muscle weakness, myalgia and postexertion malaise were described by CFS patients more frequently than those with chronic idiopathic fatigue. They contend that the symptoms suggested as characteristic of CFS are an inevitable consequence of the overlap between the symptom criteria used to establish psychiatric diagnoses and those of CFS. They also point out that previous psychiatric disorder may predict current psychiatric disorder alone, and not necessarily CFS. Hence, the symptoms thought to represent a specific process in CFS may instead reflect the joint experience of somatic and psychological distress.

#### 1.4.4 Models of the Relationship between CFS and Depression

Abbey (1996b) makes an important observation that more complex relationships may exist which could elucidate the observed association between psychiatric diagnoses and CFS. Abbey proposes four models for the relationship between depression, in particular and CFS. In the first model the depression is considered <u>primary</u> in that it can explain the clinical presentation of symptoms believed to be CFS. There are two variations of this particular model: (a) depression is believed to be the only condition; and (b) depression is seen to complicate the recovery from an illness of another aetiology. In the second model depression develops as a <u>secondary</u> phenomenon to CFS as (a) an organic mental syndrome associated with the unknown disease process inherent in CFS; or (b) as a psychological response to having a debilitating illness that is

poorly understood by the medical fraternity. The third model advocates that depression occurs as a <u>concurrent</u> disorder, independent of CFS. However, its significance lies in the fact that it modifies or modulates the clinical course and presentation of CFS. The fourth model postulates that depression is an <u>artifactual</u> diagnosis in CFS patients. Considering the overlap of certain symptoms of depression and CFS, CFS symptoms are inappropriately attributed to depression which does not exist as a separate entity. An important practical implication of these models is that psychiatric disorder in the context of CFS may easily go unnoticed by physicians, but that by monitoring and treating it some of the fatigue, depression and perhaps disability experienced by CFS patients could be alleviated (Cope et al., 1996; Howlett et al., 1996).

#### 1.5 An Integrative Cognitive-Behavioural Approach to CFS

Since there is no clear resolution as to the influence of physical and psychological factors in the cause, presentation and course of CFS, an acrimonious debate has arisen about whether CFS is a physiological or psychological illness. Those favouring a physical cause have tried to link CFS to viral pathogens and immunological abnormalities as noted in sections 1.3.1 and 1.3.2 above. Advocates of the psychological position have proposed that CFS is primarily a psychiatric condition, such as depression, which presents with prominent somatic features. This kind of mind-body dualism regarding the aetiology of CFS is considered an unhelpful polarisation as it perpetuates the view that medical disorders are "real" and that psychiatric disorders are "unreal" or "imaginary" (Demitrack & Abbey, 1996). It also encourages the stigmatisation of psychiatric disorders, as psychiatric symptomatology is perceived to be under the voluntary control of the individual. Jordan (1994) argues that logically it is difficult to dismiss the aetiological influence of either physiological or psychological factors in CFS, considering the interdependence of the two. On the strength of this, Sharpe (1996) proposes that the cognitive behavioural approach described below can transcend such dualistic thinking and provide a coherent multifactorial conceptualisation of the illness and a rational treatment.

Subsequently, the debate has shifted to differentiating the psychological and behavioural

attributes of the individual, which may predispose them to develop the syndrome or perpetuate it once it is established, from the physiological changes that may arise following the behavioural changes emerging during the illness (Demitrack, 1996). Wessely (1996) makes an important observation that what causes an illness is not necessarily the same as that which is involved in its perpetuation. In addition, he indicates that there is growing evidence to support the relevance of this premise to CFS. While the issue of aetiology is still highly contentious, the management and treatment of CFS patients is enhanced by understanding the role of physiological, psychological and social factors in the precipitation and perpetuation of the illness. In particular, cognitive, attributional and behavioural factors have become a major focus of treatment investigations as they play a pivotal role with respect to mediating disability and determining prognosis. Cognitive-behavioural therapy (CBT) has demonstrated promising results in terms of overcoming illness-perpetuating factors, such as distorted cognitive appraisals, avoidance behaviour and functional disability. The implementation and evaluation of this treatment approach to the problem of CFS continues to be an important area of investigation, and is the focus of the present study. A detailed review of the area follows below.

## 1.6 Rationale for the Application of CBT to CFS

Beck's (1976) cognitive model aims to modify the feelings and behaviours of a patient by influencing their patterns of thought. The model is based on the premise that thoughts and beliefs mediate emotional and behavioural responses in any given situation. In addition, key concepts such as schematic content, cognitive bias and compensation (referred to in sections 1.6.1 and 1.6.2 below) play an important role in that they provide the cognitive model with a more differentiated theoretical framework (Leahy, 1996; Young, 1994). A noteworthy advantage of Beck's model is that it allows for the integration of other cognitive models in a manner that preserves the integrity of all. Although cognitive therapy was initially used for depression, it has enjoyed considerable success during the past decade for a variety of disorders, including CFS (Sharpe, 1997a). Cognitive-behavioural interventions have been advocated in the treatment of medically unexplained syndromes, like CFS based on the use of CBT as an adjunct treatment in a variety of medical conditions (Abbey, 1996a). A patient's health and functioning may be influenced in at least three ways: (a) negative or catastrophic thoughts and beliefs may lead to considerable stress and even excessive emotional reactions; (b) due to inaccurate cognitive appraisals, symptoms may be misinterpreted as being beyond the patient's control

resulting in a failure to cope effectively; and (c) both excessive emotional reactions and maladaptive coping strategies may exacerbate existing symptoms and the underlying physiological abnormalities present.

Investigators have observed several common characteristics among patients who present with CFS that may serve to maintain the condition by interacting in mutually reinforcing ways. The utility of the cognitive-behavioural approach is that it integrates not only the patients' somatic symptoms and physiological state but also factors including cognitions, mood, behaviour and circumstances into a single model. In addition, the conceptualisation and formulation of the problem are individually tailored to deal with the heterogeneity among CFS patients. Thus, the cognitive-behavioural treatment plan requires a careful evaluation of the patient's problems and clear identification of the key components of the clinical presentation.

#### 1.6.1 <u>A Schema-Focused Cognitive Therapy</u>

Young's (1994) model of schema-focused cognitive therapy offers a means of identifying the source of the many cognitive distortions that lead to self-defeating behaviour, and ultimately challenging these core beliefs and maladaptive schemas. He specifically recommends his model of schema dynamics for the conceptualisation and treatment of certain psychotherapy patients. The model is based on four theoretical constructs, namely: (a) Early Maladaptive Schemas (EMS); (b) Schema maintenance; (c) Schema avoidance, and (d) Schema compensation. A schema is a cognitive structure that serves to organise experience into meaningful patterns by selectively limiting, guiding and evaluating information from the environment. In addition, schemas are stable and enduring structures which form the core of the individual's self-concept. Although schemas can be seen as creative ways of assisting the individual to think and act more efficiently, they distort information regarding the self and the environment resulting in negative automatic thoughts, self-defeating patterns of behaviour and considerable subjective distress. Young (1994) describes EMS as the deepest level of cognition in that they are stable themes that develop during childhood and are elaborated upon throughout an individual's lifetime. They serve as blueprints for the processing of later experiences. Schemas are cumulatively strengthened by ongoing patterns of everyday distressing experiences with family members and peers. According to Schmidt, Joiner, Young & Telch (1995) an EMS is a means for the child to comprehend and manage the environment. In adulthood, the EMS outlives its limited utility and creates anxiety and/or depression when it is activated by situations relevant to that particular schema.

Based on clinical experience with chronic psychotherapy patients, Young has identified 16 Early Maladaptive Schemas grouped within five higher-order areas of functioning. They are as follows: (a) in the <u>disconnection and rejection domain</u> there are six primary EMS's, namely, Abandonment/Loss; Mistrust/Abuse; Emotional Deprivation; Defectiveness/Shame; Social Isolation/Alienation; Social Undesirability (b) in the <u>impaired autonomy and performance domain</u> there are four EMS's and they include, Dependence; Vulnerability to Harm and Illness; Enmeshment/Undeveloped Self; Failure to Achieve; (c) in the <u>domain of impaired limits</u> there are two primary EMS's, namely, Entitlement/Domination; Insufficient Self-Control/Self-Discipline; (d) in the <u>domain of other-directedness</u> there are two EMS's, namely, Subjugation; Self-Sacrifice; (e) in the <u>domain of overvigilance and inhibition</u> there are two EMS's and they include, Unrelenting Standards; Emotional Inhibition. He contends that most chronic psychotherapy patients have more than one of these core schemas. This model is considered to be relevant here since specific schemas, such as unrelenting standards and emotional inhibition have been identified in patients with CFS (referred to section 1.7.1.1 below).

According to Young (1994) there are three major schema processes that explain how schemas function within the individual. These processes can occur within the cognitive realm, the affective domain, and in long-term behavioural functioning. <u>Schema maintenance</u> refers to the ways in which EMS's are reinforced. The primary mechanisms of schema maintenance are cognitive distortions and self-defeating behaviours, and these serve to maintain schemas thereby making them increasingly inflexible. On a cognitive level, information is distorted by focusing on facts and events that tend to confirm the schema, and by dismissing or minimising information that contradicts the schema. On a behavioural level, particular behaviour patterns that may have once been adaptive in the past become self-defeating in contemporary settings, and serve to confirm schemas. <u>Schema avoidance</u> is employed to avoid triggering the EMS's that lead to high levels of emotional distress. This can occur in the following three ways: (a) cognitive avoidance involves blocking any unpleasant thoughts and images that are triggered by schemas, and (c) behavioural avoidance refers to the avoidance of real-life situations or

circumstances that may trigger distressing schemas. <u>Schema compensation</u> refers to the cognitions and behaviours that overcompensate for EMS. In this regard patients adopt the opposite cognitive or behavioural style of what knowledge of their EMS would incline one to predict. Although this type of schema process may be considered as a partially successful attempt by the patient to challenge their schemas, it does not recognise the underlying vulnerability leaving the patient unprepared for the emotional consequences if schema compensation fails.

# 1.6.2 <u>A Cognitive Developmental Perspective</u>

Leahy (1996) has also focused on the role of schemas in influencing cognition and behaviour by highlighting the significance of developmental issues within the case conceptualisation of the patient. He refers to the work of Bowlby and Piaget, respectively, in identifying two specific developmental factors that are important in the emergence of early schemas. In the first instance, the infant is innately predisposed to form a close attachment but impediments to this attachment lead to the development of maladaptive schemas of future attachment. Second, these early schemas are formed at a stage in the infant's development when they are at a preoperational level of intelligence. Some of the structural limitations of preoperational intelligence include: egocentrism, centration, magical thinking and moral realism. These particular limitations bias the individual in certain ways, such as perceiving events and circumstances only from their perspective; focusing on one aspect of a problem instead of recognising variations; engaging in emotional reasoning, and believing that negative things happen to those that deserve to be punished.

Leahy (1996) explains, in a manner similar to Young (1994), how the child or adult attempts to adapt to early maladaptive schemas by either compensating for the supposed personal deficits or by avoiding situations in which personal deficits may be manifest. By adopting the strategies of compensation and avoidance the early maladaptive schema is never directly challenged or examined. However, Leahy makes a distinction between schemas and scripts which is an improvement on the work of Young as it contributes to a more refined understanding of schema dynamics. Schemas are involved in information processing and result in selective attention to or memory for information relevant to the schema. For example, if an individual believes she is inferior, she will focus on information related to her failures and dismiss information related to

her successes. Scripts, in turn, refer to the rules or suggestions which guide the individual in interpersonal situations and allow them to compensate for or avoid underlying schema. For instance, the schema "I'm weak", may result in a script whereby the patient compensates for her fear of weakness by attempting to become invulnerable. On the contrary, the patient may avoid her schema of weakness by refusing to take on any challenges.

#### 1.7 The Cognitive-Behavioural Conceptualisation of CFS

In developing a cognitive-behavioural treatment conceptualisation of a disorder or illness, it is standard practice to systematically consider the predisposing, precipitating and maintaining factors in order to establish a treatment plan. Although these factors are considered separately below, there is often considerable overlap in that what predisposes a person to developing a certain condition may also play a concurrent role in maintaining symptoms. Edwards (1996) provides a useful definition of the three factors and their interaction: (a) <u>Predisposing factors</u> - consist of dysfunctional beliefs or maladaptive schemas that have frequently developed in response to adverse personal circumstances; (b) <u>Precipitating factors</u> - involve one or more distressing recent events, such as a relationship breakdown or failure in a specific venture, and (c) <u>Maintaining factors</u> - include cognitive distortions that shape patients' perceptions of everyday events to make them consistent with the negative assumptions and schemas. In addition, there are self-defeating behaviours that evoke responses from others which confirm the dysfunctional assumptions and schemas.

#### 1.7.1 Predisposing Factors to CFS

# 1.7.1.a Perfectionistic Beliefs and the Role of Compensatory Coping

Rigid perfectionistic beliefs about achievement and performance not only predispose individuals to developing CFS but also impede rehabilitation by maintaining negative mood states associated with depression and anxiety. Surawy, Hackmann, Hawton & Sharpe (1995) point out some of the dysfunctional beliefs or maladaptive schemas that contribute to the former achievement-oriented lifestyle of CFS patients. They identify two primary types of maladaptive beliefs, namely (a) "I must achieve high standards of performance and responsibility" or "I must always perform perfectly", and (b) "I must be in control of my emotions" or "I must always cope and never show weakness". However, these expectations are often impossible to achieve and

ultimately lead to feelings of failure. A further set of negative thoughts then begin to emerge, like "I should try harder" or "I must not complain" or "if I can't do it properly, it's not worth doing at all", which reveal patients' beliefs about having to perform perfectly and always cope (Sharpe, 1996; Wessely, 1996).

In terms of Young's (1994) theory of schema development and schema dynamics, CFS patients appear to have developed a shame driven early maladaptive schema (EMS's) about themselves ("if I don't meet all my responsibilities to others all the time, then I'm a failure"). He points out that maladaptive schemas in the area of worthiness often arise when parents are "detached, critical, unpredictable, rejecting, punitive, withholding, inhibited or abusive" (Young, 1994, p 57), and children are made to feel as if they are not worthy of being loved. This is consistent with the findings of Surawy et al. (1995) who suggest that at a deeper level there exist core beliefs pertaining to a lack of self-acceptance and a profound sense of inadequacy. They contend that these core beliefs or early maladaptive schemas appear to stem from formative experiences where recognition and affection were dependent on meeting high parental expectations. If, as young children, these individuals voiced negative emotions or indicated signs of not coping the response received from parents or significant others was dismissive, critical and unsympathetic.

Moreover, in response to parental criticism and rejection, CFS patients appear to have an unrelenting standards schema ("I must always perform my responsibilities perfectly") an emotional inhibition schema ("I must always cope and never show weakness") and a self-sacrifice schema ("I must always please others"). With respect to Young's (1994) definition of schema compensation, patients with CFS behave in a manner which appears to be the opposite of the core maladaptive schema. Thus, in order to meet the expectations of others and gain acceptance and respect, CFS patients overcompensate by setting high standards at work, home and school. This, in turn, leads to prolonged self-driving behaviour and a need to maintain strict control of their emotions and avoid showing signs of weakness.

# 1.7.1.b Personality Variables and Lifestyle Factors

Recently two different studies have both observed how compensatory schema dynamics manifest in personality and lifestyle, and predispose the individual to developing CFS through the accumulated wearing down of resources. An anthropological study by Ware (1993) used a

semi-structured, open-ended instrument to document the life histories of a group of 50 patients with CFS. The study revealed that in the months and years prior to becoming ill, patients devoted up to "80 hours a week to their jobs" and often became engaged in other part-time work or projects. They got involved in numerous other activities, such as volunteer work and strict exercise programmes leaving little time left for themselves. Patients also described themselves as "workaholics", "Type A personalities" and "perfectionists" in that they adopted a strident approach to achievement and had difficulty in setting reasonable limits. Moreover, Ware noted evidence of dysfunctional experiences with parents, siblings and other family members in the life histories of the CFS patients. These experiences included: (a) family psychiatric history, such as the presence of significant depression, anxiety and substance abuse, and (b) abusive dynamics in the family of origin, namely physical, sexual or emotional abuse and constant tension or fighting between parents and/or other members of the family.

A cognitive study conducted by Surawy et al. (1995) reported findings remarkably similar to those observed by Ware (1993). Based on reports from both patients and their families, they identified a premorbid personality characterised by a preoccupation with achievement; perfectionistic tendencies and constant striving to meet the expectations of others. In addition, they noted that these individuals had considerable difficulty expressing emotional distress and struggled to acknowledge their own limitations or any signs of personal weakness. Patients typically described themselves as "bottling up feelings" and "putting on a brave face" instead of complaining or asserting their rights and needs.

Furthermore, Surawy et al. (1995) observed that CFS patients were most reluctant to consider the possibility that perhaps they were depressed, and only on rare occasions did they volunteer reports of disturbed mood. When an anxious or depressed mood was acknowledged it was most often perceived to be a consequence of the illness. A regular cognitive distortion reported by CFS patients was "I'm not the sort of person who gets depressed" while the underlying assumption seemed to be "depression is evidence of weakness." According to Sharpe (1996) these type of dysfunctional beliefs not only drive the individual to considerable premorbid striving and achievement but also bias them away from seeking an understanding of the psychosocial aspects of their condition. Surawy et al. describe a particular personality type identified by Beck, namely the "autonomous personality", which predisposes the individual to a subtype of depressive syndrome similar to CFS. Beck suggests that feelings of depression take a different form in achievement-oriented individuals compared to that observed in more social or relationship-focused people. The typical beliefs and characteristics of achievers include a preoccupation with performance, a tendency to reject assistance and pessimism about recovery. Surawy et al. contend that CFS patients have many of the characteristics of the depressed autonomous personality yet differ as the physical illness attribution of CFS alters the symptom presentation.

#### 1.7.2 Precipitating Factors of CFS

## 1.7.2.a Infectious Illnesses and Psychosocial Stressors

The predisposing factors outlined above leave CFS patients particularly vulnerable to a combination of precipitating events, such as acute infectious illnesses and psychosocial stressors. In a systematic study investigating the precipitating factors for CFS, Salit (1997) found that although the majority of patients did report an apparent 'flu-like illness at the time of onset and complained of frequent recurrences of these 'flu-like symptoms during the course of CFS, only 7% of patients had a definite infectious onset determined by laboratory tests. He also observed that 85% of CFS patients reported more stress in the year preceding the onset of their condition, and that CFS can and does occur after physically traumatic events, such as motor vehicle accidents, allergic reactions and surgery. This particular finding is largely consistent with evidence found in the study conducted by Ware (1993). In this study Ware noted that the life histories of CFS patients revealed considerable psychological distress preceding the onset of the condition. The following life stressors were documented: (a) negative life events, such as serious injury, divorce, job loss and death of a family member or close friend, and (b) chronic life problems, for example serious illness in the immediate family, troubled or failing marriage and persistent work problems.

Surawy et al. (1995) contend that the important life and acute stressors that precipitate the onset

of CFS, are those that interfere with the ability to achieve, and place excessive demands on the CFS patient. This, in turn, results in a depletion of their limited personal resources and coping abilities. A fairly minor event and/or illness can then serve as a precipitating factor or catalyst which results in an inability to cope effectively. They indicate that in terms of the cognitive theory outlined by Beck and colleagues, the patients' perception of their inability to perform may be considered as a "critical incident" resulting in the activation of their core beliefs or maladaptive schemas relating to achievement and self-worth. In an attempt to meet the requirements of these powerful beliefs and achieve set goals, patients initially mobilise all their resources but soon begin to tire and feel exhausted.

#### 1.7.3 Maintaining Factors of CFS

Once the patient begins to feel prolonged fatigue over an extended period of time, a number of different factors may then serve to maintain the tiredness and exhaustion. These maintaining factors have been identified in the literature on CFS and a detailed review of this area follows below.

# 1.7.3.a External versus Internal Attributional Style

Investigators have observed that patients with CFS tend to believe that their condition is caused by a physical disease (external attribution), such as post-viral syndrome or myalgic encephalomyelitis (ME). However, it is unclear whether this external attribution is part of a general pervasive external attributional style or if it relates to a specific belief that has emerged because of the incapacitating fatigue and disability inherent in CFS. Powell et al. (1990) compared the attributional styles, self-esteem and depressive symptoms of CFS and depressed patients, and considered the possible effects of these attributional differences. In terms of methodology, the study did not use a standardised questionnaire to assess attributional style. Instead, a self-assessment questionnaire was used to establish the attributional style of patients. This questionnaire consisted of six questions that focused on establishing the possible cause(s) of the symptoms. It offered a range of possibilities starting from a definite physical cause to a definite psychological cause. With respect to findings, Powell et al. found greater external attribution in the CFS group and noted that these patients reported fewer self-reproach symptoms, such as feelings of failure, inappropriate guilt and lowered self-esteem than the depressed controls. In evaluating the study, they suggest that an outward style of attribution protects CFS patients from cognitive changes associated with low mood but at the expense of greater vulnerability towards somatic symptoms such as fatigue. The authors do not address the issue of whether attributional style is a possible predisposing factor to developing CFS.

Howlett et al. (1996) compared a group of CFS patients with depressives and patients with chronic physical diseases (CPD) on measures of depression, illness behaviour and attributional style. In terms of methodology, the study used the Zung Self-Rating Scale for Depression (SRSD), the Illness Behaviour Questionnaire (IBQ) and the Attributional Style Questionnaire (ASQ). The ASQ measures the extent to which individuals make stable, global and internal attributions with regard to specific events and situations. No modifications were made to the ASQ questionnaire for the purposes of the study. The overall findings showed that CFS patients were more similar to depressives on measures of depression and illness behaviour, but more like CPD patients on attributional style. On closer examination, the researchers noted that CFS patients had a predominantly external attributional style, especially on the internal versus external dimension. In addition, CFS patients showed a preference for ascribing difficulties to somatic causes. In contrast, the depressed group were found to have a notably high internal attributional style and tended to have a predominantly psychological focus. With respect to illness behaviour, patients with CFS were characterised by their high levels of disease conviction that set them apart from the other two groups.

In evaluating the study, Howlett et al. (1996) point out that the external attributional style of the CFS patients differentiates them from depressives and suggests that it is not their attributional style that is responsible for their depressive tendency, but rather some other mechanism. They suggest that that cognitive-behavioural therapy (CBT) aimed at altering attributional style is likely to have limited efficacy in the psychological treatment of CFS patients, especially treatment of the depressive component of CFS. Furthermore, they point out that their findings are in contrast with other studies which have found an internal (negative) attributional style is not necessary a predisposing factor to developing CFS. Rather the tendency in CFS patients to make external attributions appears to be a consequence of having a controversial illness characterised by uncertainty surrounding the diagnosis and treatment. In a large community survey Chalder et al. (1996) studied the attributional styles of 38 patients who attributed their fatigue to Myalgic

Encephalomyelitis (ME). This ME group was randomly matched to two other participant groups who attributed their fatigue to either psychological or social factors. In terms of methodology, this study used an adapted version of the Attributional Style Questionnaire (ASQ) to measure attributions. In the study the original three dimensions of the ASQ, namely stable, global and internal were modified to include: (a) two extra dimensions of attributional style, namely universality and uncontrollability, and (b) three illness-orientated situations, one achievement situation and one interpersonal situation. The three groups, namely, the ME group, the psychological group and the social group were followed up 18 months later and definite differences were reported. The study found that the group that attributed their fatigue to ME were more fatigued but were less psychologically distressed than the other two groups who attributed their fatigue to psychological or social factors. At follow-up the ME group were still less psychologically distressed.

On closer examination Chalder et al. (1996) found that individuals in the ME group tended to attribute in global and uncontrollable ways which was significantly related to the severity of depression and fatigue. This tendency was also noted in the social group but to a lesser degree. Moreover, this tendency appeared to be pervasive across different areas of the individual's life including illness and achievement orientated situations. It has been noted that perceived controllability is a very important factor in directing motivational, cognitive and behavioural effects in terms of outcome. In this regard, patients with CFS feel unable to control their symptoms through their own effort and response. Hence, Chalder et al. highlight the importance of introducing an element of control in CBT programmes as it may be a salient factor in the success of treatment. Although the authors do not appear to specifically address the question of whether attributional style is a predisposing factor in CFS, they suggest that an external attributional style may serve to maintain the illness.

In critically examining the findings of the above-mentioned studies, it is still unclear whether

the external attributional style observed in patients with CFS is part of a general attributional style, or if it is a specific illness-related belief. It is possible that CFS patients not only make external attributions specifically for fatigue and illness incapacity, but also in relation to other areas of their lives. If this were the case then general attributional style would be an important personality factor that may predispose individuals to developing CFS. In addition, once the state of fatigue is established and patients are recognised as ill, a specific attribution to a physical cause may then serve to maintain the condition by promoting the belief that symptoms should be managed by rest. However, at this point it is impossible to conclude that attributional style is a predisposing factor in CFS. Indeed, this hypothesis is worthy of further investigation.

There are certain advantages and disadvantages associated with adopting specific illness attributions in relation to CFS. Powell et al. (1990) point out that physical illness attributions appear to reduce the stigma often associated with a functional diagnosis like depression. Any doubts about the reality of the illness and even the character of the patient are generally put to rest if the condition is perceived to be a physical problem. As a result, CFS patients are able to maintain a more positive self-view. However, there are also detrimental aspects to such an attributional style. A belief in the diagnosis of post-viral fatigue or ME implies that the condition is incurable, and offers little direction in terms of management and prognosis (Powell et al., 1990).

A recent study by Clements, Sharpe, Simkin & Hawton (1997) has provided evidence that CFS patients may hold more complex views the causes of their illness. They found that although the majority of patients believed that their illness was caused by physical factors, more than half described illness models that included the interplay of physical and psychosocial factors. Patients readily acknowledged the role of "stress" in their illness but dismissed the idea of psychological causation. CFS patients also believed they could partially control their symptoms by resting and reducing activity but that they were unable to alter the course of the underlying physical disease process. Clements et al. suggest that the external versus internal illness attributions do not accurately reflect patients' beliefs. The authors point out the need for future studies to differentiate between coping with symptoms and overcoming the disease.

#### 1.7.3.b Specific Illness Beliefs and the Avoidance of Activity

According to Wessely (1996) the specific illness belief that CFS is incurable and that the symptoms should be managed by rest has been associated with passive physical illness-oriented coping strategies in patients with CFS. Although many patients can function for brief periods, they have great difficulty sustaining their activity due to an exacerbation of fatigue and other symptoms (Sharpe, 1996). This personal experience of feeling worse after activity leads to the adoption of prolonged rest and avoidance as principal coping strategies. Wessely contends that such strategies, although effective in the short-term, may be maladaptive in the long-term and have been associated with poorer prognosis. The catastrophic thoughts about changes in symptoms such as "I'm making myself ill" or "I should rest to get better" play an important role in fuelling behavioural disengagement in that they encourage patients to make certain predictions regarding their ability to function. For example, CFS patients frequently misinterpret increased symptoms occurring with activity as indicating a worsening of the disease process resulting in distress and avoidance of activities that could promote a "relapse".

Another specific illness belief that may influence activity relates to Bandura's concept of selfefficacy (Wessely, 1996). Self-efficacy has been defined as the belief or conviction that one can successfully execute the behaviour required to produce a suitable outcome. Wessely points out that it is widely accepted that self-efficacy is an important factor in whether an activity will be engaged in, and that such a belief could have a negative effect on performance in patients with CFS. Findley, Kerns, Weinberg & Rosenberg (1998) conducted a study of self-efficacy as a psychological moderator of CFS, and found that high self-efficacy predicted lower levels of symptoms, disability and distress in CFS patients beyond the variance accounted for by demographic variables and distress. In evaluating the study, Findley et al. suggest that CFS patients with relatively stronger beliefs that activity will not aggravate their symptoms may be more likely to engage in activities and consequently report less disability. Similarly, CFS patients with relatively stronger beliefs that they can manage their somatic symptoms experience less distress. They conclude that the enhancement of self-efficacy is likely to be an important factor in treating CFS patients and could result in symptom amelioration. In terms of methodology, the study used an adapted version of the Arthritis Self-Efficacy Scale to measure CFS patients' self-efficacy to handle their CFS symptoms, and to function despite CFS symptoms. One limitation of the study was the fact that the correlational nature of the analyses precluded conclusions of causality been made. Hence, the study is unable to clarify whether the

fear of symptoms and avoidance of activity contributes to lowered self-efficacy or if poor selfefficacy results in the avoidance of activity.

