

**THE LIVED EXPERIENCE OF PERSONS WITH
CHRONIC FATIGUE SYNDROME**

A Qualitative Phenomenological Study

by

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ABSTRACT

The Lived Experience of Persons with Chronic Fatigue Syndrome

This phenomenological study examined the lived experience of persons who suffer from Chronic Fatigue Syndrome (CFS). Research into this condition has to date concentrated on causality and coping strategies and there is limited knowledge of the experiences of sufferers of this condition. In-depth interviews were conducted with five participants who met the criteria for the diagnosis of CFS. The interviews were tape-recorded, transcribed verbatim and analysed, coding for thematic content.

Eleven themes emerged from the data analysis. Living with CFS involved living with uncertainty and fear, a life-draining tiredness, and an unpredictable and undependable body and was described as a 'living death'. The illness was perceived to have power over the person's life and impacted on the sufferers' emotions and relationships. CFS sufferers lived with a perception that the illness was not considered legitimate, and this led to a struggle for acceptance of self and the condition. Creating a meaningful existence involved creating an image of coping and normality, maintaining control, taking responsibility for self. Participants, despite the impact of the illness on their lives, lived with a hope for remission and recovery and made the best of good days.

The challenges, difficulties and support needs faced by persons who live with this condition are discussed. The implications of the research highlight the need for a sensitive and responsive health care service in addressing the needs of persons with CFS.

DEFINITIONS AND EXPLANATIONS OF TERMS

CFS: Chronic Fatigue Syndrome. Previously known, especially in lay literature, as Myalgic Encephalomyelitis [ME]

FAI: Free Attitude Interview

ICD: International Classification of Diseases

MMPI: Minnesota Multiphasic Personality Inventory

QRI: Qualitative Research Interview

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS	i
ABSTRACT	ii
DEFINITION OF TERMS	iii

CHAPTER 1: INTRODUCTION

1.1	The Phenomenon of Interest: Chronic Fatigue Syndrome.....	1
1.2	The Search for Causation.....	6
1.2.1	CFS: a biological disease ?.....	6
1.2.2	CFS: a psychological disorder?.....	8
1.2.3	CFS: a form of illness behaviour?.....	9
1.2.4	CFS: a women's disease?.....	10
1.3	CFS – A Treatment dilemma.....	10
1.4	CFS - Self help options.....	11
1.5	Need for the research and evolution of the study.....	13

CHAPTER 2: METHOD OF INQUIRY

2.1	Introduction.....	16
2.2	The choice of a qualitative research design.....	16
2.2.1	The phenomenological approach.....	16
2.3	The Research Process.....	18
2.3.1	Sampling Selection.....	18
2.3.2	Choice of participants - gaining access to the study population.....	19
2.3.2	Setting and Rapport with participant.....	19

2.4	Ethical Considerations.....	20
2.4.1	Informed consent.....	21
2.4.2	Confidentiality.....	21
2.4.3	Possible benefit from the research.....	22
2.4.4	Use of transcribing equipment.....	22
2.4.5	Researcher-participant relationships.....	22
2.4.6	Management of sensitive information and need for support.....	22
2.5	Collection of data.....	23
2.5.1	The Qualitative Research Interview (QRI).....	23
2.5.2	Formulating the Question.....	25
2.6	The scientific rigor of the study.....	27
2.6.1	Reliability and Validity.....	27
2.6.1.1	Credibility.....	27
2.6.1.2	Transferability.....	27
2.6.1.3	Dependability.....	28
2.7	Transcription of data.....	28
2.7.1	Preparation of Data for Analysis.....	28
2.8	Data analysis.....	29
2.8.1	The Methodology Process in Phenomenological Research.....	29
2.8.2	Stages of analysis.....	30
	Stage 1: Initial Reading of the Data	
	Stage 2: Delineation of meaning units [themes]	
	Stage 3: Re-articulation of meaning units from a psychological perspective	
	Stage 4: Clinically situated structure	
	Stage 5: Development of central themes	
	Stage 6: Construction of extended description	
	Stage 7: Construction of a general structure	
2.9	The Research Report.....	34
2.10	Concluding Comments.....	35
	Table 1: Example of Analysis of First Three Stages.....	36

CHAPTER 3: THE CFS EXPERIENCE: PRESENTATION OF DATA

3.1	Introduction.....	38
3.2	Emergence of Themes.....	39
3.2.1	Theme: Uncertainty and Fear.....	40
3.2.2	Theme: Life Draining Tiredness.....	41
3.2.3	Theme: An Unpredictable and Undependable Body.....	43
3.2.4	Theme: Living Death	46
3.2.5	Theme: Emotions in Illness.....	48
3.2.6	Theme: Illness has power.....	50
3.2.7	Theme: Legitimacy of the Illness.....	54
3.2.8	Theme: Illness in Relationship.....	58
3.2.9	Theme: The Struggle for Acceptance.....	61
3.2.10	Theme: Creating a Meaningful Existence.....	66
3.2.10.1	Creating an image of coping and normality.....	67
3.2.10.2	Attempting to maintain control.....	67
3.2.10.3	Choices and conflicts: the challenges of CFS.....	69
3.2.10.4	Taking responsibility for oneself.....	72
3.2.11	Theme: Remission, Recovery and Hope.....	74
3.3	Concluding Comments.....	78

CHAPTER 4: DISCUSSION AND CONCLUSION

4.1	Introduction.....	79
4.2	CFS in relation to lifeworld themes.....	80
4.2.1	CFS and the lived body.....	82
4.2.2	Illness in Relationship (CFS and Lived Relationality).....	86
4.2.3	CFS and the Lived Environment (Space).....	88
4.2.4	CFS and Lived Time.....	89
4.3	Creating a Meaningful Existence.....	90
4.4	CFS as a Positive Experience.....	93

4.5	Implications of the Findings.....	94
4.6	Limitations of the Study and Recommendations.....	96
4.6	Conclusion.....	98

REFERENCES	99
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APPENDICES

Appendix A: Permission to Conduct Study.....	112
Appendix B: Introductory Letter and Consent Form	113
Appendix C: Example of Original Full Transcript – Protocol One.....	114
Appendix D: Protocol One : Example of Analysis Transformation – General Units of Meaning – Transformed Units of Meaning.....	136
Appendix E: Example of Theme of Acceptance and Researcher Reflections, Protocol One.....	162
Appendix F: Categories and Themes Emerging from the Data.....	167

CHAPTER I

INTRODUCTION

1.1 The Phenomenon of Interest: Chronic Fatigue Syndrome (CFS)

Fatigue, defined by the Longman dictionary as "great tiredness; exhaustion", is a state which most persons have experienced at some time in their daily lives. The possible causes of fatigue are numerous, ranging from over-exertion over a period of time to the fatigue that accompanies certain illness conditions.

Physicians have been confronted with the complaint of fatigue since the inception of the doctor-patient relationship. In the majority of cases, fatigue, like the remainder of its symptomatic counterparts, resolves once the patient is cured of clinical illness (Kim 1994:1070; McKenzie & Straus 1995:119). It could therefore be assumed by the health professional that, once the illness has been effectively treated, the patient's fatigue would disappear. However, persistent chronic fatigue which does not resolve with treatment is a diagnostic and treatment challenge for health professionals.

The condition defined as Chronic Fatigue Syndrome (CFS) is an increasingly popular diagnosis, particularly in the developed world. CFS, previously termed Myalgic Encephalomyelitis or Post Viral Fatigue Syndrome, has generated a number of competing hypotheses regarding its aetiology (Farrar, Locke & Kantrowitz 1995:5-6). "CFS is an example of a complex disease syndrome with physical, psychological, social and community implications" (Jason, Wagner, Taylor, Ropacki, Shlaes, Ferrari et al. 1995:143).

CFS is a heterogeneous disorder characterised by self-reported persistent or relapsing severe disabling fatigue of at least six months duration. Persons with CFS also report a combination of symptoms of varying frequency and severity, such as low-grade fever, myalgia, arthralgia, headache, sore throat, painful lymphadenopathy and muscle weakness together with various neuro-psychiatric symptoms which may include depression, anxiety, impairments in concentration and short term memory, and sleep disturbances. An acute or mononucleosis-like illness often marks the onset of the syndrome, and the illness typically follows a variable course of exacerbations and remissions. Symptoms may last for years, leading to a significant impact on the quality of life and lifestyle (Farrar et al. 1995:5-16; Fukuda, Straus, Hickie, Sharpe, Dobbins & Komaroff 1994:953).

CFS is a disorder that has raised significant diagnostic controversy among clinicians, and the debate over the very existence of the disorder as a discrete entity continues. The difficulty in establishing valid and reliable diagnostic tests, the role of emotional factors in the syndrome and the lack of development of appropriate treatment strategies have fuelled the controversy. The debate has often been polarised between those insisting on a purely biological explanation and those proposing that CFS is an entirely mental phenomenon (Farrar et al. 1995:5-16).

There is little agreement as to what constitutes the classic presentation of this syndrome and the typical demographic features of persons who have been diagnosed with this condition. In a survey of studies of this condition, Euba, Chalder, Deale & Wessely (1996:121-126) summarise the findings: CFS sufferers are more likely to be women, to belong to higher social classes (with a particular over-representation of professionals), to be functionally impaired, to have high levels of psychological distress, to hold characteristic illness beliefs, and have a poor prognosis.

A working case definition developed in 1988 by the Centre for Disease Control (CDC) required the presence of multiple symptoms or signs and the exclusion of persons with psychiatric syndromes (Holmes, Kaplan, Gantz, Komaroff, Schonberger, Straus et al. 1988:387-9). In 1994, this group revised the working case definition to include certain affective, anxiety and somatization disorders, together with guidelines for the definition and clinical evaluation of prolonged and chronic fatigue, and laboratory screening tests (Fukuda et al. 1994:953-9).

According to these guidelines, CFS may be diagnosed if:

- ◆ Criteria for severity of fatigue are met. Self-reported, persistent or relapsing fatigue lasting six or more consecutive months (clinical evaluation to exclude other causes of fatigue must be done prior to diagnosis of fatigue meeting these criteria).
- ◆ Four or more of the following symptoms are concurrently present for ± 6 months:
 1. Impaired memory or concentration
 2. Sore throat
 3. Tender cervical or axillary lymph nodes
 4. Muscle pain
 5. Multi-joint pain
 6. New headaches
 7. Unrefreshing sleep
 8. Post exertion malaise

- ◆ Laboratory screening tests to exclude the possibility of other causes of fatigue are normal.

Screening laboratory tests recommended by this research group are:

Full blood count, Erythrocyte sedimentation rate, Alanine aminotransferase, Total protein, Albumin, Globulin, Alkaline phosphatase, Calcium, Phosphate, Glucose, Blood urea nitrogen Electrolytes, Creatinine, Thyroid stimulating hormone and Urinalysis (Fukuda et al. 1994:955).

The emergence of CFS has challenged clinicians to better understand the differences between the different sub-types of fatigue. It is necessary to distinguish between CFS and other, clinically similar conditions. It is furthermore essential to be able to differentiate between fatigue for which there exists a treatable cause and other types of fatigue which may require symptomatic and/or supportive treatment.

Research into CFS has focused on the aetiology of the syndrome, notably on three kinds of factors which are thought to play a role: viral, immunological and psychological (Murray 1992:1123-1136; Lewis, Cooper & Bennet 1994:661-671; Masuda, Nozoe, Matsuyama & Tanaka 1994:512-518; Farrar et al. 1995:5-16), on intervention/treatment options (Blondel-Hill & Shafran 1993:639-651; Kantrowitz, Farrar & Locke 1995:17-24; Mechanic 1993:318-341; Wilson, Hickie, Lloyd & Wakefield 1994:544-550), and to a lesser degree, the psychological structure of the symptoms of the illness (Ray, Weir, Cullen & Phillips 1992:243-256), and the profiles of patients with CFS (Schmaling & Jones 1996:67-74).

Other areas of research into this condition have included: coping mechanisms of the sufferers (Blakely, Howard, Sosich, Murdoch, Menkes & Spears 1991:347-62; Ray, Weir, Miller & Hyde 1993:385-391; Fennell 1995:69-79; McKenzie, Dechene, Friedberg & Fontanetta 1995:59-67; Ray, Jefferies and Weir 1995:937-945), sociocultural issues in the development and the course of the disease (Abbey & Garfinkel, 1991:1638-1646; Ware & Kleinman 1992:546-60; Abbey 1993:238-261), comparisons between the diagnosis of neurasthenia and CFS (Wessely 1994:173-209; Farmer, Jones, Hillier, Llewelyn, Borysiewicz & Smith 1995:503-506), cognitive functioning and depression in patients with CFS (Krupp, Sliwinski, Masur, Friedberg & Coyle 1994:705-710). More recently, research areas have expanded to include the relationship between illness beliefs and treatment outcome (Deale, Chalder & Wessely 1998:77-83), and longitudinal studies associated with improvement in patients with CFS (Russo, Katon, Clark, Kith, Sintay & Buchwald 1998:67-76).

Qualitative research into the Chronic Fatigue Syndrome as a holistic phenomenon, however, has been minimal. There is a paucity of published work on the lived experience of CFS. Tuck & Human (1998:15-19) analysed the responses of 22 participants who completed a set of questionnaires, including a set of open-ended questions in which participants were asked to respond to the following questions: *What has the experience of CFS been like for you?* and *Describe your physical and emotional symptoms.* This information was transcribed and analysed using a thematic approach. This study, although limited in its scope, will be discussed further in the light of my own findings.

1.2 The Search for Causation

There are conflicting opinions about the aetiology of CFS, but insufficient data to support any one theory. Shorter (1993:14), detailing the history of the symptom of chronic fatigue, contends that "historical evidence suggests that chronic fatigue, much of it of an evidently psychogenic nature, has been a popular medical complaint for about a hundred years." Shorter (1993:7-15) describes four separate chains of events that resulted in the diagnosis of CFS: the 1934 epidemic of fatigue and muscle pain of unclarified aetiology, then named **neuromyasthenia**; the possible link with the organic disease mononucleosis, which has similar symptoms to CFS; the disease label of **myalgic encephalomyelitis** being given in Britain to a condition with the same symptomatology as CFS in USA; and the rheumatological diagnosis of **fibromyalgia**, the symptoms of which are being viewed as closely related if not identical to those of CFS.

CFS was finally given its current name during a 1987 meeting of infectious disease specialists in order to arrive at a case definition (Holmes et al. 1988:387-389). Researchers in Australia had been debating the issue of a suitable nomenclature and proposed the identical title. Two years later researchers in the United Kingdom renamed the condition of ME as CFS (Wessely, Hotopf & Sharpe 1998:125).

1.2.1 CFS: a biological disease?

A condition which was initially thought to be a chronic Epstein-Barr virus syndrome when first it came to the attention of the medical profession, CFS has been the subject of interest and debate since 1985 (Holmes et al. 1988:387; Wessely et al. 1998:124). More recent work has demonstrated no correlation between serological markers of the Epstein-Barr virus and clinical condition. Studies have been done on the role of human herpesvirus, enteroviruses, and more recently on human

retroviruses with inconclusive results. Wessely et al. (1998:182-183) have summarised the current findings in respect of viral causation as follows: some infections, notably the Epstein-Barr virus, may be more liable to cause persistent neurasthenic sequelae than others; the risk of chronic fatigue is determined by other factors, among which appear to be personality and previous psychological vulnerability; there is no definitive link between the enteroviruses and CFS; the complexity of the literature on viral infection, psychological vulnerability and the development of post infectious fatigue is such that further research is required. The possibility of immune dysfunction as a causative factor has led to research in the fields of both humoral and cell mediated immunity (Palca 1991, Read et al. 1988 & Strauss et al.1989, cited by Murray 1992:1125).

A further area of research is into the role of toxins, both external environmental or dietary toxins and internally generated autointoxicants. The impact of current lifestyles on health has been brought into the debate. The possible impact of excessively refined dietary foodstuffs, pollutants of air and soil, widespread use of antibiotics, is under investigation. Other hypotheses for the aetiology of this condition have included chronic hypoglycaemia, "total allergy syndrome" or "20th century disease" and chronic candidiasis (Kim 1994:1071). To date, no definitive cause[s] have been identified for this condition.

1.2.2 CFS: a psychological disorder?

A distinctive feature of CFS is its psycho/neuro-psychiatric symptomatology and presentation. This confusion has challenged the acceptance of this condition as a discrete entity by clinicians. CFS has been compared by Abbey & Garfinkel (1991:1638-46) to the nineteenth century syndrome of neurasthenia. The authors argue that the diagnosis developed out of the need to emphasise a medical rather than a psychiatric diagnosis. Furthermore, the authors state that the implication of this argument is that neither Chronic Fatigue Syndrome nor nineteenth-century neurasthenia is a definite syndrome, but rather that they represent explanatory labels for a wide variety of functional somatic symptoms.

Beard (1869, cited by Abbey & Garfinkel 1991:1639) described the fatigue of neurasthenia as "attacks of a sensation of absolute exhaustion often accompanied by the feeling that the exhaustion is so extreme that one experiences a 'going-to-die' feeling." This description has remarkable similarities to those offered by present day sufferers, and poses challenging questions to the understanding of this disorder.

Psychological symptoms, in particular depression, have been widely acknowledged as part of the clinical picture of Chronic Fatigue Syndrome. Blakely et al. (1991:347-362), in a study of the psychological characteristics of Chronic Fatigue Syndrome as compared with sufferers of chronic pain, noted raised emotionality levels on the first MMPI factor. Farmer et al. (1995:503-6), in a study using the ICD-10 Neurasthenia definition, found that almost all subjects with CDC defined CFS met the criteria for neurasthenia. Hickie, Lloyd, Wakefield & Parker (1990:534-40) contended that the pattern of psychiatric symptoms in CFS sufferers was no higher than that estimated for the general community.

Wessely et al. (1998:210) comment on the confusion relating to the classification of CFS, as they mention that CFS is currently listed in the ICD-10 classification as post-viral fatigue syndrome under neurology, and as neurasthenia under psychiatry. The authors point out that the descriptions of the conditions are close to identical, and that this reflects the divide that exists within current views of the syndrome.

1.2.3 CFS: a form of illness behaviour?

The strong psychological components of this condition and the overlap of symptoms with a wide variety of non-specific complaints raise the issue of illness behaviour. Illness behaviour seeks to explain which people consult doctors for symptoms, and when they make this decision. Wessely et al. (1998:22) identify factors considered to be important in illness behaviour as it relates to CFS. First is the nature of the person: an introspective nature and a tendency to focus on symptoms is associated with more medical utilisation, increased symptoms and increased distress. Second is the character of the symptom: symptoms that are highly visible such a fracture, or those that interfere with social functioning such as fatigue, are more likely to cause concern.

Does CFS represent yet another manifestation of the social stresses of modern day living? Does CFS legitimate a set of illness behaviours which allows the sufferer to take on the sick role, receive the sympathy and attention normally accorded to a sick person, and provide socially legitimate excuses for withdrawal from highly stressful situations? There has been strong resistance by CFS sufferers to the psychiatric labelling, and the need to 'medicalise' the condition has led sufferers to pursue their own understanding of the condition through a number of means discussed later in this chapter.

1.2.4 CFS: a women's disease?

Another interesting feature of CFS is the apparent higher frequency of occurrence in women (Murray1992:1123-1136). Abbey & Garfinkel (1991:1644) comment on the issues of gender with respect to both neurasthenia and CFS. In both conditions, the diagnosis was [and is] more commonly found among women. The social conditions for women in the late nineteenth century, they argue, have parallels with those of the current age. "Our own culture is wrestling with the expanding role of women and the mismatch between women's ambition and social possibilities.....Chronic Fatigue Syndrome sufferersfeel conflicted about their working lives and the difficulty in balancing their careers with their family obligations and their personal wishes."

1.3 CFS: A Treatment Dilemma

There is no specific treatment of proven efficacy for patients with CFS (Salit1996:541). Treatment options for persons suffering from this condition have included the use of anti-depressants, vitamin and diet therapies, immunologic therapies, corticosteroids, anti-viral therapies and cognitive behaviour therapy, as well as a wide range of complementary or alternative therapies (Wilson, Hickie, Lloyd & Wakefield 1994:545-8; Wessely et al 1998:361-374). Indeed, Wessely et al. (1998:357) state "It is hard to imagine any illness for which more unproven remedies have been advocated with greater enthusiasm than CFS". Management of patients is generally aimed at symptom relief, reduction of disability and avoidance of harm.

Many patients attending the CFS clinic at Groote Schuur Hospital over the period 1993-6 reported consultations with a number of the complementary therapists and or had made use of 'alternate' treatments in an attempt to find answers to their problems. This phenomenon is possibly due to the lack of options available from the formal health professions, or the increasing trend towards holistic non-allopathic forms of treatment, particularly in persons for whom the formal health care system has failed to provide adequate or acceptable answers. This has the potential for 'doctor shopping', at considerable expense, and does not necessarily provide the sufferer with any long-term relief.

Treatment protocols are hampered by the fact that currently there is insufficient information on the natural history of CFS, of overlapping conditions, of effective treatments, and of the role of factors that predispose, precipitate and perpetuate the illness (Salit 1996:543). Wessely et al. (1998:383-393) have suggested that treatment of patients with CFS should include education and advice, appropriate prescription of an antidepressant drug and cognitive behaviour therapy in a stepped care approach.

1.4 CFS: Self help options

Persons living with CFS have become alienated from the formal medical system and have turned to the self-help option. Self-help associations have been formed in, among other countries, the USA, United Kingdom, and in South Africa in an attempt to enable sufferers to help themselves.

Much of the information available to sufferers of this condition has doubtful origins, and there is much written for which no scientific substantiation has been published. Many sufferers have tried a variety of treatments purporting to offer cures or at least relief, and the popular literature has a number of books which give details of treatments which vary from high doses of vitamins, combinations of antidepressants and vitamins, to dietary adjustments. Internet sites range from official (e.g. www.cdc.gov) to a variety of self-help sites.

That this condition has caused many persons much distress is evidenced by the foreward to a book entitled "**50 Things you should know about the Chronic Fatigue Syndrome Epidemic**"

You woke up one morning, a couple of years ago - or maybe longer- feeling like you had the flu. Your throat ached, you were feverish, and had muscle pains, and a headache...you had overwhelming fatigue. Swallowing a couple of aspirins, you assumed you'd be better in a few days. But a week later, you still weren't well. Six months later, you still weren't better, and now, disturbing new problems arose: You couldn't remember where you'd parked the car, for instance, or you started having difficulty making change...you began to feel like you were walking around in a fog much of the time, unable to think clearly or remember things properly. And there was still the unrelenting, sometimes overpowering, fatigue....Doctor after doctor told you that nothing was wrong with you. Family and friends began to lose patience with you, told you to snap out of it and pull yourself together. ..you finally found a name for the mystery disease: Chronic Fatigue Syndrome..."(Ostrom 1992:1)

Surviving M.E., the title of a book by sufferer Joyce Fox (1996), gives practical strategies for coming to terms with chronic fatigue. This is but one of a number of popular publications that may be found on library shelves, in local bookshops and health stores. These publications serve to highlight the lack of assistance for persons with this condition. The Internet has become a source of information for those with access to this medium.

The above issues have fuelled the debate over the very existence of this disorder as a discrete and legitimate illness. Whatever the origin of this condition, and despite so much known about the presentation, if not the aetiology of the illness, little is known about the experience of the sufferer other than what has been written by sufferers themselves in the popular media and publications.

1.5 Need for the research and evolution of the study

In addition to research into the symptomatology, epidemiology, diagnosis and treatment of CFS, research in the psychosocial area has also been undertaken. Lewis et al. (1994:661-71) argued that CFS might be, at least in some individuals, a response to certain stressors, and that sufferers' perceived inadequate support systems, and the use of problem focused coping skills might increase vulnerability to CFS.

Ray et al. (1993:385-91) attempted to devise an illness management questionnaire to define ways of coping with CFS. Four major coping factors were identified: maintaining activity; accommodating to the illness; focusing on symptoms; information-seeking.

As fatigue has become increasingly recognised as a major symptom in different medical disorders as well as in the CFS, the need to measure fatigue effectively has become apparent. Schwartz, Jandorf & Krupp (1993:752-62) developed a scale which discriminated between normal fatigue and disease associated fatigue, but suggest that there is a need to better understand the nuances of fatigue symptomatology across the diverse medical disorders.

The literature review, however, reveals a paucity of information on the psychosocial issues relating to CFS, and to date studies on the lived experience of this condition are sparse. While the research continues, patients live through the experience of having CFS and living with the uncertainty of diagnosis and options for treatment, as well as what the future holds for them.

A clinic for persons suffering from CFS was established at Groote Schuur Hospital in 1993 and operated until early 1996, closing due to financial and staff constraints. As formal treatment options were limited, a support group was established in order to offer some support to persons diagnosed as suffering from this condition, for which the researcher was the primary facilitator. All patients attending the clinic were offered the option of joining the support group, which was run on a quarterly basis, in order to facilitate the inclusion of new patients. Each group programme consisted of 8-10 sessions, and patients were able to renew their contract to attend.

Initial topics discussed in the group sessions centred on issues pertaining to relief and cure - what works, what doesn't, literature read and persons who offered assistance. There was a sense of desperation among several group members for something that would help them, and indeed it is possible that group members initially agreed to attend in the hope that the group and/or clinic staff would offer solutions.

As the group progressed through the recognised group developmental stages, less time was spent looking for a cure and 'swapping stories'. Common themes that arose in the group discussions included: 'not being believed', 'not being understood' and 'not being accepted', and the difficulties that face persons who suffer from a condition which is real to the sufferer, but which elicits various, though mostly negative responses from family, friends and the health professionals.

For a number of sufferers the support group was experienced as the first place where they felt they were believed, understood and accepted. The principle of universality became evident as members began to depend on each other for support, validation

of their feelings and experiences. Group members expressed their distress at the difficulty of conveying their experience of CFS to others. A number of group members requested that information be made available to their families about the condition, as it was felt that in many instances the problem was not well understood by the families and, although the families were supportive, they needed more information. The information needed was not only factual but also that which could facilitate understanding.

In the light of this contact with sufferers of CFS, I decided to study the lived experience of living with Chronic Fatigue Syndrome. It would seem that until this condition is understood at the level of the patient's experience, limited support and treatment can be offered, as no cure is currently available. It is the researcher's opinion that if health professionals understand more of the lived experience of the CFS sufferer, and the quality of life of the sufferer and his/her family, appropriate support and treatment will be facilitated.

Accordingly, the research question investigated is: "What is the lived experience of the person who suffers from Chronic Fatigue Syndrome?" This question requires that a qualitative methodology is employed, since the approach and method a researcher uses is always dependent upon the question which is asked before he/she starts his scientific enterprise (De Koning 1979:122). The chosen research method is a valuable methodology that allows access to the phenomenon and experience of living with CFS.

CHAPTER 2

METHOD OF INQUIRY

2.1 Introduction

A qualitative methodology was selected as the most appropriate to obtain an understanding of the lived experience of CFS.

2.2. The choice of a qualitative research design

“Qualitative methods are used when there is little known about a domain, when the investigator suspects that the present knowledge or theories may be biased or when the research pertains to describing a particular phenomenon or event about which little is known” (Field & Morse 1985:11). Despite ongoing research into various aspects of CFS, little is known about the person’s experience of living with this condition. A qualitative methodology is therefore appropriate to the phenomenon under study. Furthermore, in attempting to understand the lived experience, in-depth interviewing should be undertaken, which is consistent with qualitative methodology.

2-2-1

2.1.2 The phenomenological approach

Within the qualitative paradigm, there are a number of methodologies which aim to give the researcher an understanding of the subject’s social world and generate a theoretical construction of this world. Depending on the researcher’s purpose, qualitative methods may be used for instrument development, illustration, sensitisation, or conceptualisation (Knafl & Howard 1984:20).

Researching lived experience is most suited to phenomenological methodology. Phenomenology always asks, "what is the nature of the phenomenon as meaningfully experienced?" (van Manen 1990:35-7). Phenomenology aims to describe human experience as it is lived, (Giorgi 1970:79; Oiler 1982:178; Field & Morse 1985:27-9; Habermann-Little 1991:190; Anderson 1991[a]:35) and is therefore the most appropriate methodology for the inquiry. This methodology "acknowledges and values the meanings people ascribe to their own existence" (Taylor 1993:171). The approach of phenomenology is characterised by an attitude of openness for whatever is significant for a proper understanding of human phenomena (Giorgi 1970:75-98). Fischer (1974:405) states that the phenomenological mode of research enables the researcher to "reawaken, to thematize and to eidetically understand the phenomena of everyday life as they are actually lived and experienced."

Lived experience is best understood using this methodology. Van Manen (1990:39) describes the phenomenological inquiry as "a creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and sensitive." This methodology aims to enable the researcher to come to a deeper understanding of the meaning of everyday experiences, such as that of birth, illness, and loss.

Moustakas (1994:58-9) states that "phenomenology is committed to descriptions of experiences ...descriptions retain, as close as possible, the original texture of things". Morris (1977, cited by Omery 1983:50) states that the concern of the phenomenological researcher is to understand both the cognitive subjective perspective of the person and the effect that the perspective has on the lived experience of the behaviour of that individual.

The phenomenological school of thought and method has largely been attributed to the work of Edmund Husserl. This original work has subsequently been developed further by, among others, Giorgi, van Kaam, Spiegelberg and Colaizzi, each of whom has modified the phenomenological philosophy, and the research process (Munhall, 1994: App A). The phenomenon of the lived experience of CFS is described in this study.

2.3 The Research Process

2.3.1 Sampling Method

The sampling approach was that of purposive sampling. In purposive sampling, the subjects selected are those who are best able to meet the informational needs of the study (Morse1991:27). The logic and power of purposive [or purposeful] sampling lies in selecting information-rich cases for study in-depth (Patton1990:169). This requires that the subject be a 'good informant'. A 'good informant' is one who is knowledgeable about the topic and an expert by virtue of his/her involvement in specific life events and/or associations; must be willing and able to critically examine the experience; be willing to share the experience with the interviewer; have enough time to devote to the interviews, and sufficient patience and tolerance to answer the researcher's questions (Morse1991:135). Furthermore, the researcher should preferably speak the same language, or at least be fluent in the home language of all the subjects. This minimises the risk of information loss through translation.

2.3.2 Selection of participants - gaining access to the study population

All participants were patients at the CFS Clinic, which had been run at Groote Schuur Hospital under the auspices of the Department of Psychiatry. This clinic was staffed by a psychiatrist, two social workers and the researcher, a psychiatric nurse. Patients were referred to the clinic from general practitioners and physicians. They were required to have had a full physical examination and relevant diagnostic tests to exclude other possible causes of fatigue.

Patients were assessed using the revised diagnostic criteria for CFS (Fukuda *et al.* 1994:953-959). Persons who met the diagnostic criteria, and who had indicated their willingness to participate in research, were identified from the statistical printout of the patient database. From the database, patient names were grouped according to the health practitioner/therapist who had originally assessed them. Each practitioner was asked to identify from his/her own list of patients those patients whom they considered to be 'good informants', as defined above.

Although not strictly required for the purposes of a qualitative study, the researcher chose to attempt to eliminate bias in selecting patients for interview as follows:

- at least one patient seen by each health practitioner/therapist was included to minimise any personal bias in the selection of patients
- only demographic information relating to name, address, age, gender and language was obtained from the patients' hospital folders

Each participant was contacted telephonically, and the research protocol was explained to him or her. Once verbal consent to participation was obtained, an appointment was made for a suitable time and place for the interview.

"In qualitative research, in order to ensure that the sample meets the criteria for appropriateness and adequacy, the researcher must have control over composition of the sample" (Morse 1991:135). Appropriateness refers to the degree to which the choice of informants and the method of selection 'fits' the purpose of the study as determined by the research questions and the stage of the research. Adequacy refers to the informational adequacy, and is assured by the completeness and amount of information, rather than the number of cases. Sampling is therefore continued until no new information becomes available (Morse 1991:134-5).

2.3.2 Setting and Rapport with participant

Kruger (1979:125) emphasised the importance of rapport between the researcher and the subjects, and therefore the interview situation should be as far as possible non-threatening, safe, private and comfortable. To facilitate this rapport, each interview was conducted in the setting of the participant's choice. In each case this was in the participant's own home setting. It was important for the researcher to ensure that the environment met the criteria for privacy and comfort. To achieve this, distractions such as telephone interruptions were minimised. Each participant made available a separate room in which the interview could proceed undisturbed.

2.4 Ethical Considerations

Permission for the study was obtained from the Ethics Committee of the Faculty of Health Sciences, University of Cape Town (Appendix A).

2.4.1 Informed consent

Informed written consent for the research was obtained. Informed consent is considered to be one of the means by which a patient's rights are protected. The intention is that the research will do the patient no harm (Smith 1992:99).

Informed consent should include the title, purpose and explanations of the research and the procedure to be followed. The researcher should have clearly indicated any risks and benefits of the research, and participants should be given the opportunity to withdraw from the study at any time (Munhall 1988:156; Field & Morse 1985:44).

Each participant was given a full explanation of the research process prior to beginning the taped interview. An information letter was given to each participant and a consent form signed (Appendix B).

2.4.2 Confidentiality

Confidentiality was ensured as each participant was identified with a number e.g. as Participant 1. All references to participants' names that are heard on the tape transcripts are numerically coded in the written transcript. Confidentiality applies not only to the interview and transcription thereof, but also to the manner in which the data obtained is subsequently handled. Every effort must be made to ensure that participants are not subject to exploitation through the research process (Reid 1991:545-6).

2.4.3 Possible benefit from the research.

Participants were informed that there would be no direct benefit arising from their participation. There could be no expectation of particular treatment benefit e.g. specific treatment arising from this study, although the researcher undertook to report any significant findings to the participants.

2.4.4 Use of transcribing equipment

Participants agreed to the use of the tape recorder for the duration of the interview. Only after these preliminaries was the tape recorder switched on.

2.4.5 Researcher-participant relationships

The researcher had asked each participant to make available about 1½ - 2 hours for the duration of the initial interview. This was to allow for the preliminary introductions, to allay any anxieties, and to deal with any questions which might have been unanswered during initial contact.

2.4.6 Management of sensitive information and need for support

In the process of conducting this type of research into potentially sensitive issues, the researcher needs to take into consideration the possibility that information obtained through the interview process may make the subject vulnerable and create a need for support, both during and after data collection activities (Cowles 1988:167). Ramos (1989:59) cites several authors who describe the emergence of a pseudo-therapeutic relationship, which not only complicates the research relationship but also extends the responsibilities of the researcher to giving comfort, support and advice.

Fox (1976) states that where there is a risk of memories and feelings being aroused during the research interview, which would not otherwise have occurred, the researcher should be willing to establish whatever conditions are needed to remedy the situation (cited by Wilde 1992:237). Prior to each interview, the researcher explained this possibility to the participants, and offered to facilitate referral to the appropriate support structures should this be required. This was agreed to by all participants.

2.5 Collection of data

Data was collected using the method of in-depth qualitative interviews with five participants.

2.5.1 The Qualitative Research Interview (QRI)

The purpose of the qualitative interview is to gather descriptions of the life world of the interviewee with respect to interpretation of the meaning of the described phenomena (Kvale 1983:174). The qualitative research interview may be an open-ended or free attitude interview, or a semi-structured interview. Most interviews begin with open-ended questions and eventually the focus narrows as clarifying questions are asked (Sorrel & Redmond 1995:1118).

In the free attitude interview the researcher uses only one question, and uses the interview techniques of silence, reflection, clarification, and summarising as a means of exploring the interviewee's perceptions, descriptions and experiences of his/her life-world. Habermann-Little (1993:189) states that the researcher must be an excellent listener, as participants often raise issues which are unanticipated by the researcher. As the goal of the qualitative interview is to gain a rich, deep understanding of the participant's experiences, the interview structure demands flexibility in exploring these issues. This can only be accomplished if the researcher is able to actively listen, and remain open to the participant's responses.

The semi-structured interview follows an interview guide which, rather than containing exact questions, focuses on certain themes (Kvale, 1983:174; Meulenber-Buskens 1998:1-6).

The qualitative research interview (QRI) centres on the following main aspects (Kvale 1983:174-9):

- ◆ The subject of the QRI is the life-world of the interviewee and his/her relation to it. Two people interact and talk about a theme, which is of interest to the researcher and forms part of the life-world of the interviewee. The interview aims at obtaining uninterpreted descriptions of the interviewee's experiences and feelings, and seeks to describe the meaning of the central themes in the life-world of the interviewee.
- ◆ The qualitative interview attempts to gather as rich and presuppositionless descriptions of the relevant themes of the interviewee's life-world as possible. This requires that the researcher 'bracket out' his/her own ideas and presuppositions as far as possible, and be critically aware of these, both at the time of interview and in the process of analysis.

- ◆ The qualitative interview is generally of longer duration than other types of interviews. It is necessary to create rapport between the researcher and participant, and an atmosphere of trust before the participant feels free to share information.

2.5.2 Formulating the Question

The formulation of the research question in phenomenological research usually develops out of an intense interest by the researcher in the topic or particular problem. "Every project of phenomenological inquiry is driven by a commitment of turning to an abiding concern" (van Manen 1984:3). This form of research is always the project of an individual who sets out to make sense of a particular aspect of human existence.

Moustakas (1994:105) states that a human science research question has definite characteristics. These include:

- ◆ it aims to reveal more fully the essences and meanings of human experience
- ◆ it seeks to uncover the qualitative rather than the quantitative aspects of human experience
- ◆ determining of causal or predictive relationships is not done
- ◆ furthermore the research requires the researcher's total involvement and is illuminated through careful clear and accurate descriptions of experiences.

The primary research question used in the study was as follows:

Could you describe as fully as possible your experience of living with Chronic Fatigue Syndrome. I would like you to describe in your own words any aspects of this experience that come to mind.

A sub-set of questions designed to facilitate the participant's reflection on the experience of living with CFS was prepared.

When did you first notice the symptoms of the illness, which would eventually be diagnosed as Chronic Fatigue Syndrome?

To what do you attribute your illness?

What impact does having Chronic Fatigue Syndrome have on you?

It was found that in most interviews, the participant dealt with the above questions without being asked directly. The interview follows the participant's reflections, rather than being directed by the researcher. The researcher's role is to constantly be listening to the information and to facilitate the participant's thinking relating to the primary question, using the techniques outlined above.

Immediately after the interview, the researcher is required to make notes of his/her thoughts, feelings and concerns throughout the interview. This information acts as supporting data when analysing the transcripts, and may even be analysed as part of the research study. Documentation adds to the auditability of the study. Rodgers and Cowles (1993:219–26) discuss a number of forms of documentation which they argue are important in many aspects of a qualitative study, and in particular to substantiate trustworthiness.

2.6 The scientific rigor of the study

2.6.1 Reliability and Validity

Validity and reliability in qualitative research are achieved when **rigor** in the research enquiry is maintained (Sandelowski 1986:31-36). Sandelowski cites the Guba and Lincoln proposal that auditability be the criterion of rigor. A study can be considered auditable when the reader or another researcher can clearly follow the 'decision trail' used by the investigator.

Koch (1994:976) argues that trustworthiness (rigor) may be established if the reader is able to audit the events, influences and actions of the researcher. Guba and Lincoln (1989) claim that trustworthiness exists if the criteria of credibility, transferability and dependability are adhered to (cited by Koch 1994:976). These terms are further discussed as follows:

2.6.1.1 Credibility

Credibility is the presentation of faithful descriptions. Readers confronted with the experience can recognise it. Credibility is enhanced when the researchers describe and interpret their experiences as researchers (Koch 1994:976). According to Guba and Lincoln (1981) credibility is the proposed criterion against which truth value of a qualitative study should be judged (cited by Beck 1993:263).