Recently certain studies have begun to provide evidence that beliefs related to the avoidance of activities may be more important in maintaining CFS than previously argued (Deale, Chalder & Wessely, 1998a). Deale et al. studied the effects of illness attributions on outcome in a randomised controlled trial of CBT versus relaxation. Causal attributions together with beliefs about the potential consequences of exertion and the avoidance of activities were documented before and after treatment in 60 CFS patients. The findings of the study showed that physical illness attributions did not change with treatment yet they did not affect outcome in either the CBT or the relaxation group. Another noteworthy finding was that a change in the belief that exercise is harmful was not associated with improvement. According to the authors this was unexpected as catastrophic beliefs about the consequences of pushing oneself have been associated with greater fatigue and disability in CFS. This suggests that causal attributions and beliefs about the potential consequences of exertion are less important than specific beliefs about avoidance of activities. Hence, it may be more helpful if patients are encouraged to test out beliefs about avoidance of activity through a programme of graded activity, rather than focus on correcting cognitive distortions like catastrophic thinking.

# 1.7.3.c Oscillation between Activity and Inactivity

Although avoidant coping behaviour leads to an intermittent reduction of symptoms, CFS patients soon begin to feel the need to perform and meet responsibilities. A second set of negative automatic thoughts based on "should" statements emerge. These include "I used to do more" or "I should try harder" and result in bursts of unmodulated exertion as patients attempt to perform at pre-morbid levels. During these episodic bursts of activity CFS patients achieve some of their goals but they also experience an increase in symptoms and the self-deprecatory cognitions associated with being unable to attain self-imposed standards for performance.

According to Sharpe (1996) there is an alternating dominance of cognitions whereby

catastrophic cognitions leading to an avoidance of activity are interspersed with "should" statements promoting unplanned attempts to act normally. This interacting cycle of cognitions results in an unproductive oscillation in activity which serves to confirm patient predictions and convince them that sustained activity is impossible.

#### 1.7.3.d Inactivity and Physical Deconditioning

The physiological mechanisms that cause the feeling of fatigue along with the other symptoms of CFS are poorly understood. A wide variety of contributory processes have been identified as noted in section 1.3 above, but none of them have been convincingly demonstrated. Patients with CFS complain of pain in the muscles coupled with a prolonged sensation of fatigue, especially after engaging in movement that requires muscular activity. It has been hypothesised that persistence or delay in recovery of muscle function may contribute to the myalgia and fatigue. However, Wessely (1996) points out that prolonged inactivity has the potential to produce profound physiological deconditioning and associated changes in neuromuscular functioning in CFS patients. This, in turn, can cause the onset of the well-documented postexertional muscle pain following unaccustomed exercise (this myalgia usually peaks around 48 hours). In addition, Wessely contends that postexercise muscle pain is usually localised to the specific muscles used, but that CFS patients seem to complain of widespread and diffuse pain.

Moreover, it is known that inactivity has the potential to increase the sense of effort involved on physical and mental exertion. In addition, the patient's perception of physiological changes may be exacerbated by a tendency to symptom monitoring and a sensitivity to somatic sensations. This increased focus of attention on symptoms regarded as threatening in conjunction with the physical deconditioning lead to cognitions with themes of discouragement, helplessness and frustration. Some of the cognitive distortions include, "symptoms indicate harm", "I could be damaging myself" or "I can't do anything". Such negative cognitive appraisals are known to have both direct and indirect effects on physiological functioning that may maintain or even exacerbate a chronic illness (Petrie, Moss-Morris & Weinman, 1995).

Petrie and colleagues describe a study of chronic pain in which negative cognitive

interpretations appeared to have a direct effect on functioning by increasing autonomic or nervous system arousal. The indirect effects reportedly occurred as a consequence of reduced physical activity which in turn gave rise to muscular pain and disability.

Fischler et al. (1997) conducted the first study which systematically assessed physical fatigability and exercise capacity in CFS in association with disability, somatic symptomatology and psychopathology. The findings of the study indicated that physical fatigability and avoidance of demanding tasks were significantly associated with disability and a tendency for somatisation, but not with anxiety and depression in CFS patients. In addition, physical deconditioning was noted in the CFS group as compared to healthy controls. The researchers conclude that the findings of the study are consistent with the cognitive-behavioural model of CFS, which suggests an association between avoidance behaviour and functional status impairment. Thus, these processes are potentially reversible and appear to be strongly influenced by coping strategies described (Sharpe, 1996).

Gibson, Carroll, Clague & Edwards (1993) conducted a study that examined exercise performance and fatiguability in a group of CFS and healthy control patients. They found that despite the characteristic complaints of excessive fatigue, weakness or muscular discomfort, the contractile properties of muscle in CFS patients were normal. In addition, the long-term recovery of muscle was the same as the control group. However, there was physiological evidence that CFS patients did not exercise to their full physical potential (reduced threshold for sensation, reduced peak heart rates and peak blood lactate levels), and that exercise activity was accompanied by greater effort perception. In evaluating the study, the researchers contend that physical deconditioning is only partly responsible for the reduced sensory threshold during exercise and reported persistence of symptoms. Rather, it would seem that submaximal effort coupled with certain perceptions related to performance might be the primary factors involved. In this regard, motivational or cognitive factors such as apprehension and possible fear of pain may be limiting exercise capacity in CFS patients. In addition, the limited sensory threshold evidenced could be a learned response to stimuli no longer present. These findings provide evidence that there is no risk of damage to the muscles in CFS patients, and therefore support the use of graded exercise programmes in treating patients.

1.7.3.e The Development of Self-Defeating Compensatory Strategies

The attitudes and beliefs of family members, friends and health care professionals may influence the patient's cognitions, behaviours and emotions in relation to CFS. According to Abbey (1996a) many of these significant people do not perceive CFS and other medically unexplained syndromes as legitimate illnesses due to the lack of laboratory markers defining the diagnosis. Forms of delegitimation include the trivialisation of CFS symptoms as common or part of normal life and the definition of the illness as psychosomatic by some health care providers. Consequently, CFS patients embark on a search for legitimacy of their illness. In this respect, two major compensatory strategies are adopted by patients to dispute a definition of CFS as psychosomatic. They include: (a) the belief that the condition is physical as noted in section 1.7.3.a above, and (b) the presentation of evidence that one is not psychologically unstable as described in section 1.4.3 above. Wessely (1996) points out that there are serious consequences of both approaches in that many CFS patients may not receive appropriate medical and psychiatric treatment. In addition, patients who reject any psychosocial intervention may resort to maladaptive coping patterns.

Moreover, the social environment may play an important role in maintaining the illness by shaping the beliefs and influencing the interpretation of symptoms of patients suffering from CFS. Wessely (1996) contends that the media initially portrayed CFS sufferers as exceptional members of society in that prior to becoming ill they were active, competitive and highly successful. The development of the condition was attributed to the pressures of daily living which were believed to affect people who refused to compromise high personal standards and perform at a mediocre level.

However, this particular image of the former lifestyles of CFS patients soon shifted. Instead, a stereotypical image of sufferers as "overactive, overachieving yuppies" began to emerge resulting in the name "Yuppie Flu". This popular stereotype is disliked and rejected by both CFS patients and self-help organisations as it promotes the belief that patients are "malingerers or shirkers" who are attempting to avoid the demands of living in a fast-paced society. As a result, CFS patients may over-emphasise how motivated and accomplished they were before becoming ill, in order to dispel any doubts of a psychological component in the aetiology of their condition. Wessely refers to a statement made by the president of a prominent ME Association that strongly supports this compensatory strategy adopted by CFS patients. In the

statement the president indicated that one of the distinctive differences between ME sufferers and depressives is that those with ME are highly motivated achievers. It would, therefore, appear that such organisations are part of a political strategy that serves to maintain the compensatory beliefs of CFS patient. Although these compensatory dynamics may restore selfesteem, they are ultimately self-defeating in that they do not protect against fatigue and disability. Thus, a contradiction exists whereby CFS patients focus on aspects of personality and behaviour that provide evidence against a psychiatric disorder yet, ironically, this dysfunctional strategy maintains the illness and also fuels the image of "Yuppie Flu". Patients are therefore caught in a double-bind situation resulting in feelings of intense frustration which distracts them from confronting important psychosocial problems that could be maintaining the condition (Wessely, 1996). In sum, Sharpe (1996) presents a cognitive-behavioural model of CFS which includes not only the possible physiological processes underlying fatigue, but also other aspects of the patient's clinical presentation including illness beliefs, coping behaviours, emotional state and social context. These characteristics of CFS patients are summarised in Table 2 below.

	UT 1 1' U
<u>Cognitions</u>	"I have a disease."
	"I can't do anything."
	"Symptoms indicate harm."
	"I'm not the sort of person who gets depressed."
Behaviour	Avoidance of activity
	Oscillation in activity
Mood	Frustration
	Depression
	Anxiety
Physiology	Concomitants of emotion
	Physiological deconditioning
	Other factors
Environment	Unhelpful information and advice about the illness
	Relationship/occupational problems

Table 2. Clinical Characteristics of Chronic Fatigue Syndrome

# 1.8 The Cognitive-Behavioural Treatment of CFS

CBT is a non-pharmacological approach to the treatment of CFS which helps the patient to recover by changing self-defeating cognitions and behaviour, as noted in section 1.8 above. In order to use CBT, specialist training is required as formal cognitive behavioural techniques are complex (Gelder, 1997). However, Sharpe (1997) points out that there is a growing interest in simpler non-pharmacological interventions, where relatively brief patient contact is supplemented by detailed self-help manuals together with information-giving and behavioural

programmes. These less formal therapies may also be effective in helping patients recover by altering illness-perpetuating thoughts and behaviour, and may be considered as CBT-informed practice. Investigations are therefore evaluating both formal and more experimental cognitive behavioural therapies. For the purposes of the current research various CBT studies based largely on the work of a core group of British researchers noted in section 1.2 above, will be reviewed in order to identify and evaluate principle aspects of their treatment programmes. An evaluation of their treatment approach will help to provide a framework for the current project, which is based on the work of this particular group. Furthermore, three other studies conducted by different Australian and American researchers will be presented and discussed as they offer additional insight into the cognitive-behavioural conceptualisation and treatment of CFS.

#### 1.8.1 Evidence for the Efficacy of CBT for CFS Patients

Chalder, Butler & Wessely (1996) describe a group of six patients with severe CFS who were treated as in-patients using CBT. Treatment consisted of graded consistent exposure to activity and cognitive restructuring, and included six outcome measures administered before and after the main intervention and at follow-up. The measures used were a behavioural description of problems and targets, the Social Adjustment Questionnaire, the Fear Questionnaire, a Fatigue Scale, and the short form of the Beck Depression Inventory. The programme lasted between three and eight weeks and the mean total, in- and out-patient therapist time was 14.6 hours (range 9-17). Five patients were reportedly depressed and were treated with the tricyclic antidepressant, dothiepin (50-150mg daily dose). All the patients met the operationalised Oxford research criteria for CFS, and attributed their symptoms to an ongoing viral infection. The various illness histories of fatigue ranged from between two to five years.

With respect to outcome, Chalder et al. (1996) reported that five patients were much improved after treatment in that there were notable reductions in fears and avoidance and improvement in work and social functioning. In addition, there was also a decrease in depression and fatigue scores. Four of the five patients who had improved at discharge were able to sustain their gains to 3-month follow-up. The fifth patient showed moderate increase on some measures at 3-month follow-up in comparison to discharge. The patient who showed no improvement suffered from treatment resistant depression and had considerable difficulty accepting the treatment model. She also strongly believed that her illness was due to a physical disease and that therapy

would be of little benefit. The researchers contend that illness beliefs about the nature of the condition appear to play a pivotal role in CFS. It was not possible to report with certainty whether recovery was due to therapist attention, specific techniques or medication but Chalder et al. point out that it was highly unlikely that gains were due to chance alone, especially as the patients were all severe cases. In addition, they indicate the improbability that antidepressants were able to bring about such significant improvement in the majority of patients. The findings of the study show that substantial improvements are possible in CFS patients who need in-patient treatment, despite the severity of both symptoms and disability.

Deale, Chalder, Marks & Wessely (1997) conducted a randomised controlled trial of CBT for CFS and compared it with relaxation. Sixty patients with CFS were randomly assigned to 13 sessions of either CBT (graded activity and cognitive restructuring) or relaxation over a period of 4 to 6 months. Outcome measures were completed at pre-, mid-, and post-treatment and at 1-, 3-, and 6-month follow-up. In addition, an interview with a blind assessor took place at 3-month follow-up. All patients were seen individually at weekly or fortnightly intervals, and the mean therapist time per patient was 15 hours. Ten outcome measures, involving functional impairment, fatigue, psychological distress and mood, and other variables were used. They are as follows: Medical Outcomes Study Short-Form General Health Survey, Work and Social Adjustment Scale, Long-term goals rating, Fatigue problem rating, Fatigue Questionnaire, General Health Questionnaire, the Beck Depression Inventory, Global self-ratings, Assessor ratings, and a description by patients of their illness attributions. The overall outcome was determined by degree of improvement shown on the physical functioning scale of the Medical Outcomes Study Short-Form General Health Survey from pre-treatment to 6-month follow-up. The criterion for improvement was an increase of 50 or more or an end score of 83 or more which represents the ability to carry out moderate activities, such as lifting a table, carrying parcels or packets or bowling without limitations.

The results of the study revealed that CBT was more effective than a control treatment of

relaxation in improving functional ability and fatigue in patients with CFS. At final follow-up, substantial improvement occurred in 70% of the completers in the CBT group compared with 19% of those who completed relaxation sessions. Both groups experienced a small improvement in mood status, which was attributed to non-specific treatment factors common to both interventions. At the 6-month follow-up the CBT group continued to show improvements. A noteworthy feature of this study was that it was the first to compare CBT with a psychological treatment that controls for factors such as therapist time and support, and homework practice. In evaluating the findings of the study the researchers propose that positive outcome is enhanced by teaching patients to carry out self-directed treatment and to practice relapse prevention, rather than treating them until they reach optimum functioning. Although the results of the study compare favourably with a pilot study conducted by Butler and colleagues (cited in Deale et al., 1997), they contrast with two earlier controlled trials by Lloyd, Hickie, Brockman, Hickie, Wilson, Dwyer & Wakefield (1993) and Friedberg & Krupp (1994).

Lloyd et al. (1993) conducted a double-blind, placebo-controlled trial of CBT for CFS and compared it with immunologic therapy with dialyzable leukocyte extract (DLE). Ninety outpatients with CFS were randomly assigned to one of four treatment groups: DLE and CBT; DLE and no CBT; CBT and a placebo drug, and a placebo drug and no CBT. They were seen every two weeks over a period of four months. The CBT treatment programme consisted of six sessions. At the commencement of therapy each patient received a comprehensive information booklet outlining the treatment rationale. The initial session, which also involved a close relative, lasted for 1 hour and consisted of an introduction to the programme, an explanation of the treatment rationale, presentation of the treatment manual, and evaluation of the individual's attitudes to the treatment and any family or social factors that may influence the patient's response to treatment. Subsequent sessions were conducted every two weeks, either individually or with the close family member, and typically lasted 30 to 60 minutes. The content of these sessions consisted of further emphasis on shifting the patient's concept of being a helpless victim of illness and therefore requiring ongoing rest, to re-establishing previous physical and social activities. A schedule of home-based graded exercise was recommended for each patient and was monitored by both the patient and spouse or family member. Gradual re-exposure to physical activity was emphasised as an essential part of the behavioural programme. The sessions also included discussion of problems encountered with implementation of the

programme, including individual or family difficulties that arose as a consequence of changes in cognition or behaviour, and ongoing encouragement to implement the exercise programme.

Outcome was evaluated by measurement of global well being (visual analogue scales), physical capacity (standardised diaries of daily activities), functional status (Karnofsky performance scale) and psychological morbidity (Profile of Mood States questionnaire), and cell-medicated immunity was evaluated by peripheral blood T-cell subtest analysis and delayed-type hypersensitivity skin testing. The results of the study revealed that immunologic treatment with dialyzable leukocyte extract and CBT, either alone or in combination, provided no clinically significant benefit over non-specific treatment in patients with CFS. The researchers suggest that immunologic therapy and/or CBT would not be effective in treating patients with CFS. With respect to the CBT aspect of the research programme, the authors concluded that a more intensive in-patient rehabilitation programme may be needed which focuses on increased levels of nonsedentary activity in conjunction with careful supervision of measured physical goals.

Friedberg et al. (1994) describe a comparative study of CBT for CFS and primary depression. Three groups of approximately 20 patients each participated in the study: a CFS group treated with CBT, a primary depression group treated with CBT and an untreated control group of patients with CFS. All patients with CFS were offered CBT and those refusing therapy were assigned to the no-treatment group. Treated patients were seen weekly in groups of three to seven patients or individually for a total of six therapy sessions over a period of 6-9 weeks. The CBT programme consisted of four primary components: (a) cognitive therapy techniques patients were taught cognitive coping skills to overcome catastrophic interpretations of their illness; they were helped to cognitively restructure anger and guilt-evoking beliefs; they were trained in attentional refocusing to reduce dwelling on fatigue symptoms; they were taught tolerance of illness limitations and attentional focusing on intact abilities and strengths; (b) behavioural prescription - patients were encouraged to make lifestyle changes compatible with the activity limitations imposed by the illness. On a practical level this involved reducing the workload at a job or at home, declining selected social invitations, scheduling regular rest intervals, and controlling exposure to stressful situations. In addition, patients were encouraged to write down information as a means of coping with forgetfulness and poor concentration; (c) relaxation and guided imagery - patients were introduced to these techniques as coping skills for

maladaptive stress reactions to CFS; (d) shared coping - patients were encouraged to engage in consensual validation of symptoms and disabilities. This activity helped to target iatrogenic stress. Four outcome measures were used and included: the Fatigue Severity Scale, the fatigue-related cognitions scale, the Center for Epidemiological Studies Depression (CES-D) scale and the Brief Symptom Inventory.

The results of the study revealed that for the CFS-treatment group, there was a trend toward reduced depressive symptoms but no significant changes in stress symptoms or fatigue severity. In contrast, depressed patients without CFS showed significant reductions in depression, stress and fatigue severity scores. No significant changes in any measure were observed in the CFS control group. However, the study identified two CFS subgroups within the main CFS-treatment group: those with and those without substantial depressive symptomatology. The depressed CFS subgroup were identified by higher levels of cognitive magnification of CFS symptoms, and showed significant reductions in depression, stress symptoms, fatigue severity and fatiguerelated thinking. According to the researchers this finding suggests that depression in this subgroup was mediated by maladaptive thinking. However, despite the constructive changes in thinking about fatigue, fatigue severity itself remained elevated in both CFS-treatment groups. In evaluating the study, the researchers point out that graded activity was not an important component of the treatment programme. Instead, patients in the current study had to be encouraged to rest rather than risk setbacks from exercise that would have been easily tolerated prior to the onset of CFS. They found that the CFS-treatment group tended to overwork which revealed their difficulty in adjusting to the sudden loss of premorbid functioning. In sum, the findings of the study suggest that a subset of CFS patients who have high levels of depressive symptomatology and maladaptive thinking regarding fatigue are more likely to benefit from CBT than those CFS patients without depression. Thus, CBT can be used to treat symptomrelated stress and depression, and thereby improve the quality of life of CFS patients.

In critically examining the studies conducted by Friedberg et al. (1994) and Lloyd et al. (1993),

Deale et al. (1997) point out that the negative findings reported in both studies could be due to differences in the nature and delivery of the interventions. The study by Lloyd et al. produced unsustained improvement as the intervention was possibly too brief. The treatment included 6 sessions and lasted for 10 weeks, compared with the 13 sessions over 4 to 6 months in the present study. It was pointed out that a longer treatment duration allows for improved skills acquisition, relapse prevention and suitable practice and experimentation while still having therapist contact. In the study by Friedberg et al. graded activity was excluded from the treatment programme as it provoked relapse. In this respect, Deale et al. suggest that activity levels should only be increased after a manageable programme has been established that includes an initial redistribution of activities interspersed with sufficient rest.

A simple CBT-informed study by Chalder et al. (1997) evaluated the efficacy of a self-help booklet and specific advice compared to a no treatment control in reducing chronic fatigue in a primary care population. The study was part of a larger population prevalence survey of chronic fatigue and psychological morbidity. The patients were allocated to either the intervention group or the control group using a simple randomisation procedure, and there were no exclusion criteria. Although the majority of patients in the intervention group were chronically fatigued, they did not fulfil the criteria for CFS, which by definition implies considerably more disability than chronic idiopathic fatigue. The primary measures for the present study were the Fatigue Questionnaire and the 12-item General Health Questionnaire. The intervention group spent between 10 and 15 minutes with a nurse who discussed certain aspects of the booklet and focused on other pertinent information.

The results of the study revealed that the self-help group showed greater improvements in fatigue and psychological distress than controls. In addition, the physical functioning of the intervention group improved slightly in comparison to the control group. Chalder et al. (1997) contend that this improvement was due to the contents of the booklet which highlighted the importance of maintaining a balanced approach to rest and activity. At a 3-month follow-up, 63% of the self-help completers achieved a good outcome in comparison with 39% of the control group. The researchers suggest that medical practitioners should use written information as part of their management of patients with fatigue as self-help books are effective and affordable. Moreover, by intervening at an early stage (primary care level) the extreme disability

evidenced in some patients could be alleviated. However, they point out that the self-help intervention may not be sufficient in promoting changes in CFS patients who are more disabled than their chronic fatigued counterparts.

Wearden et al. (1998) conducted a randomised, double-blind, controlled treatment trial of fluoxetine (20mg) and graded exercise for CFS, and assessed the efficacy and acceptability of these treatments. The study lasted for six months and patients were assigned to one of four treatment groups: exercise and medication; exercise and a placebo drug; no exercise and medication, and no exercise and a placebo drug. Three outcome measures were completed at weeks 12 and 26 and included: the 14-item Fatigue Scale; the Medical Outcomes Survey Short-Form Scales and the Hospital Anxiety and Depression Scales. In addition, participants were interviewed by a psychologist with the revised Clinical Interview Schedule and had a full physiological assessment. Patients attended approximately eight appointments and no psychological treatment was provided.

The results of the study indicate that there was a high drop-out rate amongst patients who were allocated to the exercise groups (exercise and medication or exercise and placebo drug). On closer examination the following findings emerged: (a) trial completers in the exercise and medication group experienced significant improvements in fatigue and functional work capacity, and small improvements in depression; (b) trial completers in the exercise group experienced the same benefits as the first group in terms of fatigue and functional work capacity but little improvement in mood; (c) the patients in the medication group experienced a significant but unsustained reduction in depression, and (d) the placebo group experienced the least improvement across the various functional domains. Overall, the two treatments produced important but modest benefits to CFS patients in that graded exercise resulted in improvements in functional work capacity and fatigue, while fluoxetine produced small but unsustained reductions in depression. In evaluating the study, Wearden et al. (1998) recommend that if the cognitive component of a CBT programme had been included in the study, it could have reduced the high drop-out rate and improved adherence to exercise by offering patients a supportive yet pragmatic explanation of behavioural changes. In this regard, graded exercise can be effective if patients are reassured that controlled activity does not necessary cause a worsening of symptoms. A further recommendation was that greater improvement may have

resulted with a more flexible medication dosage regime based on patient response to the drug.

Deale, Chalder & Wessely (1998b) responded to the findings of Wearden et al. and were critical of the limitations regarding treatment delivery and mechanisms of change. In response to the issue of greater support and explanation needed by CFS patients, Deale et al. contend that the low number of appointments coupled with the long spaces of time between sessions may have contributed to reduced motivation and treatment compliance. In addition, they indicate that frequent sessions are needed to ensure that the treatment model is accepted and internalised, so that when there is a resurgence of symptoms the treatment is not abandoned in favour of rest. Regular sessions encourage discussion about illness-related fears and help prevent noncompliance. The authors note that most of the CBT studies that have reported positive results in treating CFS patients have included between 12 and 16 treatment sessions. Moreover, with respect to the graded exercise component of the treatment, they contend that individually tailored exercise regimes over a longer period of time may have yielded more positive results. In this regard if patients are expected to make relatively rapid changes with little support, then feelings of anxiety may understandably emerge leading to non-compliance. However, they conclude that pragmatic treatment trials, such as that reported by Wearden et al. (1998) face the unique challenges associated with working in real life situations. These difficulties are in contrast to those encountered in explanatory trials that evaluate treatment efficacy under controlled conditions.

Bertagnolli et al. (1997) report a single case-study of a CBT group intervention with a 39 year old Caucasian woman diagnosed with CFS for three years. The particular patient was selected from the group for an in-depth review as her symptoms were severe and influenced most areas of her functioning. In addition, she was able to utilise the CBT strategies and apply them to many areas of her life. The researchers present a CBT conceptualisation and detailed case formulation of CFS, including some disease specific cognitions. The case formulation approach proposed by Persons was used and consisted of five primary features namely: (a) assessment of symptoms and behavioural problems; (b) alleviation of symptoms; (c) implementation of interventions aimed at the level of symptoms and behavioural problems; (d) interventions developed according to the individualised assessment and formulation, and (e) hypotheses regarding underlying mechanisms were proposed, tested and modified where necessary. Based

on this model it was hypothesised that the problems experienced by the patient were fuelled by a series of automatic thoughts resulting in the maintenance of CFS. By examining these thoughts it was felt that the underlying mechanisms at the root of the patient's problems could be understood. Although these thoughts arise from the underlying mechanisms, they also tend to reinforce them. Three primary automatic thoughts were identified and challenged by the group and they included: (a) "if I am not doing things for people, then I am a burden to them and they will abandon me"; (b) "if I don't excel then I am not worthwhile", and (c) "if I challenge myself then I will become sick". In examining these maladaptive thoughts the patient's underlying assumptions seemed to be: (a) "I am a fragile burden", (b) "others will abandon me if I don't do things for them", and (c) "the world is an empty, unpredictable and draining place."

Interventions were then formulated taking into account these powerful underlying assumptions. The treatment was divided into six modules and consisted of approximately 16 sessions in total. The first three modules were aimed at assisting the patient in developing more adaptive health related behaviours while the remaining modules focused on applying CBT techniques to improve coping strategies. In the Stress Module the patient was guided through various relaxation procedures. The guided visualisation exercise was particularly helpful for the patient, as the goal of this exercise was to create a mental image of a room that would include elements that would foster a sense of relaxation. After this exercise the patient reported feeling increased anxiety and depression as her room remained empty and she was unable to mentally decorate it. A discussion ensued which provided her with some insight into how CFS had limited her life resulting in her becoming more aware of the need to expand her activities. The Exercise Module reviewed the importance of graded exercise and included an assessment of the patient's current level of exercise tolerance. It was noted that the patient was deconditioned and an individualised exercise programme was designed for her. However, after a few weeks she stopped exercising as she believed that the increase in symptoms was directly related to her walking. The group leaders challenged her automatic thought of "the walking caused the increase in symptoms" to "I may have progressed too quickly and may need to slow down" by encouraging her to walk a shorter distance and at a slower pace, but were unsuccessful. During the Thought Module the patient was encouraged to examine the link between her automatic thoughts, her mood state and her symptoms. She found the ABCD technique of Ellis particularly useful in helping her to analyse how her beliefs would interact with situations and how her negative automatic thoughts would result in her becoming distressed. A second technique that she found effective was the "downward arrow technique" of Burns. The aim of this technique is to identify the core belief that is making particular thoughts distressing. The patient described a fear that her boyfriend could leave her due to her limited activity tolerance. By using this technique, she realised that the core belief driving this fear was that if she was not busily contributing to the household she was a burden. The discussion then revolved around examining the evidence she had for this belief. The Activity Module had three aims: (a) to help patients identify what kinds of activities were pleasurable for them; (b) to gradually increase the number of pleasurable activities they participate in through realistic goal setting, and (c) to identify pleasurable activities they can participate in at times when their symptoms are limiting their activity tolerance. For the patient, an important first step was to identify less fatiguing activities that were also pleasurable. However, she had difficulty discovering alternative activities. It soon became clear that a particular automatic thought of "if I challenge myself I will become sick" became activated when she explored new activities. She had not acquired the ability to discern between those activities that were overly taxing and those that were within her functional capacity. The group leaders encouraged her to use goal-setting skills so that she could participate in a specific activity but in a modified manner. At this point the Pleasure Predicting Technique of Burns was introduced. Through using this technique she began to acquire disconfirmatory evidence to the belief that "if I challenge myself, I will become sick". The People Module included assertiveness training and an evaluation of the patient's social network. The aim of this module was to change maladaptive relationships while maintaining satisfying relationships. The patient expressed an interest in expanding her social network to include people with whom she shared interests other than CFS. In subsequent discussions she indicated that she was achieving this goal in that she was starting to socialise with new acquaintances.

Outcome measures were used to evaluate the effectiveness of the CBT group intervention and included: the Brief Symptom Inventory (BSI), the Center for Epidemiological Study Depression Scale (CES-D), Perceived Stress Scale (PSS) and the Fatigue Severity Scale (FSS). The results of the study revealed no improvement in the patient's level of fatigue. However, the treatment was effective in helping her cope with the psychological aspects of CFS in that she was less psychologically distressed and experienced more perceived social support after the group intervention. In evaluating the study, Bertagnolli et al. (1997) contend that CBT can be effective

in changing maladaptive automatic thoughts that accompany CFS evidenced in positive behaviour change. The case study supports the premise that social isolation and behavioural inactivity commonly experienced by CFS patients can be altered by using CBT techniques. The authors point out that although the research discusses one group participant in detail, other group participants described similar patterns of cognitions and behaviours, and reported varying decreases in psychological distress and resumption of activities. At follow-up (exact time not specified although reportedly brief) the patient indicated that she still experienced bouts of fatigue and associated symptoms but that her ability to tolerate activity was increasing and that she had a more positive outlook on life. Her ability to prioritise and schedule activities also continued to improve. Owing to the brief follow up, the authors were unclear about whether the continued use of CBT techniques would eventually result in a decrease of physical symptoms along with a continued decrease in psychological symptoms.

## 1.8.2 Summary of Findings on CBT for CFS

Taken together, the cognitive-behavioural research of CFS reviewed above highlights the following general issues pertaining to the establishment and implementation of a CBT treatment programme: (a) the need to develop a clear yet flexible conceptualisation of the problem that accepts the patient's experience and understanding of the illness (Chalder et al., 1996;) (b) the importance of developing a collaborative relationship which encourages the patient to share their illness beliefs and consider other possible causative factors of CFS (Chalder et al., 1996;) (c) the need to tailor the cognitive and behavioural interventions to the needs of the individual patient, and to flexibly use a range of techniques rather than adhere to a strict treatment regime (Deale et al., 1998;) the use of appropriate self-help literature may be included (Chalder et al., 1997;) (d) the need to ensure that the treatment intervention is of suitable duration (12-16 treatment sessions on a weekly or biweekly basis) to allow for adequate skills acquisition, relapse prevention and meaningful experimentation with therapeutic guidance and support (Deale et al., 1997). In addition, regular sessions promote discussion about illness-related concerns thereby encouraging treatment compliance (Deale et al., 1998;) (e) the importance of including a carefully planned graded activity programme, especially where patients are severely disabled. This programme should emphasise a balanced approach to rest and activity and would need to include a redistribution or even a reduction of activity in conjunction with planned resting times. Activity levels would then be gradually increased only once the initial phase has

been consolidated (Deale et al., 1997). In terms of evaluating the effectiveness of such a programme, the following issues emerged: (a) the potential of CBT to produce cognitive shifts away from fearful automatic thoughts and maladaptive coping strategies leading to substantial improvement in fatigue, functional ability and even mood (Deale et al., 1998;) (b) the value of teaching patients to monitor their cognitions and apply specific coping skills to attempt and sustain behavioural changes in everyday situations (Weardon et al., 1998;) (c) the effectiveness of cognitive-behavioural techniques in terms of coping with the psychosocial aspects of the illness (Bertagnolli et al., 1997). In addition, there are potential benefits in relation to dealing more effectively with practical issues, such as the planning and scheduling activities.

Although the research findings have demonstrated the effectiveness of cognitive-behavioural strategies in decreasing disability and symptoms of many CFS patients, they are not uniformly effective across all patients. Some patients benefit little while others report improvements in certain areas, such as functional ability or mood, yet remain fatigued and symptomatic. Clearly there is still a need to implement and evaluate cognitive-behavioural treatment programmes in order to assess whether CBT can be improved to accomplish more complete recovery.

# 2. METHODOLOGY

# 2.1 Rationale for the Aims of the Study

The main purpose of this study was to critically examine the cognitive-behavioural approach of CFS outlined by Sharpe et al. (1997) by conducting three in-depth case studies. It was noted that Sharpe et al. focus on the maintaining factors in treating CFS but that it is a standard part of the cognitive-behavioural approach of Young (1994) and Leahy (1996) to take more account of the predisposing factors and to target them as part of treatment. An additional aim was to present a full cognitive developmental case conceptualisation of CFS and thus the aims of the study are as follows:

- 1) To identify patients suffering from CFS.
- 2) To conduct a thorough cognitive developmental assessment and case conceptualisation.
- To use the assessment and conceptualisation as a basis for devising an individually tailored treatment programme.
- 4) To document the progress of the psychotherapy process.
- 5) To evaluate the effectiveness and applicability of the treatment programme.
- 6) To examine specific theoretical issues in light of the case material.

# 2.2 The Case Study Research Method

The case study method has played an important role in advancing scientific knowledge, particularly in the field of clinical psychology (Kratochwill, Mott & Dodson, 1984). This knowledge has been developed by the systematic observation and accurate description of individual cases resulting in a greater understanding of specific phenomena and an increased range of practical therapeutic skills for clinical intervention (Edwards, 1990). Edwards (1996) distinguishes two primary phases in the advancement of knowledge, namely, (a) a phase of discovery followed by (b) a phase of verification. He contends that both phases form part of a continuum and that in practice most case studies include descriptive work, the examination of theory and even perhaps the development and testing of theory. The current case study is located at the theory-testing pole of the continuum in that it tests specific principles and generalisations within a well-developed existing theory pertaining to the treatment of patients with CFS. However, it also includes aspects of the descriptive phase as the theory testing is based on accurate descriptions of individual cases.

Although it is beyond the scope of this section to include a detailed account of case study methodology, it is necessary to provide an outline of the principles that guide this research approach for the purposes of the present study. Edwards (1996, 1998a) describes a number of steps that need to be followed when testing propositions and developing the existing theory: (a) the researcher must develop accurate, in-depth descriptions of individual cases; (b) the case study should include a clear conceptualisation of the case material in behavioural and psychological terms that will be of practical value. The conceptualisation serves to open up the essential qualities of the case being investigated by using suitable constructs or categories, such as predisposing, precipitating and maintaining factors; (c) the case study includes the testing and re-testing of these constructs against new cases. If the observations and associated hypotheses from one case are repeatedly confirmed in other cases, it becomes a general principle. The limitations of the application of this principle are then identified by actively searching for cases in which the generalisation is no longer applicable. If a particular case requires that new phenomena be acknowledged, new distinctions made, or a different relationship between phenomena be recognised, it can provide the basis for further revision and refinement of the existing theory.

Bromley (1986) points out that this process is similar to the building up of case-law in jurisprudence. Edwards (1999) explains that the term "case-law" refers to the concepts, distinctions and principles which enable researchers to study particular phenomena in an intelligent way and gradually build up a well-systematised body of knowledge based on the careful study of individual cases. Moreover, case law develops by critically examining the concepts and categories in close relation to the case material, thereby achieving a more differentiated body of principles.

A special feature of case study methodology is its flexibility to include both qualitative and quantitative data. It can be valuable to incorporate an experimental component into a case study whereby specific variables are identified for quantitative measurement and repeated measures are taken before, during and after the treatment intervention is introduced (Edwards, 1996, Kazdin, 1982). By pursuing a single-case experimental design it is possible to detect whether any effect was produced by the treatment. In accordance with Barker, Pistrang & Elliott (1994) the present study followed a simple <u>AB</u> design, in which <u>A</u>, the baseline phase, was followed by

<u>B</u>, the treatment intervention to reduce fatigue and disability. A pre-treatment measurement of four dependent variables (fatigue; work and social adjustment; depression and anxiety) was obtained to establish a baseline measure for each patient. This pre-treatment data collection phase was concerned only with obtaining information and at no time was any therapeutic suggestion or intervention implemented. The measures were repeatedly used in the treatment phase and again at follow-up to evaluate the effectiveness of the treatment.

Edwards (1996) points out that when a multifaceted intervention has been successful, it is important to establish whether some aspects of the intervention were more effective than others. It is therefore necessary to isolate these particular components and critically assess them in light of the case conceptualisation and treatment method. This, in turn, allows the researcher to evaluate the effectiveness and applicability of the particular treatment programme. However, many uncontrolled variables such as extra-therapy events and non-specific factors in the therapy process itself may be responsible for a specific outcome. Kratochwill et al. (1984), building on Kazdin (1982) identified twelve factors that can be used to overcome these obstacles and improve the case for attributing a positive outcome change to a particular intervention. Some of them include: (a) using repeated measurements to assess outcome; (b) noting the chronicity of the case; (c) noting the response to previous interventions, and (d) observing the size and impact of the effect. As already noted, many of these factors were included into the present case study thereby permitting more differentiated questions regarding the effectiveness of specific interventions to be examined, and strengthening the conclusions drawn.

A number of steps can be taken to enhance the validity, both internal and external, in case study research. The case study preserves external validity by employing qualitative methods that stay as close as possible to the events or details of patients' everyday lives. This helps to ensure that the conclusions drawn from the study can be generalised outside of the particular case. Moreover, internal validity is enhanced by basing claims upon evidence from the case material, and linking them to theoretical concepts in a logical and coherent manner. In this regard, alternative explanations must be canvassed and cases must be sought which enable competing theories to be evaluated against each other.

A final noteworthy feature of the case study method is its compatibility with cognitivebehavioural psychotherapy (CBT). CBT is based on a tradition of common-sense pragmatism that incorporates the physiological, psychological and social aspects of patient functioning into a single model, as noted in section 1.5 above. This integrated approach to patient management and treatment is an ideal setting within which to examine the case study method and to use the psychologically rich case material obtained for testing and developing theory.

## 2.3 The Selection of Participants

The programme included three South African participants. The inclusion and exclusion criteria for the present study were based on the Oxford criteria for CFS (referred to in section 1.2 above). The inclusion criteria included: (a) a medical practitioner's diagnosis of CFS, and (b) the experience of severe, disabling fatigue established by means of a questionnaire (Appendix I). The exclusion criteria included: (a) the presence of established medical conditions known to produce chronic fatigue, and (b) the existence of specific psychiatric conditions, namely, Schizophrenia, Bipolar Disorder, Substance Abuse, Eating Disorder and Organic Brain Disease.

With respect to recruiting participants, one patient was found by means of an advertisement placed in a local newspaper, which requested volunteers for participation in a research study into CFS. The other two patients heard about the study through informal word-of-mouth reports and volunteered to join the research programme. Each participant was provided with information about the nature of the cognitive-behavioural programme in standardised written form (Appendix II), and their written consent was obtained.

#### 2.4 Data Collection Phase One

Date collection phase one refers to the collection of both quantitative and qualitative data from the pre-treatment phase up until the actual implementation of the cognitive-behavioural treatment programme. There were four major data sources and they included: the self-report measures; the Schema Questionnaire; the assessment interviews; a diagnostic evaluation and the mental state examination. The four self-report measures were administered three times prior to the commencement of the treatment intervention, including a baseline measurement and two further measurements during the assessment phase (weeks 1 and 3).

## 2.4.1 Quantitative Assessment Measures

Various self-report inventories and questionnaires were used to collect information on specific aspects of the physiological, psychological and social functioning of the patient. The majority of these measures have been used by Deale et al. (1997) as noted in section 1.8.1 above. The inventories and questionnaires used to assess patient functioning are listed below.

# 2.4.1.a <u>Fatigue Questionnaire (Chalder, Berelowitz, Pawlikowska, Watts, Wessely, Wright &</u> <u>Wallace, 1993)</u>

The Fatigue Questionnaire is made up of eleven questions and is designed to measure the severity of subjective physical and mental fatigue. The fatigue symptoms are each rated on a four-option continuum from 0 "less than usual" to 3 "much more than usual". The Likert scoring method was used as recommended by Chalder et al. (1993). Additional questions included in the questionnaire pertain to the percentage of time tired and two questions on muscle pain at rest and after exercise. These extra questions are not included in the formal scoring of the scale but provide useful information that can be perused for qualitative purposes.

# 2.4.1.b Work and Social Adjustment Scale (Marks, 1986)

The Work and Social Adjustment Scale consists of five visual analogue scales and is designed to assess impairment in relation to work, home management, social leisure activities, private leisure activities and ability to form and maintain relationships. Patients are asked how much their illness affects each of the designated areas of functioning and the responses are rated on a nine point scale ranging from 0 "not at all" to 8 "very severe". It was scored based on the suggestions of Marks (1986).

## 2.4.1.c The Beck Depression Inventory-II (Beck, Steer & Brown, 1996)

The Beck Depression Inventory-II (BDI-II) consists of 21 multiple-choice questions and is used to measure the severity of the patient's depression. Each item is rated on a four-point scale ranging from 0 to 3. It was administered and scored as recommended by Beck et al. (1996).

#### 2.4.1.d The Beck Anxiety Inventory (Beck & Steer, 1993)

The Beck Anxiety Inventory (BAI) is made up of 21 descriptive statements of self-reported anxiety symptoms and is designed to establish the severity of the patient's anxiety. Each item is rated on a four-point scale ranging from 0 "not at all" to 3 "severe". It was administered and scored following the guidelines prescribed by Beck et al. (1993).

#### 2.4.2 Qualitative Assessment Measure

## 2.4.2.a The Schema Questionnaire (Young & Brown, 1990)

The only qualitative self-report questionnaire used in the study was the Schema Questionnaire (SQ) (Young et al. 1990) which is a self-report inventory designed to measure the 16 primary EMS's. The SQ consists of 205 statements that a person might use to describe him/herself. There are six possible responses ranging from 1 "completely untrue of me" to 6 "describes me perfectly", and the person is encouraged to make their selection based on how well the particular statement describes them. In addition, answers are based on what the person feels to be the most accurate reflection of their emotional state rather than on what they believe to be true, intellectually. The SQ was administered on one occasion. The method of analysis is explained in section 3.8 below.

Although there are no statistical norms for the questionnaire at present, two studies (Lee, Taylor & Dunn, 1999; Schmidt et al., 1995) have conducted investigations into the psychometric properties and factor structure of the SQ. Schmidt et al. describe an investigation which involved assessing the underlying factor structure of the SQ along with its reliability and validity. The questionnaire was administered to 1129 graduate students and 187 patients attending an outpatient treatment clinic. When the responses of the student sample were factor analysed, 12 of the 16 factors proposed by Young et al. (1990) emerged. One factor not proposed by Young et al., namely, Fear of Losing Control, emerged. The authors indicated that the Fear of Losing Control factor seemed to represent a separate entity from general Emotional Inhibition. They contended that, as such, it needed to be assessed differentially as it was a refinement of the previously hypothesised Emotional Inhibition EMS. Further, when the results of the patient sample were analysed, 15 of the 16 factors emerged.

The Fear of Losing Control factor, which had been observed in the student sample, was not found in the patient sample. In addition, the Social Undesirability EMS failed to emerge as a factor in either sample. In this regard, they suggested the Social Undesirability EMS should not be considered as a conceptually distinct scale. Overall, the results of the study provided support for the existence of the set of core schemas proposed by Young et al.

Lee et al. (1999) assessed the underlying factor structure of the SQ in an Australian clinical population of 433 people. Of the total number of patients in the study, 221 (62%) had a DSM-IV Axis II diagnosis and 135 patients had an Axis I diagnosis (American Psychiatric Association, 1994). The diagnostic status of the remaining 87 participants was unknown. The main aim was to determine whether the factor structure that emerged in Schmidt et al.'s clinical sample was reliable. Further, the study investigated the structure of the SQ in the patients that had an Axis II diagnosis compared to the patients with only an Axis I diagnosis. When the responses were analysed 14 of the 16 EMS's hypothesised by Young et al. (1990) emerged as independent factors. These 14 factors were also obtained by Schmidt et al. (1995) in their patient sample. As with the Schmidt et al. study, the EMS factor Social Undesirability did not emerge as a separate factor. The other EMS that did not emerge as a separate factor was Emotional Inhibition. Rather it was found to consist of two independent factors, namely, Emotional Constriction and Fear of Loss of Control. Both of these factors contained items that reflected emotional inhibition but differed according to the underlying cause of the inhibition. A similar result was obtained by Schmidt et al. in their student sample.

With respect to the relationship between the higher-order factor structure of the SQ and psychopathology, the study found that this structure applied equally to Axis I and Axis II groups even though each of these differed significantly on their mean scale scores. In this respect the Axis II patients scored higher on all derived scales, compared with patients with only an Axis I diagnosis. These differences were significant for 14 of the 16 scales. The two exceptions were Vulnerability and Subjugation. In the study these scales coupled with certain others appeared to load on two of the higher order factors, namely, Disconnection/Rejection and Impaired Limits. These two scales showed the greatest differences between the two groups.

#### 2.4.3 <u>The Pre-Assessment Meeting</u>

Sharpe et al. (1997) have outlined five main stages in the cognitive-behavioural assessment and treatment of patients with CFS. These stages will be reviewed as the current study followed the guidelines presented for each stage of the process. At the first meeting, the researcher spent approximately 45 minutes with each patient and the following issues were addressed: (a) the CBT research consent form was read and signed as noted in section 2.3 above, and (b) the pre-treatment baseline measures were completed referred to in section 2.4.1 above. In addition, each patient received two informational guides to a cognitive-behavioural approach to fatigue obtained from Trudie Chalder at King's College Hospital in the United Kingdom (Appendix III).

#### 2.4.4 <u>Stage 1: The Assessment Procedure</u>

The assessment procedure consisted of a series of clinical interviews where a thorough history was taken for each patient. In addition, it included a diagnostic evaluation and mental state examination.

## 2.4.4.a The Clinical Interviews

At the second meeting, the researcher commenced the cognitive-behavioural assessment, which consisted of four one-hour individual sessions over a two week period. Although these sessions were all tape recorded, the researcher did not need to refer to them as detailed notes were taken of patient responses. The quantitative assessment measures were administered for the second time (week 1). Although Sharpe et al. (1997) suggest a maximum of three one hour individual sessions in which to complete the assessment, the researcher found that an extra session was necessary for each patient in order to obtain all the necessary data. In this regard, the clinical interviews were conducted to obtain information about the patient's presenting problems, cognitions, emotions, behaviour, social situation and physiological state. The interviews were structured in that they focused on various aspects of patient functioning, such as life stressors, coping strategies and psychosocial adjustment and obtained specific examples of the different problems experienced. However, they were flexible, as patients were able to proceed at their own pace. In conducting the interviews care was taken to make the patient feel more comfortable and to assist with the disclosure of psychologically meaningful material. Such an approach is considered standard practice in cognitive-behavioural interviewing, and is achieved by adopting a conversational tone of voice, the use of supportive statements, searching

questioning and empathising with the patient's difficulties and concomitant distress. The researcher designed the interview guide based on a standard clinical interview outlined by Sharpe et al. (1997) for use with patients suffering from CFS. The main aspects of patient functioning examined in the interview, included:

(i) <u>Presenting problem</u>: listing all the problems (somatic, psychological and social); clarifying the nature of the symptoms experienced, especially fatigue; inquiring into changes in lifestyle, activity, sleeping patterns and associated distress. In this regard, a detailed behavioural account of the patient's previous and current lifestyle was obtained by asking them to describe a typical day, hour by hour. This was later supplemented by asking patients to keep a diary for the first few weeks of treatment. A detailed sleep history was taken, including periods of daytime rest or sleep, and the emotional aspects of the illness were explored.

(ii) <u>History of the illness</u>: clarifying the onset and course of the illness; exploring the patient's illness beliefs, including their understanding of the cause of the symptoms and any "worst fears"; examining coping strategies in terms of what they did when they felt tired, and how they arrived at their current strategies.

(iii) <u>Current situation</u>: examining the current home situation and identifying all the family members and their relationships with the patient; exploring the patient's employment history and the existence of any financial benefits contingent on remaining ill. In this regard, it was important to elicit any potential obstacles to a return to their previous jobs and to explore the patient's attitude toward rehabilitation.

(iv) <u>Background</u>: exploring family and personal history in terms of checking for a family history of depression, the recollection of any childhood trauma or abuse, and long absences from school or a history of somatisation; examining past medical and psychiatric history; exploring premorbid personality and lifestyle in terms of attitudes such as perfectionism, a belief that the expression of emotional distress is a sign of weakness, vulnerable self-esteem and a tendency to "oversubscribe to social norms" resulting in exhaustion (Sharpe et al., 1997).

(v) <u>Treatment History</u>: inquiring into previous treatment experiences in order to avoid repeating failed treatments and to find out why previous attempted therapies failed; querying whether the

patient was engaging in any concurrent therapies; establishing whether the patient was taking any medication, and confirming the dosage level and when they started or stopped.

## 2.4.4.b Diagnostic Evaluation and Mental State Examination

With respect to the issue of diagnosing CFS, all three patients were screened by means of a structured questionnaire as described in section 2.3 above. This questionnaire was based on the Oxford criteria referred to in section 1.2 above. In addition to confirming the diagnosis of CFS, the researcher also conducted a mental state examination as outlined by Kaplan, Sadock & Grebb (1994), and reviewed possible DSM-IV diagnoses (American Psychiatric Association, 1994). The two primary aims of the mental state examination were to (a) identify any diagnosable organic diseases and (b) identify any treatable psychiatric conditions. In this regard, Sharpe et al. (1997) suggest that specific inquiries be made about certain symptoms in order to exclude any alternate diagnoses. These researchers contend that psychotic disorders, eating disorders and substance misuse are usually distinguishable but that depression and anxiety syndromes are more difficult to differentiate from CFS. They point out specific differences in symptom presentation between depression, anxiety and somatoform disorders respectively, and CFS. These differences are outlined as follows:

(i) <u>Depression</u>: CFS patients do not often report a pervasive and persistent lowering of mood evidenced in major depressive disorder. In addition, the loss of interest and pleasure is usually an indicator of a depressive disorder. Although the majority of CFS patients describe having to give up previously enjoyable activities, this may be due to a physical inability to perform the activity rather than losing interest per se. Sharpe et al. (1997) recommend that the clinician inquire whether the patient still enjoys sedentary equivalents, for example watching sport on television.

(ii) <u>Anxiety</u>: Many of the somatic symptoms reported by CFS patients overlap with those listed under generalised anxiety disorder. However, CFS patients rarely spontaneously describe feeling worried unless it is about the effect of the illness. A further inquiry would therefore need to focus on feelings of tension and apprehension. Moreover, patients may report that they have ceased certain activities like shopping or socialising due to fatigue, but careful questioning could reveal a phobic anxiety with avoidance. If episodes of acute symptoms occur coupled with paraesthesia then the existence of panic attacks should be explored (Sharpe et al., 1997).

(iii) <u>Somatoform Disorders</u>: Sharpe et al. (1997) warn against making a diagnosis, such as undifferentiated somatoform disorder which has few positive implications for management. However, both hypochondriasis and somatisation disorder have specific implications in terms of treatment and need to be investigated. Hypochondriasis is usually rare in patients with CFS who normally seek confirmation that they have a legitimate condition. On the contrary, hypochondriacs usually need reassurance that they are not ill with a serious disease. According to Manu and colleagues (cited in Sharpe et al., 1997) a minority of CFS patients will meet the criteria for somatisation disorder and the prognosis is poor.

# 2.5 Data Reduction Phase One

Data reduction phase one refers to the process of selecting and transforming the quantitative and qualitative data obtained in data collection phase one of the programme. With respect to the quantitative data, the three sets of self-report measures (baseline to week 3) were scored based on the guidelines prescribed by the respective researchers referred to in section 2.4.1 (a-d) above. The qualitative data were initially organised according to six broad areas of standard clinical evaluation as outlined in Sharpe et al. (1997).

Later the data under each of these main headings was further reduced by including relevant subheadings that served to differentiate and focus the material. An explanation of how this was achieved follows below.

# 2.5.1 Presenting Problem

The data based upon the detailed notes from the first two assessment interviews were reduced by including specific sub-headings. These sub-headings were related to the issues covered in sections 2.4.3.1 (a), (b) and (c) of the interview guide. They included: (1) somatic, psychological and social problems; (2) sleep disturbances; (3) typical day (pre- and post-illness); (4) associated distress; (5) illness beliefs; (6) coping strategies, and (7) current views pertaining to the illness and ability to work.

# 2.5.2 Family and Personal History

The data based on the detailed notes from the third assessment interview were reduced by using the sub-headings related to issues covered in sections 2.4.3.1 (b), (c) and (d) of the interview guide. The sub-headings included: (1) parents; (2) siblings; (3) early home atmosphere and influence; (4) early development; (5) education and occupation; (6) sexual and marital history; (7) children, and (8) interests and habits; (8) psychiatric and medical history, and (9) onset of current illness related to personal history.

# 2.5.3 Summary of Treatment History and Medication Regimen

The data based on the detailed notes from the fourth assessment interview were reduced by using sub-headings related to issues covered in sections 2.4.3.1 (d) and (e) of the interview guide. The sub-headings included: (1) medical and psychiatric history, and (2) medication.

## 2.5.4 Diagnosis

The qualitative data based on the detailed notes from diagnostic evaluation and mental state examination were reduced by using the Oxford criteria for CFS (cited in Demitrack et al., 1996) and the DSM-IV criteria (American Psychiatric Association, 1994). In addition, relevant data from the four clinical interviews and scores from the self-report measures were used to justify the diagnoses.

# 2.5.5 Case Conceptualisation

Once the assessment process was completed, a cognitive-behavioural conceptualisation of the illness was constructed for each individual case. The construction of the case conceptualisations was achieved by: reading through the organised data from the assessment interviews in order to gain an overall perspective of each case; grouping the relevant data under three broad headings, namely, predisposing, precipitating and maintaining factors. According to Sharpe (1996, 1997b) the purpose of the conceptualisation is (a) to highlight the factors that maintain the illness in order to develop suitable treatment strategies and tactics, (b) to include psychological and social factors into the physiological model of aetiology, and (c) to demonstrate how physiological, psychological and social components may interact in mutually reinforcing ways to perpetuate the condition. Later, this data was then incorporated into the construction of a full cognitive developmental conceptualisation based on Leahy (1996) and Young (1994). This enriched conceptualisation to hypotheses about how early schemas and scripts predisposed them to developing CFS, and ultimately served to maintain the condition through specific cognitive distortions and self-defeating behaviours.