2.6.1.2 Transferability

Transferability is also considered as "fittingness". Guba and Lincoln (1985) state that a study meets the criterion of fittingness when its findings can 'fit' into contexts outside the study, and when its audience views its findings as meaningful and applicable in terms of their own experiences (cited by Sandelowski 1986:32).

2.6.1.3 Dependability

Dependability requires that the study be audited, as discussed above.

In order to meet the above criteria, the researcher is required to keep extensive field notes of experiences, ideas, to reflect upon these during the course of the fieldwork and analysis. If a tape recorder or other mechanical device is not used to record the interviews, extensive descriptions should be available to the reader. The setting in which data was collected should be described in detail (Beck 1993:265). Beck (1993:263-6) furthermore states that researchers should continually be aware of the effects of their own presence on the participants and the nature of the data collected. Readers should be provided with rich excerpts of the original text transcripts.

2.7 Transcription of data.

Interviews were tape-recorded and then transcribed by a transcriber.

2.7.1 Preparation of Data for Analysis

Transcriptions of interviews provide the 'raw data' for analysis. Before analysis could begin, each audiotape was carefully listened to by the researcher while reading the transcript and the data was 'cleaned'. It is important for accuracy to ensure that all words are correctly transcribed, and all non-verbal and paralinguistic communication noted, i.e. words which were repeated during the course of the interview were transcribed as such, e.g. *I thought...thought*. This process is essential to facilitate the understanding of the units of general meaning. Interruptions and other sounds or occurrences are noted at the point of the tape at which these occurred.

Sandelowski (1994[a]:311-14) argues that the researcher should be clear in the purposes for which the raw data is being transcribed, as this will influence decisions relating to the notation process, and the features of the interview which must be preserved. These decisions, she argues, directly influence the nature and direction of analysis.

2.8 Data analysis

2.8.1 The Methodology Process in Phenomenological Research

Spiegelberg (1976) states that the essential operations in the phenomenological method are (cited by Oiler 1982:180):

Bracketing: the researcher suspends anything that he/she thinks that he/she already knows about it, and attempts to bring the experience into focus without bias. Hycner (1985:28) describes this process as "suspending as much as possible the researcher's meaning and interpretations and entering into the world of the unique individual who was interviewed.....using the matrices of that person's world-view in order to understand what the person is saying, rather than which the researcher expects that person to say".

Bracketing ultimately means a suspension of belief in the existence or non-existence of the phenomenon: not being concerned with the explanations of what the phenomenon 'really' might be (Boeree 1998:4).

In order to be able to bracket one's suppositions about the phenomenon under study, it is useful for the researcher to list these suppositions either by writing these down prior to commencing the research or by dialoguing with a supervisor or research committee.

Intuiting: is an attempt to look at the experience with 'wide-open eyes' and to become absorbed in the phenomenon without being possessed by it.

Analysing: Descriptions are compared and contrasted. The relationships between the various components of the phenomenon are identified and categorised.

Describing: An attempt is made to describe what has been observed.

2.8.2 Stages of analysis

The analysis of the transcribed interviews was done based on the methodology of Giorgi (1975:87-95), with adaptations by Colaizzi (1978:48-71), using guidelines formulated by Hycner (1985:280-294).

Stage 1: Initial Reading of the Data

Each transcribed description was read several times in order to gain a holistic concept and grasp of the data. This was done in conjunction with listening to the interviews in order to ensure that the nuances of language use and emotions were captured, and to stay as close as possible to the lived experience of the participants, as much of the richness is lost in the transcribing. An example of a transcribed description is given in Appendix C.

Stage 2: Delineation of meaning units [themes]

Each transcript was read through with the aim of identifying themes or manageable units of meaning as expressed by the subject [also described as natural meaning units or units of general meaning]. Each description is broken up into manageable, discernible units of meaning. The researcher asks "what statements or phrases seem particularly essential or revealing about the experience being described?" These statements or phrases are then highlighted in the text, and in this manner natural meaning units which arise out of the text are identified.

Once natural meaning units have been identified, the researcher then identifies themes and reflects on the themes in an attempt to validate the appropriateness of these, and may further explore the interviewee's experience in the light of the new understanding or awareness which has been discovered.

Van Manen (1984:20) describes phenomenological themes as "the structures of experience". Themes are more than conceptual formulations or categorical statements. A theme is an experiential structure that makes up the experience, described by van Manen (1984:20) as "knots in the webs of our experiences, around which certain lived experiences are spun and thus experienced as meaningful wholes." The meaning units for selected transcripts are delineated in the analyses, an example of which appears in the Appendix D.

Stage 3: Re-articulation of meaning units from a psychological perspective

Each unit was altered to a form in which it was expressed in the neutral third person, in order to ensure that the understanding of the text is reflected from the perspective of the interviewee and not that of the researcher (Appendix E).

Stage 4: Clinically situated structure.

This stage involved the regrouping of the transformed meaning units into interlinking themes, which accurately reflect the pattern of the respondents' experience of CFS.

Stage 5: Development of central themes.

The central themes that unfolded as the transcripts were read and the natural meaning units integrated were described and articulated, to allow the researcher to immerse herself in the content of the transcripts, in order to grasp the logic.

Stage 6: Construction of extended description.

The clinically situated structures and the central themes were read and re-read until common themes emerged from the data.

The reflective question asked of the participant facilitates the process of thinking through the context of his/her experience, the nature of that experience, and the meaning of the experience for him/her. Thus the themes that emerge from the researcher's reading of the transcripts should open up the essence of the experience to the reader. "The essence or nature of an experience has been adequately described in language when the description reawakens or shows us the lived meaning or significance in a fuller or deeper manner" (van Manen 1984:2).

Van Manen (1990:88) further enlarges upon the concept of the theme as emerging lived meanings of life:

A theme is the needfulness or desire to make sense. The person who lives with CFS needs to make sense of this illness experience in order to live with it and through it. As the researcher, I need to understand what the significance of this experience is for the person.

Theme is the sense that we are able to make of something. As the participant puts into words what his/her experience means, theme-like statements are produced. The researcher attempts to capture the themes through the analysis of the transcript data.

Theme is the openness to something. I, as the researcher, can only identify a theme if I am open to the fullness of the person's experience.

Theme is the process of insightful invention, discovery, and disclosures. The theme is the researcher's tool for getting at the meaning of living with CFS. It must be recognised that no thematic formulation can fully unlock the deep meaning or the full mystery of the person's experience.

Stage 7: Construction of a general structure

In the final stage a structure which attempts to explicate the phenomenon of study with reference to the themes identified was constructed.

Using the first three stages of the above schema, a selection of text is presented in Table 1 (page 36).

2.9 The Research Report

Qualitative reports differ significantly from research reports showing results of descriptive, epidemiological or experimental studies. The report writer attempts to demonstrate his/her understanding of the phenomenon being studied, and in doing this, makes extensive use of writing and rewriting in order to faithfully explain the phenomenon and lived experience of the research participants. Quoted words and phrases from research participants are therefore a common feature of qualitative research reports.

45

Quoting is a process that requires selection and editing. "Researchers must decide whether to quote, what to quote, and where a quote begins and ends for a particular purpose" (Sandelowski 1994[b]:480). The purpose of the appropriately used quotes is to evoke a vicarious experience of some aspect of 'lived experience', the goal of a phenomenological study, and to contribute towards a 'thick description' of the experience. Sandelowski (1994[b]:482) further states that "Quotes are used to validate research findings and to vitalise the research report, thereby contributing to both the scientific and artistic value of the presentation".

2.10 Concluding Comments

In this chapter the logic and rationale for the methodology utilised in this research has been discussed. The lived experience of persons living with CFS has been explicated using the phenomenological process.

TABLE 1: EXAMPLE OF ANALYSIS OF FIRST THREE STAGES

ORIGINAL TRANSCRIPT	STAGE 1: READING OF DATA AND DELINEATION OF MEANING UNITS	STAGE II: DELINEATION OF MEANING UNITS [THEMES]	STAGE III RE-ARTICULATION OF MEANING UNITS FROM A PSYCHOLOGICAL PERSPECTIVE
<p>...but it didn't ever, not even in the early days, begin to touch on WHY and what could possibly be wrong. <i>How did that make you feel - when people just couldn't give you answers?</i></p>	<p>but it didn't ever, not even in the early days, begin to touch on WHY and what could possibly be wrong. How did that make you feel - when people just couldn't give you answers?</p>		<p>No one dealt with why or what was wrong</p>
<p>It was a horrible place to be in, because I knew myself that I wasn't like that. I know even today, I'm not like that. I am someone else on a good day and I cope extremely well, and I do all that I am supposed to be doing. And yet there is....there was that part of me that just suddenly couldn't physically cope.</p>	<p>It was a horrible place to be in, because I knew myself that I wasn't like that. I know even today, I'm not like that.</p>	<p>because I knew myself that I wasn't like that. I know even today, I'm not like that. [conflict between her own image of herself and the person she is portraying]</p>	<p><i>It felt horrible because she knew herself as someone different [not a tired, depressed person]</i></p>
	<p>I am someone else on a good day and I cope extremely well, and I do all that I am supposed to be doing.</p>	<p>someone else on a good day</p>	<p><i>She sees herself as someone else on a good day, who copes extremely well, and can do all that she is supposed to be doing</i></p>
	<p>And yet there is....there was that part of me that just suddenly couldn't physically cope.</p>		<p><i>There was however, a part of her that just suddenly couldn't cope.</i></p>
<p>And people were not addressing that; they weren't able to see past what I was showing physically. To that person underneath - that was still trying to cope. And it it..hurt me a lot, not being heard. And I think right then I began this cover-up-thing which I still do today. <i>You talk about not being heard. How does that feel; not to be heard?</i></p>	<p>And people were not addressing that; they weren't able to see past what I was showing physically. To that person underneath - that was still trying to cope.</p>	<p>they weren't able to see past what I was showing physically. To that person underneath [feeling hurt; not being heard]</p>	<p><i>People were unable to see past her physical symptoms.</i></p>
	<p>And it it..hurt me a lot, not being heard. And I think right then I began this cover-up-thing which I still do today.</p>	<p>it..hurt me a lot, not being heard.... I began this cover-up-thing [cover-up behaviour]</p>	<p><i>Not being heard was very hurtful. It was the point at which her cover-up strategies began.</i></p>
	<p>You talk about not being heard. How does that feel; not to be heard?</p>		

TABLE 1: EXAMPLE OF ANALYSIS OF FIRST THREE STAGES [continued]

ORIGINAL TRANSCRIPT	STAGE I: READING OF DATA AND DELINEATION OF MEANING UNITS	STAGE II: DELINEATION OF MEANING UNITS [THEMES]	STAGE III RE-ARTICULATION OF MEANING UNITS FROM A PSYCHOLOGICAL PERSPECTIVE
Horrible. I must say in the last year or two, I have found more people willing to listen than in all the years that I've I've..had this ... whatever you want to call it	Horrible. I must say in the last year or two, I have found more people willing to listen than in all the years that I've I've..had this		<i>It feels horrible not to be heard</i> <i>She has experienced more willingness of people to listen to her over the last year or two.</i>
! I still don't know what to call it, if it's an illness or not. I hate even to label myself with that word, but now in the last year or two, I found people who are willing to listen. But in the early days there wasn't anyone. And it hurt a lot because it made me....	... whatever you want to call it! I still don't know what to call it, if it's an illness or not. I hate even to label myself with that word, but now in the last year or two, I found people who are willing to listen. But in the early days there wasn't anyone.	. I hate even to label myself with that word <i>[labelling a negative experience]</i>	<i>She still doesn't know what to call this condition. She hates to label herself with that word[ME/fatigue]</i> <i>In the early days no one would listen to her</i>
it made it necessary for me then to go along with what they were saying to me: that in fact I might just be neurotic. I might just be a depressant. I could just be one of those hypochondriac people that I personally have no time for! And I had to consider that I was like these two people. And yet I knew myself deep down; I knew that if somebody would just help me cope with this thing I ...I would keep going. But I didn't find that in the early days.	And it hurt a lot because it made me. ...it made it necessary for me then to go along with what they were saying to me: that in fact I might just be neurotic. I might just be a depressant. I could just be one of those hypochondriac people that I personally have no time for! And I had to consider that I was like these two people. And yet I knew myself deep down; I knew that if somebody would just help me cope with this thing I ...I would keep going. But I didn't find that in the early days.	it hurt a lot <i>[feeling hurt]</i> I might just be neurotic. I might just be a depressant. I could just be one of those hypochondriac people that I personally have no time for! <i>[non-acceptance of labels]</i> if somebody would just help me cope <i>[needing someone to recognise her pain – needing to be heard]</i>	<i>It hurt a lot</i> <i>It was necessary for her to go along with what others were saying - that she might be neurotic or depressed. She has no time for these types of people, but had to consider that she herself might be one</i> <i>She knew that if someone would help her she could keep going</i>

CHAPTER 3

THE CFS EXPERIENCE: PRESENTATION OF FINDINGS

3.1 Introduction

As discussed in the previous chapter, the phenomenological method requires that the researcher 'immerse herself' in the data, using inductive reasoning to 'let the data speak'. Each transcript is individually read and reread until essential categories, which relate to the meaning of the lived experience for the participant, emerge. Then the process of identifying overall themes is begun. It is important that the researcher remains true to the methodology and does not begin to superimpose her own ideas on to the data. In each case, the reader of the research must be able to track the researcher's process.

The research question: "*Could you describe as fully as possible your experience of living with CFS*", was structured to enable the researcher to attempt to understand the lived meaning of the person's experience. Lived meaning refers to the way that a person experiences and understands his/her world as real and meaningful. The researcher attempts to describe those aspects of a situation as experienced by the person in it.

As the participants reflected on their experience of living with CFS, it became evident that, although each person's experience was unique, there were common experiences and understandings of the illness and its impact on their lives.

For the participants, there were phases of the disease experience. These can be summarised as:

- The experience of becoming ill
- The experience of the symptoms of CFS and its impact on their day to day lives
- The experiences of making contact with health professionals, their interaction with them and their subsequent interactions with the health care system.
- The experience of living with the condition. This was described in a number of ways: relationships to themselves; relationships to others, their life-world, their coping mechanisms and dealing with the present and planning for the future.

The five participants [four female, one male] who consented to take part in my study had all been patients of the CFS clinic which at that time was run in the Department of Psychiatry at Groote Schuur Hospital. Interviews ranged in length from 1½ - 2 hours. The themes that emerge from the lived experiences of the participants are described. For each of the participants, there was a sense of wanting to share with me in order that others might possibly benefit from my findings. It was stated by all participants that they had felt that the health profession as a whole had “let them down”.

3.2 Emergence of Themes

The categories (clusters of natural meaning units) emerging from the analysis of the interview transcripts number over forty. These were grouped into naturally emerging central themes. A table of categories which emerged is given in Appendix F.

3.2.1 Theme: Uncertainty and Fear:

Because the illness is usually only diagnosed after some months of contact with the health professional[s], the sufferer has had to deal with many uncertainties and fears. The conflict for the person is increased, as it is difficult to see that he/she is ill. There is no obvious problem, and the symptoms are varied, and in some cases inconsistent, thus creating a confusing picture for the health professional. For the sufferer, there is a sense of being misunderstood and this engenders a lack of confidence in the health system. The response from the health professional is usually one of "there is nothing wrong with you", and the sufferer is left to try as best as possible to carry on in the hope that things will improve. It becomes very difficult for the person to believe in him/herself, as it appears that personal credibility is lost – no one seems to believe that he/she is ill, and questions start to arise – is this a psychological complaint?

And I actually thought I was dying. I was convinced that I had leukaemia or something and that they have just never picked up on anything. I used to often be in tears because I couldn't understand what was wrong with me...But I felt so sick! I looked fine and nobody could see anything wrong with me. People thought I had a psychological problem.

Well I felt totally helpless because I actually thought to myself: what is going on here? I must be losing my mind. There must be something. I must have a serious problem if ...if everybody thinks that I'm imagining this and I look fine. And they can't understand that I'm saying I am feeling so weak and so sick and peculiar. And you know I can't cope with this, I can't manage this any more. It's like you're falling apart totally. And nobody can give you any answers or...or help you...

And I would go to the doctor and I'd be told there's nothing wrong with me. They would do tests and say, no you're a very healthy person, nothing wrong with you.

I'm not saying anything to anybody any more. I'll just keep quiet about how bad I feel and I'll carry on, which is what I did.

I kept going to gym at least three times a week to try and prove to myself that this is all in the mind and that I was going to overcome it; if I worked through it I would get over it

There is conflict between the perceived self and the real self – the familiar self that the person has known. The familiar self becomes unfamiliar, and this creates a sense of uncertainty.

It was a horrible place to be in, because I knew myself that I wasn't like that. I know even today, I'm not like that.

I am someone else on a good day and I cope extremely well, and I do all that I am supposed to be doing.

And yet there is...there was that part of me that just suddenly couldn't physically cope.

3.2.2 Theme: Life Draining Tiredness

The first experience that all participants related in detail is the tiredness. It pervades the person's entire body, saps energy, and is experienced physically, psychologically, mentally, spiritually and emotionally. The tiredness is described as being unlike any other tiredness that the participants have experienced, and is so draining and all embracing that it seems as if the very life force is being drained from the body. It is demoralising and debilitating. It permeates the life of the sufferer, impacts on his/her thinking, activities, relationships, social intercourse, employment and leisure. The tiredness drives sufferers to seek assistance from the health professionals, and if no help is forthcoming, from any other who offers some hope.

It's not a normal tiredness it's a terrible exhaustion where it's just too much effort to move a limb even.

..it feels like somebody who is dying I can imagine. ..you can feel your life pulling and draining out of your body ..

Your.... body sort of just runs out of energy like a battery going flat

So - it was like a deathly kind of tiredness.. like every single part of my being was just completely exhausted - to the point that I wanted to die.

*It's not normal to feel like this, and the only way I can describe this is that I can imagine somebody who is **dying** feels like this. I mean everything is being drained out of you.*

You know when people say to you they are really tired -- well that's not it. It's tired like you want to die tired. That's how it felt for me, you know because in the first three months I was dead, you know.

The sufferer becomes aware that everything requires energy, even activities which he/she had not been consciously aware of as needing energy. Even listening to someone speaking takes energy, sometimes more energy than the sufferer is able to expend.

It was like I'd go and have a bath and by the time I got out of the bath I was actually puffing and puffing as if I'd run around the block...

*And you see that's what people don't understand: is that you are so tired it actually takes energy to **listen** to somebody. Then you really realise that kind of ...I don't know how to put into words what I am trying to say.. but when you get to a point when you realise it takes **energy** to listen; I'm exerting energy just to **listen**... And I kept on wanting to say to her, please just shut up! I don't have the energy to listen.*

Sleep, which for a tired person is the means of revitalisation, does not prove to be the answer for a person with CFS. There is the hope that sleep may make things better, but it does not predictably help.

*You know I think initially, because you are so exhausted, you just want to sleep... just want to sleep. Just let me sleep because you are **so** fatigued, you know*

....so your bed is everything to you . Just like your best friend. Just to be able to get in there and just lie and sleep

You cry yourself to sleep most of the time. You just know when you sleep and when you wake up you can perhaps feel better. Even if it's for a while. Sometimes it will settle down if I sleep... But some days it just doesn't pick up. And I will just tail off into the end of the day and wait for a new day.

3.2.3 Theme: An unpredictable and undependable body

There is unpredictability of the illness and of the person's ability to control it. This engenders a mistrust of the body and its ability to cope with the illness, and the person becomes insecure. There is a fear of relapse which increases the uncertainty for the sufferer, who is unable to predict when this might occur. The familiar body, to which the participants had related for many years, had now become foreign; a body on which they were unable to depend, which might 'give out' at inconvenient times, and which dominated their thinking, their plans, their day to day lives.

... I start realising that I'm not able to concentrate as I was up until that point. My body starts to ache, my throat starts to hurt and suddenly, out of the blue, I will feel I'm coming down with something.

Tiredness started creeping back in. I couldn't cope any more with an eight-hour-day which I was putting in...