# 2.5.6 Problem List and Treatment Plan

Based on the cognitive-behavioural model of CFS proposed by Sharpe et al. (1997) and the cognitive developmental model advocated by Leahy (1996) and Young (1994), the main predisposing and illness perpetuating factors were carefully identified by the researcher for each individual case. A personalised problem list was then compiled for each patient which highlighted these specific issues and explained how they would be addressed in the course of treatment. The specific treatment strategies selected were often combined to target a number of maintaining factors, simultaneously. For instance, activity scheduling and cognitive therapy respectively, were used to stabilise intermittent bursts of activity and also address maladaptive beliefs about performance. Hence, the aim of the treatment was to challenge inaccurate cognitions and maladaptive coping behaviour starting with simple behavioural interventions and moving to reviewing specific cognitions and illness beliefs, and then more general attitudes.

#### 2.6 <u>Treatment Contract</u>

At the sixth meeting, the developmental case conceptualisation was introduced in a collaborative yet matter of fact way and the quantitative assessment measures were administered for the fourth time. The treatment process (including the contracting session) consisted of twelve one-hour individual sessions which were all documented on audiotape. In addition, the researcher took detailed notes of the content of all the sessions. According to Leahy (1996) the case conceptualisation allows the researcher and patient to piece together the chronic pattern of maladaptive behaviours and associated distress by providing a developmental analysis of the problem. In addition, this helps the patient to understand why they are so emotionally committed to a self-defeating pattern of behaving, thinking and relating to self and others. The three participants did not hold very strong beliefs about a definite physical causation in that they indicated to varying degrees that stress or psychological factors had played some role in the onset of their illness. Each patient was then encouraged to contribute their own views to developing the conceptualisation. It was emphasised that the treatment would be individually tailored to their specific needs and some discussion was necessary outlining how this would occur on a practical level. The researcher used examples from the patient's own history to explain what issues needed to be addressed in order to reduce the self-defeating behaviour.

In accordance with Sharpe et al. (1997), Leahy (1996) and Young (1994) the goals of therapy were negotiated with the patient. The contract emphasised participation in the programme coupled with homework involvement. Patients were reminded of the written consent form that they had signed which summarised the main aspects of the study: (1) the cognitive-behavioural assessment and treatment programme would consist of approximately 16 one hour individual sessions in total; (2) the assessment would involve a detailed interview while the treatment programme entailed a specific four stage process, including homework assignments, self-monitoring tasks and experimenting with new behaviour; (3) medical records would possibly need to be consulted and the data obtained from the programme would be used for research and publication purposes; (4) confidentiality and anonymity were ensured and information regarding the results of the study would be given to the participants; (5) participants would be allowed to withdraw from the study after a discussion with the researcher. The contract was accepted and they verbalised their willingness to engage in the treatment programme.

#### 2.7 The Design of the Treatment Intervention

The treatment intervention designed for this study was based on the models outlined by Sharpe et al. (1997), Leahy (1996) and Young (1994) as mentioned at the beginning of this chapter.

## 2.7.1 Stage 2: Identifying and Reviewing Behaviour and Thoughts

At the seventh meeting, the researcher began to implement the treatment plan and therapeutic interventions that were based on and guided by the developmental case conceptualisation. From this point on, the quantitative assessment measures were administered every two weeks. Although the goals focused largely on stabilising fluctuating patterns of activity and gradually increasing reduced activity levels, they were individually tailored for each patient. None of the patients were bedbound but their respective patterns of activity were dysfunctional in different ways resulting in considerable fatigue and disability. The first step in reviewing behaviour involved the establishment of a baseline of rest and activity. Patients were asked to keep a diary in which they monitored everything they did on a daily basis. This information was important in terms of helping to set clear, manageable targets that could be consistently carried out by the patient. The initial target included scheduling rest and activity and spreading it more evenly throughout the day, instead of conducting life in response to symptoms. Patients were informed that they should carry out the same amount of activity regardless of how they felt and that they should avoid doing more on a good day as the aim was to develop a consistent approach to activity. Later the main target involved increasing activity levels in a gradual and gentle way in keeping with the needs outlined in the case formulation. Behavioural experiments were negotiated with the patient whereby they tried out new behaviour in everyday settings and tested certain hypotheses regarding physical and mental functioning. If an experiment was less than successful then the information gained was used to evaluate the obstacles that needed to be overcome.

With regard to reviewing maladaptive thoughts and beliefs, a primary aim was to assist the patient in monitoring negative automatic thoughts and generating more adaptive ones based on careful consideration of all the evidence. In the current study patients were asked to write down the thoughts they had that left them feeling upset in relation to their functioning using the modified Record of Dysfunctional thoughts form (Greenberger & Padesky, 1995) (Appendix IV).

The form was reviewed in detail during the sessions and the patient was encouraged to consider the advantages and disadvantages of holding particular thoughts and beliefs. In addition, they were invited to generate other more helpful alternatives and test them as part of homework assignments.

#### 2.7.2 Stage 3: Re-evaluating Unhelpful, General Attitudes

Other attitudes that hampered the rehabilitation process were reviewed and they included persistent worry about symptoms, distress in relation to an inability to function and poor assertiveness skills. Sharpe (1996) contends that these concerns are often linked to a rigid, pessimistic understanding of the illness and to underlying beliefs regarding self-image. These unhelpful attitudes were explored and challenged through discussion and by using the Record of Dysfunctional thoughts form noted in section 2.7.1 above. Patients were then encouraged to select and apply the most helpful and accurate ways of thinking about their situation based on information from the therapeutic discussions and the behavioural experiments. It was also observed by the researcher that other issues such as memories of childhood neglect, punishment and abuse emerged together with chronic relationship problems. These issues were dealt with during treatment as they were contributing to the maintenance of the illness.

#### 2.7.3 Stage 4: Problem Solving Practical Difficulties

An important part of the rehabilitation process involved dealing with practical, everyday problems that emerged as the patient began to improve. The transition from being ill to gradually regaining ones' functional ability created difficulties for certain patients. Some of these conflicts included, establishing a balance between aspirations and a realistic lifestyle, coping more effectively with financial concerns, learning time management skills and negotiating interpersonal situations with greater honesty and assertiveness.

Problems were discussed in detail during the sessions and patients were helped to work through particular problems systematically, using a step-by-step approach and then evaluating and implementing the best possible solution. Thus, patients were trained in the steps of problem solving.

#### 2.7.4 Stage 5: Consolidating Gains and Planning for the Future

The last three sessions of the programme were devoted to transferring the responsibility for treatment to the patient. In this regard, the current study followed the outline provided by Deale & David (1994) which was almost identical to that of Sharpe et al. (1997) but offered a more detailed account of the actual steps involved in the process. The steps included: (a) informing patients that symptoms can continue to arise intermittently but that they can be managed effectively, (b) encouraging patients to identify any remaining issues that need to be addressed in order to promote further change and recovery, and (c) asking patients to identify aspects of the programme that they found most useful and getting them to draw up an action plan to cope with any future setbacks. Patients were also informed that there was a one-month individual follow-up session of approximately one hour to evaluate how they were coping.

### 2.8 Data Collection Phase Two

Data collection phase two refers to the collection of both quantitative and qualitative data from the beginning of the treatment phase of the intervention through to the 1-month follow-up interview. There were four major data sources and they included: the process notes of each session, patient records of homework assignments including self-report measures (referred to in 2.4.1), audiotapes of the sessions and the follow-up interview. The four self-report measures were administered seven times on a biweekly basis (from week 5 to follow-up) during the course of the treatment, including a follow-up measurement.

#### 2.9 Data Reduction Phase Two

Data reduction phase two involves the process of selecting and abstracting both the quantitative and qualitative data obtained in data collection phase two of the programme. In terms of the quantitative data, the seven sets of self-report measures were scored according to the recommendations of the respective researchers noted in section 2.4.1 above, and in the same manner as described in data reduction phase one of this study. At this point the outcome measures for each patient were displayed graphically from baseline to treatment and post-treatment showing the changes in patient functioning as reflected by each of the four variables. The qualitative data based on the process notes of each session and homework assignments were reduced through organising the material into session summaries. The construction of the summaries were based on specific steps recommended by Miles et al. (1994) which included:

reading the process notes and perusing the homework assignments; disregarding repetitious or irrelevant data; grouping thematically similar material together into coherent, descriptive paragraphs. The qualitative data from the follow-up interview was also summarised into a session summary using the above-mentioned data reduction method. At the end of this data reduction phase there were twelve session summaries in total.

#### 2.9.1 The Selection of a Single Patient

Although there were significant improvements in all three cases, the researcher realised that writing up three case studies would be beyond the scope of this research. At this point it was decided that Amy's case would be used to form a single participant case study. Her case was selected for an in-depth review because at the assessment her symptoms were quite severe and impacted on most areas of her functioning. Second, her case history was complex and revealed that past formative experiences were negatively influencing her ability to cope effectively in the present. Third, Amy was able to utilise the CBT strategies and apply the insights and skills learned in the programme to her everyday life. For the purposes of the study, it was decided that a pseudonym would be used to ensure confidentiality and anonymity.

## 2.9.2 The Case Narrative

A case narrative of Amy's experience of the programme was written by the researcher to provide a narrative description of the psychotherapy process. The narrative was constructed from the twelve session summaries referred to in section 2.9 above. The process of reducing the data from the summaries was again based on the steps recommended by Miles et al. (1994). First, the researcher read through all twelve session summaries, and underlined key terms and issues in order to gain an overall perspective. Second, repetitious and irrelevant data was omitted. Third, specific references to the treatment intervention were identified for inclusion in the narrative. Fourth, commentary which revealed the link between dysfunctional beliefs or underlying schema dynamics and current maladaptive coping strategies was singled out for inclusion in the narrative. Fifth, the description of the cognitive-behavioural work and the emergence of the schema-related material were organised to reflect the close alignment between these two important aspects of the psychotherapy process. The aim of this was to show the reader how cognitive-behavioural strategies routinely evoke underlying maladaptive schemas related to interpersonal issues.

### 3. <u>THE PRESENTATION OF AMY'S CASE OF CFS</u>

3.1 <u>The Case History</u>
Name of Patient: Amy
Date of Birth: April 1951
Age of Patient: 48 Years
Education: Bachelor of Arts degree (BA)
Occupation: Self-Employed Businesswoman
Marital Status: Married
Number of Children: Two

#### 3.1.1 Presenting Problem

In approximately 1997 (age 46) Amy began to experience the onset of persistent, debilitating fatigue soon after opening her small business. In addition, she reported muscular pain, an aching body especially after participating in exercise, visual problems, eczema, concentration difficulties, poor memory particularly when very tense or fatigued, slips of the tongue and word finding difficulties. She also encountered a range of psychological and social problems, such as intense frustration due to her inability to perform daily tasks coupled with feelings of tension, irritability and worthlessness when compared to others. Prior to becoming ill, Amy was an active person who participated in league tennis, cycling and aerobics. However, she soon had to terminate these enjoyable sporting activities as she was too tired to participate in them. She also found that she was unable to attend social engagements with her husband, Brian, as her symptoms fluctuated so much that she was unable to predict how she would feel during an event, and if she would be able to cope.

Amy indicated that she had difficulty falling asleep along with interrupted sleep in that she would wake up several times in the early hours of the morning, leaving her feeling exhausted the next day. She tried to avoid daytime naps as they were not refreshing and often left her feeling worse. She described the fatigue as "a heavy feeling" in that her "head felt thick" and it was an effort to do anything, almost as if she was coming down with a fever or 'flu. She also found that the fatigue was ever present and seemed to get progressively worse as the day proceeded. Although she was aware that she was physically fatigued, she had to remind herself mentally that she was ill otherwise she became irritable regarding her inability to perform.

Moreover, Amy reported feelings of distress in relation to a lack of understanding and support from former work colleagues and friends. She no longer had the energy to maintain these friendships and discovered that without her input people stopped contacting her. This left her feeling lonely and isolated. She also felt guilty because Brian had to take on extra responsibilities, such as cooking dinner and attending to her business clients which she thought was unfair. In fact, she described her illness as "a curse" as it restricted her from participating fully in her family. She stated that she had a good husband and two supportive children but was unable to enjoy and reciprocate their love and attention.

With respect to illness beliefs, Amy believed that her case of CFS was caused by a range of physical, psychological and social problems. She indicated that infections like glandular fever and tonsillitis together with the various antibiotic treatments, had played a role in reducing her general health and stamina. She also mentioned that she had difficulty coping with emotional stress that stemmed from her childhood background. Over time, this had also taken its toll on her physical health.

In terms of coping, Amy pushed herself to perform daily tasks and to keep commitments. If she had an important engagement she often took anxiolytic medication to assist her in coping with the demands of the situation, as noted in section 3.3 below. She found that without this medication she became extremely anxious that she would fail to perform adequately. Once her tasks were completed, she lay on her bed and read or listened to the radio. Moreover, she tried to avoid social gatherings, as she felt obliged to talk to those who were standing alone leaving her feeling completely exhausted. She also opted to leave the room when people started arguing and wanted her to become involved, as she felt too tired to cope with the conflict. However, she most often tried to avoid letting an interpersonal encounter become "heated and angry" by keeping quiet.

In order to cope with feelings of loneliness and isolation, she contacted certain people whom she knew "needed a call". These people generally had significant problems of their own and needed considerable emotional support. Amy found that by listening to their problems she felt better about herself as she could still "contribute" in a meaningful way. However, she did not have the opportunity to share her concerns or talk about issues that were important to her.

Although Amy found it extremely tiring to work, she believed that she would feel worse emotionally if she did not work at all. She mentioned that work had always been important to her as it provided her with the opportunity to prove herself as a person. She felt that the brief social contact with clients helped to reduce feelings of isolation, as she did not have the energy to initiate social relationships and create new interests outside her home. On a practical level, she also found the extra income useful.

## 3.1.2 Family and Personal History

Amy grew up with her parents and two brothers in a socially and economically disadvantaged home which was characterised by domestic violence. Her father had a Standard 7 education and worked as a clerk for Spoornet. He was a violent alcoholic who physically and sexually abused the mother for most of the marriage. Amy described her relationship with her father as ambivalent in that on the one hand, she was very fearful of him and his unpredictable behaviour, while on the other she idealised him. He, in turn, favoured her above her brothers. In 1995, he became a Christian and stopped abusing alcohol. As a result, his relationship with Amy's mother improved. Two years later in 1997, he died of heart failure. Amy's mother had a Standard 8 education and worked in a clerical capacity and later as a secretary until she retired. The mother was described as a passive, dependent woman who allowed the father to dominate and abuse her. In fact, she protected him by denying the abuse or by implying that she was somehow to blame for his violent behaviour. In later years she informed Amy and her brothers, John and Paul that she had remained in the marriage because of them, leaving them all feeling terribly guilty. Amy reported that her older brother John (age 57) had a Standard 6 education and worked as a security guard. He was divorced with five children and she had little contact with him. Her younger brother Paul (age 48) had a Standard 10 education and worked as an audiovisual technician. He was married with three children and she had some contact with him as the mother lived with him and his family.

Amy recalled that the first incidences of abuse emerged in 1959, when she was 8 years old. She described how her father would abuse alcohol and then beat the mother with various household objects. During one of these violent episodes the mother suffered a fairly severe blow to the head after the father hit her with a glass milk bottle. The open wound bled profusely and Amy begged her mother to seek medical assistance but she ignored this suggestion. Consequently,

Amy had to take the glass out of the wound herself and clean it up to the best of her ability. On these occasions her older brother, John would flee from the house on his bicycle while she was left to comfort her younger brother, Paul and her mother. She felt angry with John for abandoning her but soon learned not to show her feelings as it upset Paul. In 1961 (age 10) she became aware that her father was regularly raping her mother at night. She would lie awake in bed and listen to her parents and wonder why her mother spent hours in the bathroom in silence, after the ordeal. Amy described powerful feelings of shame and disgust in relation to these abusive and humiliating incidences. Moreover, at the same time she was sexually molested for a brief period by her father's best friend and drinking partner. In the afternoons when the family was resting, this man would entice Amy to a spare bedroom and invite her to fondle his penis. There was no sexual penetration and she soon learned to avoid him. When she expressed her dislike of this man to her mother, she was told that she "must be nice to him" as he was a family friend and assisted them financially. Throughout her childhood and adolescence she never invited friends over to her house because she was afraid of her father's violent and unpredictable behaviour. In addition, she never felt comfortable about staying over with friends for weekends or even holidays.

Amy completed her primary and high school education at a government school that had few resources and was situated in a poor suburb. She stated that she enjoyed school academically and socially as she could "escape from all the family problems" and achieve success. She was a hardworking pupil who was always top of her class. In 1968 (age 17) she was nominated head girl of the school and was the only pupil in her class to continue her studies at university. She recalled how she knew that education was her only chance to succeed in life yet she felt guilty about pursuing tertiary studies as her mother wanted her to leave school early in order to help support the family. From 1969 to 1972 (ages 18-21) she completed a BA degree majoring in History and Counselling Psychology. In addition, she completed a teaching diploma. Despite being a popular student who was involved as spokesperson in many organisations, she struggled to cope with persistent feelings of inadequacy and inferiority, and showed symptoms of binge eating, self-induced vomiting and laxative abuse. She believed that by participating in many different activities she somehow "managed to fool people" into thinking that she did not have any "hang-ups".

However, when she went home for holidays the symptoms got worse but she attempted to cope by having various holiday jobs that kept her busy and limited the time she spent with her family. It was only 25 years later, in 1994 (age 43), that a formal diagnosis of bulimia nervosa was made by a psychiatrist.

In 1973 (age 22) she commenced her first teaching job and met her husband who was described as "a stable, dependable and supportive man". In 1974 (age 23) they got married. She recalled how previously she had been wary of men and had later made a decision not to get involved with someone like her father who was perceived to be volatile and abusive. In 1975 (age 24) she contracted pyelitis (inflammation of the kidney) which lasted for one year before it was correctly diagnosed. During this period she was regularly booked off from work resulting in her feeling very guilty about not being able to perform at work. In 1976 (age 25) Amy's first child was born and she experienced postnatal depression requiring hospitalisation. She stated that she felt very inadequate as a new mother and had little support from her extended family and friends. In 1978 (age 27) after the birth of her second child she began making a concerted effort to inform herself regarding the needs of her children as she did not want them to grow up in an emotionally and socially disadvantaged home environment as she had done. During this period Amy continued to teach and only had three major breaks, when she had pyelitis in 1975 and when she had her two children in 1976 and 1978. In approximately 1984 (age 33) she had a hysterectomy for gynaecological reasons. In 1985 (age 34) she contracted psoriasis (chronic skin condition exacerbated by psychological stress) which lasted for nearly ten years.

Amy was a dedicated teacher who enjoyed interacting with the pupils at school and receiving positive feedback from them. She would often counsel those who needed advice and found that she felt valued by them, especially when they expressed appreciation for her input. Her relationships with her colleagues were satisfactory and she found it stimulating to share ideas with them. However, in 1992 (age 41) she encountered a period of intense stress and tension due to a number of separate disagreements with three teaching colleagues. The disagreements ranged from being requested to divulge confidential information about certain pupils to receiving little support for an application she made for a permanent teaching post. Consequently, she believed that all her efforts in the classroom and on the sports field were unappreciated leaving her feeling "degraded and inadequate". In 1994 (age 43) she experienced

"burnout" in that she was unable to get out of bed in the mornings to go to school and was frequently tearful for no apparent reason. She was booked off from work for two weeks by a psychiatrist who diagnosed bulimia nervosa and depression. She was medicated with antidepressant medication for two years and also saw a psychologist for ten sessions of psychotherapy, where she started to disclose certain aspects of her abusive childhood. In 1995 (age 44) she had a recurrent bout of glandular fever along with tonsillitis which was medicated with a series of antibiotics. One year later in 1996 (age 45) she resigned from her teaching job due to widespread teacher redeployment and experienced a termination of the bulimic episodes along with a remission of the psoriasis. Early in 1997 (age 46) she opened her own business from home which involved considerable contact with the public, and soon after this began to experience persistent fatigue. Toward the end of the year she consulted her general practitioner (GP) who diagnosed CFS and prescribed antidepressant medication. Amy reported that although her GP did not provide her with any information about her condition, she was sympathetic and showed a willingness to listen to her concerns in this regard.

## 3.1.3 Summary of Treatment History and Medication Regimen

Although aspects of the medical and psychiatric history have been presented in section 3.1.2 above, a summary of this material follows below.

(a) 1969 (age 18) - Amy showed symptoms of binge eating, self-induced vomiting and laxative abuse but did not disclose the problem to anyone. A formal diagnosis of bulimia nervosa was eventually made by a psychiatrist 25 years later.

(b) 1975 (age 24) - onset of pyelitis (inflammation of the kidney) which lasted one year before it was correctly diagnosed and treated.

(c) 1976 (age 25) - onset of postnatal depression after the birth of her first child requiring hospitalisation.

(d) 1984 (age 33) - hysterectomy and commencement of Hormone Replacement Therapy (HRT).

(e) 1985 (age 34) - onset of psoriasis (chronic skin condition exacerbated by psychological

stress) which affected her face and finger nails. Amy was unclear with respect to the type of medication prescribed. The condition went into remission in 1996.

(f) 1991 (age 40) - onset of recurrent tonsillitis medicated with antibiotics.

(g) 1994 (age 43) - Amy experienced "burnout" and was medicated with Prozac, an SSRI antidepressant, for two years. At the same time she was prescribed Lexotan, a benzodiazepine derivative with anxiolytic properties, and has continued to take this medication.

(h) 1995 (age 44) - onset of recurrent glandular fever also treated with antibiotics.

At present Amy is medicated with the following prescription and non-prescription medications. The prescription medications included: Hormone Replacement Therapy (HRT); Aurorix (150mg daily), an MAOI antidepressant, Lexotan (3mg twice daily) an anxiolytic and Trepiline (10mg at night), a tricyclic antidepressant, prescribed in a low dosage as a sleeping agent (at this dosage level it serves to augment the effectiveness of the Aurorix). In terms of non-prescription medication, Amy also took Grandpa headache powders (approximately 10 per month) for headaches, pain and fever. In addition, she took a herbal energy supplement Formula 2001 along with multivitamins, including a regular vitamin B injection.

## 3.1.4 Diagnosis

In terms of the Oxford criteria for CFS (cited in Demitrack & Abbey, 1996), Amy had experienced a definite onset of severe, disabling fatigue soon after opening her own business early in 1997. The fatigue affected her physical, neurological and psychological functioning in that she reported post-exertional muscular pain, visual problems, eczema, sleep irregularities, concentration difficulties, poor memory, slips of the tongue, word finding difficulties and mood disturbances. The fatigue had been present for at least six months during this time it was present at least 50% of the time resulting in her having to terminate previously enjoyable activities. Her baseline fatigue score on the Fatigue Questionnaire (Chalder et al, 1993) was 29, which indicates excessive, chronic fatigue. Amy reported that her GP had diagnosed CFS after conducting various multifaceted blood tests to rule out established medical conditions known to produce chronic fatigue. Later, she consulted a specialist physician who confirmed the diagnosis

of CFS. Although she had experienced recurrent glandular fever approximately three years prior to being diagnosed with CFS, it was unclear whether there was definite laboratory evidence of this infection at the time of onset in 1997. Thus, a diagnosis of postinfectious fatigue syndrome (PIFS) could not be made. With respect to the psychiatric exclusion criteria there were no indications of schizophrenia, bipolar disorder, substance abuse or gross organic brain disease. The fact that Amy had previously suffered from bulimia nervosa was not considered a psychiatric exclusion as it had been in remission for nearly four years prior to her diagnosis of CFS. Her current weight was reportedly between 59-61 kg's and her eating pattern did not reveal any noteworthy abnormalities, such as binge eating, self-induced vomiting or excessive exercise.

In terms of DSM-IV (American Psychiatric Association, 1994) Amy had experienced two definite major depressive episodes prior to developing CFS. The first episode occurred after the birth of her first child (postpartum onset) and the second episode was the "burnout" experience she had four years prior to receiving her diagnosis of CFS. In the clinical interviews she presented as an attractive, friendly yet somewhat withdrawn and defeated woman. She reported intense feelings of sadness and worthlessness coupled with tearfulness and a loss of interest in activities mostly triggered by thoughts about her illness but also about her self-worth worth as a person. Even on days when she felt less fatigued she still described persistent thoughts about how inadequate she was as a person when compared to others. In addition, she experienced insomnia, fatigue, inappropriate guilt and poor concentration. These symptoms meet the criteria for a diagnosis of Major Depressive Disorder (Recurrent, Severe). Her baseline score on the Beck Depression Inventory was 30, which indicates a severe level of depression and is consistent with this diagnosis. Moreover, Amy also became tense and anxious when confronted with performance situations and often had to resort to anxiolytic medication in order to cope. These symptoms meet the criteria for a diagnosis of Social Phobia. Her baseline score on the Beck Anxiety Inventory was 19, which indicates a moderate level of anxiety. Although she avoided conflict situations in case she was asked to get involved, it was reportedly due to feelings of fatigue and not significant anxiety.

#### 3.1.5 Case Conceptualisation

Amy's case history provides the basis for understanding some of her vulnerability to developing CFS. She grew up in an unstable family environment where she was frequently exposed to violent physical and sexual abuse. These formative experiences left her with overwhelming feelings of disgust, anger, fear, helplessness and shame. She also could not rely on her parents for security, empathy and acceptance, as they were incapable of providing the care she needed. Instead, she assumed the role of parentified child and attended to her mother after she had been physically assaulted by the father, and also comforted her younger brother Paul. To this was added her own experience of sexual molestation committed by her father's best friend and drinking partner. It seems likely that this abusive experience would have exacerbated underlying feelings of anger, shame and humiliation resulting in a greater sense of insecurity and inferiority. In addition, these feelings were systematically invalidated by her mother who actively encouraged her to deny them by behaving in a manner contrary to her natural inclinations. So Amy began to learn that her feelings, opinions and needs were unimportant and that it was not worth expressing them as nobody cared. She also realised that she had to be strong for others, as they were reliant on her for support and protection. Consequently, she was left feeling lonely and isolated, especially from her peer group. This was evidenced in her being too fearful to invite friends to her house and not feeling safe enough to stay over with them at their homes for weekends and holidays. However, she successfully blocked off these painful memories and negative experiences and found a way of being strong and effective in other areas of her life.

Amy obtained considerable success at school, university and in the workplace by becoming a proficient achiever. She also married a man capable of loving her and raised two well-adjusted children. In receiving recognition and admiration for her noteworthy achievements, she was able to compensate for a cluster of underlying core beliefs about her worth as a person. Some of these core beliefs which seemed to direct her behaviour included: "I'm a worthless person", "my needs don't count", "I'm different to others" and "others are better and more capable than me". However, when she was confronted with challenging situations that required managing the demands of interpersonal relationships and dealing effectively with criticism these beliefs were activated leaving her feeling inferior, inadequate and depressed. It would seem that the series of disagreements with three teaching colleagues sparked off her core beliefs to such a degree that her usual compensatory coping skills became ineffectual resulting in her feeling like a failure.

Soon after these disagreements she experienced "burnout" which together with recurrent glandular fever and tonsillitis began to reduce her general health and stamina. The widespread teacher redeployment present in her profession also served to undermine her coping resources and finally caused her to resign from her teaching and open her own business. Although a complex array of physical, psychological and social factors contributed to the genesis of her illness, it seems likely that the decision to leave her teaching job and work from home was a critical incident that finally precipitated the onset of CFS. Up until now she had partially managed to creatively avoid triggering her underlying core beliefs by achieving at work and by creating a model family. However, her decision to open her own business ultimately caused the compensatory coping strategies to fail as the new occupation did not provide her with the rewards and positive reinforcement she needed to feel good about herself.

Once the fatigue was present a set of conditional beliefs pertaining to work and achievement contributed to maintaining her symptoms. Some of these conditional beliefs included: "if I achieve, I will be admired and accepted by others", "if I keep myself busy, I will not have to think about past experiences" and "if I stop working, it will mean that I'm a failure". In order to meet these conditions Amy overcompensated by becoming strident in her approach to achievement. She also made compulsive demands on herself to perform perfectly. But her inability to acknowledge her own achievements coupled with the lack of recognition from significant others reinforced the belief "I'm a worthless person". At times she was able to overcome her sense of worthlessness by engaging in episodic bursts of activity and achievement. However, these attempts to perform at her pre-morbid level were unsuccessful as they caused an exacerbation of fatigue, thereby reinforcing the feelings of worthlessness and failure. In addition, she was plagued by thoughts about her poor performance leaving her feeling extremely anxious, tense and irritable. Moreover, in order to ward off feelings of isolation and worthlessness she engaged in other self-defeating behaviour, such as supporting other people emotionally. Although this behaviour initially resulted in positive feelings of self-worth, it could not provide a genuine sense of fulfilment and connection, as her own need for care remained unmet. Hence, this compensatory coping strategy was self-defeating as it did not challenge her underlying beliefs.

Despite all the success she achieved, the experiences of deprivation and abuse remained

unacknowledged and so the core underlying beliefs continued to exert unrelenting pressure resulting in a cycle of fatigue, depression and disability.

# 3.1.6 Problem List and Treatment Plan

Certain aspects of Amy's case conceptualisation were singled out as being significant in terms of guiding the treatment process. The problem list presented below highlights these specific issues and briefly explains how they were addressed within the course of treatment.

3.1.6.a <u>Difficulty in prioritising daily activities</u> - Before going to bed every night Amy compiles a list of chores and activities that need to be completed the next day. She usually manages to complete some of the items on the list while the others remain incomplete due to fatigue. This leaves her feeling angry and frustrated with herself as she cannot complete a list of seemingly simple tasks. She also feels inadequate as her level of functioning and ability to successfully perform activities is so limited. In terms of addressing this problem it was decided that Amy needed to carefully examine how she was going about drawing up her daily list. For instance, she was not discriminating between important and less important activities and was also not taking into account the time frame she had in which to complete the various tasks.

3.1.6.b Excessive engagement in activities - Although there are certain social activities in which Amy can no longer participate, such as playing various sports and attending work related functions with her husband, she compensates for these limitations by forcing herself to remain involved in as many other activities as possible. This behaviour is self-defeating as it exacerbates the fatigue and disability, which then reinforces feelings of worthlessness and failure. It also prevents her from acknowledging her limitations and the underlying feelings of loss in relation to her functional ability. It was decided that Amy needed to establish a more manageable routine where she would gradually reduce the compulsive self-driving behaviour. It was pointed out that she needed to pace herself in terms of scheduling activities, planning regular rest intervals, engaging in regular gentle exercise and selecting suitable social invitations.

3.1.6.c Unresolved feelings about early childhood experiences - Amy's early experiences of domestic violence and sexual abuse led to the development of underlying assumptions about herself, others and the world. Some of these assumptions included: "I am an inferior, inadequate person who is not worthy of being loved", "my needs are unimportant compared to the needs of others" and "I must not show my feelings or express my views as nobody really cares". In response to these beliefs she developed compensatory scripts which led to the self presentation of a strong adult persona. However, this coping self hid her vulnerability and need for care and support. For instance, when she is criticised or finds herself in a demanding situation her underlying core beliefs are activated and she is unable to maintain her persona and compensatory style of coping. This results in feelings of inadequacy, inferiority and depression. In order to help her to change these beliefs and underlying assumptions, it was decided that she needed to better understand the role of these past experiences in setting up the negative beliefs and self-defeating scripts.

3.1.6.d <u>Social isolation</u> - Amy has few close friends and desperately wants them. With the onset of CFS she no longer has the energy to maintain relationships. This leaves her feeling lonely and isolated and also serves to reinforce maladaptive thoughts about her worth as a person. She copes with these feelings by contacting certain people who need considerable emotional support. By listening to their problems she indirectly feels better about herself. This is a self-defeating behaviour, as others perceive Amy to be in control of her life as she never talks about her problems or concerns. Consequently, they do not contact her or offer assistance. It also reinforces the belief that she is "inferior and not worthy of receiving care". In terms of addressing the social isolation it was decided that Amy needed to understand how past relationships coupled with her illness prevented her from initiating and maintaining meaningful, reciprocal social relationships with other people. The plan was to help her find new ways of relating to people and to get her own needs met, thereby reducing her tendency to focus excessively on the needs of others.

#### 3.2 The Case Narrative

The first treatment session (week 5) involved sharing the case conceptualisation and problem list with Amy (referred to in sections 3.1.5 and 3.1.6 above). This was an enlightening yet painful process as many of the issues discussed resonated deeply with her. This was evidenced by her tearfulness throughout the session. She disclosed how difficult it had been to talk about her past and that she had felt "annoyed" by her excessive emotionality during the assessment process. However, she admitted that poor self-knowledge and an inability to plan and prioritise activities appropriately, left her feeling constantly frustrated and disappointed with herself. She admitted that she had opened her own business due to overwhelming feelings of guilt in relation to resigning from her teaching job. She also expressed considerable regret about not being able to do more for others "...who are really struggling". Later in the session she related how she had shared her experience of postnatal depression with a young female neighbour who was suffering from a similar condition. This resulted in the young woman visiting her. This session set the tone for the subsequent treatment sessions in that a simultaneous focus on the past and the present provided a basis for a more informed understanding of the predisposing, precipitating and maintaining factors and how they interacted in mutually reinforcing ways. For homework she watched a video (Padesky, 1996) on identifying and evaluating negative automatic thoughts. In addition, she was asked to consider a recent situation where she had felt like "a disappointment" and then attempt to complete the first three columns of the Record of Dysfunctional Thoughts form (RDT). She also had to complete the outcome questionnaires.

At the second session (week 6) she reported that the video had been helpful as it had demonstrated that it was "normal" to feel sad and tearful when thinking about "negative things" (past memories and painful emotions). She expressed some ambivalence about whether she had "worked through" her past experiences. She felt that she had perhaps dealt with these issues in her previous therapy. Her RDT form was discussed and the following pertinent issues emerged: (a) reliance on many different medications in order to feel more energetic, and (b) feelings of intense frustration, disappointment and helplessness when the various medications were not effective. Some of the automatic thoughts identified by Amy included: "other people get ill and soon recover, what's wrong with me?" and "my family needs me and I'm unavailable because I'm ill". This eventually led to a discussion about her use of medication(s) to control her symptoms. In particular, her prolonged use of Lexotan was discussed and the therapist

expressed concern that it had the potential for dependence and abuse. She was encouraged to evaluate the advantages and the disadvantages of taking this medication. She expressed some uncertainty about stopping it without some type of replacement as she still had to function on a daily basis. Moreover, Amy reported that she had seen a physician as she was struggling to cope with her eczema. After conducting various blood tests he indicated that it may be allergy related and recommended that she eliminate certain foods and energy supplements from her diet. He also confirmed her diagnosis of CFS and suggested that she focus on finding suitable social and spiritual support, especially from her church. Amy reportedly felt very angry and disappointed with the physician as she was hoping that he would be able to identify and treat her problem. She also resented his advice pertaining to her need for social and emotional support. The remainder of the session was spent focusing on what activities she was engaging in during the course of her day. This was done by drawing up a list of a typical day and evaluating how she was managing to complete the various tasks. At the end of the session she expressed appreciation for the therapy as she felt that she was being helped to cope with the illness. Her homework was to keep a daily journal of her activities and to monitor her eating, sleeping, resting and exercise patterns. In addition, she had to complete columns four and five of her RDT form.

During the third session (week 7) it became clear that Amy was struggling to acknowledge the fact that she had CFS. On her RDT form she avoided using the pronoun "I" when describing her thoughts and feelings. Although this avoidant tendency was less marked in the previous session, the therapist still pointed it out to her. This led to an in-depth discussion about her experience of being a disappointment to others. She had always felt like "a disappointment" but had managed to ward off feelings of worthlessness and failure by achieving in her various roles as wife, mother and teacher. In particular, she found that by counselling others she was able to compensate for underlying core beliefs about failure. The therapist commented that it seemed safer for her to listen to others and counsel them instead of attending to her own conflicted emotions. In addition, the therapist suggested that having an illness like CFS was an opportunity to examine her lifestyle and manner of dealing with emotional stress. Amy was reluctant to "focus on herself" as it made her feel "worse". She was then reminded of the video she had watched and of some of the ideas it contained, such as examining the advantages and disadvantages of focusing on thoughts and feelings. Toward the end of the session she

expressed considerable ambivalence about how she should cope with her illness. On the one hand, she thought it better to "just switch off" and deny her emotions, while on the other she desperately wanted to re-assess her lifestyle and believed that the therapy was making her "think about things". Her homework was to monitor her activities in her daily journal and complete the outcome questionnaires.

The fourth session (week 8) was spent discussing her activity scheduling and general functioning using the information from her journal. She was also beginning to prioritise and plan her day by asking herself the following three key questions: (a) "what is important that needs to be done today?" (b) "what can I postpone to another time?" and (c) what is the worst that can happen if I don't do task A or B or C?" She was also doing some gentle walking twice a week and had coped with this exercise. However, she found it hard to adjust and cope if there was a sudden change of plans. This issue was explored and it emerged that she was anxious about presenting as unkempt and fatigued to clients and family as they might "judge" her negatively. She believed that the illness had altered her appearance and also triggered off depression leaving her feeling unconfident as a person. After sharing these thoughts she became self-deprecatory in that she thought her concerns "sounded stupid, vain and empty" and believed that similar issues did not "throw other people". With further questioning Amy admitted that she felt very tense about her performance, especially in face-to-face encounters (business or social). She identified three reasons why she felt this way: she had to listen closely to other people; she had to appear interested and also make appropriate conversation, and she had to try to divert the other person's attention away from herself by asking the questions. For homework Amy was asked to keep an hour-by-hour account of her activities instead of a daily journal as there seemed to be a paucity of detail in certain areas. She reluctantly agreed to complete this task as she believed that she would feel "very guilty" about seeing her fluctuating, unsatisfactory performance.

At session five (week 9) Amy reported that by keeping an hourly journal she had become more aware of how busy she was during the course of her day. This left her feeling somewhat surprised, as she did not realise that mental activities, such as concentrating, reading and calculating were tiring and demanding tasks. Previously, she believed that only "physical work" resulted in fatigue. She also indicated that the previous session had helped her to acknowledge that she had CFS. One particular incident in her journal revealed that she was still struggling to pace herself in terms of activities. This issue was discussed and she realised that she needed to schedule time out for herself. The remainder of the session was spent completing her RDT form from session two. The attention was on column four, which involved identifying evidence that supported the hot thought "I'll be a disappointment...". She recalled five significant events in her life that had served to reinforce underlying beliefs about rejection, inadequacy, inferiority and failure.

The first experience occurred at university when she commenced a relationship with a young doctor who had recently ended a relationship with a woman from an elite family. The young man's father did not approve of Amy's working class background and persuaded his son to end the relationship. This left Amy feeling "rejected and not good enough" as a person. The second incident involved the failure to obtain her BA degree free of specific conditions. The university was of the opinion that because she did not pass her final year oral examination for History, her degree could not be issued without a proviso to this effect. Although she attempted to redo the oral on three occasions, she was unsuccessful for various different reasons. In sharing this disappointment Amy recalled how going to university had been a major decision in her life as her family were against it. She also believed that education was her "ticket to freedom" as it would allow her to move out of her socio-economic group and achieve a better life. However, her "incomplete" degree left her doubting whether she should have gone to university in the first place, and wondering if perhaps her family were correct in trying to dissuade her from embarking on tertiary studies. The third event happened when she contracted pyelitis during her first year of teaching. It took the doctors nearly one year before the correct diagnosis was made during which time she was regularly booked off from work. Amy believed that the principal and teaching staff must have thought that she was "a misfit" who was "not handling the job" and was "always absent from school". She was a young teacher who was trying to prove herself in her first teaching post but could not perform adequately due to the illness. Her confidence "took a

big knock" and she felt unaccepted by the staff resulting in her resigning from the post. The fourth incident occurred when her first baby was born and she suffered severe postnatal depression. The birth was difficult and the baby was very ill during the first year until he was diagnosed as being allergic to breast milk along with many other foodstuffs. Amy also had little support from her family, friends and the medical fraternity leaving her feeling guilty and a failure as a mother. These feelings were exacerbated by the belief that her own mother had coped easily with childbirth and childcare while her mother-in-law had enjoyed considerable support when raising her children. Lastly, Amy reiterated the three separate altercations with her former teaching colleagues prior to her resigning from the profession. She wondered whether she had portrayed herself as being overly competent, thereby raising the expectations of others when in fact her abilities were quite average. She now realised that in retrospect these altercations were significant.

After relating these incidences she became very tearful in that over the years she had tried to cope with feelings of disappointment by "programming" herself "to forget". But the feelings had "chipped away" at her "nerves" leaving her feeling tense, fearful and consequently fatigued. She also admitted that in all the above-mentioned situations nobody had ever told her that she was "not to blame". Initially she had difficulty understanding why she was still preoccupied with obtaining acceptance and affirmation from others. She thought that she was "acting like a stupid child" but then later queried whether this could "cause CFS". It was at this point that the therapist explained that CFS was a complex illness and that a strong need for affirmation could lead to a tendency to strive for recognition and achievement, resulting in an overextended lifestyle and even symptoms of chronic fatigue. Her homework was to complete the outcome questionnaires.

In session six (week 10) the therapist provided Amy with some feedback regarding her busy daily schedule. She admitted that she still felt "guilty" about resigning from her teaching job resulting in her pushing herself to perform at home. It had been a major adjustment to open her own hospitality business and invite "strangers" (guests) into her home as it evoked painful memories about her own childhood home. She always felt insecure living with her parents and tried to escape by working outside her home or by playing sport. She realised that her home was now her work and that the act of inviting guests into her own house resulted in feelings of

extreme tension and anxiety. To compensate for these feelings, she went to a considerable amount of trouble to ensure that her home was a safe and comfortable haven and that her guests would approve of her as a person. Later in the session she expressed feelings of anxiety about not obtaining the acceptance and affirmation she needed due to her illness. She was concerned that she would become too fatigued to take adequate care of her appearance, and thereby lose the respect and admiration of others. She explained how her mother had "let herself go", by dying her hair black which made her look "cheap". In addition, other people had noticed that her mother was an emotionally cold person resulting in Amy overcompensating in order to avoid being perceived in the same manner by family and guests. She acknowledged that she was unhappy with herself and explained how she made a concerted effort "to show warmth" as she believed that she was an emotionally cold person. In sharing these thoughts she became tearful as she felt that she was depriving her family of genuine love and care. Her homework was to search for evidence which contradicted the negative thought that she was "a disappointment". In this respect, she was encouraged to bring her guest book to the next session. She also had to continue keeping her hourly journal.

The seventh session (week 11) was spent reviewing her homework and discussing related issues. Amy had gathered considerable evidence from various different sources which contradicted her core beliefs and underlying assumptions about being "a disappointment" to others. She documented this positive information on her RDT form in column five, as it did not support her hot thought "I'll be a disappointment...". First, Amy and her husband had celebrated their 25th wedding anniversary by inviting family and friends to their home for a special meal. She received positive feedback from her guests in that they commented on the "lovely atmosphere". Her children also commended her for all her hard work. During the course of the evening Amy's sister-in-law gave her a letter in which she thanked her for all the care and support received in relation to dealing with a personal problem. Amy was somewhat overwhelmed by all the positive feedback but believed that it was a double achievement in that she had organised the party while suffering from CFS. Later in the week her husband told her that she had always contributed to the family in a meaningful way leaving her feeling positive. In reviewing her guest book it was noted that all her guests were impressed by her "excellent service", "friendly home atmosphere" and "superb cooking". However, she queried the sincerity of these comments in that she wondered whether her guests had felt "pressurised" to write them.

She then wondered if feelings of inadequacy played a role in causing and maintaining her CFS. She tended to take negative comments personally and compensated for these feelings by adopting a perfectionistic style of approaching tasks. In her current business she was obsessed with ensuring that her service was "A-plus". She wanted everything to be perfect and ordered because she felt imperfect as a person. She felt compelled to "...control what I can control.... as I can't control my illness....". She then realised that she was not as worthless and disappointing as she had previously thought. She also did not always have to "prove" herself to be a worthwhile person leaving her tearful.

Toward the end of the session Amy reported that her mother had asked if she could come and live with her and her husband, Brian, as she was unhappy with her present living arrangements. Amy realised that she needed to consider her own needs and set firm limits with her mother. She was "not strong enough" to have her mother live with her on a permanent basis but she was willing to have her spend a holiday with them. She acknowledged that her mother was a "very manipulative woman" in that she used guilt to make her children believe that they "owed" her as she had remained married to their father. However, Amy now felt that this was unacceptable as her mother had chosen to remain married to the father and that as children they had all suffered enough. She recalled how prior to this therapy she would have felt terribly guilty about refusing such a request as she was the only daughter and understood how her mother had suffered. In addition, she had occupied the role of maternal figure in the family who always took care of others. Amy reminded the therapist that she would be on holiday for one week. She then asked for a brief summary of what had been achieved in the therapy. The therapist reiterated the goals of the programme and highlighted some of the work done using the homework assignments as a guide. The importance of maintaining a manageable routine was stressed. Amy then spontaneously mentioned that her mother-in-law followed a manageable routine resulting in others perceiving her as "strong". She realised that she had never thought of her mother-in-law as a powerful role model and that this was helpful in terms of guiding her daily functioning. Amy's homework was to complete the outcome questionnaires and not overextend herself during her holiday.

In session eight (week 12) the termination of therapy was briefly discussed and a date was set for the one-month follow-up session. She reported that her holiday had been somewhat stressful as she and her husband had a disagreement about the planning of the holiday. She found it difficult to express her views regarding the type of holiday she wanted, while her husband expressed feelings of frustration in relation to her illness. In addition, he believed that he had been unsuccessful in organising a relaxing holiday. Amy queried many of the issues that had been covered in the previous session and the therapist provided a brief summary of what had been discussed prior to her holiday. She then reported that she had started to allow herself to relax more and withdraw from others when she felt tired and needed to rest. She felt that the therapy had assisted her in realising that she needed to take better care of herself and dismiss the unrealistic demands of others. She cited her mother's pending visit and reiterated many of the points made in session seven. She acknowledged how she had been denied appropriate care and support as a child resulting in numerous social and emotional deficits. She was able to see that her inability to form meaningful friendships as an adult was largely due to her these childhood deficits. She became tearful when expressing her longing for a circle of close female friends. She then reiterated the sentiments expressed in session one about feeling depressed after the assessment process as the therapy challenged her core beliefs and long-standing coping strategies. She acknowledged that as a child her parents had been poor role models leaving her very uncertain about what was appropriate behaviour and normal general functioning as an adult.

The discussion led to how her perfectionistic tendencies were a compensatory coping strategy to deal with poor self-confidence and feelings of inadequacy. However, these tendencies were unhelpful in the long-term as they forced her to function beyond what was appropriate leaving her feeling completely fatigued. There was some discussion on the aetiology of CFS as Amy was reading a book about the condition. The therapist provided some psycho-education about the multifactorial nature of the illness. Her daily routine was reviewed and she was reminded of the importance of scheduling two or three rest periods during the course of her day and of continuing her mild exercise (two short walks per week). It was also agreed that she needed to schedule two pleasurable activities for herself every week.

In discussing this matter, Amy became angry, as she was "sick" of focusing on herself as her body did not "give her pleasure" and had "let her down". While sharing these thoughts she was laughing and crying simultaneously. She later stated that she was in danger of "losing control". Her homework was to continue keeping her journal and to incorporate two pleasurable activities into her weekly routine.

In session nine (week 13) Amy reported feeling "upset and thrown" as a member of her extended family had made a hurtful comment about her being ill with CFS "so it's all in the mind". In the particular situation she had tried to remain calm and provide the other person with a fairly broad-based definition of some of the aetiological factors involved in CFS. Although Amy's definition was adequate and highlighted the complexity of the illness, she demanded a definition of CFS from the therapist and queried whether she should pursue the issue further. The discussion then shifted to her feelings regarding the incident and it emerged that she was overly sensitive to the "critical" comments made by family, friends and guests resulting in her feeling "judged". Such comments exacerbated her need to prove herself as a person for fear of being singled out as "strange and different". Later in the session she queried whether she had CFS or "clinical depression" as she had suffered from depression in the past and had been medicated with antidepressants. The therapist reiterated the psycho-educational material expressed in session five about the possible causes of CFS. It was also explained that there was a complex relationship between CFS and depression and that the two illnesses could be comorbid conditions. Her negative past experiences left her vulnerable to feelings of depression which led to the adoption of compensatory coping strategies, such as self-driving behaviour. This, in turn, left her completely fatigued and also served to exacerbate feelings of depression. Amy also felt that her inability to control the illness triggered a secondary depression. She revealed that having CFS meant that she was not "in control" of her life and health. She recalled how her father had dominated the family with his "blinding temper" leaving her "petrified of him". Similarly, she felt that her illness was controlling her and that she was powerless to effect any real change in her life. The remainder of the session was spent discussing her negative feelings in relation to keeping her journal. It emerged that she still found it difficult to "focus" on her thoughts, feelings and activities as it left her feeling depressed. She wanted to avoid these painful feelings. However, she had attempted to implement the suggestions made in the previous session about including two pleasurable activities during the course of her week. She

still found that listening to other peoples' problems was rewarding for her as it left her feeling "appreciated". The therapist queried whether she was able to share her ideas and concerns in these conversations and her response was negative. She felt that because other people did not really understand CFS, she would rather keep quiet about herself and her problems. She also expressed a strong need to nurture her family as they were the most caring people in her world. On further questioning it became clear that she did not want her illness to detract from her family life and important relationships. Amy expressed a fear that her adult daughter was feeling neglected, as she was not always available to spend time with her since becoming ill with CFS. She then presented a practical problem that emerged when she went shopping for groceries. Amy and the therapist brainstormed the various options available and arrived at a suitable solution. Her homework was to implement the solution during the week, to keep her journal and to complete the outcome questionnaires.

During session ten (week 14) Amy and the therapist re-visited the issue of why it was difficult for her to keep a journal. She felt frustrated, angry, defeated and guilty when she was unable to complete what she initially planned to do during the day. She believed that she was "failing" by not accomplishing what others were managing to achieve leaving her tearful. She identified two specific thoughts that frequently occurred during the day: (a) "will I get through everything?" and (b) "this is not a big thing (tasks like shopping or booking in a guest), many people my age have to go off to school and work." It was pointed out to Amy that these automatic thoughts placed her under considerable pressure to complete all her tasks and encouraged her to ignore what she was managing to achieve in the day. She also realised that her former work environment (school) had a clearly demarcated structure which involved assembly every morning, a regular number of teaching periods and two break times all marked by a ringing bell at the appropriate intervals. She admitted that her current work environment was much less structured leaving her responsible for planning her day. Amy and the therapist discussed what tasks she had completed prior to coming to the session and she had difficulty acknowledging what she had achieved. She also found it difficult to relax at the end of the day. She felt that having CFS "made her different" to other people leaving her feeling tense and anxious. On further questioning she stated that while growing up she had always felt different to the other children because of her family background leaving her feeling uncomfortable. She then became very tearful in that she longed to function just like other people and be included in their lives

and activities. She expressed a strong desire to "run away" as her illness was out of control. She lamented the loss of her energy and stamina as she felt too fatigued to engage in pleasurable activities. Later she mentioned that she was beginning to set time aside to pursue personal interests. For homework she was given a Cognitive Therapy booklet (Edwards, 1998b) dealing with cognitive distortions and correcting negative thoughts. She also had to record and tick off daily activities completed in her journal and write a positive comment after each completed task. She was reminded of termination and the follow-up session.

In session eleven (week 15) Amy reported that the Cognitive Therapy booklet referred to above, had been useful in that it made her realise that she was not the only person who encountered difficulties due to negative thinking. Previously, she thought that something was wrong with her, which exacerbated feelings of failure. She identified her main cognitive distortion as personalisation in that she was unable to separate criticism of her behaviour from criticism of herself. She reiterated many of the sentiments expressed in session nine in that when people disagreed with her or made ambiguous statements she felt "judged" by them. In these situations she automatically thought that because she attended a school with poor educational resources, that she "was stupid". She also identified with the maxim "your work is your worth" as she had always used work as a way of escaping from early memories of domestic violence and sexual abuse. By keeping busy she was able to avoid thinking about herself and her illness. She stated that her avoidance of conflict situations stemmed from two interrelated past experiences: (a) she was never given the opportunity to talk about problems and fears, and (b) whenever her parents argued it always ended in her father physically assaulting her mother.

Her journal was reviewed and she found that by writing down all the tasks she had completed, she was able to see what she was managing to achieve in her day. However, she found it difficult to give herself positive feedback or reinforcement after completing tasks. Despite this difficulty she believed that the therapy had enabled her to acknowledge what she had achieved in her life and the skills she had acquired, resulting in a reduction in feelings of worthlessness. She still tended to overextend herself and a discussion followed highlighting the importance of consistently maintaining a daily routine. In this discussion she expressed concern about not functioning effectively in her work. Her fear was that her fatigue was negatively affecting the quality of her service. Amy and the therapist examined the evidence for and against this fear and

it emerged that her service was of a high standard. However, she was still concerned about persistent feelings of irritability, anxiety, tension and fatigue. An in-depth discussion revealed how her abusive family background influenced how she perceived herself and her illness, and how she coped with problems. Some of the sentiments expressed were reported by Amy in session ten but she was now able to elaborate on her thoughts and feelings. She recalled the hatred she felt as a child when she realised that her family was "different" to other families. She also felt "different" to the other children at school leaving her feeling lonely and isolated. At school she was known as the "iron maiden" as she never showed her feelings or shared any information about herself with teachers or friends. As she got older her relationships with her brothers became even more distant in that she was "left out" by them whenever they engaged in enjoyable activities. Later when she was at university her brothers accused her of thinking that she was "better than them" which evoked feelings of disconnection and isolation. Amy was able to acknowledge that having CFS made her "different" from other people and excluded her from participating in many social activities, especially with her husband Brian.

The remainder of the session was spent discussing certain aspects of the Cognitive Therapy booklet, such as the value of identifying negative automatic thoughts and testing their validity. For example, Amy found it difficult to pay attention to her feelings, particularly in social settings with her extended family. In these situations she tried to participate in too many activities leaving her feeling completely exhausted. She then expressed a fear of losing the love and support of her family, especially that of her husband. She believed that he was displeased with her as she was always "tired and unable to do anything". She reiterated similar sentiments to those expressed in session nine about her daughter possibly feeling neglected by her. Amy and the therapist discussed her tendency to catastrophise and she was able to recognise this as a problem. Toward the end of the session she referred to her mother's pending holiday with her and reiterated many of the thoughts expressed in session seven. She reported that the therapy had helped her to perceive this particular situation with greater objectivity, and to weigh up its advantages and disadvantages.

She also believed that by verbalising her thoughts and feelings she was able to see that she could not be available for everyone. She then asked for a RDT form, as she wanted to use it as a guide in the coming week. Her homework was to identify the useful aspects of the treatment programme and complete the outcome questionnaires. She was also reminded of termination.

In the final session (week 16) Amy admitted that throughout the treatment she had always felt tense when completing the four self-report questionnaires. She knew that it was important to monitor her progress but she disliked focusing on her problems. She identified two conflicting automatic thoughts with respect to completing the questionnaires: (a) "I want to do this task really well", and (b) don't take it so seriously....just do what you can manage". She then recognised a similar pattern in her everyday functioning in that she pushed herself to perform resulting in feelings of tension. Later in the session she returned to this issue and admitted that her self-driving behaviour had been a fairly successful coping strategy. At this point Amy and the therapist reviewed the benefits she had experienced in terms of learning to monitor her thoughts and feelings. She now realised that she was a worthwhile person. She also experienced a shift in how she perceived CFS. She used the analogy of a defiant child and the fact the parents accepted the child but did not necessarily condone the problematic behaviour. This analogy allowed her to establish some distance between herself as a person and the knowledge that she was ill with CFS. By accepting herself she could start to take better care of her needs and identify her priorities more carefully, and thereby break the cycle of depression, fatigue and disability.