And I was afraid of that because it would just come suddenly.

So I struggle with the unpredictability of it. Again it's something I can't control or contain. I don't have a handle on it.

I remember I used to pray...oh God let me just do the shopping

The symptoms of CFS have been described in an earlier chapter. However, for the person who experiences these symptoms, that list would not in any way describe their real experiences. Every aspect of the self is affected:

My head sort of ... it goes fuzzy, that's all I can say. My brain sort of ... it gets more and more difficult to concentrate and to put things in sequence.

My body starts to ache, my throat starts... starts to hurt and suddenly, out of the blue, I will feel I'm coming down with something... but it is a combination of the physical, what's happening in my body physically and what it does to me mentally.

*...think the muscular pains were incredible. I remember lying on the bed not being able to keep my legs **still** from the pain. Just having to **move** them because it was so terribly sore.*

...I couldn't do things that I wanted to do. I had no energy. And I just knew there was something ... that's how I felt about it, I don't know how else to describe it, but that it was eating my brain.

...dizziness, and the blurred vision, headaches and things like that

...get this strange weakness and then it would go away again

...needed to sleep longer and longer.

Awareness of the body, its frailty, unpredictability and the effect on the mind is evident in the above quotes. The perception of self, and of one's vulnerability when illness takes over the body, impacts on the person's experience of the lived body. The meaning and relevance of the person's life is challenged as he/she lives with pain, weakness, tiredness and altered mental patterns. How does the person relate to his/her body, which is no longer familiar and for which no one has any cure? Participants expressed their frustration, anger and sense of despair as they learned to live with the erratic nature and unpredictability of the condition. Their inability to control their own destiny is enormously frustrating and the feelings range from wanting to give up [to die] to intense anger.

...then there is the feeling that you must keep going. If you kept going when you were not ill, then you must keep going even though you are ill. And so I still keep pushing myself

...overall feelings that I had was tiredness - real "gatvol" feeling; didn't care ..you know when you're lying in bed and its like ..you're telling the body to do something and it just actually says, forget it!....and I just couldn't function, not because I didn't want to. You know my body was just not functioning. And my mind wasn't functioning.

Hadler (1996:2397), describing patients with fibromyalgia, states that a sense of vulnerability is part of the morbidity of any chronic disease. "The vulnerable state is not a diagnosis; it is dynamic, an ongoing testing and discarding of morbid thoughts. It is a life of somatizing." This statement is lived out in the lives of persons with CFS.

Part of me would love to just go and crawl into bed, but circumstances don't allow for that. So I more or less talk myself back up into a place of coping.

...and then you get irritated with yourself, because you know that is not your normal... type of thing.

Just the physical disability to ...to do anything. And the fighting in your mind

The constant tension between the self that is ill, tired and limited, and the desire to do something, be elsewhere, to be the self that was, is further impacted by the difficulty of knowing that the condition that one has is not recognised or believed by the medical profession. This sets up a conflict between the person and his/her body and mind – if what one is experiencing is not real – what is one's lived reality?

*...know I've always been very much into my mind; if I choose to do something I'm strong enough in my head to kind of **make** me do it*

...you take so much for granted you know when you've got your health. And one of the things I used to say to myself before I got sick was as long as you have my health I can do anything I want. Then I lose it and I can't even get out of bed. You know then you have to look at life in a different way. It's like I can't do anything I want now, because I am physically incapable. So what does that mean for me, you know.

...what did it mean ...I don't know, I think for a long time it was just a kind of a searching. What does it mean? What if it continues? You know if I was sort of paralysed from the neck down, what would it mean for me? Being able to do nothing. Because in a sense I could do nothing. You know what does it mean about me. You know ...and the thing is that I think I am...

3.2.4 Theme: Living Death

The CFS sufferer experiences a tiredness which is so overwhelming and debilitating that it is compared to a perception of what death must be like. The ultimate paradox is expressed by this participant, who describes the lived reality – CFS is a living death:

Living death means that you're actually alive, and people see you as normal. As someone who should be performing normal duties and physically looking okay, but... inwardly and mentally, you feel totally dead. You're physically exhausted. Mentally, you are just thinking: I cannot go on like this. Why is this disease or illness not just something that terminates life? Because you....you just cannot do what you want to do...I would say the best description is the living death.

The question that arises for the person with CFS is "Why does it not kill me? Because I do not have the strength to do it myself." There is a sense of waiting for something to happen – time drags on, with no end in sight. Suicide is considered as a way out of the situation, yet is not an option. There is tension between the desire to die, yet not being able or prepared to do anything about the desire. There is the wish

that it would happen, without the sufferer having to take responsibility for the event. The tiredness is so bad for the sufferer that death would be welcome – but the person is too tired to initiate any mechanism for dying, i.e. suicide.

Wanting to die becomes justifiable. The sufferer is in a state of waiting for something to happen. There seems to be no end to the illness, no hope of getting better, the tiredness is perceived as being close to near death, and so thoughts of death are comforting.

I know I did...I hit a time of real desperation. And of rather wanting to be dead

*Although there were times that I was so depressed I went through time when I just wanted to kill myself. I think I was sort of three years ill then, and three years is a **long time** when you can't do anything. And then it just was: what's the point? **What's** the point? Gee I'd rather have cancer and know I'm going to die, at least something is going to happen.*

*I remember one night I was very bad. In the beginning you're scared something is going to happen and that you're going to die. And then afterwards you're feeling **so** ill for so long. And then you think, well ...perhaps it will be all right. I mean not that I ... I would never thought suicidal or anything.... But it would also be all right to go home.... and not feel that way.*

There were also other times when you were feeling so sick that you want things taken out of your hands. And just to happen.

...only outcome ...was suicide. Because the illness was not going to kill me ...not necessarily an option that is the weak option. In fact it could be the strong option...

3.2.5 Theme: Emotions in Illness

Many emotions were expressed by the participants as they told their stories. The emotions reflected their responses to the attitudes of others, as well as their own sense of self.

Much anger was expressed in relation to a number of experiences that participants had endured. There was anger directed towards medical professionals, who were perceived as not understanding, not accepting and even condemnatory in their attitudes towards sufferers. In particular, anger was expressed about the labelling experience. There was anger expressed at the unpredictability of the illness, its power to destroy the sufferer's plans and competence. The length of time that the illness had lasted, as well as the lost time were sources of anger and frustration. For one participant, anger stemmed from having to justify a decision to leave a restaurant before the meal had arrived in order to be able to have enough sleep to get to work the next morning.

It's a strong word!...I built up quite a bit of anger I think over the years for the non-understanding from the medical people, ...because from the doctors that I went to I had hoped if not to have a cure offered, or a programme offered that would benefit or help me, at least I went asking for understanding and I didn't always get it. And I took that as a form of condemnation or a judgement or a criticism, or whatever you want to call it. So that's been an extra burden.

What I also came across is - since I've been in hospital - as being sort of labelled depressed, you know. Which is highly infuriating, really! It just gets my goat.

... I have a real sort of desire to keep going with my life with as much momentum as I can. And then on a day when I can't, it makes me angry. And I struggle because of the suddenness of it you know. In a day I can start well and kind of fall apart by lunchtime, or I can pick up and keep going till late at night. It is such an unpredictable thing.

...I suppose to a large degree some of the underlying anger was still the fact that I was not well...and I was not back to my former self. I was not coping. And I was not achieving the way I used to.

.... I think I still feel that kind of: you know why can't I get better? Isn't seven years enough? You know some people come and say to me - isn't seven years enough? You know I want to really get angry with them. I'm living the seven years, thank you. But you do, you say to yourself Gee isn't it long enough? Isn't it time to be over?

Anger turned to hurt, particularly when the medical professionals refused to acknowledge the legitimacy of the illness. Sufferers felt that they were not heard.

And it hurt me a lot, not being heard. And I think right then I began this cover-up-thing which I still do today.'

You feel ridiculous going to the doctor.

Depression and despair became part of the reality of participants' lives. As has been found in other studies, participants maintained that the depression occurred concurrently or subsequently to the onset of CFS, and was not perceived to be the cause of the illness. The depression seems to be linked to the enduring nature of the illness, the lack of concrete help, and the fact that their symptoms and problems were not taken seriously by health professionals. A sense of desperation was expressed at the inability of people to understand [or perhaps accept] the reality of the experience:

And I think when things really started getting me down was when I found that after about three months, when I thought, well really it's time things start going away now and you get better, that it didn't. That it really started impacting on me and I probably then started feeling depressed.

...I acknowledge that I was probably depressed. I mean given the circumstances ...there is no reason why I shouldn't have been depressed.

And also because you're ill for so long it's going to affect you emotionally. It's got to. And to just go and like put the people on anti-depressants because gee they're depressed. Of course they're depressed. You know ...Anybody would be depressed after having been sick for four years. And somebody says to you: I don't know what you've got, don't know where it came from, I don't know how to cure you.

But you feel lost because you feel nobody understands how you feel.

But you're so desperate.

3.2.6 Theme: Illness has power

Illness has power. It creates conflict for the person in that he/she is no longer able to control the pattern of life. Choices are limited by the nature of the illness, the unpredictability of it. In rendering familiar routines impractical, if not impossible, CFS has authorised the assertion of control over their lives (Ware & Kleinman, 1992:555). Sometimes it is possible to override the effect or power of the illness, but eventually, the person has to succumb to the effect of the illness on the body. The power of the illness creates a situation of forced choices for the sufferer.

The hardest thing is to acknowledge that, as much as I've tried to control it and contain it, it still happens. It is still a part of my life. And I obviously don't have control over it... it still has the ability to make me fall apart, if that's not too vague. I have a real sort of desire to keep going with my life with as much momentum as I can. And then on a day when I can't, it makes me angry. And I struggle because of the suddenness of it you know. In a day I can start well and kind of fall apart by lunchtime, or I can pick up and keep going till late at night. It is such an unpredictable thing.

...it makes me swing between being fairly rational and just depressed and unable to cope. So I struggle with the unpredictability of it. Again it's something I can't control or contain. I don't have a handle on it.

There're kind of two threads. The physical I can sometimes override; that example I gave you of an office situation. Where I can override it -- I've still got two hours to go or whatever it is. So I override the discomfort and what I'm feeling and I keep going till it's time to go home. But sometimes when it comes to a function in the evening I know that I don't have it mentally. I don't have what it takes to carry on a conversation, or be bright socially, or handle whatever I will be called upon to handle. And then I just have to cancel.

The illness makes the sufferer feel so desperate that he/she is prepared to go to great lengths just to feel better, to get relief from the pain and discomfort, despite the discouragement of allopathic health professionals. Sufferers are willing guinea pigs for untested treatments, in the hope that something may prove to be the answer to their problems.

*And I even went to a neurologist as well because of the dizziness, and the blurred vision, headaches and things like that. He seemed to know about ME. And he just kept saying to the others: **don't** let her try anything unconventional. And that seemed to be sort of echoed with the doctors; don't try anything that hasn't been tested. But you're so desperate. There was a newspaper clipping, about... something about blood circulation. And then I'd heard about injections and then you try to find out all these things...you were prepared to try them. **Anything** just to feel better.*

The sufferer is faced with decisions about his/her sense of self, self worth. When one's sense of who one is and one's worth is valued in terms of what one can **do**, then this illness creates doubts and conflicts about one's sense of self worth. It is difficult to make others understand the situation, that the choices that have to be made are about being able to go to work, cope with activities of daily living, her very survival. Even at the point when things start to improve, and there is sufficient recovery for the person to be able to take up some of his/her previous activities, the choices continue.

At some place...in the first couple of years I had to decide whether I had any worth. ...when all I could do was sleep 12-hours a day, and eat, and bath.

And that is the whole thing that people don't understand, that I am the one that has to actually get up in the morning. Make myself something to eat. Bath myself. Dress myself. You know now go to work and earn a living. I'm the one that's got to do that.

I get completely exhausted and that person doesn't. You know I'm the one that coming off worse every time. So you learn about making difficult choices. Ja ..it's quite interesting

...But yet I'm still learning...and there are still choices to be made...You're working but you haven't got all your energy back yet. Now how are you going to manage that? What are the choices that you're going to make now? To get some kind of balance.

And it doesn't matter what anybody else thinks or says, because I've got to know myself what's within my limits. And if you... if you can't get to that stage where you can work out what's in your limits, then I think you're going to have a problem getting better. And it is difficult.

The illness also forces the sufferer into a state of social isolation. The person is unable to meet valued and expected social functions. Contact with friends is severely reduced, family events limited, and the person becomes more and more isolated. Often this is just in order to conserve enough energy to meet the sufferer's perceived obligations, particularly if the person is still employed. As social interaction becomes more limited, their perceptions of themselves change from competent, healthy social beings to that of inadequate and dysfunctional invalids.

We couldn't go and have social functions... I was an invalid, and that's basically how it had to be viewed. Every...every time the family considered an event they would first take into account, what will I do? Will I stay at home - would I go with, what would I do? Socially we were a non-entity.

And you sort of ... you don't cut yourself off from your family - I mean you can't, but there were times where you just ...were trying to stay alive

I mean I couldn't have a social life at all any more. When I got home from work at night I'd have to go and lie down and rest most of the time before I could make supper and do whatever. And on weekends I was really too tired to go out and do things. I basically wanted to just do what had to be done and recuperate...

I mean I'd never spent so much time on my own in my entire life! Literally days on end because I just couldn't. I just didn't have the energy to kind of talk to anybody.

The power of the illness to change the pattern of living, and in particular the participants' social contact, is reflected in the transcript extracts. Isolation is not just about being on one's own, it is also about the sense of "aloneness", which is a deeper experience than just being on one's own. It is as if one is alone in one's innermost being with no choice about being there. Anderson and Bury (1988:251) contend that social isolation among persons with chronic illnesses reflects as much social processes operating as it does the direct effects of functional disability. Thus it may be argued that persons living with CFS live not only with the limitations of the condition itself, but also with the perceived stigma attached to the condition, and this compounds the isolation experience.

But I think the huge thing for me was the loneliness. The isolation. That I really struggled with.

I'd lost so much of my life because for at least three years I was almost a recluse. You know I lost friends

That's it, you know. I think a part of my thing was that I walked it very much alone.

And I didn't want to talk to anybody; I was too fatigued you know. And umm...so there was a huge amount of isolation.

...you have a lot of time to think, a lot of time to think. And initially it is very scary. Because all of a sudden you are just on your own. There's nobody else, just you. Day in and day out., there's nobody else, its just you... and so I think....

For this participant there were difficult choices that had to be made with respect to relationships:

What are the things that are stressing me? And how can I work with them? And if I can't work with them then I've got to actually just get rid of them. You know whatever it might be. Maybe it's relationships. I made a choice six months ago, somebody that I've been friends with for seven years, and I decided actually I am not going to be that person's friend any more. Because the relationship is too stressful for me you know. It's too unhealthy for me. And it was a very, very very difficult choice but I had to choose what was good for me

3.2.7 Theme: Legitimacy of the illness

For an illness to be effectively treated, it is preferable to have a clear diagnosis of the problem, and this has been seen to be vital to the psychological and emotional wellbeing of the patient (Cooper 1997:195). The health professional takes a history of the presenting problems, symptoms and impact of the symptoms on the person's daily living. Once the illness or condition has been diagnosed, a prescription for the most appropriate treatment is given. The patient is expected to comply with the treatment, and the symptoms should be alleviated or disappear (Wellard 1998:49). If all goes well, the person recovers from the illness, and proceeds to carry on with his/her life as normal. The person who becomes ill wants to be recognised as ill, in order that he/she can be effectively treated and hopefully recover. The illness, now legitimised, allows the person to take on the sick role but carries with it the obligation to get well.

Not all conditions respond to this approach, however. Disease and illness patterns vary. Some may require other types of intervention and management, yet for many, treatment is ineffective or response is poor. Many conditions are chronic in nature, and need to be managed as such. What happens when it is difficult to diagnose an illness, because it doesn't 'fit' the current criteria? The cause[s] are not yet identified, the symptomatology cannot be confirmed with established diagnostic tests, and the sufferer often doesn't look ill. If there is uncertainty about the diagnosis, or indeed the reality of the symptoms, the issue of legitimacy arises. Other causes for the symptoms are sought, the person may even be "blamed" for the problem. There is no recognition of illness, and therefore of the person.

Well, when you get the response from people which clearly you can see in their undertone; they don't want to come out clean on it, but the undertone is suspicious. They're kind of saying: "but there's nothing wrong with you! You look normal. You've got no blood anywhere. You've got no broken limbs. You can walk normally. You can talk normally. You can't be ill! It must be a figment of your imagination. err...You are just using this as a means to have a lekker holiday." Whatever they think, but they don't believe you.

...they kept asking me do you have marital problems! And all sorts...financial problems and all sorts of things like that, which I didn't have anything like that. I knew then it was ME.

I don't think my own doctor believed at first. I mean he could see I was ill. And he could see by the things they were writing on the accounts. It would be called anything else except ME. They were sort of treating each thing that sort of cropped up

Participants described their great need to be believed – that the illness was genuine, the symptoms real, and in particular, not attributable to a psychiatric disorder. Even partial legitimisation of the condition makes a difference to the person.

But not willing to take me seriously over many years is another issue that affected me personally. I always tried to present myself as I've said, as an honest person. I've never hidden what I've been feeling. And so with that honesty very often what I got back was just like a superficial judgement of who I was as a person ... I knew what psychosomatic was, and I knew there was no way that I was imagining there was anything wrong with me.

I got a letter also from doctor saying that umm... sort of permission to come and go. Like I got special parking ...medical parking...in front of the building. And those little things helped

The establishment of a CFS clinic at Groote Schuur Hospital offered new hope to the sufferers – for recognition, legitimisation and treatment. The clinic did not meet all the needs of those who attended and although it did not offer answers, it did at least provide the sufferers with a sense of legitimisation, and of being heard and believed.

And I suppose that's where the clinic came in. I thought... now research is going to be done. They're probably going to be in contact with all over the world. We're going to get new information. We're going perhaps try a diet or we're going to try injections of some sort. We're going to be used ... perhaps testing regular blood samples. I thought that was another thing that would perhaps have been done.

But it was wonderful just hearing other people's situations. I mean I still had a husband that stuck by me through everything.

The participants described a lengthy trail of seeking assistance from a variety of health professionals and complementary health practitioners in their desperate attempt to get answers, understanding and help. The reality of this journey was painful, and each had to come to terms with the experience of being labelled. Health professionals, unable to 'fit' the symptoms and illness into a known disease pattern, unable to find diagnostic tests which revealed useful information, labelled the condition, and by implication, the sufferer.

Labelling is a negative experience. The person feels devalued, and not accepted. Labels, varying from 'depressed' to 'neurotic', challenge the person's self-esteem.

...I still don't know what to call it, if it's an illness or not. I hate even to label myself with that word...what they were saying to me: that in fact I might just be neurotic. I might just be a depressant. I could just be one of those hypochondriac people that I personally have no time for! And I had to consider that I was like these two people

And so not only were you not being heard, but you were very scared of being labelled as something that you didn't want to be.... yes over the years I've had all those labels. As much as I have tried to present myself as a well-balanced person

I am not sure who the real person is sometimes! But because of the labels that I've had, of being a depressed person, of being a neurotic, which is one label that a doctor once gave me. I fought tooth and nail to present something different. You know to myself and to others.

I come back to the fact that this chronic fatigue is somehow not a medically acceptable thing - or acknowledged thing. Very few as I see it are willing to look at it as an entity.

And I don't mean... because I know a lot of people say, oh you are just depressed, that kind of thing

But its like...when you say you've got ME, one person said to me, oh you are just very tired. You know its like that is like stupid because its like actually I know nothing about ME, but I am assuming that you are just tired, or you depressed. ...I'm not too sure exactly how many people have ME, but I'm sure thousands have got it, and I don't think we are all depressed, and I don't think we all want to lie on our beds and like kind of "veg out"

The person with CFS begins to doubt his/her sanity – perhaps this is all in the mind. No one understands how he/she feels, the symptoms are similar to depression, tests don't reveal any answers, varying treatments are tried, yet the sufferer does not get any better. Participants reflect on what others must be thinking about them:

You know and another thing: people who don't know you and they know you are ill and not at work and you're going for blood tests, and you meet them or whatever and you're thinking in your mind: this person probably thinks that I've got AIDS, or something! Or they're perhaps thinking that you're imagining these things...