The remainder of the session was spent discussing aspects of therapy which she found most useful and developing an action plan for the future. She identified the following five points: (a) prioritising activities, especially when there was no clear structure; (b) identifying and working with negative patterns of thinking; (c) re-affirming self-worth; (d) sharing her problems in a safe environment, and (e) evaluating the advantages and disadvantages of taking various medications, such as tranquillisers. Consequently, she realised that she needed to establish a balance between taking care of herself and being sensitive to the needs of others. Her action plan for the future was first, to prioritise activities and pace herself based on a better understanding of her needs and second, to take time out each day to focus on herself - "to refuel". She still found it hard not to overextend herself and needed to be reminded that maintaining a manageable routine was imperative. She expressed some regret that the treatment had not produced immediate results (".... thought it would be more effective"). However, she did acknowledge that there were certain factors which she needed to "put into practice" in her everyday life. The therapist supported this view and explained that psychological interventions differed from medical treatments or medications in the following ways: (a) the therapeutic relationship was collaborative in that patients also needed to assume responsibility for their rehabilitation; (b) one of the benefits of psychological interventions was the skills acquired during the course of therapy. However, these skills needed to be applied in everyday situations in order to yield long-term, meaningful results.

At the follow-up session Amy reported that she had been able to continue to apply many of the insights and techniques learned in the programme to her everyday life. She had kept her action plan next to her bedside and had referred to it when necessary. In completing the outcome questionnaires for the last time she indicated that she found it "quite therapeutic" in that she enjoyed the task. At the beginning of treatment she had disliked this task. She recalled how she had approached it in a very serious manner, as she wanted to do it "really well". She now felt relaxed yet able to answer the questions with the required care. While completing these questionnaires she realised that she was feeling considerably less depressed and anxious, especially about not recovering from CFS. She attributed these improvements in mood to the treatment programme and to joining a new social group where she felt accepted and experienced "no pressure to perform". Although she had had a busy month (her mother had arrived on holiday) leaving her feeling fatigued, she was learning to pace herself by giving herself more time to complete tasks. Consequently, the duration or period of time spent suffering from fatigue and exhaustion had reduced and was continuing to do so. She was also managing to spend time simply focusing on herself leaving her feeling refreshed. She found that she had more creative energy to devote to previously enjoyable craft activities which was ultimately rewarding. Moreover, she reported that her eczema was slightly better.

Amy recalled how she had felt distressed during the assessment phase of the treatment programme due to sharing her childhood memories of violence and abuse. She thought that by distancing herself geographically from her family of origin, she had resolved her problems. However, she now believed that the therapy had provided her with the opportunity to address the pertinent aspects of her past and work through them in a meaningful way. She continued to consider her past and had been able to share it with her husband, Brian in a new way. Since the recent arrival of her mother she had contemplated trying to reconnect with her emotionally by sharing some of her feelings about their past experiences. However, she had decided against this as it did not seem to be appropriate. Her husband and children were now able to

experience something of the mother's manipulative behaviour resulting in a greater understanding of what Amy had to endure as a child. She also accepted that she was an anxious person but realised that she could control it by learning to anticipate anxiety-provoking triggers and situations. She felt that by identifying her limitations she could address them in a more constructive manner and not be "so hard" on herself.

# 3.3 Quantitative Presentation of the Outcome Measures

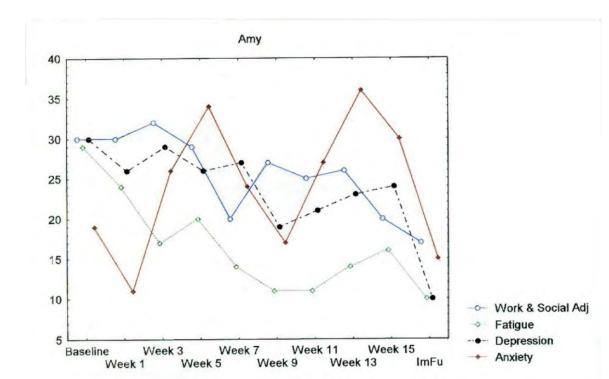


Figure 1.

#### 3.3.1 Commentary on the Outcome Measures

The quantitative assessment measures were administered on ten occasions in total during the course of the programme, including a baseline measurement and a one month follow-up measurement as noted in sections 2.4 and 2.8 above. More specifically, the outcome measures were administered three times prior to the implementation of the cognitive-behavioural treatment programme (baseline to week 3) and seven times during the treatment phase including follow-up (week 5 to follow-up). Although there were reductions in all four outcome measures, it can be seen from the graphs displayed in Figure 1 that these were not uniform. In the paragraphs which follow below, links will be drawn between the quantitative trends in outcome and qualitative data from the case narrative.

#### 3.3.1.a Fatigue Questionnaire (Chalder et al., 1993)

There was a substantial decline in Amy's level of fatigue from baseline to follow-up. From a baseline score of 29 there was a sharp reduction in her level of fatigue culminating in a score of 17 in week 3. This decline was then followed by a slight increase evidenced in week 5 (session 1) which was short-lived. This significant pattern of fatigue reduction corresponded with the assessment and contracting phase of the programme. During the first half of the treatment programme from week 5 until week 11 (session 1 until session 7) there was another, more steady decline Amy's level of fatigue reflected in two scores of 11 in weeks 9 and 11 (sessions 5 and 7). Although this decline was followed by a slight increase in fatigue toward the end of treatment, there was another reduction in her level of fatigue which was sustained at follow-up. Her final fatigue score was 10.

# 3.3.1.b Work and Social Adjustment Scale (Marks, 1986)

Although Amy's ability to work and socialise fluctuated somewhat during the course of the programme, there was a substantial overall decline which was sustained at follow-up. Starting with a baseline score of 30 there was no clear shift in her level of disability until week 7 (session 3) when her score dropped to 20. This noteworthy reduction in disability corresponded with the sharing of the case conceptualisation and treatment plan, and the commencement of treatment. There was no additional qualitative data that could clarify this reduction or provide a further explanation.

Her level of disability then returned to her previous level of functioning evidenced in a score of 27 in week 9 (session 5). However, after this increase there was a second reduction in disability between weeks 13 and 15 (sessions 9 and 11) which was sustained at follow-up. Her final work and social adjustment score was 17.

#### 3.3.1.c The Beck Depression Inventory-II (Beck et al., 1993)

There was a substantial reduction in Amy's level of depression from baseline to follow-up. Starting with a baseline score of 30, which indicated severe depression, her progress showed small fluctuations until week 7 (session 3). After this session she experienced her first significant decline in depression culminating in a score of 19 (mild) in week 9 (session 5). In this session Amy reported that she was feeling "more positive" as the previous session helped her to acknowledge the fact that she had CFS. However, this decline in depression was followed by a steady increase which culminated in a score of 24 in week 15 (session 11). No specific qualitative data could explain this increase or provide any extra information. Between the end of treatment and follow-up there was a second noticeable reduction in her level of depression evidenced in her score of 10 (mild).

## 3.3.1.d The Beck Anxiety Inventory (Beck et al., 1993)

Amy's level of anxiety showed marked fluctuations throughout the treatment programme. From her baseline score of 19, which indicated a moderate level of anxiety, there was a sharp decline. This decline was then followed by a significant increase in anxiety which culminated in a score of 34 (severe) in week 5 (session 1). The pattern of elevated anxiety corresponded with the end of the assessment process and the beginning of the contracting phase of the treatment. No additional qualitative data could clarify what raised her anxiety to such an elevated level. After this increase there was a sharp decline in anxiety evidenced in a score of 17 (moderate) in week 9 (session 5). However, this was followed by another significant increase in anxiety, which reached a score of 36 (severe) in week 13 (session 9). At this session Amy reported that she was feeling very "upset and thrown" as her sister-in-law, with whom she has a close relationship, made a hurtful remark about CFS being a psychiatric illness. After this session there was another noteworthy decline in her level of anxiety, which was sustained at follow-up, evidenced in a score of 15 (mild).

# 3.4 Qualitative Presentation of the Schema Questionnaire (SQ) (Young et al. 1990)

The SQ consists of 16 schemas grouped within five higher-order areas of functioning, as noted in section 1.6.1 above. However, there are an unequal number of items (questions) in each scale, which make it impossible to compare the total scores. For this reason it was necessary to calculate the scores for each scale out of the maximum score and then convert this figure to a percentage in order to facilitate comparisons. The results are presented in Table 3 below.

# Table 3. Results of Amy's Schema Questionnaire

(1) Area of Disconnection and Rejection		
(a) Social Isolation	52/60	87%
(b) Mistrust/Abuse	80/102	78%
(c) Emotional Deprivation	37/54	69%
(d) Defectiveness/Shame	62/90	69%
(e) Abandonment/Loss	54/108	50%
(f) Social Undesirability	15/54	28%
(2) Impaired Autonomy and Performance		
(a) Failure to Achieve	31/54	57%
(b) Vulnerability to Harm/Illness	35/84	42%
(c) Enmeshment/Undeveloped Self	24/66	36%
(d) Dependence and Incompetence	23/90	25%
(3) Impaired Limits Domain		
(a) Insufficient Self-Control	30/90	33%
(b) Entitlement	20/66	30%
(4) Other-Directedness Domain		
(a) Self-Sacrifice	89/102	87%
(b) Subjugation	42/60	70%
(5) Overvigilance and Inhibition		
(a) Unrelenting Standards	71/96	74%
(b) Emotional Inhibition	22/54	41%

The noteworthy differences in percentage scores suggest that there are certain schemas that are more prominent than others. In this regard, Young et al. (1990) use the terms primary and secondary schemas to differentiate between the prominent and less prominent schemas. However, they do not specifically indicate how they go about making this distinction. It seems likely that the distinction is based on a natural cut-off point or break in the percentages. For example, Amy's primary schemas are those which are represented by high percentages (87%-70%). At this point there is a natural break in her percentage scores, and the next cluster of schemas are situated at a lower percentage mark (57%-50%). Although this distinction between primary and secondary schemas is to some extent arbitrary, it is helpful from a descriptive standpoint to be able to make this distinction. Amy's primary and secondary schemas are presented in Table 4 below.

(1) Primary Schemas		(2) <u>Secondary Schemas</u>		
(a) Self-Sacrifice	87%	(a) Failure to Achieve	57%	
(b) Social Isolation	87%	(b) Abandonment/Loss	50%	
(c) Mistrust/Abuse	78%			
(d) Unrelenting Standards	74%			
(e) Subjugation	70%			

Table 4. Amy's Primary and Secondary Maladaptive Schemas

### 3.5 Summary of Medication Usage During Treatment

Early in the treatment programme the therapist expressed concern that Amy was taking Lexotan, as it is a benzodiazepine derivative with the potential for abuse and dependence, as noted in section 3.2.1 above. She was encouraged to evaluate the advantages and disadvantages of taking this medication and to consider stopping it under the guidance of her GP. However, in consultation with her GP it was decided not to change her medication routine. The GP was of the opinion that Amy was not ready to cope with such changes. Thus, throughout the treatment programme and follow-up period there were no changes in medication usage or in dosage levels.

#### 4. DISCUSSION

## 4.1 The Discussion Outline

The discussion of Amy's case is organised according to the following six main areas: (a) establishing whether CBT was responsible for the positive outcome change; (b) highlighting certain general issues pertaining to CFS; (c) identifying specific issues pertaining to CFS, such as the schema dynamics; (d) evaluating the efficacy of the CBT model in treating patients with CFS; (e) offering recommendations for medical practitioners, and (f) evaluating the study and providing indications for future research.

#### 4.2 <u>Did CBT Help the CFS Patient?</u>

The present study provides support for the use of a cognitive-behavioural intervention in the treatment of patients with CFS. Given the fact that CFS is a chronic debilitating condition, it seems unlikely that a patient could show noteworthy improvements in their illness without intervention. In this respect, Amy's case revealed that she had been ill with CFS for nearly three years during which time there had been little improvement in her symptoms and disability. However, after the implementation of a cognitive-behavioural intervention there was a significant decline in fatigue coupled with a moderate decline in functional disability and depression after only sixteen sessions of therapy. These improvements suggest that a spontaneous remission of symptoms was unlikely given the nature and duration of her illness. Instead, it would seem that a substantial part of both Amy's symptoms and disability were reversible due to the cognitive-behavioural intervention. These findings are consistent with the work of a number of prominent researchers of CBT for CFS (Bertagnolli et al., 1997; Chalder, et al., 1996; Deale et al., 1997; Sharpe, et al., 1997).

With respect to the issue of previous treatment interventions, Amy's case revealed that she had ten sessions of psychotherapy after her "burnout" experience approximately five years ago. However, she did not respond to this treatment. Although she began to disclose certain aspects of her abusive childhood, she did not reveal the full extent of the abuse. It is possible that this psychotherapy lacked the focus necessary to yield favourable results, or that the treatment duration was too brief to effect positive results. Nonetheless, it seems clear that non-specific therapist factors, such as attending sessions regularly, talking about distressing problems in a safe environment and receiving support and empathy from a therapist were not enough to enable

her to talk about her life and share her problems in an open and honest way. Further, it may be argued that even if the non-specific factors had enabled her to share her past they may not have been sufficient to effect positive change. In this regard, Amy's case revealed that she needed more focused therapeutic input whereby she was encouraged to monitor her automatic thoughts and identify self-defeating patterns of behaviour. She had to be shown by the therapist how to change problematic behaviour, and had to be invited to experiment with new behaviour.

Moreover, the current treatment included both non-specific factors and specific cognitivebehavioural interventions. In this respect, it was found that a positive therapeutic relationship enhanced the effectiveness of the cognitive-behavioural interventions. Similarly, it seems likely that without directive, focused interventions for patterns of cognitive distortion and problematic behaviour the chances of a positive outcome were slim. Despite the interdependence of the two sets of factors, it seems unlikely that non-specific factors alone could account for the improvements observed in the current study. This is confirmed by Amy's failure to respond to the previous psychotherapy intervention. In addition, feedback from her at the end of treatment confirmed that although non-specific factors were important, they were insufficient to account for the improvements. In particular, she identified three specific cognitive-behavioural factors as being effective. They included: (a) identifying and working with negative patterns of thinking, (b) learning basic problem solving skills, and (c) learning to prioritise activities. It would therefore appear that these specific interventions were largely responsible for bringing about positive change in symptoms and functional disability. Thus, the claim that non-specific therapist factors were responsible for the positive outcome of the present intervention can be largely discounted.

Another issue that was considered was whether the changes in the dependent variables could be accounted for by changes in medication usage. In this respect, Amy's case showed that for the past six years she had been medicated with anxiolytic medication and that for the past three years she had been taking antidepressant medication. Although it would have been a valuable treatment aim to have reduced Amy's dependence on the anxiolytic medication noted in sections 3.1.3 and 3.5 above, the fact that her medication routine remained unchanged was a definite advantage for the present study. It served to confirm that the cognitive-behavioural treatment programme helped in reducing fatigue, functional disability and depression. These

improvements occurred even with the added stress of her mother's request to come and live with her and her husband on a permanent basis. In addition, the treatment intervention raised Amy's awareness of the medication issue. Feedback from her at the end of treatment confirmed this as she found the mutual discussion about medication an enlightening one. Hence, there were no significant changes in medication usage during the course of the programme which could account for the positive results at follow-up. Thus, the claim that an extra-therapy factor like medication was responsible for the improvements observed at the end of this study can also be discounted.

Furthermore, the study revealed that no major external events occurred in Amy's life during the course of therapy which could have accounted for the positive results. For instance, there were no notable positive or negative events, such as the forming of a new relationship or the death of a family member that influenced the course of the therapy and contributed to the therapeutic changes observed in the study. At follow-up although Amy attributed her improvements in mood to the treatment programme and to joining a new social group, it seems unlikely that she would have been able to join this group and feel accepted by the other members if she had not first experienced a shift in how she perceived herself, others and situations in general. Rather, it would seem that the treatment intervention helped her to view situations more objectively resulting in her relating to others in a more open manner. This view is consistent with standard cognitive-behavioural literature in that if a patient has been socially withdrawn, it is expected that at the end of such a programme they should start making new friends and becoming more socially active. In fact, from this perspective Amy's increased social activity is another positive indication that the treatment programme was effective.

With respect to strengthening the conclusions made regarding the effectiveness of the programme, the present study incorporated eight of the twelve factors identified by Kazdin (1981) and elaborated on by Kratochwill et al. (1984) as noted in section 2.2 above. The eight factors included in this study are discussed below. First, the study included continuous assessment of the outcome measures through self-monitoring. This provided an accurate measure of Amy's progress during the programme, which helped to rule out many of the threats to internal validity. Second, the researcher was able to directly plan for the implementation of the cognitive-behavioural intervention, and thereby draw more valid inferences from the

quantitative and qualitative data. Third, the researcher was able to show that the condition was chronic prior to the implementation of the treatment. Thus, it was unlikely that the positive changes evidenced in the study could have occurred without the planned intervention. Fourth, the intervention had a substantial effect on symptoms and disability in that Amy's scores for fatigue, functional disability and depression were significantly reduced at follow-up. Fifth, the impact of the treatment was noticeable from the beginning of the intervention, especially with respect to fatigue. Sixth, the treatment procedure was standardised in that it followed the guidelines outlined by Sharpe et al. (1997). In addition, the specific steps followed by the researcher were clearly reported allowing for replication of this same treatment across other CFS cases. Seventh, the credibility of the study was improved by gathering multiple measures of Amy's symptoms and functioning. The four outcome measures allowed the researcher to assess which dimensions of her functioning were most affected by the intervention. In this respect, it was clear that there were noteworthy improvements in fatigue, functional disability and depression. It was also clear that her level of anxiety showed marked fluctuations throughout the treatment and that this particular dimension was less responsive to the intervention. Lastly, the study included a follow-up interview which assessed the maintenance of the treatment effects. This provided valuable information regarding the efficacy of the treatment in that Amy was able to apply the insights and skills learned in the programme to her everyday life. This was confirmed by the outcome measures which showed a substantial consolidation of therapeutic gains at follow-up.

The four factors that were excluded from this case study were: objective data; data from the other cases treated by the therapist; the heterogeneity of these other treatment cases, and regular and detailed checks on the accuracy of implementing the treatment. In terms of objective data, the researcher could not gather such data, as there are no objective measures currently being used in the assessment and treatment of CFS patients. Although the other two cases were treated with positive results, it was not possible to include this information due to practical constraints. In principle, if there had been more time and resources it may well have been possible to include this data in the case study. However, given the extensiveness of this research study and the above-mentioned limitations this was not feasible. With respect to the issue of heterogeneity, the present case study was somewhat different to the in-patient cases reported in some of the studies of CFS in that Amy was a CFS patient who had notable depressive symptoms. This

study therefore contributed to variation of cases and thereby extended the case-law regarding the implementation of CBT programmes for CFS. Although the present study included continuous assessment, Kazdin recommends that researchers should schedule repeated checks on the implementation of an intervention for the purposes of accuracy. In this respect, it was not possible to carry out repeated evaluations of this process in the manner suggested by Kazdin. However, the researcher did follow the guidelines outlined by Sharpe et al. (1997) and reviewed them where appropriate. This method of evaluation seemed to be quite sufficient for the purposes of the study.

#### 4.3 General Issues Pertaining to CFS

Given the fact that the study provides substantial evidence that the treatment intervention was responsible for the therapeutic changes, it is necessary to examine certain issues that emerged in the study in relation to the general literature on CFS.

## 4.3.1 The Relationship Between Chronic Stress and Infectious Illness in CFS

The present case study provides evidence for the relationship between chronic stress and infectious illness in the precipitation of CFS. There was evidence from the case history of a build up of psychological stress over a protracted period of time which together with a series of recurrent infectious illnesses led to the accumulated wearing down of Amy's personal resources and coping abilities. In this respect, her case revealed that six years prior to the onset of CFS she encountered a period of intense stress and tension due to a number of separate disagreements with three teaching colleagues. These encounters left her feeling "degraded and inadequate". Two years later she experienced "burnout" and was booked off from work by a psychiatrist. This pattern of psychological distress is commensurate with the findings of Salit (1997) and Ware (1993) who both noted that the majority of patients with CFS reported considerable psychological stress in the year(s) preceding the onset of their condition. In addition, Ware specifically identified persistent work problems as one of the chronic life stressors that plagued individuals prior to developing CFS.

Moreover, one year later she had a recurrent bout of glandular fever along with tonsillitis which were both medicated with a series of antibiotics. It seems likely that at this stage the cumulative effects of work stress, personality variables and psychiatric illness resulted in a deterioration in her body's ability to cope with the acute infectious illnesses. It is also possible that the infectious and non-infectious stressors placed additional stress on her HPA axis functioning as noted in section 1.3.3 above. This could have led to a disturbance in this important stress regulatory system. These findings and hypotheses are consistent with the those of Demitrack (1996) who contends that CFS is a complex syndrome which emerges due to a variety of disparate yet interrelated factors. He points out that a primary impairment in the body's ability to mediate stress effectively could lead to sustained activation of the immune system and even cause sleep disturbances. These theories, therefore, suggest that the onset of CFS differs from major depression and even stress-related "burnout". According to Demitrack CFS is more appropriately analogous to several complex medical conditions, such as hypertension, where many direct and indirect biological and psychological factors lead to the development of the syndrome. In contrast, depression and "burnout" appear to be precipitated primarily by psychological events.

The study also provides significant support for the role of maladaptive coping strategies in the precipitation of CFS. Although it has been shown that a combination of infectious and non-infectious stressors were responsible for the onset of Amy's case of CFS, the critical incident was the failure of her compensatory and avoidant coping strategies, noted in section 3.1.5 above. Her case revealed that she experienced the onset of persistent fatigue after she resigned from her teaching job and opened her business from home. In this light it seems somewhat ironic that she developed CFS after embarking on a less stressful career. However, on closer examination it was the failure of these specific coping strategies which was the critical factor responsible for precipitating the onset of her condition. This finding is commensurate with the theories of Demitrack (1996). He points out that the behavioural characteristics of patients with CFS are known to be as complex as the physiological hypotheses and findings. Symptoms may also be brought about and/or shaped by the behavioural responses employed by the patient or others in the patient's environment.

#### 4.3.2 Different Attributional Styles in CFS

The present study reveals that patients with CFS do not necessarily believe that their condition is specifically caused by a physical disease (external attribution). In this respect, Amy believed that her case of CFS was caused by a range of physical, psychological and social factors. A variety of infections like glandular fever and tonsillitis together with the various antibiotic treatments noted in section 4.3.1 above, played a role in reducing her general health and stamina. In addition, she had difficulty coping with emotional stress which stemmed from past formative experiences. Over the course of time, these different factors took their toll on her physical health and led to the onset of CFS. These findings are consistent with those of Clements et al. (1997) who noted that although the majority of CFS patients believed that their illness was caused by physical factors, more than half described illness models that included the interplay of physical and psychosocial factors.

However, the findings of the present study are in contrast with those of Powell et al. (1990) and Howlett et al. (1996) who both noted that patients with CFS tended to have a predominantly external attributional style, especially on the internal versus external dimension. This tendency to attribute to external factors differed from the internal attributional style of depressed patients. Powell et al. observed that CFS patients reported fewer self-reproach symptoms than depressed controls. This ultimately served to protect them from significant psychological distress. Similarly, Howlett et al. noted that CFS patients were characterised by their high levels of disease conviction. In this respect, Amy's case revealed that although she had a more sophisticated attributional style, she often experienced feelings of failure, inappropriate guilt and lowered self-esteem. This finding serves to confirm the view that her style of attribution in relation to CFS was influenced by depressive symptomatology. It would therefore appear that there may be two subgroups of CFS patient who have different attributional styles. The first subgroup may well have a simple external attributional style as noted by the above-mentioned researchers. However, this study along with the research described by Clements et al. (1997) suggest that there is another subset of CFS patients who hold more complex views regarding the cause of their illness.

## 4.3.3 The Complexity of the Relationship Between CFS and Depression

The possibility existed that Amy did not have CFS per se but rather that she was suffering from severe depression. In this respect, the current literature on CFS reveals that a great deal of attention has been given to the general issue of diagnostic classification. Although the psychiatric overlap between the symptom criteria used to establish psychiatric diagnoses and CFS has been at the centre of the debate, there has been little consensus on the nature of the relationship between CFS and depression (Abbey, 1996b). It would appear that there are three primary viewpoints with respect to this complex issue each with its own set of implications regarding management and treatment. The first group of researchers has proposed that it is generally useful to distinguish the CFS cluster of symptoms and the depression symptom cluster. However, when both sets of symptoms occur together as they do in a syndrome like CFS it is not helpful to try and separate the different symptoms (Wessely et al., 1996). Rather, these researchers contend that the focus should be on providing effective management and treatment, and that premorbid and current psychiatric disorders should not be used to exclude CFS patients from receiving treatment. According to the second group of researchers it is possible to distinguish between CFS and depression on the basis on differing attributional styles, as noted in section 4.3.2 above (Howlett et al., 1996; Powell et al. 1990). They contend that the predominantly external attributional style of the CFS patient differentiates them from depressed patients and suggests that it is not their attributional style that is responsible for their depressive tendency, but rather some other mechanism. Furthermore, these authors suggest that cognitive-behavioural therapy aimed at altering the attributional style is not likely to have a great deal of efficacy in the psychological treatment of CFS patients, especially treatment of the depressive component. The third group of researchers have identified two CFS subgroups within their main CFS-treatment group: those with and those without substantial depressive symptomatology (Friedberg et al. 1994). According to these researchers the depressed CFS subgroup were identified by higher levels of cognitive magnification of CFS symptoms which suggests that this subset of CFS patients may be more responsive to cognitive-behavioural intervention.

In this respect, Amy's case revealed evidence of both premorbid and current psychiatric disorder. Although she believed that both external and internal factors were responsible for the onset her condition, she still experienced depressive self-reproach symptoms. This suggests that that depression was a concurrent disorder to CFS in that it modified the clinical course and presentation of the chronic fatigue. This particular finding is consistent with one of the models proposed by Abbey (1996b) to elucidate the complex relationship between depression and CFS. With respect to the issue of management and treatment, the present study found that both diagnoses were valuable in terms of pointing to possible factors that needed to be addressed in treatment. However, the cognitive-behavioural case conceptualisation of this study moved beyond diagnostic categories in that it was individually tailored to Amy's specific problems. Neither diagnosis could have adequately explained the role of the core maladaptive schemas and compensatory self-driving behaviour evident in the present case. This seems to suggest that although a thorough diagnostic evaluation is important in terms of informing the treatment on a general level, a flexible and personalised cognitive-behavioural case conceptualisation takes the treatment plan a step beyond diagnosis. These findings are commensurate with those of Wessely et al. (1996) who noted that diagnostic categories were limited in terms of developing effective treatment strategies for CFS patients.

#### 4.4 Specific Issues Pertaining to CFS

From the study it is clear that Amy's thoughts and behaviour, especially in interpersonal situations were guided by an assortment of maladaptive scripts and schemas. In this respect, it is important to identify the particular dynamics involved and to carefully examine how they served to maintain CFS.

#### 4.4.1 The Schema Dynamics of CFS

The results of the SQ revealed the existence of a potent set of schema dynamics. On her list of primary and secondary schemas, there was a prominent set of core maladaptive schemas which related to a profound sense of disconnection and rejection. These schemas included: a social isolation schema; a mistrust/abuse schema; an emotional deprivation schema; a defectiveness/shame schema and an abandonment/loss schema. Developmentally, these findings are consistent with the findings of Surawy et al. (1995) and Young (1994). In particular, Young (1994, p.54, 57) contends that maladaptive schemas in the area of disconnection and rejection

often arise in an unstable family environment where parents are "detached, explosive, unpredictable, rejecting, punitive, unforgiving, withholding, inhibited or abusive". In these circumstances children do not receive reliable love, nurturance and dependable mothering and fathering. This leads the child to feel rejected. In addition, children do not receive empathy from their parents leaving them feeling misunderstood. He points out that these children are not encouraged to socialise with other children or may feel too anxious to initiate friendships due to the lack of security and stability at home. Without the positive experiences of socialising with peers individually and in groups, children are left feeling lonely and isolated. This theory of schema development is consistent with Amy's life history as she grew up in an abusive home environment where her parents fought continually. On top of this she was sexually abused as a child and her experience of abuse was then systematically invalidated by her mother. In addition, she never invited friends home as she was ashamed of her family and fearful of her father's unpredictable behaviour. She also never felt comfortable about staying over with friends for weekends or even holidays leaving her lonely and isolated. Amy's family and personal history are also commensurate with the findings of Ware (1993) who noted that the life histories of CFS patients were characterised by evidence of dysfunctional experiences with parents, siblings and other family members.

Although these formative experiences left Amy feeling mistrustful, ashamed, defective and lonely, she managed to cope in life by developing two major compensatory schemas. There is evidence in the present study that an unrelenting standards schema and a self-sacrifice schema were part of her compensatory strategy that developed to offset the core schemas related to disconnection and rejection. In this respect, her unrelenting standards schema led her to believe that whatever she did was not good enough and that constant striving was the only way to rectify the situation. Further, her self-sacrifice schema led her to sacrifice her own needs in order to take care of others. These findings are largely consistent with the theory of Young et al. (1993, p.302) who indicate that in certain circumstances the unrelenting standards schema, in particular, can arise "as a way to compensate for feelings of defectiveness, social exclusion, deprivation or failure". They point out that in these situations children try to rise above their childhood environment as they feel inferior in relation to peers, or feel that their parents are inferior.

Although Amy's unrelenting standards schema and self-sacrifice schema were largely responsible for guiding her behaviour, other more general compensations or scripts also served to direct her behaviour in everyday interpersonal situations. This distinction between specific compensatory schemas and general compensations or scripts is helpful as there are certain compensatory processes evident in the case narrative which cannot be explained solely by the two major compensatory schemas. This process of differentiation is consistent with the work of Leahy (1996), whose distinction between schemas and scripts is an improvement on the work of Young as it contributes to a more refined understanding of the underlying dynamics.

#### 4.4.2 The Role of Compensatory Scripts in CFS

With respect to general compensations, Amy's behaviour in interpersonal situations seemed to be guided by a powerful script which allowed her to compensate for or avoid her core underlying schemas. In particular, there was a core set of cognitions related to a fundamental sense of defectiveness. Some of these negative cognitions seemed to include: "if people knew the real me they would not love me or take care of me" or "if other people found out about my defects they would not like me or want to be friends with me". As a result, she adopted strategies of compensation and avoidance. In this respect, her compensatory behaviour involved the development of a self identity that seemed to be the opposite of the core maladaptive schema. For instance, she presented herself in social settings as a capable, successful and outgoing person. This compensatory strategy developed in childhood when she realised that education was her only chance to succeed in life. Her compensatory scripts enabled her to succeed at university despite feeling guilty about having aspirations that were different to those of her family. They also enabled her to marry a stable, dependable man and raise two welladjusted children. Through creative compensation she constructed an identity capable of forming a stable marriage and contented family life, and thereby gained recognition and respect from others. However, she also adopted an avoidant coping strategy, which allowed her to avoid activating her core schemas. For example, she avoided meaningful self-disclosure, as there was a risk that others would get too close to her and see her flaws. This behaviour allowed her to avoid the fear of being rejected by others. In particular, she befriended people who were incapable of listening to her problems and concerns as they had significant problems of their own and needed considerable emotional support. These type of friendships were "safe" in that she did not have to reveal too much of herself or share any of her own ideas or concerns.

Similarly, she did not openly express her needs and wishes to her husband and instead followed his ideas and suggestions on most issues. On one level this pattern of behaviour helped her to avoid revealing herself to other people, but on another level it was self-defeating as it reinforced feelings of loneliness and isolation.

#### 4.4.3 The Role of Specific Compensatory Schemas in CFS

The present study also revealed the underlying dynamics of the unrelenting standards schema and the self sacrifice schema, especially in the work arena and in social settings. With respect to the unrelenting standards schema, Young (1994, p.61) points out that there is usually "an underlying belief that one must strive to meet very high internalised standards of behaviour and performance in order to avoid criticism". This self-driving behaviour typically results in "feelings of pressure or difficulty slowing down along with hypercriticalness toward oneself and others". In addition, unrelenting standards is "often present as (a) perfectionism, the inordinate attention to detail, and an underestimate of how good one's own performance is relative to the norm; (b) rigid rules or "shoulds" in many areas of life; or (c) a preoccupation with time and efficiency, so that more can be accomplished". The findings from the case narrative are consistent with the schema theory of Young in that Amy's unrelenting standards schema manifested in all three areas namely: compensatory perfectionistic tendencies, "should" statements and a preoccupation with time and efficiency. With respect to perfectionistic tendencies, she went to a considerable amount of trouble to ensure that her guests would feel at ease when staying in her home. Later she reported two specific beliefs that were maintaining to her self-driving behaviour in this regard. They included: (a) "my service must be A-plus" and (b) "my home must be a perfect haven". Consequently, she was under constant pressure to perform and meet her own high internal standards. But such behaviour left her feeling completely fatigued.

Eventually she would reach a stage where she needed to rest in order to regain her energy. However, these periods of rest were short-lived and ineffectual in that she would start rehearsing negative thoughts based on "should statements" about her limited performance. The "should" statements included: "I should be completing all my daily tasks, what's wrong with me?". This behaviour was also driven by overwhelming feelings of failure in relation to not accomplishing what others were managing to achieve during the course of their day. This was confirmed by her frequent reports about being "a failure" because she was not performing according to her premorbid level of functioning. These negative cognitions led to bursts of unplanned activity, which were only partially successful as they caused an exacerbation of symptoms. In this respect, her case showed that compensatory perfectionistic beliefs coupled with "should" statements contributed to an unproductive oscillation between activity and inactivity.

These findings differ somewhat from those of Sharpe (1996) who noted that there were two interacting cycles of cognitions which maintained the oscillation between activity and inactivity. The first cycle was based on a catastrophic misinterpretation of symptoms leading to distress and to avoidance of activity; the second cycle was based on "should" statements that led to frustration and to brief, but unsustainable bursts of activity. This interacting cycle of cognitions ultimately served to convince the patient that sustained activity was impossible. In this regard, Amy's case revealed that an exacerbation of symptoms did not lead to prolonged periods of rest and avoidant behaviour as noted by Sharpe. The illness belief held by many CFS patients about rest being the best treatment option did not play a prominent role in her case. Instead, her periods of rest were brief and punctuated by a series of "should" statements based on perfectionistic beliefs which led to prolonged self-driving behaviour.

In terms of time and efficiency, Amy pushed herself to complete an unreasonable number of tasks everyday. This left her feeling constantly frustrated and irritated with herself, especially when she was unable to meet all her commitments. She also experienced feelings of anger coupled with high levels of anxiety, particularly in relation to not completing her chores within a given time. Eventually, she was able to identify two automatic thoughts which revealed her constant sense of time pressure and tendency to compare herself with others. They included: (a) "will I get through everything?" and (b) "this is not a big thing (a task like shopping or booking in a guest), many people my age have to go off to school and work".

According to Young (1994) one of the basic schema dynamics is schema compensation, which involves the adoption of cognitions and behaviours that overcompensate for EMS. In this respect, Amy was engaging in compensatory self-driving behaviour that left her feeling fatigued and unable to relax at the end of the day. As her functional ability began to decline core maladaptive schemas were regularly triggered. Eventually the schema compensation behaviour began to fail and was replaced by schema maintenance behaviour. According to Young schema maintenance is accomplished by cognitive distortions and self-defeating behaviour patterns. On a cognitive level, the schema will highlight or exaggerate information that confirms the schema and will minimise or deny information that contradicts it. On a behavioural level, the schema will generate certain behaviours that are self-defeating in that they elicit responses from others which tend to confirm the core maladaptive schemas.

Amy's schema maintenance behaviour involved a tendency to distort everyday evidence and information by minimising the importance of what she was managing to achieve in the course of her day. The basic underlying assumption seemed to be that running her own business was not "real" work. Earlier she had expressed surprise that mental activities, such as concentrating, reading and calculating were tiring and demanding tasks in their own right. It was therefore not surprising that she was plagued by feelings of frustration, anxiety and failure. In addition, she also discounted positive feedback received from guests in relation to her high standards of client service. She believed that the positive comments written in her guest book were insincere as her guests felt "pressurised" to write them. Clearly she was underestimating her good service by negating information which contradicted her punitive unrelenting standards schema. This pattern of distorting certain kinds of information prevented her from receiving genuine recognition for her hard work, and thereby served to reinforce her core maladaptive schemas. Furthermore, Amy's schema maintenance behaviour was also evident in her self-defeating behaviours. In this respect, she pushed herself to perform and achieve according to her premorbid level of functioning. However, she was very self-critical of her own efforts in this regard leaving her feeling constantly frustrated and irritated with herself, especially when she was unable to meet all her commitments. In addition, this contemptuous attitude toward her own hard work reinforced a sense of failure in relation to the emptiness of what she had achieved and confirmed her core maladaptive schemas.

In addition, Amy's case revealed evidence of schema avoidant behaviour. More specifically, as a child she avoided her abusive home environment by working outside her home or by playing sport. This pattern of avoidance continued into adulthood where she was involved in many different activities outside her home leaving her with little time for herself. According to Young (1994) one of the basic schema dynamics is schema avoidance, which often involves the avoidance of specific situations that trigger core schemas. Amy learned that by spending limited time at home she could avoid the psychological pain associated with her abusive childhood. However, when she opened her own hospitality business and began inviting "strangers" (guests) into her home, she was unexpectedly reminded of her childhood home. These painful memories made it extremely difficult to perform everyday tasks, especially those related to her work. In the present context she was no longer able to walk out of her house to avoid triggering past memories. Instead, she was forced to confront them. Her inability to perform coupled with the challenge of having to deal with past experiences and painful memories depleted her personal resources and coping abilities.

With respect to Amy's self-sacrifice schema, Young (1994) indicates that there is an "excessive focus on voluntarily meeting the needs of others in daily situations, at the expense of one's own gratification". He also points out that the most common reasons for adopting this schema are "to prevent causing pain to others, to avoid guilt from feeling selfish, or to maintain the connection with others perceived as needy". This usually results from an acute sensitivity to the pain of others. He contends that often this type of behaviour will "lead to a sense that one's own needs are not being adequately met and to resentment of those who are taken care of". The findings from the case narrative are largely consistent with Young's theory of schema development in that Amy developed a self-sacrifice schema to relieve the pain and suffering of others, to avoid feeling guilty and to maintain close ties especially with significant people in her life. In terms of relieving the pain of others, she reported that as a child her role in the family was to comfort her mother and younger brother whenever the father became abusive. However, she did not report feelings of resentment in relation to caring for these family members. Instead, her anger and resentment were directed at her older brother who did not offer his support during these times. This particular finding extends the theory of Young in that it suggests that feelings of resentment may be directed at other significant figures who do not assist the patient in taking care of those who are most needy.

Another way in which she relieved the pain of others was to overidentify with people who seemed anxious or unsure of themselves in social settings. In these situations she would immediately approach the person and start a conversation with them in order to make them feel at ease. As a result, she never really got the opportunity to socialise with people she personally wanted to get to know on a more meaningful level. In these situations she did not report feelings of resentment toward the strangers she befriended. Instead, she seemed to be confused about why her own needs were not being adequately met leaving her feeling despondent and defeated. This finding also expands on the theory of Young in that self-sacrificing behaviour does not only lead to feelings of resentment of those who receive care and support. It would appear that other feelings, such as confusion, sadness and despondency may also be triggered by excessive self-sacrificing behaviour.

With respect to avoiding feelings of guilt and maintaining connection with others, Amy tended to put the needs of her current family before her own. In particular, she found it very difficult to "say no" to her husband and children when they made requests as it left her feeling guilty about focusing on her own needs. In addition, her self-sacrificing behaviour helped to maintain a sense of connection with her family. She reported that her behaviour was motivated by a fear of being abandoned by them. This finding is consistent with those Bertagnolli et al (1997) who noted that the core belief driving their patient's self-sacrificing behaviour was a fear of being abandoned by others because she was "a burden". These findings add to the theory of Young in that he does not specifically list fear of abandonment as a possible reason for engaging in self-sacrificing behaviour. In this respect, it would seem that Young's theory relating to the self-sacrifice schema needs to be carefully reviewed as the current study has noted important refinements of this theory.

In terms of Young's (1994) theory of schema dynamics, Amy's self-sacrificing schema was reinforced by schema maintenance behaviour. On a cognitive level, there seemed to be two specific maladaptive beliefs that were maintaining her behaviour in relation to family and strangers, respectively. They included: (a) if I don't meet the needs of my family they may abandon me" and "I must befriend lonely people but I need to be careful that I don't reveal too much of myself in case they see my defects and reject me". The underlying assumption seemed to be that her needs were unimportant and insignificant in comparison with the needs of others.

As a result, she tended to distort evidence and information by minimising the importance of her own needs. For instance, she often expressed considerable regret about not being able to do more for others "who are really struggling". Furthermore, Amy's schema maintenance behaviour was also evident in self-defeating behaviour. In this regard, she focused all her attention on meeting the needs of others and ignored her own need for attention, understanding and support. This left her feeling lonely and despondent. However, there was an element of schema compensation in this self-defeating pattern of behaviour. By providing others with care and support she was concealing the fact that she felt uncared for by family and friends. In a sense she was providing others with the care which she wanted herself.

4.5 Evaluating the Efficacy of the CBT Model in Treating CFS Patients Although previous research findings have demonstrated the effectiveness of cognitive-behavioural strategies in decreasing disability and symptoms of many patients with CFS, there have also been some mixed results regarding the overall effectiveness of this treatment approach, as noted in sections 1.8.1 and 1.8.2 above. Some patients appear to benefit little from treatment while others report improvements in certain areas, such as mood or functional ability yet remain fatigued and symptomatic. This has led to a debate about which components of the CBT model are more effective, and whether these particular components could be fashioned into a simpler approach aimed specifically at treating patients with CFS (Sharpe, 1998a). In this respect, the current study revealed a number of pertinent issues in relation to adopting a CBT model to treat a patient with CFS. Special attention will be given to the points of contrast and similarity with respect to the current literature on CFS. A discussion of these areas follows below.

## 4.5.1 The Quality and Nature of the Therapeutic Relationship

The present study suggests that engaging the patient and establishing a collaborative therapeutic alliance is essential to the treatment of CFS. In particular, a non-judgemental atmosphere along with empathy and compassionate attention helped to build a meaningful therapeutic relationship with the patient. In this respect, Amy's case revealed that through the therapist empathically listening to her concerns and allowing her to talk about her life she felt understood and supported. This was important, as Amy was initially reluctant to talk about her past and acknowledge the role it played in influencing her present functioning. In addition, the collaborative relationship enabled her to share her views on CFS in a more open and honest

way. Although the relational component is a standard part of all CBT interventions, it is not emphasised enough in the current literature on CFS. This body of literature focuses largely on the technical aspects of change while the relational aspect of the therapy seems to be of secondary importance in contemporary treatment programmes. The findings of the present study therefore confirm that the therapeutic alliance is the cornerstone of treatment in that it provides a positive base from which to launch the cognitive-behavioural intervention.

#### 4.5.2 Sharing the Case Conceptualisation with the Patient

The current study also found that completing a thorough cognitive-behavioural assessment and sharing the cognitive developmental case conceptualisation with Amy had a positive impact on treatment outcome. In this regard, Figure 1 in section 3.3 above revealed an overall reduction in fatigue, functional disability and depression which corresponded to this particular phase of the treatment programme (baseline to week 5). It seems likely that answering searching questions about what she felt was in some ways therapeutic. In addition, through the therapist sharing the developmental case conceptualisation with her she became more aware of how formative experiences played a role in her current problems, and how she could go about addressing these issues with therapeutic support. It is hypothesised that this was an educative process that helped her to start gaining a sense of control over her illness. This hypothesis is consistent with the findings of Chalder et al. (1996), who reported that perceived controllability was an important factor in directing motivational, cognitive and behavioural effects in terms of outcome in CFS. But Amy indicated that although this phase of the therapy was an enlightening experience, it was also a painful one. That this experience was a challenge is entirely understandable as she was being invited to confront previously avoided issues. However, the positive therapeutic relationship enabled her to embark on this challenging process as it provided her with sufficient support and guidance.

# 4.5.3 <u>The Role of the Therapeutic Relationship in Augmenting Cognitive-Behavioural</u> <u>Strategies</u>

The current study found that although both cognitive and behavioural components of the treatment approach were necessary in terms of positive outcome, it was the collaborative therapeutic alliance which enabled these specific interventions to be effective. In this respect, Amy's case revealed that behavioural interventions, such as the graded activity programme were met with resistance. This is an important issue which has received little attention in the current literature on CFS. Although Deale et al. (1997) have stressed the importance of including such a programme in treating patients with CFS and have even outlined the steps that need to be followed, they have not specifically addressed the issue of patient resistance. In particular, Amy was most reluctant to keep a journal and reflect on her daily routine as she was constantly reminded of how little she was managing to achieve in her day. This left her feeling frustrated, incompetent and angry. These powerful feelings had the potential to derail the intervention through premature termination. The key automatic thought in this situation seemed to be: "look at how little I'm doing during the day, what's wrong with me?" Her negative response was somewhat surprising as this self-monitoring task had the potential to provide her with a sense of empowerment and accomplishment.

In addition, the present study found that although she was very opposed to the activity component of the programme, she was not opposed to the exercise routine per se. She found it difficult to adhere to a manageable routine where she had to redistribute and even reduce her workload, schedule regular rest intervals and be selective in terms of social activities. In addition, she was opposed to the inclusion of pleasurable activities in her weekly schedule. It seemed that learning to pace herself and taking regular breaks triggered negative automatic thoughts with themes of failure, guilt and incompetence. These findings are partially consistent with those of Friedberg et al. (1994) who noted that their CFS-treatment group tended to overwork due to their difficulty in adjusting to the sudden loss of premorbid functioning. However, Amy was willing to engage in mild physical exercise and include it in her weekly routine. Her more positive attitude in this regard could be ascribed to the fact that she did not specifically link her fluctuating exacerbation of symptoms to exercise alone. This finding is in contrast with that of Bertagnolli et al. (1997) who reported difficulties in getting their patient to comply with the graded exercise component of their programme. The patient believed that

walking was responsible for her increase in symptoms resulting in her stopping all exercise. Although the researchers challenged her automatic thoughts in this regard, they were unsuccessful. Unfortunately the study did not provide any additional commentary or offer any suggestions in relation to dealing with this problem.

Although the cognitive component of the programme helped her to weigh up the advantages and disadvantages of persisting with the various behavioural self-monitoring tasks, her negative automatic thought in this regard was not actively targeted and restructured in the therapy. Instead, the positive therapeutic relationship offered a platform from which to explore the underlying resistance in a non-threatening way. By expressing her resistance in a safe and supportive environment she was able to make the connection between the content of the maladaptive thought and the underlying emotion. This less directive approach was sufficient to ensure treatment compliance as she persevered with the homework assignments. As a result, the negative thought restructured itself during the therapy and this was confirmed at follow-up. It would seem that even if a patient does not like homework tasks it is important that they are encouraged to complete them anyway as benefits often accrue during the course of therapy. It could also be argued that the empathic stance adopted by the therapist was quite appropriate given the schema-driven nature of Amy's thoughts and behaviour. If her negative automatic thought had been specifically targeted for restructuring she may have felt misunderstood by the therapist which could have severely hampered the treatment process. In this instance her cognitions needed to be addressed in an empathic, collaborative manner and not in a confronting or overtly challenging way as described by Bertagnolli et al. (1997). The findings of the study therefore suggest that the collaborative therapeutic alliance enabled the specific cognitivebehavioural interventions to be effective. Her feedback at the end of therapy and at follow-up revealed how the relational component of the intervention augmented the cognitive and behavioural components in such a way, that she was able to integrate past painful experiences which were hampering her ability to function effectively in the present.

#### 4.5.4 <u>The Specific Guidelines Regarding Treatment Delivery</u>

Current research findings have presented varying reports about the mechanisms of change in CBT programmes for CFS. For instance, a recent randomised controlled trial evaluated the benefits of CBT versus relaxation in patients with CFS (Deale et al., 1998a). Behavioural or graded activity was found to be the key component of treatment while the cognitive component of CBT was believed to be of secondary importance in terms of positive outcome. In contrast, another randomised trail evaluated graded exercise and reported a high refusal and drop-out rate amongst patients (Wearden et al., 1998). These researchers concluded that if the cognitive component of a CBT programme had been included in the study, it could have reduced the high drop-out rate and improved adherence to exercise by offering patients a supportive yet pragmatic explanation of behavioural changes.

However, soon after these particular results were published they attracted the critical attention of Deale et al. (1998b) who indicated that the poor results of the study could not be attributed specifically to the lack of cognitive restructuring or input. Instead, they contended that the low number of appointments together with the long periods of time between sessions contributed to reduced motivation and poor treatment compliance. They pointed out that the studies which reported positive results ensured that the treatment intervention was of a suitable duration and that sessions were conducted on a regular basis (12-16 treatment sessions on a weekly or biweekly basis) (Bertagnolli et al., 1997; Chalder et al., 1996; Deale et al., 1997;). In examining the studies which reported poor or limited results, it is noted that they did not adhere to the above-mentioned guidelines regarding treatment delivery (Friedberg et al., 1994; Lloyd et al., 1993). Deale et al. point out that both these studies were possibly too brief in that the treatments included 6 sessions and lasted for approximately 6 to 10 weeks. This was insufficient time to allow for adequate skills acquisition, relapse prevention and meaningful experimentation with therapeutic guidance and support.

In this respect, the present study provides support for adhering to the specific guidelines outlined by Deale et al. (1994; 1998b) and Sharpe et al. (1997) regarding treatment delivery in CBT programmes for CFS. In fact, it seems unlikely that Amy could have been helped by a brief more formal treatment programme (6-10 sessions in total) as she had a long-standing history of CFS and a complex constellation of schema-driven maladaptive behaviours. The

regular weekly sessions and the longer duration of the current intervention, respectively (16 sessions in total) were important in terms of keeping her focused on addressing her main problems and allowing her time to become suitably acquainted with the principles of the treatment programme. In addition, she had sufficient time to integrate the skills learned and experiment with new behaviour in everyday settings. This finding is largely consistent with those of Chalder et al. (1997) who noted that brief CBT-informed programmes were possibly not appropriate for CFS patients, who were by definition severely disabled. Instead, these patients were in need of a longer more personalised therapeutic intervention.

#### 4.5.5 The Value of the Developmental Perspective

Moreover, the present study highlights the need to implement a cognitive-behavioural strategy which includes a developmental perspective in treating patients with CFS. In particular, Amy's case showed that when compensatory behaviours were targeted as part of the treatment plan then significant past experiences and painful memories were triggered in the therapy. This reaction is understandable as compensations develop in order to protect the patient from their EMS's and the associated psychological pain. In this respect, the cognitive developmental case conceptualisation of this study enabled Amy to understand why she had adopted particular compensatory strategies and how they had become outdated and ineffective in her current life. This helped to contextualise the illness and ultimately made it easier for her to relinquish the compensatory behaviours.

Further, the case conceptualisation also included the schema-focused developmental model which revealed the nature of the underlying EMS's and enabled Amy to see the historical development of these negative schemas and how they were negatively influencing her ability to cope with her condition. More specifically, she could see how the compensatory schemas were ultimately maintaining the chronic fatigue and functional disability. In this respect, the work of sessions eight and eleven, in particular, resulted in significant insight and schema restructuring following the sessions. The recognition of the full impact of her parents neglect and abuse while growing up was a major step which enabled her to disidentify herself from the part of her that always took care of others. This enabled her to assess situations more objectively and to carefully consider her own needs and personal limits in a way that had never happened before. That these processes took place demonstrate the credibility of incorporating a schema-focused

approach in the treatment of CFS. This suggestion of including a developmental perspective in treating patients with CFS is not an ill-considered or outrageous one. In fact, well-respected writers in cognitive theory, such as Leahy (1996) advocate the inclusion of such a perspective in treating all patient populations groups. Although this view is not a new one, it has been neglected in the current literature on CFS.

Moreover, the other CBT studies reported in the introduction to this study have not specifically included a developmental component in their treatment interventions. In addition, they have not shown how CFS patients manage to give up compensatory or avoidant behaviours successfully, and deal with the underlying core schemas that are routinely evoked in this type of work. Instead, these interventions have been aimed primarily at overcoming the illness-maintaining factors, like distorted cognitive appraisals and avoidant behaviour by employing cognitive restructuring and graded activity. It is possible these studies may have indirectly incorporated a developmental component in their treatment interventions and simply not commented on it, as it was not an active ingredient of the programme. Nonetheless, it is suggested that a cognitive developmental approach and/or schema-focused model should be included in CBT treatment programmes as the integration of relevant historical material enables the patient to relinquish their compensatory behaviours in a more meaningful way.

## 4.5.6 The Importance of the Action Plan

During the follow-up period there was evidence of a significant consolidation of therapeutic gains in that the improvements observed at the end of treatment were sustained. This seems to suggest that Amy was functioning differently at the end of the treatment programme. Although she had previously expressed feelings of frustration that the treatment had not produced positive results immediately, she did acknowledge that she needed to be more consistent in applying the insights and skills learned in the programme to her everyday life. The qualitative data gathered at follow-up was valuable in terms of strengthening the conclusions made regarding the effectiveness of the programme. In addition, it helped to determine whether she had been able to apply the skills learned in therapy and if so, how she had managed to achieve this goal. Although it would have been valuable to conduct a 3-month and 6-month follow-up in order to assess the long-term benefits of treatment, this was not possible due to practical reasons.

At follow-up, the study found that the self-directed action plan was instrumental in enabling her

to continue applying specific skills learned in the programme to everyday situations. In this regard, she compiled a list of the most useful aspects of the treatment programme and incorporated these points into her action plan. Her list included specific cognitive-behavioural techniques in combination with more general therapeutic factors. She reported that she kept her action plan in a convenient place where she could refer to it easily. This specific intervention made an important contribution to the consolidation of therapeutic gains at follow-up. This finding is consistent with the theories of Deale et al. (1994) who indicate that such a treatment plan helps to ensure that the principles of the programme are incorporated into daily life, and that patients are able to cope with any future setbacks.

#### 4.6 <u>Recommendations for Medical Practitioners</u>

The findings of the present study highlight the importance of educating CFS patients about their condition in a collaborative manner. Although there is a great need to provide patients with relevant information concerning their illness, this educative, information-giving needs to be combined with empathy. This is particularly important when dealing with controversial syndromes like CFS where there is little certainty regarding aetiology and treatment. In this respect, the current literature on CFS reveals that medical practitioners encounter a number of problems in managing these patients. Ax et al. (1997) noted that when doctors diagnosed CFS and offered advice pertaining to possible changes in lifestyle or suggested additional psychiatric/psychological support, patients rejected it as it contradicted their beliefs that CFS was a physical, uncontrollable illness. In addition, they pointed out the existence of a paradoxical relationship in which patients needed relevant information about the aetiology and management of their condition, yet often rejected this information if it contradicted their illness beliefs. These findings are consistent with those of Twemlow et al. (1997) who observed that CFS patients were generally satisfied with medical care if the system was congruent with their expectations.