Basically it's that other people are now having this perception that you are now suddenly this type of person. You're not just somebody who is normal, involved in life, living your life, doing things whatever. You now are this person who seems to have this problem which is nonsense. You know there's no name for it or anything. So you're almost...well you are put in a group with somebody who has a psychological problem. And people don't have much sympathy for psychological problems by the looks of it so ... And a lot of people still label ME as being in the mind

Labelling and lack of recognition of CFS as a legitimate illness has significantly impacted the participants' experience of their world. It creates difficulties in being in the sick role, and of moving out of it.

3.2.8 Illness in Relationship

Illness occurs in the context of one's relationships with others. Partners, parents, children and friends and colleagues – few relationships are not impacted by the effect that the illness has on the sufferer. All participants emphasised the impact that living with CFS had had, and was continuing to have, on their relationships. Partner and family relationships seem to take the greatest strain. The partner with CFS is unable to meet role obligations, feels guilty, angry and frustrated.

*And for myself, you know I kind of felt guilty that I was letting **them** down.*

...and also guilty because you're a mother and a wife and you're not able to do the things that you know you're responsible for doing.

Now and again I find that he will voice something which shows his concern. And perhaps, I don't want to say anger, but regret that there is this thing

Sufferers with partners described significant support and understanding for their situation by their significant others. This was appreciated, but it did not relieve the frustration.

But I have very, very seldom had anything from him other than support. So I'm so grateful for that.....And I very seldom have seen him angry or disappointed in me.

*It was difficult for A [husband] as well because he suddenly was now...at a loose end; he had to sit at home with me and I think he also got quite ...bored almost...And he would have to go out on his own and I hated it because I'd want to **desperately** be involved and go, but I couldn't. It was a terrible...and I'd almost envy him going, but I couldn't tell him that he couldn't go and he had to sit with me because he's still alive and healthy. You know he's also got to have something in his life. So that was just the way it had to be*

My husband he would ...he could just look at me. I mean he went through nights and days of everything. And he was very understanding. He would take me if I couldn't perhaps drive to the doctor or whatever. I would be taken and things like that.

One participant reflects how she got to the point that she asked her husband why he stayed:

*I mean I still had a husband that stuck by me through everything. And one day I was just so...so down and I said to him: why do you stay with me with all this? ...And he gave me a very simple answer.... And he said to me: when we got married I said in sickness and in health. And that hit me like a ton of bricks you know. That this is what it **really** means to stick by each other.*

For participants with children, there was a sense of not being able to fulfil the parent role as they would have chosen to. They noted not only the effect on family roles and dynamics, but also on the practical aspects such as limited finances and the impact that this had on the children. It further accentuated the guilt for not being able to be there for children and not being able to provide sufficiently for them.

Things were starting to impact badly because it was affecting the family. ... because they were now entering their teenage years. And I was just not around. So we couldn't go out. I couldn't play games with them. We couldn't go and have social functions.... I was an invalid, and that's basically how it had to be viewed. ... every time the family considered an event they would first take into account, what will I do? Will I stay at home - would I go with, what would I do? So it was quite an impact on the family Ja and I don't think they fully understood. And also because they weren't there to see how ill I was. It's difficult you know what I mean...So again that impact economically on the family...the family's life had to change in terms of ...Ja, suddenly you're not providing sufficiently...they couldn't expect to have a new pair of shoes ...a new this or new that. Because there wasn't money - bottom line. And I had to deal with that issue and it was obviously eating me up.

Friendships for the participants were significantly impacted. Participants perceived that people had difficulty in accepting their situations and did not know how to relate to them.

*You know I lost friends....people can't really cope. Not with that degree of illness.... people don't really know how to support you because you know often people want to kind of fix heal and convert; they want to make you better. And with ME you can't really do that, you can't make it better. You can only **support** them in whatever way they need to be supported...I found generally the people kind of really ja...struggled with it*

I think it's much easier for people if you're kind of bleeding or dying or something. Instead of just having this malingering kind of whatever that they can't see anything.

It's very difficult. It's very difficult, because you know I think that's also why I've got a few good friends that stood by me, you know...because it's difficult to continue saying: no I can't do that. No I can't do that

But the thing is that they don't see me after I had done shopping for a couple of hours you know. Or after I'd been at work for a day or after whatever... People don't see that, they're not exposed to that.

The social restrictions extended to places that the person with CFS was prepared to visit. One participant described her need to be close to medical care:

And we're outdoor people so we like going away for weekends and that. And umm...when it wasn't so bad (sort of in between) wherever I went I wanted the reassurance that there's a doctor nearby. Because you never knew.

3.2.9 Theme: The struggle for acceptance

Self-acceptance is a goal to which most people would aspire, as it allows us to be who we are. This is considered to be a sign of mental health. Yet for the sufferers of CFS, the struggle for acceptance occurs at a number of levels.

There is the need to accept one's illness. The experience of the body which feels ill, yet does not look ill, becomes part of the struggle for acceptance. Acceptance of their situation is difficult for all participants. There is a struggle to accept the diagnosis, the impact that the illness has on the sufferer's life, relationships and belief in him/herself. Self-acceptance is undermined by non-acceptance from others.

You can't be ill! It must be a figment of your imagination

And I didn't want to believe that I was ill and I thought it's a virus and I'm going to get over it; because I was told it is a virus and it will pass. So I was expecting it to pass like next week (laughs)...before I learned more about it. And I wasn't getting any better.

...you get the response from people which clearly you can see in their undertone; they don't want to come out clean on it, but the undertone is suspicious. They're kind of saying: "but there's nothing wrong with you! You look normal. You've got no blood anywhere. You've got no broken limbs. You can walk normally. You can talk normally. You can't be ill!

Self-acceptance is further impacted by the reaction of the health care professionals to persons with CFS. For most sufferers, the road to diagnosis and treatment is long and tortuous, a tale of tests, misdiagnosis, more tests, referrals, labelling and rejection.

I started with my GP at the time. And it was always just a question of: well take a few days; and it's tiredness or it's depression, it's usually those two!..I mean that's what I was manifesting, but it didn't ever, not even in the early days, begin to touch on WHY and what could possibly be wrong...and people were not addressing that; they weren't able to see past what I was showing physically.

it hurt me a lot, not being heard

this chronic fatigue is somehow not a medically acceptable - or acknowledged thing

I went asking for understanding and I didn't always get it

It made me feel that I was different and inadequate

*Agh! For me I couldn't believe that educated people, especially medical people, could **not** accept that it's possible that these people suffering from yuppie flu have a genuine problem that they do not understand.*

Labels that one is given impact on the person's acceptance of him/herself. Each label has meaning, and one has the choice of living up to the meaning attached to the label, or fighting against it. One participant described how she tried to fight – to be different. Yet in that struggle, she loses the right to be ill and have her illness accepted. There is furthermore the frustration of living with a disease which is not going to go away, and which has a relapse – remission pattern. This illness has the effect of taking control away from the person. Control has to do with the sense of self, creating a sense of meaning for life. Not knowing the cause, or course of the illness leads to anxiety, worry and frustration, particularly at the inability to deal with new challenges.

And then as it went on and on I read and I heard that it could be years. And I wouldn't accept that at all. I said no, this is not going to happen to me.

Because you feel frustrated. You 're so frustrated, you want to do those things and you know you can't.

I had to learn then to pace myself, and things that were priority previously were not priority... at that time. And then of course when you'd get a relapse after feeling fine - that is very difficult. To accept that you're getting ill again, and you don't want to be. You don't want to be ill.

Lack of acceptance influences the person's ability to cope with the illness. Because this participant cannot accept her illness, she cannot allow herself the freedom to be ill – is being ill a freedom? For most persons, that illness is seen as a restriction on one's normal day to day activities and on the choices one has – but the CFS sufferer it seems that because the illness is not accepted by the health professionals he/she is not free to be ill.

*You know to myself and to others. Haven't always succeeded in that, and sometimes maybe that's why it's a struggle to put that down and just acknowledge that on certain days I am just ill. I suppose it's because I've never had the freedom to actually be ill. Either I haven't allowed myself, or I don't want to admit that that's **still** happening in my life.*

And I need to know that I can go through a day like this, even an interview like this. Because it's important that I say what I need to say. And I am seen as I am. In the context of a whole person, instead of just presenting what other people expect. And always having to find what they expect...So that if I could contain and control this illness, I feel somehow I would regain something of what life has done to me. Or the fruit of what's happened in my life, which I sometimes feel is partly to blame - if I'm right.

Accepting the limitations that illness places on relationships is a challenge for sufferers. One participant described her frustration and sense of failure, when, even if her friends said that they understood and accepted her situation when she cancelled an appointment, she was unable to accept it – as if it is she who can change the illness.

And the psychiatrist would keep telling me that I've got to realise that I've got a debilitating disease. And I had to learn then to pace myself, and things that were priority previously were not priority.... at that time. And then of course when you'd get a relapse after feeling fine - that is very difficult.

I know it's strange. I hate to make that confession that I'm ill.

I don't mind the not going to wherever it is. I mind having to make that admission I think. I mind having to acknowledge that I'm still fighting this thing. Maybe it's an admission of failure? Maybe I don't like to give in. It could be even more complicated than that.

For this participant, admitting that she is ill is the struggle. This illness appears to have a different impact on her – is it because it is not perceived to be legitimate? The struggle that goes on - to cope, and go on coping, until it becomes impossible to continue- and then having to accept that one cannot go on any more – to be able to take refuge in the illness. What does this mean? Taking refuge from the struggle of having to keep going? On the one hand she talks about the freedom to be ill, and now it is about refuge in illness. This seems to epitomise the struggle for acceptance that characterises this illness. The acceptance of a failing body was difficult for ALL the participants, particularly as most of them had described themselves as hard workers, high achievers, striving to meet others' expectations of them, as well as their own.

There's this pattern in my life of coping, coping, coping. And then there comes a time when I don't want to cope any more. And so there is this tiredness and this feeling ill. So I would like to take refuge in it and I would like to acknowledge it, but then part of me says: well no, you actually can't do that. So there is this conversation that goes on sometimes in my mind. Until I eventually -- I just give in.

One participant described the difficulty that she had with self-acceptance. It seems that she is looking for any kind of explanation for her anxiety, her indecision, and her inability to accept herself. This illness has challenged the core of her ability to accept herself. It has taken away the control that she needs over her life and her body, it has impacted on her relationships and on her ability to make decisions about her life. She cannot accept the person that she now is, the limitations that are part of her daily existence, and the person she has become. Acceptance was made a little easier when she discovered that others felt similarly to her.

...I hate acknowledging that there are these things happening in our lives; that drain us of energy and take us away from being productive, and keep certainly myself so caught up in me. I would rather that I didn't have to face all that.

You know so you get angry with yourself momentarily, because you do understand you know...why it is. And once you understand these things and you know other people are experiencing it, it makes the acceptance perhaps.... easier. But initially you don't know anything; it's a strange thing and all these things that are happening to you, what does it mean, or you know...

Acceptance is about the reality of relationship – in that we see ourselves in relation to others. We are who we are only because of our relationships to others. If others do not believe our stories and our experiences, our lives and our inner selves are invalidated.

3.2.10 Theme: Creating a Meaningful Existence

Each participant, faced with an illness not readily accepted by health professionals, family and friends, and general society, has to take on the challenge of coping and creating meaning at a multi-dimensional approach to living: physical, emotional, social, spiritual, intellectual. In order to do this, participants employed a variety of different coping strategies with varying degrees of success.

3.2.10.1 Creating an image of coping and normality

Participants described the challenge of “being real”, yet presenting to others what they felt the other could deal with or wanted to hear.

And so I present to them what I think they want to hear. I will present a good, almost like a case history, if I go for an interview to a medical person. Or to an employer I will present a coping person - which I am - a lot of the time. That is not necessarily a false thing that I present, but I find myself wanting to give this good impression of someone who isn't ill. I don't know if that's true you know on a day like today, when I am sort of fuzzy anyway. I am not sure who the real person is sometimes! But because of the labels that I've had; of being a depressed person; of being a neurotic, which is one label that a doctor once gave me. I fought tooth and nail to present something different. You know to myself and to others. Haven't always succeeded in that, and sometimes maybe that's why it's a struggle to put that down and just acknowledge that on certain days I am just ill. I suppose it's because I've never had the freedom to actually be ill. Either I haven't allowed myself, or I don't want to admit that that's still happening in my life.

This participant had considered cancelling her appointment with me, the researcher, for the scheduled interview. Yet her need to prove to herself that she could cope was such that she did not cancel. This excerpt from the transcript of the interview reveals her great need to be able to be recognised as someone who is coping well:

It is very important to me, that is why ... one of the reasons I didn't phone today and say: don't come. It's because I thought: there are days you know, when I am like this. Where I don't have two thoughts in my head. But come to the push, I can actually do it! And I need to know that I can go through a day like this, even an interview like this. Because it's important that I say what I need to say. And I am seen as I am. In the context of a whole person, instead of just presenting what other people expect. And always having to find what they expect

3.2.10.2 Attempting to maintain control

Maintaining control is important for the CFS sufferer. The illness which is unpredictable and devastating in its impact on daily living, needs to be contained as much as possible. There is the hope that if the sufferers are able to control the illness, they could regain at least some of their lives. There is an element of bargaining with one's body, one's emotions, and one's experience of God.

Activities are rescheduled, appointments changed or cancelled, but there continues to be a sense of guilt for letting the other party down. One participant would ask her husband to make the necessary arrangements rather than face the fact that she cannot meet her commitments. She recognised that many people do in fact understand the situation, but that it is her own need to cope that pushes her to continue.

Yes, even being sick I feel there is a limit to how much I can be sick; how long I can be sick; when I can be sick; how I can be sick! It's almost as if I sometimes see that as a thing that I must still control. I must still control, when it happens and how much it happens, and what it does to my circle. The hardest thing is to acknowledge, that as much as I've tried to control it and contain it, it still happens. It is still a part of my life. And I obviously don't have control over it.

By ignoring it; by keeping going when I am aching from head to foot; by trying to keep as many appointments as I make. Occasionally I cancel. So that if I could contain and control this illness, I feel somehow I would regain something of what life has done to me.

Participants described how they forced themselves to keep going, even when their real desire was to opt out and take time for themselves. There is a constant sense of struggle with the need to cover up or to be honest about how they are feeling. Some participants seemed to find it easier than others to deal with this conflict. This is possibly related to the length of time they have lived with the illness and the support they received from others.

I just have that time where things dip and I feel so tired. Part of me would love to just go and crawl into bed, but circumstances don't allow for that. So I more or less talk myself back up into a place of coping. And then I take something as I've said - whatever it is, and on I go. Probably not with the same energy or momentum. But I do keep going.

I kept pushing through with this illness all the time and I was going to just keep on going because that's the sort of person I was. If I got sick which was like a cold or flu or whatever, you didn't go to bed and stay home from work, because there were things to be done and unless you were really totally wiped out that you spend a day recuperating - you.... so what if you weren't feeling up to par, you went and did whatever needed to be done and it passed and then you were through it and you carried on.

Ja. It's not as straightforward as it sounds sometimes. Because there's this programming that goes on in each of us maybe - where you have levels of expectation - others and your own. And you try to match that, and you're trying to be honest with what's happening in your life.

3.2.10.3 Choices and conflict: the challenges of CFS

"The goal of occupying as normal a place as possible in the life of the community has implications for many aspects of the patient's life – from the management of the treatment regimen and the control of symptoms to the management of social isolation, changed vocational status and family relationships" (Anderson & Bury 1988:3). For the person with CFS, this statement holds true as they attempt to maintain normality in their activities of daily living. Participants reflected on the importance of trying to do the normal things that everyone else did, making adaptations in lifestyle, eating patterns and responsibilities so that it would be possible to feel as if their lives were normal.

Despite the desire to maintain a normal existence, being able to set appropriate limits was a challenge for all participants. Learning to say no did not come easily, as there was a great desire to 'catch up' whenever they were feeling well.

...try and get up every morning even if you do nothing other than shave and get dressed, rather than just lie in bed and do nothing.

...change our eating style and move from a basis where we perhaps had meat four or five times a week to maybe having meat ... well initially we had no meat for about the first few months ... to a fruit and vegetable based... a life science diet

And then you have to say no. You have to keep on saying no.

*And it has taken quite a few years (probably about four years) to be able to say no. And just go: **no!** And it actually is for my good. And I don't give a stuff whether you don't like it, or whether you can't handle it, or if you decide you're not going to be my friend any more, because if you really are a friend you would want what is good for me. And I think that's the big thing with ME, it's kind of things that a lot of people have to learn, and it's kind of very difficult. Why do I do the kinds of things I do. You know what...what drives me*

When I've got to sleep I've got to sleep, and if I've got to go to bed at nine o'clock - that's it. Which is still relatively difficult to do, you know. To say: I'm going to bed at nine o'clock. And to not feel that you owe people explanations.

The life of the person living with CFS is that of ongoing choices. These choices are not those that the average healthy person is called upon to make, rather these choices are about coping with the fatigue – what and how much can one do and still be able to get through the day? The concept of allocation of energy was described, as if participants had to carefully decide on energy resources available to them at any one point, and for which activities this energy would be used. Energy is experienced as a finite, limited resource, which has to be allocated carefully to the best advantage for the individual. Choices have to be made about how much the person can do, when he/she can do it, and the amount of recovery time that will be needed.

And I mean I know as a ME person one of the big things I have to watch for is stress. You know...Stress fatigues you. Whether you're a well person, it fatigues you, you are just not aware of it. When you have ME it fatigues you and you are aware of it. So those are the kinds of things that I constantly have to be aware of. What are the things that are stressing me. And how can I work with them? And if I can't work with them then I've got to actually just get rid of them.

But you know there's always that tug-of-war between doing what is good for you and doing what is healthy for you and managing your illness. And ...going to a party.

I don't think it can ever stop being a conflict. Because one always naturally is drawn towards going to a party rather than staying at home on your own

So in a sense I do walk a very fine line. Because I know my job is very stressful. So I've got to be careful. But I mean I think it's great. You know I'm earning money, which is fantastic. You know ...And....I'm sort of kind of coping. I'm actually doing more than coping. I seem to be kind of getting it to work. Ja and one of the things is I have a sense of humour. I don't know how anybody can get through without a sense of humour.

You know and it's still allocating my energy, you know. umm... I have one thing on during the week that I sort of alternate, it's either a Tuesday or a Wednesday night. ...One weekend I'll go out and the weekend afterwards I'll try and sleep or whatever. You know it's still a case of kind of juggling. Ja and of being able to say no, I can't do that.

*What I found initially is trying to ... you know I actually used to sort of allocate my energy. I used to sit and go okay.... So you go, OK I'm going to need this much to have a bath. And I'm going to need this much to eat. And this much to dress myself. Or will I have enough to go to the groceries shop or to Pick and Pay to buy groceries? But that's what I found and I still have to do that. After a year I would literally kind of like **measure** it because that's all I had. And I knew that I didn't have any more of it. And then eventually you start to get the feel, how much you've got and when you're going over the line. umm... But it is also a tricky thing to gauge. Like when you go over the line you have a relapse*

Coping with employment was a major challenge for all of the participants. All were employed, although not necessarily as the major breadwinner. The stress was greatest for the participant who was single and solely responsible for her own income.

And now I've taken another job, which is not quite what I do, but part of the reason why I've taken it is because I finish at half past four. And I don't have the responsibility that I used to have. You know and so what I see as kind of building up to that, if that's what's going to happen. Maybe that's not what's going to happen. But I made a case of kind of doing what I can do. And we'll just have to see how things progress and take it from there.