In this regard, Amy's case revealed that when she consulted two different medical practitioners about her condition she encountered varying responses, neither of which were particularly effective. She first consulted her general practitioner (GP) as she was suffering from chronic fatigue. Although her GP provided her with a diagnosis of CFS, she did not offer any practical advice in terms of how to manage the condition. Instead, she expressed feelings of sympathy

and demonstrated a willingness to listen to Amy's concerns about the condition. Amy left the consultation feeling reasonably satisfied with the medical care she received from her GP. A few years later she consulted a specialist physician as she was experiencing eczema believed to be related to her case of CFS. The physician offered her advice in terms of managing the eczema. He also confirmed her diagnosis of CFS and recommended that she get social and emotional support in order to cope with the illness. At this point Amy reported feelings of anger and disappointment as he did not identify and treat the problem. These findings suggest that there are a number of important issues that need to recognised by medical practitioners when managing patients with CFS. Although many of these issues have been highlighted by Sharpe (1998a; 1998b), the current study serves to reiterate the importance of such concerns. A guideline based on the findings of the present study follows below:

(a) The doctor-patient relationship should be a collaborative one where the patient's experience of the illness is accepted as legitimate. Allowing the patient to tell their story serves a valuable unburdening function. This is important as many CFS patients experience repeated disconfirmation of their illness which can lead to feelings of alienation and shame. This is consistent with the views of Abbey (1996a) and Deale et al. (1994). In particular Deale et al. indicate that the majority of CFS patients have accumulated concerns about the consultation that have often been shaped by past encounters with other health care professionals. They point out that these patients fear that their condition will be trivialised, greeted with scepticism or dismissed as being a psychiatric disorder.

(b) Patients' illness beliefs, unhelpful fears, views on potential diagnoses and idealised expectations regarding treatment should all be elicited and collaboratively explored. This is important as such issues have the potential to lead to misunderstanding, resistance and a lack of treatment compliance.

(c) If the CFS patient also meets the symptom criteria for depression then this diagnosis should be made. This is consistent with the findings of Friedberg et al. (1994) who identified two CFS subgroups, namely, those with and those without substantial depressive symptomatology. An additional diagnosis like depression is important as it enables the patient to receive appropriate psychiatric treatment. In this respect, the present study found that Amy was a CFS patient who had notable depressive symptoms and that both diagnoses were valuable in terms of guiding the treatment intervention on a general level.

(d) The diagnosis or combined diagnoses should be explained to the patient. For instance, an illness model that highlights the interplay between physiological, psychological and social factors needs to be presented and elaborated upon. If there are questions or concerns in this regard they should be addressed in a sensitive yet matter of fact manner. For example, the present study found that the illness model had to be repeatedly discussed in an open manner at various points in the therapy.

(e) Patients should receive written information pertaining to their diagnosis. This view is supported by the findings of Chalder et al. (1997) who observed that patients who received self-help material coupled with specific advice pertaining to CFS, showed greater improvements in fatigue and psychological distress than controls.

(f) Patients may be encouraged to keep a diary in which they can record their automatic thoughts and behaviours in relation to CFS. Once a consistent record is available this can used as an ongoing source for discussion. If this proceeds well then patients may be encouraged to start challenging some of their thoughts and behaviours.

If the above-mentioned steps are followed there may be a greater chance that the well-meaning, sound advice given by medical practitioners will be heeded by CFS patients. However, if the patient has a long-standing, established case of CFS and is unwilling to consider change then referral to a suitably trained clinician may be necessary.

## 4.7 Evaluation of the Study and Indications for Future Research

Besides the aim of assessing a specific cognitive-behavioural intervention in treating CFS, the present study also evaluated the usefulness of using a case study methodology in this kind of research. It has been noted in the introduction to this study that CFS is a complex heterogeneous condition with a combination of factors producing symptoms in individual cases. In this respect, the flexible dual quantitative and qualitative data collection processes enabled the therapist to

document and assess both the general and specific aspects of the condition accurately. Furthermore, it has also been observed in this study that CBT is a sophisticated therapeutic intervention in that there are many different yet interrelated components which can effect positive therapeutic change. Thus, without an in-depth investigation it would have been difficult to evaluate the subtle aspects of this treatment approach in relation to treating CFS patients.

In this regard, the detailed cognitive-behavioural assessment process revealed that CFS patients do not necessarily believe that their condition is caused by a physical disease (external attribution). In fact, it would appear that a subgroup of CFS patients may hold more complex views regarding the cause of their illness. However, most previous studies have reported that CFS patients tend to have a predominantly external attributional style. On closer examination these studies have generally used quantitative methods of investigation, such as the Attributional Style Questionnaire (ASQ) which measures the extent to which patients endorse certain categories of beliefs that have been generated by investigators. In contrast, the interview guide used in the assessment process of this study was specially designed by the researcher as noted in section 2.4.4.a above, to elicit in-depth information. This qualitative assessment measure enabled Amy to describe her illness beliefs in her own words. As a result, she was able to identify single factors that were responsible for the onset of her condition and explain the interaction between them. These findings suggest that future research should focus on the ways in which quantitative and qualitative methodologies can be used to complement each other. The design of future questionnaires could benefit from more detailed descriptions of illness beliefs. Patients should be able to select their answers from a greater range of options. They should also be allowed to describe the interaction between causative factors. These recommendations are consistent with the work of Clements et al. (1997) who also noted the existence of a more sophisticated attributional style amongst patients with CFS.

The present study also found that the repeated outcome measures were useful in terms of charting Amy's progress during the course of treatment. In this respect, they provided valuable evidence that there was a significant improvement in symptoms and functional disability as noted in sections 3.3 and 4.2 above. It can be argued that the repeated outcome measures needed to be administered on a weekly basis rather than every two weeks. By monitoring the dependent variables more regularly it may have been possible to obtain additional information regarding

the relationship between the therapeutic procedures and the fluctuations evidenced on the outcome graphs. It may have also been helpful to make detailed inquiries into the nature of the fluctuations and the surrounding circumstances. Unfortunately, due to practical constraints, it was not possible to investigate the causes of the fluctuations in detail. This was an inadequacy of the study which needs to be rectified in future studies of this type. Nonetheless, the quantitative data gathered was valuable in terms of providing clear evidence regarding the positive outcome change. It served to strengthen the conclusions made regarding the effectiveness of the programme.

Another general issue that was illuminated by the case-based method used in this study, was the value of the case conceptualisation in terms of guiding the treatment process. The study found that although a diagnostic evaluation was important in terms of informing treatment on a general level, a flexible and personalised cognitive-behavioural case conceptualisation took the treatment plan a step beyond diagnosis. The case conceptualisation of this study enabled the researcher to show how past formative experiences continued to exert an influence on present functioning. In particular, it was possible to identify Amy's past compensatory and avoidant behaviours, and see how they had ultimately failed her leaving her vulnerable to developing CFS. It was also possible to observe the powerful underlying beliefs that were contributing to her present self-driving behaviour. This information guided the researcher in terms of selecting cognitive-behavioural interventions. It also helped with respect to knowing when to implement these particular strategies. Although a personalised approach to treatment is standard practice in CBT, it is not generally reported in such detail in studies of CFS. This may be due to the fact that the researchers simplify what clinicians/therapists routinely do in clinical practice by using a battery of standardised assessment questionnaires and psychiatric schedules to obtain important information from the patient. It may also be due to the fact that researchers are selective in terms of what they report in their studies and only focus on the technical aspects of the treatment intervention. Nonetheless, the current study shows that these type of problems can be overcome by using the case study method.

The study also found that the case conceptualisation involved understanding the role of dysfunctional beliefs and maladaptive schemas. In this respect, the study found that there was a potent set of core maladaptive schemas in the area of disconnection and rejection. In addition, it was noted that specific compensatory schemas had developed to offset the core schemas, and that this compensatory strategy played an important role in maintaining the condition. It may be argued that the administration of a self-report measure, such as the Schema Questionnaire (SQ) was sufficient to identify this particular constellation of schema dynamics. However, it was found that the case-based methodology used in this study enabled the researcher to document the development of the core schemas and observe their strength in influencing behaviour, thought and feeling. Further, it was possible to gain an in-depth understanding of how the compensatory schemas operated on a practical everyday level and thereby served to maintain the chronic fatigue and functional disability.

In addition, it was observed that when the compensatory schemas were targeted as part of the treatment plan then significant past experiences and painful memories were triggered in the therapy. However, the case study method allowed the researcher to show how the developmental perspective of the study helped the patient to understand why she had adopted particular compensations and how they had become outdated and ineffective in her current life. In particular, the rich and detailed case narrative provided additional insight and commentary into how the integration of relevant historical material enabled the patient to relinquish the compensatory behaviour. This in-depth qualitative data is particularly valuable as previous CBT studies have not shown how CFS patients manage to relinquish compensatory or avoidant behaviours successfully, and deal with the underlying core schemas that are routinely evoked in this type of work. Future research might benefit from incorporating a cognitive developmental and/or schema-focused model into the treatment of patients with CFS. In fact, further accounts of individual cases like the one presented in this study would be valuable in documenting whether a cognitive developmental perspective in combination with a schema-focused model does enable the patient to relinquish compensatory behaviours. In addition, future research could perhaps focus on implementing and evaluating this enriched cognitive-behavioural treatment model, and comparing its effectiveness with the standard CBT treatment programme for CFS. It is suggested that meaningful research results must first begin on the individual level before being applied in large-scale studies.

#### 6. <u>REFERENCES</u>

- Abbey, S. E. (1996a). Psychotherapeutic perspectives on Chronic Fatigue Syndrome. In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic Fatigue Syndrome: An integrative approach</u> <u>to evidence and treatment</u> (pp. 185-211). New York: The Guilford Press.
- Abbey, S. E. (1996b). Psychiatric diagnostic overlap in Chronic Fatigue Syndrome. In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic Fatigue Syndrome: An integrative approach to evaluation and treatment</u> (pp. 48-71). New York: The Guilford Press.
- Abbey, S. E., & Demitrack, M. A. (1996). Psychiatric assessment of patients with Chronic Fatigue Syndrome. In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic Fatigue</u> <u>Syndrome: An integrative approach to evaluation and treatment</u> (pp. 130-153). New York: The Guilford Press.
- American Psychiatric Association (1994). <u>Diagnostic and statistical manual of mental disorders</u> (4th ed.). Washington, DC: Author.
- Ax, S., Gregg, V. H., & Jones, D. (1997). Chronic Fatigue Syndrome: Sufferers' evaluation of medical support. <u>Journal of the Royal Society of Medicine</u>, 90, 250-254.
- Barker, C., Pistrang, N., & Elliot, R. (1994). <u>Research methods in clinical and counselling</u> <u>psychology</u>. Chichester: John Wiley & Sons.
- Beck, A. T. (1976). <u>Cognitive therapy and the emotional disorders</u>. New York: International Universities Press.
- Beck, A. T., & Steers, R. A. (1993). <u>Beck Anxiety Inventory manual</u>. The Psychological Corporation. San Antonio: Harcourt Brace & Company.
- Beck, A. T., Steers, R. A., & Brown, G.K. (1996). <u>Beck Depression Inventory manual</u> (2<sup>nd</sup> ed.). The Psychological Corporation. San Antonio: Harcourt Brace & Company.

- Bertagnolli, A., & Morris, S. (1997). Cognitive-Behavioral interventions with Chronic Fatigue Syndrome: A single case study. Journal of Cognitive Psychotherapy, 11, 127-139.
- Bromley, D. B. (1986). <u>The case-study method in psychology and related disciplines</u>. Chichester: Wiley.
- Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D., & Wallace, E. P. (1993). Development of a fatigue scale. <u>Journal of Psychosomatic Research</u>, 37, 147-153.
- Chalder, T., Butler, S., & Wessely, S. (1996). In-patient treatment of Chronic Fatigue Syndrome. <u>Behavioural and Cognitive Psychotherapy</u>, 24, 351-365.
- Chalder, T., Power, M. J., & Wessely, S. (1996). Chronic fatigue in the community: A question of attribution. <u>Psychological Medicine</u>, 26, 791-800.
- Chalder, T., Wallace, P., & Wessely, S. (1997). Self-help treatment of chronic fatigue in the community: A randomized controlled trial. <u>British Journal of Health Psychology</u>, 2, 189-197
- Cleare, A. J., & Wessely, S. G. (1996). Chronic Fatigue Syndrome: A stress disorder? <u>British</u> Journal of Hospital Medicine, 55, 571-574.
- Clements, A., Sharpe, M., Simkin, S., Borrill, S., & Hawton, K. (1997). Chronic Fatigue Syndrome: A qualitative investigation of patients' beliefs about the illness. <u>Journal of</u> <u>Psychosomatic Research</u>, 42, 615-624.
- Cope, H., Mann, A., Pelosi, A., & David, A. (1996). Psychological risk factors for chronic fatigue and Chronic Fatigue Syndrome following presumed viral illness: A case-control study. <u>Psychological Medicine</u>, 26, 1197-1209.

- Deale, A., Chalder, T., Marks, I., & Wessely, S. (1997). Cognitive behavior therapy for Chronic Fatigue Syndrome: A randomized controlled trial. <u>American Journal of Psychiatry, 154</u>, 408-414.
- Deale, A., Chalder, T., & Wessely, S. (1998a). Illness beliefs and treatment outcome in Chronic Fatigue Syndrome. Journal of Psychosomatic Research, 45, 77-83.
- Deale, A., Chalder, T., & Wessely, S. (1998a). Commentary on: Randomized, double-blind, placebo-controlled trial of fluoxetine and graded exercise for Chronic Fatigue Syndrome. <u>British Journal of Psychiatry, 172</u>, 491-492.
- Deale, A., & David, A. S. (1994). Chronic Fatigue Syndrome: Evaluation and management. Journal of Neuropsychiatry, 6, 189-194.
- Demitrack, M. A. (1996). The psychobiology of chronic fatigue: The central nervous system As a final common pathway. In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic</u> <u>Fatigue Syndrome: An integrative approach to evaluation and treatment</u> (pp. 72-109). New York: The Guilford Press.
- Demitrack, M. A., & Abbey, S. E. (1996). Historical overview and evolution of contemporary definitions of chronic fatigue states. In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic Fatigue Syndrome: An integrative approach to evaluation and treatment</u> (pp. 3-35). New York: The Guilford Press.
- Demitrack, M. A., & Greden, J. F. (1991). Chronic Fatigue Syndrome: The need for an integrative approach. <u>Biological Psychiatry</u>, 30, 747-752.
- Edwards, D. J. A. (1990). Research and reality: How clinical theory and practice are actually developed Case study method in cognitive behaviour therapy. In J. Mouton & D. Joubert (Eds.), <u>Knowledge and method in the human sciences</u> (pp 359-374). Pretoria: Human Sciences Research Council.

- Edwards, D. J. A. (1996). Case study research method: The cornerstone of theory and practice in cognitive therapy. In M. Reinecke, F. Dattilio & A. Freeman (Eds.), <u>Cognitive therapy with children and adolescents: A casebook for clinical practice</u> (pp. 10-37). New York: Guilford.
- Edwards, D. J. A. (1998a). Types of case study work: A conceptual framework for case-based research. Journal of Humanistic Psychology, 38, 36-70.
- Edwards, D. J. A. (1998b). <u>Cognitive therapy: A guide for clients</u>. Unpublished booklet, Rhodes University, Grahamstown.
- Edwards, D. J. A. (1999). <u>The development of scientific knowledge through case-based</u> <u>research: Definitions of terms and fundamental principles</u>. Paper presented at the convention of the American Psychological Association Boston, United States of America.
- Findley, J. C., Kerns, R., Weinberg, L. D., & Rosenberg, R. (1998). Self-efficacy as a psychological moderator of Chronic Fatigue Syndrome. <u>Journal of Behavioral</u> <u>Medicine, 21</u>, 351-362.
- Fischler, B., Dendale, P., Michciels, V., Cluydts, R., Kaufman, L., & De Meirleir, K. (1997).
   Physical fatigability and exercise capacity in Chronic Fatigue Syndrome: Association with disability, somatization and psychopathology. <u>Journal of Psychosomatic Research</u>, 42, 369-378.
- Friedberg, F. (1996). Chronic Fatigue Syndrome: A new clinical application. <u>Professional</u> <u>Psychology: Research and Practice, 27, 487-494</u>.
- Friedberg, F., & Krupp, L. B. (1994). A comparison of cognitive behavioral treatment for Chronic Fatigue Syndrome and primary depression. <u>Clinical Infectious Diseases</u>, 18, S105-S110.

- Gelder, M. (1997). The scientific foundations of cognitive behaviour therapy. In D. M. Clark & C. G. Fairburn (Eds.), <u>Science and practice of cognitive behaviour therapy</u> (pp. 27-46). New York: Oxford University Press.
- Gibson, H., Carroll, N., Clague, J. E., & Edwards, R. H. T. (1993). Exercise performance and fatiguability in patients with Chronic Fatigue Syndrome. <u>Journal of Neurosurgery and</u> <u>Psychiatry, 56</u>, 993-998.
- Greenberger, D., & Padesky, C. A. (1995). <u>Mind over mood: Change how you feel by changing</u> <u>the way you think</u>. New York: The Guilford Press.
- Howlett, M., & Lindgger, G. (1996). Attributional style and illness behaviour in Chronic Fatigue Syndrome. <u>South African Journal of Psychology</u>, 26, 39-46.
- Jordan, N. C. (1994). <u>A neuropsychological investigation into the cognitive profile of myalgic</u> <u>encephalomyelitis</u>. Unpublished Master's thesis, Rhodes University, Grahamstown.
- Kaplan, M. D., Saddock, B. J., Grebb, J. A. (1994). <u>Synopsis of psychiatry:</u>
   <u>Behavioural sciences, clinical psychiatry</u> (7th ed.). Baltimore: Williams & Wilkins.
- Kazdin, A. E. (1982). <u>Single-case research designs: Methods for Clinical and applied settings</u>. Oxford: Oxford University Press Inc.
- Kratochwill, T. R., Mott, S. E. & Dodson, C. L. (1984). Case study and single case research in clinical and applied psychology. In A. S. Bellack & M. Hersen. (Eds.), <u>Research</u> <u>methods in clinical psychology</u> (pp. 55-99). New York: Pergamon.
- Leahy, R. L. (1996). <u>Cognitive therapy: Basic principles and applications</u>. Northvale, New Jersey: Jason Aronson Inc.
- Lee, C. W., Taylor, G., & Dunn, J. (1999). Factor structure of the Schema Questionnaire in a large clinical sample. <u>Cognitive Therapy and Research</u>, 23, 441-451.

- Lloyd, A. R. (1998). Chronic fatigue and Chronic Fatigue Syndrome: Shifting boundaries and attributions. The American Journal of Medicine, 105, 75-105.
- Lloyd, A. R., Hickie, I., Brockman, A., Hickie, C., Wilson, A., Dwyer, J., & Wakefield, D. (1993). Immunologic and psychologic therapy for patients with Chronic Fatigue Syndrome: A double-blind, placebo-controlled trial. <u>The American Journal of Medicine</u>, <u>94</u>, 197-203.
- Marks, I. (1986). <u>Behavioural psychotherapy: Maudsley pocket book of clinical management</u> (pp. 37-39, 45-46). Bristol, Wright.
- Miles, M. B., & Huberman, A. M. (1994). <u>Qualitative data analysis: An expanded sourcebook</u>. (2nd ed.). Thousand Oaks CA: Sage.
- Padesky, C. A. (1996). <u>Testing automatic thoughts with thoughts records</u>. Video produced at the Center for Cognitive Therapy and at New Harbinger Publishers. Newport Beach: CA.
- Petrie, K., Moss-Morris, R., & Weinman, J. (1995). The impact of catastrophic beliefs on functioning in Chronic Fatigue Syndrome. <u>Journal of Psychosomatic Research</u>, 39, 31-37.
- Powell, R., Dolan, R., & Wessley, S. (1990). Attributions and self-esteem in depression and chronic fatigue syndromes. <u>Journal of Psychosomatic Research</u>, 34, 665-673.
- Salit, I. E. (1997). Precipitating factors for the Chronic Fatigue Syndrome. Journal of Psychiatric Research, 31, 59-65.
- Schmidt, N. B., Joiner, T. E., Young, J. E., & Telch, M. J. (1995). The Schema Questionnaire: Investigation of psychometric properties and the hierarchical structure of a measure of maladaptive schemas. <u>Cognitive Therapy and Research</u>, 19, 295-321.

- Sharpe, M. (1996). Cognitive-behavioral therapy for patients with Chronic Fatigue Syndrome: How? In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic Fatigue Syndrome: An</u> <u>integrative approach to evaluation and treatment</u> (pp. 240-262). New York: The Guilford Press.
- Sharpe, M. (1997a). Chronic fatigue. In D. M. Clark & C. G Fairburn (Eds.), <u>Science and</u> <u>practice of cognitive behaviour therapy</u> (pp. 381-414). New York: Oxford University Press.
- Sharpe, M. (1997b). Cognitive behavior therapy for functional somatic complaints: The example of Chronic Fatigue Syndrome. <u>Psychosomatics</u>, <u>38</u>, 356-362.
- Sharpe, M. (1998a). Cognitive behavior therapy for Chronic Fatigue Syndrome: Efficacy and implications. <u>The American Journal of Medicine</u>, 105, 1045-1095.
- Sharpe, M. (1998b). Doctors' diagnoses and patients' perceptions. <u>General Hospital</u> <u>Psychiatry</u>, 20, 335-338.
- Sharpe, M., Chalder, T., Palmer, I., & Wessely, S. (1997). Chronic Fatigue Syndrome: A practical guide to assessment and management. <u>General Hospital Psychiatry</u>, 19, 185-199.
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic Fatigue Syndrome: A cognitive approach. <u>Behavior Research Therapy</u>, 33, 535-544.
- Tompkins, M. A. (1997). Case formulation in cognitive-behavioral therapy. In R. L. Leahy (Ed.), <u>Practising cognitive therapy: a guide to interventions</u> (pp. 37-59). Northvale, New Jersey: Jason Aronson Inc.

- Twemlow, S. W., Bradshaw, S. L., Coyne, L., & Lerma, B. (1997). Patterns of utilization of medical care and perceptions of the relationships between doctor and patient with chronic illness including Chronic Fatigue Syndrome. <u>Psychological Reports, 80</u>, 643-658.
- Ware, N. C. (1993). Society, mind and body in Chronic Fatigue Syndrome: An anthropological view. In G.R Bock & J Whelen (Eds.), <u>Chronic Fatigue Syndrome: Symposium on</u> <u>Chronic fatigue syndrome, Ciba Foundation, London, 12-14 May 1992</u>. Chichester: Wiley.
- Wearden, A. J., Morriss, R. R., Mullins, R., Strickland, P. L., Pearson, D. J., Appelby, L., Campbell, I. T., & Morris, J. A. (1998). Randomized, double-blind, placebo-controlled treatment trial of fluxetine and graded exercise for Chronic Fatigue Syndrome. <u>British</u> <u>Journal of Psychiatry, 172</u>, 485-490.
- Wessely, S. C. (1996). Cognitive-behavioral therapy for patients with Chronic Fatigue Syndrome: Why? In M. A. Demitrack & S. E. Abbey (Eds.), <u>Chronic Fatigue Syndrome:</u> <u>An integrative approach to evaluation and treatment</u> (pp. 212-239). New York: The Guilford Press.
- Wessely, S., Chalder, T., Hirsch, S., Wallace, P., & Wright, D. (1996). Psychological symptoms, somatic symptoms, and psychiatric disorder in Chronic Fatigue Syndrome:
  A prospective study in the primary care setting. <u>American Journal of Psychiatry, 153</u>, 1050-1059.
- Wessely, S., Chalder, T., Hirsch, S., Wallace, P., & Wright, D. (1997). The prevalence and morbidity of chronic fatigue and Chronic Fatigue Syndrome: A prospective primary care study. <u>American Journal of Public Health, 87</u>, 1449-1455.

- Woodward, R. V., Broom, D. H., & Legge, D. G. (1995). Diagnosis in chronic illness: Disabling or enabling - the case of Chronic Fatigue Syndrome. <u>Journal of the Royal</u> <u>Society of Medicine, 88</u>, 325-329.
- Young, J. E. (1994). <u>Cognitive therapy for personality disorders: A schema-focused approach</u> (Revised ed.). Sarasota, Florida: Professional Resource Exchange.
- Young, J. E., & Brown, G. (1990). Schema Questionnaire (2nd ed.). In J. E. Young (1994)
   <u>Cognitive therapy for personality disorders: A schema-focused approach</u> (Revised ed.).
   Sarasota, Florida: Professional Resource Exchange.
- Young, J. E. & Klosko, J. S. (1993). <u>Reinventing your life: How to break free from negative</u> <u>life patterns and feel good again</u>. New York: Plume.

## 6. APPENDICES

## APPENDIX I

## PARTICIPANT QUESTIONAIRE

1. Has your diagnosis of CFS been confirmed by a medical practitioner by the exclusion of any other possible conditions?

## **Broad Clinical Syndromes**

- <u>Chronic Fatigue Syndrome (CFS)</u>
- 1. Have you experienced the principal symptom of fatigue with definite onset and not lifelong?
- 2. Have you experienced severe, disabling fatigue, which affects physical and mental functioning?
- 3. Have you experienced at least six months of fatigue during which it is present at least 50% of the time?
- 4. Which of the following other symptoms have you experienced?
  - Myalgia
  - Mood disturbances
  - Sleep irregularity
- 5. Have you ever been diagnosed with any of the following medical or psychiatric conditions?
  - Established medical conditions known to produce chronic fatigue
  - Schizophrenia
  - Manic depressive illness
  - Substance abuse
  - Eating disorder
  - Organic brain disease

- <u>Postinfectious Fatigue Syndrome (PIFS)</u>
- 1. Do you have a subtype of CFS which is associated with an infectious illness?
- 2. Do you fulfil the criteria for CFS as specified above, and, in additions have:
  - Definite evidence, including laboratory corroboration, of infectious illness at onset
  - Full syndrome is present for at least six months after onset of infection

## APPENDIX II

# CHRONIC FATIGUE SYNDROME (CFS): COGNITIVE-BEHAVIOURAL THERAPY RESEARCH CONSENT FORM

The aim of this study is to implement a cognitive-behavioural assessment and treatment programme and evaluate the practicality and credibility of this approach. I hereby consent to participate in the programme on the following understanding:

- 1. The programme is part of a Masters research project in Clinical Psychology. It will be conducted by a trained clinician from Rhodes University and will consist of approximately 15 one-hour sessions in total.
- The assessment will involve a detailed interview where personal information will be required (1 to 3 one-hour sessions). In the case of participant minors (i.e. under age 21) additional information will be needed from parents/guardians(s).
- 3. The remaining 12 sessions will be devoted to the cognitive-behavioural treatment programme which includes homework assignments involving self-monitoring of thoughts and behaviour and experimenting with new behaviour. The programme involves a four stage process namely: (1) identifying and reviewing thoughts and behaviour: (2) evaluating attitudes; (3) problem solving, and (4) consolidation of gains and consideration of future plans.
- 4. The researcher may need to consult medical records so as to facilitate competent assessment.
- 5. The treatment programme is flexible so that participants will be able to proceed at their own pace.

- 6. The data obtained from this assessment and treatment programme will be used for research and publication purposes. Personal details and identifying information will be deliberately altered in the report in a way which will ensure the confidentiality and anonymity.
- 7. General information regarding the results of the study will be given at the end of the treatment programme to individual participants.

I agree to participate in the full programme and grant permission to consult my medical records, and allow the data/material obtained from the programme to be used for research and publication purposes. Furthermore, I understand that I am entitled to withdraw from the research study at any time but I undertake to do this only after a thorough discussion with the researcher.

Signature	-
Signature of parent/guardian (if under 21 ye	ears)
Date	

## APPENDIX III

## TWO INFORMATIONAL GUIDES ABOUT CBT FOR CFS

## APPENDIX IV

# RECORD OF DISFUNCTIONAL THOUGHTS FORM

Identifying and working with my patterns of negative thinking

1	Situation Context	
	Who? What? When? Where?	
2	Emotions/ Moods	
	(rate/100)	
3	Automatic Thoughts And images	
4	(circle hot thought)	
4	Evidence that supports the hot thought	
5	Evidence that does not support the hot thought	
6	Alternative, balanced thoughts ( <i>rate belief/100</i> )	
7	Action plan	
8	Current emotions/moods	
1	( <i>rate/100</i> )	