3.2.10.4 Taking responsibility for oneself

The realisation that the strength and determination to cope with the illness depended on the individual, is seen in these quotes:

So I think one of the big things is taking responsibility for yourself.

*also you know the whole thing of not just relying on one person to kind of **fix** you.*

CFS sufferers, having realised that the health profession is unable to meet their needs for information and help, have had to take up the challenge of dealing with this illness themselves. This has meant that the participants in this study began to educate themselves about the condition and explore alternatives, as this enabled them to feel more in control, rather than relinquishing the control to the illness or the health professional.

Learning to cope with CFS means learning to set realistic goals for oneself. This requires that the sufferer be in touch with his/her body, feelings and world. There is a realisation that the person alone is going to have to make the decision about how to cope, what to include in the day, what to omit.

But also of becoming educated yourself. What actually are my options and what actually is out there besides the GP. He doesn't even know what I know in any case

Look I don't set myself goals like that. What I do is I kind of work with what I've got now. All right. So if I'm feeling comfortable within that kind of a time frame - I work with that. One of the things that I have noticed is that when you've got more energy it is apparent. It's kind of like - maybe it's like an esoteric thing.... Its like I have progressed

When I sense that I have more energy and am naturally more awake, OK, then I try for half past eight and see how that goes. And if that works then we go with half past eight. And so it's not like I'm setting a goal because maybe I can't achieve that and then I am going to be disappointed. But it's like.... kind of feeling out each little step and ...building on what you have

Participants had learned to recognise the tell-tale signs of over-tiredness, stress and other factors which could herald impending relapse. They could then decide to pull back on their activities, and expend what energy they had to the best advantage.

Because I think you kind of get to know things. Like with me it's my throat. okay...As soon as I feel that scratchy throat or that post nasal drip starts dripping I know, oh oh, we are overdoing it. Ja and then I like take it easy straight away because then I know I've overdone it, definitely. Then I've gone past my limit. So I'm very aware. Like for me that's the warning bell. The thing is to not get there. Because once I get sick it's like a whole big mission. So the thing is to not get there.

The thing is to know that boundary. And that you don't kind of step over. ja...That's also quite tricky you know

And I have to be continually aware of...how much energy I've got and what I do. And be responsible to that. Because at the end of the day I'm the one that's going to suffer. And not anybody else you know.

...but I can't get too hung-up on what I'd like to be because otherwise I think it will kind of depress me. So to a certain degree I have to say, look I have to make the best with what I've got now.

Despite the variety of coping strategies described, perhaps the following quotes from two participants accurately sum up the constant battle to cope with CFS:

I think perhaps because, even after all this time I still fight what is happening to me.

But if I reflect and ask, what would I have done differently, I cannot really say that I would have done it differently

3.2.11 Theme: Remission, Recovery and Hope

The pattern of this illness for the sufferers is one of periods of illness, pain and fatigue, followed by periods in which they felt better. Feeling better was both positive and negative, in that while they enjoyed feeling good, there was the constant fear that it might not last, and that there would be a relapse.

All participants described their experiences of the good days, as being days in which they wanted to do as much as possible. This was in spite of the knowledge that to do too much might mean that they would suffer a relapse or at the least a minor setback, such as having to go to bed for a few days to recover. There was a constant tension experienced between feeling really bad, down and ill, and the occasional days when they felt really good. This created a dilemma for the participants: if they used the 'feeling good' time in order to do all the things that left on hold, there was a sense of knowing that they would have to 'pay' for this level of activity. There was the further tension resulting from the hope that this would be the beginning of recovery, in the face of the reality that it was probably only a 'good day'.

The odd days in between which I felt fine ...you want to do everything.

*You sort of got excited within yourself... this is the last time I'm going to be ill... **not** going to happen again.*

And when I started feeling better in between, every time you would feel better you think it's over. And you get so... happy and you think this is the end of it.

*Because I cannot afford to have a relapse. I **can't**. It's not just in terms of then... what do I do financially, and I have responsibilities you know. It means starting all over again. Trying to get a **job** after having been sick for seven years is like **major***

*Yes especially when you started feeling better. You sort of got excited within yourself. Because every time: this is the last time I'm going to be ill now. And it's **not** going to happen again. You didn't want to **believe** that it could happen again. I mean you always have that: I know I'm going to get better. I mean I didn't for one minute ... I didn't know when ... and of course there are times when you are in despair and you think it's never going to happen. And just cry to the Lord and say it's enough.*

There was recognition that the management of this illness demands that the individual take responsibility for her his/health:

And it's a case of kind of really taking responsibility for your own health and making your own choices.

*But... I have improved, but I know and I've had to teach myself to say: no, it's not what somebody else is telling you is the case, it's what your **body** is telling you and what you feel. And I've had to learn to say...listen to myself and say: no, no, no, I actually can't do this. And it's not a big defeat by saying I can't do it, it's just being realistic. And saying I can't do this, this is what I can do up to here, and that's what I can do. And it doesn't matter what anybody else thinks or says, because I've got to know myself what's within my limits.*

Despite the negative experiences that CFS sufferers have lived through, all of the participants stated that there have been some positive aspects of their experience. Participants reflected that the experience had forced them to take responsibility for their lives, make appropriate choices, and new learning had been possible.

My own spiritual journey has been very important to me. And I just think there are things that I could never have learnt about myself, and who I am, you know, if I hadn't got sick. OK maybe I would have learnt them in a different way, but this is how I learned, you know through my experience

I think ME is also about growing up, you know...I think it has a lot to do with being an adult. You know I think a lot of people stay children in many areas of their lives, you know. And I think a lot of being an adult is being able to say, this is who I am and this is what I want. This is what I choose to do. This is what I know is good for me, you know. ...So making choices for yourself and actually standing by those choices.

That were kind of there but that I was unaware of. You know in a sense my kind of own inner strength. umm.. I think I have less fear now about things, whatever those things might be, than before I got sick. Because now I feel as if I've walked through hell and I've come out on the other side. And I'm actually stronger, I'm not weaker. umm..I think that's the most important thing; that I'm a stronger person in my character you know...than I was before....

I think so often we leave the responsibility of ourselves, of our health, personality, character, spiritual journey or whatever, in the hands of other people. And what other people say about us, you know. And we are so affected by what other people think about us.

There continued to be questions that could not be answered. CFS not only challenges the person to grapple with existential questions of life, its meaning and purpose, but also affords the sufferer the opportunity to take up the challenge.

...what did it mean ...I don't know, I think for a long time it was just a kind of a searching. What does it mean? What if it continues? You know if I was sort of paralysed from the neck down, what would it mean for me? Being able to do nothing. Because in a sense I could do nothing. You know what does it mean about me. You know ...and the thing is that I think I am me.

*And whatever I've discovered about myself, and the things I like about myself, and I have more that I like about me now, or I'm more in touch with the things that I like about me than before I got sick. And I think I've **grown** a lot more as a person. I've grown up a lot more. umm...I've become more of a person. I've become more **me** if that makes sense.*

And maybe in a way it's been a learning experience because maybe life wasn't meant to be that fast anyway. So it was very difficult. I had to think about ...to convince myself that it was for the good that I couldn't do things and that I had to sit back and take time to actually look at things and just lie in the garden and watch the birds. Things that I would never have done before because you're too busy doing things

The person with CFS has to come to terms with a new self, to re-evaluate, to find a new awareness of value and worth. The positive experience seems to relate to 'coming to terms with who I am', 'how I function', personal growth and development, and the recognition that life can have meaning even when lived at a different pace. All of the participants reflected that they have become more health conscious, have learned to take control of their lives rather than let external factors dictate how they should live. The quest for perfection, the need to 'do it all', and to be totally self-sufficient, had been impacted by this experience, and there is a sense of acceptance of self, in a body with limitations, in a world which does not provide all the answers.

...I mean I have ... I've had to have long looks at myself. I've been driven to look at my whole picture of who I am as a woman, as a mother, wife, career person. And I can see that there are still good things in me; that I am still able to function, regardless of what's happening.

I just think there are things that I could never have learnt about myself, and who I am, you know, if I hadn't got sick.

*I think I've **grown** a lot more as a person*

The whole experience has changed my whole way of thinking and my whole way of life.

...I had to learn that everything can't be done now and be kept perfect and be on track

3.3 Concluding Comments

In this chapter the lived experience of the participants in this study has been described through reflection on the extended descriptions taken from the transcribed interviews. CFS is described as an all-encompassing experience. No part of the sufferers' life is left untouched. The person with CFS has the choice of succumbing to the illness, or taking on the challenge of creating for him/herself a sense of meaning, which facilitates acceptance and growth.

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CHAPTER 4

DISCUSSION AND CONCLUSION

4.1 Introduction

In the preceding chapter I have attempted to describe the experience of living with CFS, using the descriptions of the participants in my study. In phenomenological research, the essence or nature of the experience has been adequately described when the description reawakens or shows us the lived meaning of the experience in a fuller or deeper manner (van Manen 1984:1). In describing the experience, common themes emerging from the data have been identified.

Living with CFS was found to be a complex and dynamic experience, which impacted on all dimensions of the person's lived world. The themes that emerged relate to the person's *physical* world – themes of tiredness and the unpredictable and undependable body; the *emotional* world – themes of fear, uncertainty and other emotions; the *intellectual* world – themes of the struggle against the power of illness; the *social* world – themes of illness as it impacts on relationships and acceptance in society; and the *spiritual* world – themes relating to creating meaning in one's life. Themes that emerged strongly relate to how an illness which is not considered to be legitimate or to 'fit' into a recognised model impacts on the sufferer. There is a great need for an illness to be found acceptable, to the sufferer, his/her family and social network and to the health professionals.

In reviewing the literature which relates to not only CFS but also that of chronic illness in general, it is evident that little is known about the experience of making chronic illness a part of one's life. Michael (1996:252), in a study exploring how chronically ill adults integrate chronic illness into their lives states: "Although

chronically ill individuals visit hospitals, physicians offices, and ambulatory care facilities, it is only for brief meetings that are often related to assisting people to manage their illnesses at home.....health professionals frequently fail to understand what it means to integrate changed treatments into their lives." Although numerous studies have been done, most have concentrated on particular aspects of the chronic illness, and it is only fairly recently that studies using the phenomenological approach studies to look at lived experience have been published.

In this chapter the themes which emerged from the study will be discussed in the light of available literature on CFS and the broader field of chronic illness, in an attempt to present the similarities and differences in the way in which persons with CFS experience their world.

4.2 CFS in relation to lifeworld themes

Merleau-Ponty (1962) describes the four essential life world themes as existentials (cited by van Manen 1990:103-5). These are *lived space* (spatiality), *lived body* (corporeality), *lived time* (temporality) and *lived human relation* (relationality or communality). The four fundamental existentials of spatiality, corporeality, temporality and relationality may be seen to belong to the existential ground by way of which all human beings experience the world, although not all in the same modality. These lifeworld themes can be recognised in the data and will be discussed in the light of the findings of this study.

Lived space (spatiality) is felt space, the world in which human beings move and find themselves. Everyone inhabits space in a unique manner, and, for the person with CFS, space has become an issue as he/she is forced to confront the limitations of the world in which he/she now lives. Lived body (corporeality) refers to the

phenomenological fact that we are always bodily in the world, and that we relate to others through the body.

We can reveal or hide things about ourselves in our physical or bodily presence. This has particular significance for persons with CFS as they begin to experience their bodies differently. We relate to ourselves through our understanding and acceptance of our bodies in the fullest sense. This too is challenged by the illness.

Lived time (temporality) refers to our temporal way of being in the world. The temporal dimensions of past experience, present and future constitute the horizons of the person's temporal landscape. This lived time is assumed to be a universal and fundamental feature of the lifeworlds of all human beings, regardless of, although shaped by, biographical and historical time (Sandelowski 1999:80). For the person with CFS, there is a memory of a time in which he/she was well, the current and/or past experience of the illness, and the uncertainty of a future in which the illness will be a part of all hopes, dreams and challenges. Lived other (relationality) is the lived relation we maintain with others in the interpersonal space that we share with them (van Manen 1990:104). We find our sense of purpose in our relationships with the other – whether this be in community or in a religious experience of the Other (God). Living with CFS impacts on the person's relationships with others – family, friends, community as the illness dictates the extent of these relationships.

In effect, illness shapes our world: our sense of time and priorities, our experience of space, our felt relations with others, and our sense of self and of the body (van Manen 1998:12).

The person with a chronic condition has to learn to live with the impact of the disease/condition, and the impact of this on his/her life. Frank (1995: 8-13), writing of his experience as a cancer survivor, argues that the modernist view expressed by Parsons does not address the increasing numbers of persons whom modern medicine has placed in what he terms "a remission society" - persons who are effectively well, but not cured. Members of the remission society, argues Frank, include persons with chronic illness, the disabled, and those recovering from serious conditions or addictions.

4.2.1 CFS and the lived body

Themes relating to CFS and the lived body, reflecting the fatigue, exhaustion and unpredictability of the body emerged strongly from the transcribed data. The inability of the body to respond in the expected manner impacted on the person's ability to connect with his/her lifeworld. Moss (1977:61, citing O'Neill 1970), considers the lived body not only to be the mortal frame but rather an opening out on a world into a network of possible relationships with my world – the "schema of my world".

How does the person with CFS experience his/her body? For the healthy person, there is sense of 'healthy unawareness' as the individual accepts that the body functions silently as the person interacts through the body with his/her world. The individual knows his/her body, has a sense of how the body should or will function in different situations. "When we speak of our body as an aspect of our world then our sense of it is a kind of unaware awareness; indeed, our primary occupation is in the world and with the world" (van Manen 1998:11). This illness forces the person to become aware of the body in a different way. People define themselves in terms of their body's varying capacity for control (Frank 1995:30). Illness and disease creates a loss of predictability, and may cause further loss. The unpredictability of CFS – its pattern of relapse and remission, creates a sense of loss of control over one's body.

Tiredness is part of every day, permeates everything that one chooses to do and the way in which the person relates to the world, and is the controlling factor. The body is inarticulate, states Frank, yet not mute.

The person with CFS who, disregarding the body's communication, attempts to continue with his/her normal pattern of life, finds that the body 'rebels' and does not respond as anticipated. The person's interaction with the world is different. Yet the body does not obviously look ill, and the feeling of being unwell is difficult to explain. The person with CFS engages in a process of observation of his/her body – what it can and can no longer do, becomes self-reflective and acutely aware of every symptom. CFS impacts on the person's sense of self – identity and situatedness. Having a condition which is not fully legitimised by health workers, and in particular the medical professionals, the person with CFS who engages with the health service finds that his/her illness is not recognised, and has the perception of not being heard or being taken seriously. The person with CFS therefore spends energy in trying first to convince the health care profession of the lived reality of the illness, and then has to live in as normal a manner as possible, as a person with a chronic illness, yet has to prove him/herself to be well, in order to maintain a place in the social and employment milieu in which he/she lives. The person's self worth is devalued. Naming the disease, even though the verdict may be feared, may actually give relief to the sufferer, as it enables the person to give the disease a place in his/her life. However, in the case of CFS, naming the disease gives rise to further uncertainties, as there is a query of its legitimacy, it has no predictable outcome, no acceptance, and the sufferer has no sense of control over the situation.

Bury (1988:90) states that the meaning of chronic illness can be understood from the perspective of the consequences of the illness for the individual and the significance or connotations that a condition carries. This has particular reference to CFS, as sufferers struggle to gain legitimacy. "To be an invalid is bad enough but for this to mean the individual is *invalid* is another matter altogether" (Bury1988:91).

The experience of being labelled and of having an illness not considered to be fully legitimate is a theme that is highlighted in studies done by Ware (1993:71), who examined the illness experience of persons with CFS from a socio-anthropological perspective. She reports that the experience of being "delegitimised" in one's experience of having a "real illness" led to suffering in the form of frustration, anger and self-doubt, and to the questioning of the person's rationality.

The participants in my study described a lengthy trail of seeking assistance from a variety of health professionals and complementary health practitioners in their desperate attempt to get answers, understanding and help. Cooper (1997:195), reporting on a study of ten interviews with sufferers of CFS, also identified this pattern, stating that participants in the study found themselves seeing a number of doctors and consultants in an effort to find a diagnosis. According to Cooper (1997:197-8) labelling was identified as a problem by the female participants. In this study, sufferers reported being labelled as 'malingerers', 'school phobics', or 'bored housewives'. Labelling is not confined to CFS however, as it is recognised as an issue by other researchers into the field of chronic illness. "Being labelled by the disease they experience, and the treatments they use, people with chronic illness are set apart from others (Wellard 1998:51). It would appear however, that in the case of CFS, until the illness itself is fully legitimised, the labelling experience will continue to be a painful reality for sufferers.

If a person's illness is not considered to be genuine, how then can he/she get treatment, and is it possible to get well? In a paper entitled "*If You Have to Prove You Are Ill, You Can't Get Well*", Hadler (1996:2397-2400) discusses the issue of the vulnerability of persons who have a chronic condition such as fibromyalgia. In the absence of impairment, he argues, society is not prepared to believe them and in fact goes to great lengths to challenge their perception.

The twentieth century has been marked by the appearance of a number of 'syndromes' which have been denied legitimate illness or disease status. These include repetitive strain injury, multiple chemical sensitivity and CFS (Cooper, 1997:186-7). The experiences as described by the participants in this study reflect the impact of this lack of acceptance on their sense of self.

Cooper (1997:202-3) further discusses the influence of lack of acceptance of the legitimacy of an illness on the social position of the sufferer. The person is refused 'permission' to enter the sick role, is blamed for his/her condition, social identity is devalued and stigmatised, and it is difficult to obtain sanction for absence from employment or to obtain a disability benefit. According to Fennell (1995:70), CFS has been trivialised, stigmatised and minimised by the media, the medical community, society and the public.

In the discourses on normalisation in the exploration of chronic illness, it is apparent that persons with chronic illness fail to meet the expected 'norms' of society or of the health professionals by their failure to 'comply' or to restore themselves to normal health (Wellard 1998:53-54). This further isolates and marginalises the person with chronic illness, and in particular the person with CFS.

In a study on immigrant women's experience of chronic illness, Anderson (1991[b]:714-5) found that the women in this study were placed in a double bind; labelled as non-compliant if they did not meet the demands of the health professional, and having to bear the consequences of this label. This, argues Anderson, in and of itself accentuates their (the participants) marginality and further diminishes self worth.

4.2.2 Illness in Relationship (CFS and Lived Relationality)

In the preceding chapter I have described the effects of CFS on the sufferer's relationships. The person living with CFS, in order to cope with the demands of daily living, has to eliminate all activities that are a perceived threat to achieving the his/her goals for survival. This varies for each person, and may be holding onto a job, or maintaining 'normal' family relationships. Restricting other social contacts, thereby increasing the person's social isolation, was one of the coping mechanisms used by all the participants in my study. Charmaz (1983:169-172) contends that "living a restricted life causes social isolation and social isolation leads someone to live a restricted existence", both of which she identifies as a source of suffering which leads to a loss of self.

Ware (1998:397-399) refers to the concept of 'role constriction', in that the person with CFS is unable to continue to fulfil valued and expected social function (spouse, parent, employee, friend). The person's relationships with others are severely impacted by the change in roles. There is withdrawal from social situations. In the realm of employment, however, her study noted enormous resistance by CFS sufferers to being marginalised by their illness. CFS sufferers met the daily challenge of work through the use of a variety of compensatory mechanisms.

Schweitzer, Kelly, Foran, Terry & Whiting (1995:1370) described similar findings in a study of 23 subjects with CFS. Not only were the number of social activities restricted, but the number of friends were reduced, and about 40% of the subjects described the loss of friends through lack of understanding or acceptance of CFS.

Schweitzer *et al.* (1995:1370) also reported on the impact that CFS had had on the participants' social and family relationships. This study reported that CFS had initially led to strained family relationships and that family members had appeared to be unwilling or at least resentful of having to offer support or to accept that the illness was real. However, the researchers reported that at the time of the study, 65% of the participants' family members were supportive and were able to take on responsibilities for tasks normally taken on by the person with CFS. My own findings concur with this study with respect to the impact on relationships with children, in that a similar response of not having enough energy to devote to activities with children was reported by participants. Lopis (1994:105-107), a medical practitioner, in relating his personal experience of having lived with CFS for four years, described the impact of the CFS on his family and social networks in terms of unpredictable illness, looking well yet feeling ill and disruption to his family life.

The impact of chronic illness on family relationships has been documented in research studies on a variety of chronic illnesses, including: arthritis (Bury 1988:108-9), rheumatoid arthritis (Ryan 1996:3); diabetes (Kelleher 1988:137-155), psoriasis (Chrissopoulos & Cleaver 1996:40); Parkinson's Disease (Pinder 1988:67-85; Marr, 1991:326); multiple sclerosis (Robinson 1988:55-63).

While each illness/disease condition has specific difficulties related to the level of disability, acceptance by significant others, and support needed, there are significant similarities in the impact of a chronic illness on the relationships. These impacts need to be better understood by health professionals.

4.2.3 CFS and the Lived Environment [Space]

According to Kruger (1979:51), the space of our everyday lives is the space in which we are doing things, and interacting with things. Space is always structured in terms of time, and is the foundational characteristic of the way in which we open up the world to ourselves. The person living with CFS experiences his/her lived space or environment as different. It is particularly difficult for the person who does not inhabit that same space to really understand what it feels like, its mood qualities, its landscape.

The person loses contact with his/her social environment, and lived space becomes restricted in the main to the home environment, and limited contact with the world outside. This outside contact is determined mainly by survival needs, as reflected in the participants' descriptions of going shopping, maintaining their jobs in whatever way possible, and in their severe limitation of tiring social activities. Awareness of the loneliness of the space is expressed as a deep sense of aloneness and isolation. The lived space becomes a powerful entity in the person's life. It has to be engaged with, tolerated and appreciated.

Tuck & Human (1998:17) found that CFS sufferers lost "everything you've worked for", referring to house, car, job, business, friends. This loss of connection with the person's environment is also described in the literature on living with chronic illness. Marr (1991:326-327) discusses the difficulties in maintaining activities of daily living for persons with Parkinson's Disease.

4.2.4 CFS and Lived Time

A person's perception of time is influenced by the dynamic interplay of self and situation (Flaherty 1992:153). Time is not only a measurement, it characterises a person's existence (Kruger 1979:55). Illness changes one's perceptions of time. For the person with CFS, time is experienced in a number of ways: as slow, as loss, as a struggle. Time ceases to have meaning, as the person exists, rather than lives, in time.

Although this existential theme did not emerge as strongly as other themes in the findings from this study, there was for all participants a sense of lost time. Lost time is measured in years, as the sufferer reflects on the time that was not available to him/her due to the effects of the illness. Time was also experienced as a struggle – a sense of having to 'push through' to be able to get through just one hour, just one day at a time.

There was the constant paradox: time taking so long – in wanting to get better, for the symptoms to improve. For the person who has always been able to plan his/her use of time, there is the recognition of learning to live with a process of an illness, rather than a finite event. Yet when the person feels well, there is the sense of having to fit so much into the time available – which is uncertain, and therefore there is great pressure of time. Flaherty (1992:142) argues that the experience of time does not occur because there are different kinds of people but because people find themselves in different kinds of circumstances.

Bury (1988:111-112), discusses the concept of 'temporalising' with reference to chronic illness. Sufferers, in coping with the fluctuations of the illness, use a time-related framework to decide if and when a health professional needs to be consulted, and how to manage the symptoms. Bury maintains that the temporal aspects of chronic illness are central to its development and experience.

As a consequence of the illness there is also the sense of *created* time – as the person has the time to think, feel and become involved in him/herself. This is often experienced as free time, yet this is the time that was previously filled with activity in which the person with CFS can no longer participate. There is more time for reflection.

4.3 Creating a meaningful existence

Four sub-themes emerged from the categories as the participants endeavoured to create a meaningful existence for themselves: creating an image of normality, attempting to maintain control, dealing with choices and conflicts and taking responsibility for oneself. Michael (1996:264), in a phenomenological study in which 17 chronically ill adults were interviewed, found that in gaining control of altered life direction, participants were helped to integrate chronic illness in their lives. Finding meaning is a key component of spirituality and this in turn impacts on the person's ability to live with the chronic illness.

Coping strategies emerged as one of the mechanisms to construct meaning in the life of the person with CFS. This is an aspect of the illness in which significant research has been done. Ray *et al.* (1993:385-391) designed an illness management questionnaire (IMQ) to assess ways of coping with Chronic Fatigue Syndrome. After interviewing 21 patients to explore their appraisals of their illness and coping strategies, an illness management questionnaire comprising four scales was designed.

- maintaining activity (attempting to ignore symptoms, carrying on even though unwell and disregarding possible adverse effects of activity)
- illness accommodation: (organising and planning one's life to avoid over-exertion and control stress)

- focusing on symptoms (a preoccupation with symptoms, linked with an appraisal of one's life as dominated by the illness)
- information seeking (seeking for relevant information and a readiness to try remedies)

The IMQ was sent to 292 patients. 207 completed questionnaires (a response rate of 72%) were analysed. This study did not identify causal relationships or relate coping to the course of illness and current functioning. However, in subsequent research using the IMQ, Ray *et al.* (1995:937-945) examined the implications of patients' approaches to managing chronic fatigue, using the scale to assess coping in CFS, and its relationships to functional impairment and emotional status. One of the findings of this study indicated that maintaining activity was negatively related to impairment, while illness accommodation and behavioural disengagement was positively related. While this study does not directly relate to my own, it is of interest to note that the scales developed by Ray *et al.* (1993: 385-391) and utilised in the 1995 study, contain elements of the themes that emerged in the analysis of the transcribed data from my study.

Fennell (1995:69-79) contends that providing appropriate education about the stages of the CFS illness experience can be an important coping tool in facilitating the adjustment process of persons with CFS. Fennell (Table 2, page 92) mapped four stages in the progression of the illness. In each there are four sub-divisions: physical, psychological, social and work environment. These categories are further subdivided as appropriate for each stage.

Table 2: The Progressive Model of the CFS Experience (Fennel, 1995:69–79).

STAGE 1	STAGE II	STAGE III	STAGE VI
A. Physical 1. Onset 2. Crisis 3. Diagnosis	A. Physical 1. Plateau 2. Stabilization	A. Physical 1. Continued Plateau 2. Relapse (Crisis)	A. Physical 1. Continued Plateau 2. Physical Improvement
B. Psychological 1. Denial 2. Intrusive fear and shame 3. Death Ideation	B. Psychological 1. Relief 2. Confusion and Searching 3. Limit Rejection and Boundary Confusion	B. Psychological 1. Grief Reaction 2. "Can't go Home Again" 3. Engulfment in Sick Role	B. Psychological 1. Value clarification 2. Norm, Development
C. Social 1. Suspicion /Support 2. Initial Isolation	C. Social 1. Increased Conflict 2. Normalisation Failure	C. Social 1. Separation/Loss 2. Increased Realisation or Experience of Stigmatisation	C. Social 1. New Friends/ Spouse/Partner 2. New sources of Help or Health Care
D. Work Environment 1. Disruption 2. Absence 3. Concern/Conflict	D. Work Environment 1. Intermediate Solutions 2. At risk	D. Work Environment 1. Negotiation 2. Separation	D. Work Environment 1. Modified Schedule 2. Alternative employment 3. Disability benefits

This model tracks in a linear manner many of the coping strategies and lived experience of the participants in my study. Themes emerged which relate to all four categories identified by Fennel.

McKenzie *et al.* (1995:60–62) in a study involving 265 CFS subjects from nine countries who completed a postal questionnaire, found that the reported coping strategies suggested ten categories of self care: (1) Attitude, e.g. accepting the illness; (2) Rest; (3) Support: this included networking with other CFS patients and taking better care of themselves; (4) Activity limits in order to cope; (5) Spiritual endeavours, including prayer, yoga and meditation; (6) Avoiding stress; (7) New interests/hobbies or skills; (8) Reprioritising goals; (9) Diet/nutrition; (10) Self-education.

Coping strategies, according to the researchers, appeared to serve the following purposes: to manage symptoms; to adjust to the physical and social restrictions of the illness; and to handle the disbelief often encountered from physicians, social security officials, employers, family members and the general public.

4.4 CFS as a Positive experience

Finding positive aspects in what is essentially a negative experience created for some participants in my study a sense of hope. Ware (1993:67-9) described similar findings in her study. CFS served as a catalyst for a change of lifestyle. Participants depicted the illness as a chance to stop and think, to take stock, to re-evaluate their lives. Participants in her study were able to say something positive about their experience, primarily in that they had gained more than they had lost – particularly with respect to “being a better person for it.”

Being able to find the positives seems to be an important aspect of living with chronic illness. According to McWilliam, Stewart, Brown, Desai & Coderre (1996:1-7), in a study of how older people with chronic illnesses experience health, responding positively to the challenges of the environment was found to be an integral part of creating meaning in a state of chronic illness. Persons living with chronic heart disease also spoke of the positive aspect of their illness (Winters, 1997:12).

The construction of positive meaning in respect of a serious illness seems to be associated with an ability to continue to obtain pleasure and satisfaction from living (Fife, 1994:315). This would also seem to hold true for persons with chronic, although not necessarily life-threatening illnesses. This has implications for the role and function of health professionals, as their role changes from that of “curer” to carer and supporter of the person with CFS.

4.5 Implications of the findings

In reviewing the literature on the experience of living with chronic illness, it is evident that there is overlap in many of the experiences identified by participants in various studies. Marr (1991:325-29) identified the themes of *impact of the disease, dealing with the disease, maintaining independence and normality, and effort* in a study of persons living with Parkinson's disease. Michael (1996:255), in a phenomenological study of persons with chronic illness, identified major themes as *confronting loss, fluctuating emotions, implementing changes, and gaining control over altered life direction*. Aspects of all of these themes have been identified in my own findings. One theme however, which appears to be significant in relation to CFS, is that of 'illegitimacy' or 'delegitimization'. This is an issue that requires greater explication and understanding as it appears to have far reaching impact on the sufferer's ability to create a sense of meaning in the illness experience.

There is a deep need for each of us to create a sense of meaning in our lives. Frank (1991:136) suggests that illness is an opportunity for self-reflection of a kind not otherwise available. Living with CFS forces the sufferer to reflect on the meaning of life, and to engage with his/her lifeworld in a new way. For the participants in this study, this has meant that they have had to take up the challenge of self-acceptance in a world which does not sufficiently acknowledge their problems.

In addition to finding a positive meaning to living with CFS, it would seem that one of the main challenges for the person living with CFS is that of living well. What does living well mean? Living well with CFS is about taking control of one's life, engaging in constructive relationships with supportive health professionals who will listen, and work *with* rather than prescribe *for* the person with CFS. This requires a significant cognitive shift particularly for the health professional. Health professional training needs to address the issue of relationship with clients and patients in a new way and in greater depth.

“The danger for ill people is that they are often taught how to be ill by professionals. Illness is not presented to the ill as a moral problem”, states Frank, “people are not asked what do you want to become through this experience” (1995:159). Ill people, particularly those with a chronic illness, need to tell their stories. Michael (1996:263) supports this, through research conducted with patients living with chronic illness, in which she found that patients who sought health care in the hope that they would be seen as more than their illness and find help, found instead that they were misunderstood and felt insignificant. Michael further states that health professionals were seen as contributing to the patients’ experiences of loss, and that there has been a trend in which patients’ stories of **who** they are have receded from view. This is confirmed in my own findings, in which persons with CFS felt ‘unheard’.

“It is difficult to provide care to a population that has a serious chronic illness without outward manifestations of a disease or disability” (Tuck & Human 1998:18). The participants in my study described how the lack of obvious manifestations of their illness impacted on their sense of acceptance by the health professionals with whom they came into contact. My own experience of comments by colleagues, on learning that I was working in the CFS clinic, and was undertaking this study, confirmed this sense of disbelief about the reality of this illness. There is a tendency to discount what we do not understand as being not credible.

Increasingly the health care professional is becoming aware that people require not only health care assistance, surgical intervention, or pharmaceutical treatment, but that the professional must be more involved in the way that people experience and live with problems in different, sometimes deeply personal and unique manner (van Manen 1998:23). For the person with CFS, engaging with health professionals has generally been a negative and frustrating experience. This is, I believe, at least in part due to the manner in which professionals are trained. There is a need for reflective awareness in the health professional, an understanding of the modalities of

the body experience, and of how the individual interacts and engages with his/her world through the lived body. Frank (1991:123) states that the responsibility of the ill is to witness their own suffering and to express this experience so that the rest of the world can learn from it. I believe this applies particularly to health professionals, but it requires that we should be willing to learn.

There is a great need for health professionals to hear the stories of the chronically ill, so that they can begin to engage with the wider realm of the meaning of chronic illness to the sufferer. Yet ill people do not tell their stories so that medical workers can make decisions, argues Frank (1995:160-1). He contends that self-stories are told to make sense of a life that has reached some moral juncture. Indeed, for the participants in this study the telling of their stories was in no way related to the possibility that they might be helped – for all of them their disillusionment with the medical profession was clearly stated. It was for each of them a means of sharing in the hope that there would be better understanding.

4.6 Limitations of the Study and Recommendations

In a qualitative study, the findings cannot be generalised to the population. In this qualitative study, however, the findings provide a greater insight into the lived experience of person with CFS. Hycner (1985:295) states that if the 'worlds' of the participants can be illuminated in the findings, we can learn much about the phenomenology of human kind in general. As stated in the introduction, there is a paucity of published literature on the lived experience of person with CFS. It is hoped that this study will contribute to the body of knowledge of this illness.

A question that has not been satisfactorily answered in this or other studies is the issue of normalisation. Participants in my study referred to their attempts to live normally within the restrictions of the illness. Does 'normalising' a chronic illness in fact further disadvantage the person who feels that he/she has to be treated normally when in fact this is not appropriate and he/she needs special consideration? There is an expectation, particularly as health care costs rise, that people should be able to take responsibility for self-care. Most people without a chronic condition take for granted their ability to care for themselves and maintain themselves, whereas for the person with CFS self-care and maintaining one's place in his/her lifeworld is an ongoing challenge. Is the right to have their illness acknowledged and the right to appropriate and sensitive health care denied by the demand for normalisation?

It is evident that not only should further work be done into understanding the experience of the person with CFS, but also into the understanding of the illness condition, as a part of the greater whole of illnesses which challenge conventional medical diagnosis and treatment. As medical science continues to challenge the frontiers of disease diagnosis and management, so many more persons are 'saved', only to live with an illness which requires understanding, empathic long term management and integration into society. Increased acknowledgement and understanding of the experience of the person with CFS will facilitate the appropriate care and support of the individual.

"The ill have already fulfilled their responsibility by being ill. The question is whether the rest of us can be responsible enough to see and hear what illness is, which ultimately means seeing and hearing what life is" (Frank 1991:128). This statement is particularly pertinent to the person with CFS – he/she has demonstrated the illness condition, what remains is for it to be heard and understood.

4.8 Conclusion

Currently CFS is an 'unfinished' and 'unlegitimised' illness, and finds itself in the category of illnesses of which medical science has no clear understanding. Thus the person who lives with CFS is subjected to varying responses from the profession, from frank disbelief, to condescending support. This study represents a further step towards the understanding of CFS as a holistic phenomenon, as it has attempted to engage with the sufferer's lived experience of the illness. The themes identified have reflected the all-embracing nature of the condition.

Despite the limitations of this study as discussed above, the study has demonstrated that CFS is experienced as an integrated whole, encompassing body, mind and spirit (Tuck & Human 1998:18). CFS challenges health professionals to re-evaluate the 'care versus cure' debate, examine the moral and ethical questions relating to chronic illness, and to engage with the person, rather than the illness condition, in our practice.

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APPENDICES

NOTE:

Appendices C to E attempt to demonstrate the process of analysis in order for the reader to 'track' the researcher's decision trail. This is done using the transcript of one interview (Protocol One) as an example.

Appendix F identifies all the categories that emerged from the transcribed data.

University of Cape Town

APPENDIX A: PERMISSION TO CONDUCT STUDY

University of Cape Town



Faculty of Medicine

Observatory, 7925
Tel: (021) 406-6911
Fax No: (021) 47-8955

5 December 1995

ERC REF NO:188/95

**Ms M Mayers
Dept of Psychiatry**

Dear Ms Mayers

AN ENQUIRY INTO THE LIVED EXPERIENCE OF SUFFERERS OF CHRONIC FATIGUE SYNDROME

I have pleasure in informing you that formal approval for the above study was granted by the Research Ethics Committee on the 5 December 1995.

Included is a list of Research Ethics Committee Members who have formally approved your protocol.

Yours sincerely

**Prof. JP de V van Niekerk
Dean: Faculty of Medicine**

rec9501205

University of Cape Town

RESEARCH PROJECT: Chronic Fatigue Syndrome

Dear

Thank you for agreeing to participate in the research project on lived experience in Chronic Fatigue Syndrome. I appreciate your willingness to give of your time to assist me.

It would be appreciated if you would sign the consent form below, granting permission for me to use the information obtained in my research.

Mrs Pat Mayers

PARTICIPANT CONSENT AGREEMENT

I agree to participate in the research study of "What is the experience of living with Chronic Fatigue Syndrome?" This has been explained to me by the researcher, Pat Mayers. I understand the purpose of this study and am participating voluntarily. I grant permission for the data to be used in the process of completing a Masters degree.

I agree to be interviewed and grant permission for the interviews to be tape-recorded. I understand that all personal information will be kept confidential and no identifying information will be used in the writing up of the research.

I understand that I am free to withdraw from the study at any time should I choose to do so.

Research Participant

Name:

Address:.....

.....

Tel:.....

Date:.....

Researcher

Mrs Pat Mayers

10 Marlbrook Road
Constantia Hills 7800
Tel: 754724

Date:.....

APPENDIX C: EXAMPLE OF ORIGINAL FULL TRANSCRIPT - PROTOCOL ONE

**Interview with participant 1, in participant's home, a 3rd floor flat
52 year old married woman, working part time.**

How are you feeling today?

Today especially? Not that good today. I don't know why.

This combination as I've said to you of things that...that come - you know with the best will in the world, and as much as I've tried to reschedule my days, and how much I do in a day, it's always that I come to a place where there's an accumulation of things. umm...And then I physically don't.. stop coping.

And has this been a pattern?

Ja. I've tried so ... you know it has been about 10 years now I suppose, and I've got into a way of coping, but it's such a pattern. And even though I recognise it and I can see where things are going, it still...gets to me. I think perhaps because, even after all this time I still fight what is happening to me.

Hmmm.

I can't quite accept it and I struggle to accept it when I'm having a bad day.

When you first started to feel like that (you said that was about 10 years ago), and ...what happened for you then?

I didn't know what was happening. I had **no** idea. I worked through the fact that umm...I was possibly developing into a hypochondriac. I was single at the time and I felt maybe this was one way of...of getting attention for myself, or finding some sort of subconscious weird way of getting people to help me in my...in my circumstances. I didn't really know why I was ill without reason, and it didn't help me that the doctors couldn't find anythingto work with.

So you went to a lot of doctors?

I did you know. Initially I should say it was just a question of the odd er...bouts of what felt like a flu attack, or days where I just couldn't get out of bed and face the world. And I felt ...umm... it took me a while to get to go to people for help. But eventually I did. I started with my GP at the time. And it was always just a question of: well take ..take a few days; and it's tiredness or it's depression, it was usually those two! And it **was**, I mean that's what I was manifesting, but it didn't ever, not even in the early days, begin to touch on WHY and what could possibly be wrong.

How did that make you feel - when people just couldn't give you answers?

It was a horrible place to be in, because I knew myself that I wasn't like that. I know even today, I'm not like that. I am someone else on a good day and I cope extremely well, and I do all that I am supposed to be doing. And yet there is....there was that part of me that just suddenly couldn't physically cope. And people were not addressing that; they weren't **able** to see past what I was showing physically. To that person underneath - that was still trying to cope. And it it...hurt me a lot, not being heard. And I think right then I began this cover-up-thing which I still do today.

You talk about not being heard. How does that feel, not to be heard?

Horrible. I must say in the last year or two, I have found more people willing to listen than in all the years that I've I've...had this ... whatever you want to call it! I still don't know what to call it, if it's an illness or not. I hate even to label myself with that word, but now in the last year or two, I found people who are willing to listen. But in the early days there wasn't anyone. And it hurt a lot because it made me....it made it necessary for me then to go along with what they were saying to me: that in fact I might just be neurotic. I might just be a depressant. I could just be one of those hypochondriac people that I personally have no time for! And I had to consider that I was like these two people. And yet I knew myself deep down; I knew that if somebody would just help me cope with this thing I ...I would keep going. But I didn't find that in the early days.

And so not only were you^{not} being heard, but you were very scared of being labelled as something that you didn't want to be?

Yes over the years I've had all those labels. As much as I have tried to present myself as a well-balanced person. And I think having come through the nursing side of things more than others maybe ... than anyone else maybe, I have been.. I've been nervous of labels

And while you've been nervous of labels, what has happened? Do you think that you've in some way adapted the way that you feel?

Ja. I would think in a lot of instances I have adjusted myself to what people expect.

Hmmm.

And so I present to them what I think they want to hear. I will present a good, almost like a case history, if I go for an interview to a medical person. Or to an employer I will present a coping person - which I am - a lot of the time. That is not necessarily a false thing that I present, but I find myself wanting to err...give this good impression of someone who isn't ill. I don't know if that's true you know on a day like today, when I am sort of fuzzy anyway. I am not sure who the real person is sometimes! But because of the labels that I've had; of being a depressed person; of being a neurotic, which is one label that a doctor once gave me. I fought tooth and nail to present something different. You know to ..to myself and to others. Haven't always succeeded in that, and sometimes maybe that's why it's a struggle to put that down and just acknowledge that on certain days I am just ill. I suppose it's because I've never had the freedom to actually be ill. Either I haven't allowed myself, or I don't want to admit that that's still happening in my life.

Who has not given you the freedom?

Probably me. You know for instance my circle, my immediate family circle, never question when I have a bad day. My husband doesn't question it. He very rarely will argue with the fact that I am having a bad day. My children - neither.. of them will. They will be most supportive. My circle of friends are supportive -- my work situation, my current work situation anyway, not all my work situations have been sympathetic. But my current one is but it's ingrained in me now...not to admit something. In case maybe I come back in under some sort of condemnation I suppose.

Condemnation?

It's a strong word! laughs... As I say, it's a strong word. I build up quite a bit of anger I think over the years for the non-understanding from the medical people, because from the doctors that I went to I had hoped if not to have a cure offered, or a programme offered that would benefit or help me, at least I went asking for understanding and I didn't always get it. And I took that as a form of condemnation or a judgement or a criticism, or whatever you want to call it. So that's been an extra burden

And have you perceived that as coming from them? They've placed a judgement on you?.

Ja. I suppose again having worked through umm...years of working with doctors as a member of the medical profession I feel somehow betrayed, as I think about it. I had hoped that they would find something. And...and not having found any way of coping with M.E. is **one** side of the picture. But not willing to take me seriously over many years is another issue that affected me personally. I always tried to present myself as I've said, as an honest.umm...person. I've never hidden what I've been feeling. And so with that honesty very often what I got back was just like a superficial judgement of who I was as a person. So, something like this now, is probably the first time that umm...who I am as a whole person is being looked at. Not just this person who may or may not be sick

And that is actually quite important.

It is very important to me, that is why ... one of the reasons I didn't phone today and say: don't come. It's because I thought: there are days you know, when I am like this. Where I don't have two thoughts in my head. But come to the push, I can actually do it! Laughs And I need to know that I can go through a day like this, even an interview like this. Because it's important that I say what I need to say. And I am seen as I am. In the context of a whole person, instead of just presenting what other people expect. And always having to find what they expect. If that makes sense. Uncertain laughter. I think most of my life I have been a person who has tried to match people's expectation, even as a child. And even as a nurse, and even as a career person. It's...it's part of my nature just to meet expectations.

Did you ever feel that you were having to meet expectations of what people thought you should be when you were sick?

Yes, even being sick I feel there is a limit to how much I can be sick; how long I can be sick; when I can be sick; how I can be sick! Laughs It's almost as if I sometimes see that as a thing that I must still control. I must still control, when it happens and how much it happens, and what it does to my circle. The hardest thing is to ..is to acknowledge, that as much as I've tried to control it and contain it, it still happens. It's still a part of my life. And I obviously don't have control over it.

How do you try and control it?

By ignoring it; by keeping going when I am aching from head to foot; by trying to keep as many appointments as I make. Occasionally I cancel. By just ... I don't talk about it. If people say: how are you? I will try and be honest, but I won't go into detail. I very seldom talk about it. Not even to my family. Maybe that's denial, and it probably is, but it's ...umm.. I'm afraid that if I focus on it I'll be acknowledging that it is still part of my life -- after all these years. So maybe that's not too helpful or honest, self-conscious laughter... but it's part of my struggle I think

What other aspects of this struggle do you have?

I think that it makes me ... umm...it still has the ability to make me fall apart, if that's not too ...too vague. I have a real sort of desire to keep going with my life with as much momentum as I can. And then on a day when I can't, it makes me angry. And I struggle because of the suddenness of it you know. In a day I can... I can start well and kind of fall apart by lunchtime, or I can pick up and keep going till late at night. It is such an unpredictable thing. And so.. I don't always put all the blame at the door of chronic fatigue, because I still don't have very well contained menopause either, but that combination makes me very ... it makes me swing between being fairly rational and just depressed, unable to cope. So I struggle with the unpredictability of it. Again it's something I can't control or contain. I don't have a handle on it

And it seems like, for you as a person who likes to have some sense of order and control in your life, this has been a big thing.

Yes I think so. You know I ... it's like most people; I suppose you work through your childhood insecurities, and you go through your marriage and so forth. I haven't had a very sort of secure lifestyle in a number of ways. Which is not unusual to other people's stories, but it just happens to be mine. I've worked through many, many years of ..of circumstantial stuff which has brought its heartache and its insecurities and its fears maybe. So that if I could contain and control this illness, I feel somehow I would regain something of what life has done to me. Or the fruit of what's happened in my life, which I sometimes feel is partly to blame - if I'm right. I don't know if anyone knows why one ends up with chronic fatigue. But I know stress is related -- stress is a trigger. And it must...it must have laid the foundations for it you know. And not being able to control it means that these circumstantial things that I've worked through are still having some effect. And I wish they didn't have.

What circumstantial things are there?

Do you mean currently, or what I look back on.

When you look back on particularly the last ten years of dealing with the chronic fatigue.

I've had to deal with not only my own illness, but I've worked through remarriage and with the joy of remarriage - and it has been. There are always many things to work through. And the adjustment of two lifestyles, and the two children that were brought into it. And then because of illness in my husband there's been a sort of role change. So that over the years.... as he has been progressively unable to maintain a full-time job - and then not anything at all - the roles have changed, so I continued in...in working. And I don't mind it, I have a lovely job. But I think subconsciously and deep down... I know that there's been a role change. And our lifestyles have changed too. We've gone into full-time ministry - which is unpaid. I work through a lot of the fact that umm ..it's financially insecure in one way, and I've had to sort of let go of a lot of things that have been a form of security in terms of my own home and umm...structures that one came to rely on. I don't...in my mind I don't have a problem with this. It's just occasionally I think that that structure shook me more than I knew -- losing that shook me more than I knew. And I think as a woman, even if you make those decisions with your mind, your emotions may not always keep up with your decisions. And I didn't regret, and I still don't regret making those choices. But I do have to be honest that there has been cost along the way. And just running like a thread through all of this has been the tiredness. Wanting to do so many things with my life, with my new marriage and the opportunities that have come. And I catch glimpses of myself wanting to run with all these new challenges, and not ever being able to maintain long enough without coming to a screeching halt, laughs, every so often.

How do you know that you're not going to be able to maintain? Is there anything that tells you in your body, the way you feel- that something is beginning to happen?

It's hmm, as I've said before, often unpredictable. But I can be working well at a morning's work and suddenly -- it is as if somebody pulls a plug, and I just realise that I just haven't got the momentum any more. umm...My head sort of ... it goes fuzzy, that's all I can say. My brain sort of ... it gets more and more difficult to concentrate and to put things in sequence. I start shuffling my papers, I start realising that I'm not able to concentrate as I was up until that point. My body starts to ache, my throat starts to hurt and **suddenly**, out of the blue, I will feel I'm coming down with something. So ..at that point that I'm faced with a choice ..I suddenly feel it. Out of the blue. I mean I'm not sitting thinking about it or feeling sorry for myself or anything -- I'm having a good morning. So physically I will pick it up; that my reserves have gone. And whatever was...I was using to go through my workload, it's either not there or cut in half. So then at that point I have a choice. And I usually get myself tea or a snack, or something that will kind of just bring up my energy levels a bit. And it may do so, but physically then there is a change. Sometimes it will settle down if I sleep, or if I talk it through with someone, or if I take a Med-lemon. laugh... But some days it just doesn't pick up. And I will just tail off into the end of the day and wait for a new day.

And in the new day, what happens?

Very often I'm ...I'm able to find some more good hours in the new day. Mornings are never good. It takes me an hour or two to really get my body going and my mind together. Then I will find a place in ... I usually find in every day a few good hours, before this thing hits. And then it's not everyday that I can't pick up again - some days like today I don't. I don't pick it up again. But very often I do. I just have ..that time where things dip and I feel **so** tired. Part of me would love to just go and crawl into bed, but circumstances don't allow for that. So, I more or less talk myself back up into a place of coping. And then I take something as I've said - whatever it is, and on I go. Probably not with the same energy or momentum. But I do keep going.

You mentioned earlier you don't often cancel appointments, but sometimes you have to. How does that work for you? How does it make you feel when that happens?

I **hate** it. If I get up in the morning and I am actually so sore or so fuzzy in my head that I can't put things together, then I actually have to let my husband pick up the phone and say: she's not coming to work today. But I agonise over it until I get to that place -- usually with a lot of remorse and umm...guilt. And then once a choice is made **for** me usually, then I can relax into the freedom that I then have to actually feel the way I'm feeling.

You say the choice is made for you

I know it's strange. I **hate** to make that confession that I'm ill. So if I can I will get my husband to do it. He's not always here obviously, that was just an early morning example. But during the day if I can't make something then I'll phone a friend or make a call in the evening. I try and leave it as late as I can just in case I perk up - and I know I can manage it. But it is a combination of the physical, what's happening in my body physically and what it does to me mentally. There's kind of two threads. The physical I can sometimes override; that example I gave you of an office situation. Where I can override it - I've still got two hours to go or whatever it is. So I override the discomfort and what I'm feeling and I keep going till it's time to go home. But sometimes when it comes to a function in the evening or I know that I don't have it mentally. I don't have what it takes to carry on a conversation, or be bright socially, or handle whatever I will be called upon to handle. And then I just have to cancel. And I do. A lot of people just ..know where I'm coming from. And as I've said, they don't seem to mind. It's me that minds. laughs

What do you mind most?

I don't mind the not going to wherever it is. I mind having to make that admission I think. I mind having to acknowledge that I'm still fighting this thing. Maybe it's an admission of failure? Maybe I don't like to give in. It could be even more complicated than that. A little laugh. There's this pattern in my life of coping, coping, coping. And then there comes a time when I don't want to cope any more. And so.. there is this tiredness and this feeling ill. So I would **like** to take refuge in it and I would like to acknowledge it, but then part of me says: well no, you actually can't do that. So there is this conversation that goes laughs...on sometimes in my mind. Until I eventually -- I just give in.

Quite a lot of ambivalence there

Ja. It's not as straight forward as it sounds sometimes, because there's this programming that goes on in each of us maybe - where you have levels of expectation - others and your own. And you try to match that, and you're trying to be honest with what's happening in your life. And maybe I'm different to others -- I don't know. But I do... I do go between back and forth. Little laugh.

What do you mean by saying that maybe you are different to others?

I don't know how others cope. Maybe that's what I'm trying to say. I don't know how anyone else copes with this. Whether they have the same internal struggles with what they feeling, or whether they just come out and say. Maybe it is me as a person who makes things more difficult than others. I maybe ...not as honest as I've said I am. I still do find I cover-up and then...

There are times when you seem to be quite hard on yourself as a person.

I know. It's probably the thing that my friends and family will say most about me. I am hard on myself. I don't know where it began. As a child maybe. These expectations that I've always put on myself to match up to. From an early age it has been there. And I will allow a certain leeway. a little laugh. I'm very generous with everyone else, but not with myself. I don't know quite how to change that, but it is who I am.

How do you think in any way this has impacted on the fatigue that you had? The fact that you are that kind of person, do you have...do you sense that there's any connection at all?

I would think so, I would think so in one way. I think a lot of people would agree that the chronic fatigue comes from ... or it's ..there's a common denominator between those who are achievers, or people who push themselves to meet goals -- to keep commitments and to meet their responsibilities. Those kind of people; there seems to be a common denominator there. And with that then there is the feeling that you must keep going. If you kept going when you were not ill, then you must keep going even though you are ill. So at a certain point there's ... certainly in my case, I just don't acknowledge half the time. And so I still keep pushing myself and I know it could ... I wonder though. I don't know if it would have perpetuated it as long as it has done. I often ask myself if I am self-perpetuating this thing. And I haven't got an answer. Slight laugh. If I were kinder to myself would it go away - is a question. Laughs.

That is a good question.

It's a good question. Well, on a day when I just am a bit selfish in terms of taking time for myself when I want to, I have a more peaceful day. If it were just that it were that simple, and it was an either or situation. There's just so many threads running through - certainly my life. Circumstantially and also what I see is kind of the fruit of this thing. Which part of what I have found in myself over the years, is this fretfulness. You know this anxiety. This inability to make choices. Unable to at a certain point just to be real and say: This is it, end of the road, end of the story. It's who I am and there's no more arguing. I find myself unable to be that cut and dried. So as much as I see all of this, I don't actually know the answers; to how to improve who I am ... who I've become.

Do you see yourself as different from who you were?

I wonder. I suppose underneath who I am over all the years I have been a fairly anxious personality in some ways. But I look back on myself and I do remember myself certainly being more carefree. More able to.. just laugh at things. Not take things so seriously. Not be so caught up in who and what I am or have become. So again I hesitate to put all the blame at the door of chronic fatigue, although I think that's the major.. major thing in my life. But I do know that I am fifty-two and at a questionable age anyway. Where a lot of things are in question - a lot of things are not as they were. And I am seeing myself as someone different anyway. So I do try and keep the bigger picture.

Who is that person that you see yourself as now?

Now? Ha. little laugh. Not very nice. My daughter has just gone overseas and she had a long talk with me. Trying to impress upon me that I was still a person of worth and all the rest of it. I just somehow feel **now** that I am searching for the person I was - in...in a couple of ways. And I do see myself as someone who has grown too intense, too introverted, too hard on herself. Unable to laugh as much as I used to, and just find a bit of freedom and **fun really**. So it's as if my life has got a bit narrow in some ways

Do you think that fatigue has done that?

I certainly think it had a role to play. But I don't want to lay everything at the door... I do know though that if I didn't have to cope with feeling tired so much of the time and having so much physical sort of pain and umm drawbacks then, it would be one less thing to cope with. A major part of my life would just be a little less complicated. I have a feeling that my mind would be able to make better choices - better decisions. And ja, it would be a big chunk of my life that I wouldn't have to have a look at all the time you know. I could do without that.'

Ja.

And just have menopause for instance. laughs But no, I do see it as a real drawback in my life.

What is the tiredness like for you? If you had to describe that tiredness, what is it?

Well, just before you came I was sitting in the chair there ... and it is partly a purely physical thing. Where you are actually so tired you feel you can't move properly. You can't use your limbs properly. You just want to lie down. Your head feels so heavy, so empty. In my case the muscles are all hurting. There's very often a headache and a sore throat. That would be the physical side of things. And then ..there are very definitely mental things as well. Where the mind gets cloudy and unable to concentrate as I've said. You can't connect things. And then when you faced with a choice, or a decision that you have to make, you actually could snap. That combination, certainly with me. Faced at that time with something that I have to decide one way or the other, it doesn't matter what it is. About brushing my teeth, to going to work, or cancelling an appointment, or acknowledging that I need whatever I need at that time, it's almost beyond me. It sounds ridiculous, but that's how bad it can get.

On your very worst days do you get out of bed?

Most days now. I certainly ... having a job I need to get up everyday. So then I find myself at work, even on a day when I would rather not go to work. That is quite a good thing. If I need to I will come back and go back to bed - in the afternoon. umm...It doesn't often happen that I stay in bed, unless I develop a real cold or something on top of what I am already feeling. I don't nowadays spend much time, like days, in bed. I usually get up everyday.

Was there a time when you would spend days in bed?

Ja. Several years ago. I would find especially when I wasn't working. If I felt in that day that this thing had really closed in on me, I would just spend the morning sleeping or reading. I would just stay there until I felt I could get up. It was ...it was good, I sometimes longingly think. I would still like to have that option, but as I'm working I don't have that option. Except over the weekends and then I usually find that things need doing anyway, so I get up.

And it seems like.. you've continued to try and fight it even at your worst days.

Ja, it looks like it. I think ... if I think about it, I'm fighting what I see happening in me as much as I'm fighting what I see happening in my husband. I hate acknowledging that there are umm...these things happening in our lives; that drain us of energy and take us away from being productive, and keep certainly myself so caught up in me. I would rather that I didn't have to face all of that.

You mentioned your husband. How do you think that your having chronic fatigue has affected your relationship and him?

Now and again I find that he will voice something which shows his concern. And perhaps, umm...I don't want to say anger, but regret that there is this thing. If he was a fit, active man who needed a wife alongside of him.. for you know, three office functions a week or travelling, then it would be more noticeable than it is. He's not in a fixed employment and he's also slowed down a lot in the last three years with his pacemaker. but...So I suppose the fact that I am often tired or taking time out doesn't have that much of an affect on him, but it does mean very often that I'm not there when we could just have an evening together, chatting or going somewhere, or meeting all our commitments or something. So he is aware of it. But I have very, very seldom had anything from him either than support. So I'm so grateful for that. He just entered in right from the beginning to trying and to understand what was happening. And I very seldom have seen him angry or disappointed in me.

Do you talk about it much?

Yes especially now since I went to the chronic fatigue for a few sessions - the clinic I mean. And he has been willing to chat and I've been able to say a little bit of what I was able to talk through, and I think for us the frustration - both of us feel the frustration of not knowing what it is or how to actually deal with it. And the knowledge that there isn't anything one can do about it is a frustration for both of us I think. If we could practically work at it, it would help some of the frustration. It's just here - just part of our lives. At least with his pacemaker you know they review it from time to time, and so on. You kind of feel... small laugh. umm...And in any case, something like that is more of a medically acceptable thing you know. I come back to the fact that this chronic fatigue is somehow not a medically acceptable thing - or acknowledged thing. Very few as I see it are willing to look at it as an entity. As a ...as a recognisable thing. But he's been largely very supportive for the times that it has taken its toll on our marriage or our relationship. We've just been able to talk and keep going through it.

When you say taken its toll on your marriage and relationship, what has it done?

How has it impacted?

Well, I'm often irritable. Tiredness and the ...and the pain that goes with the fatigue sometimes makes me very irritable and fretful. And I find myself having to take it out on someone. Not consciously, but I just find myself snapping or tearful, and then he bears the brunt of that. Laughs a little. umm...And then I suppose on a closer level, although that has affected him too. I mean physically, well,... ja I suppose, over the years his libido and mine have sort of tapered down to...to a level. But it's common ground. I mean I'm often, I shouldn't say this, but I'm grateful in one way that his health is ..is also at a sort of um....not a comparable level to mine, but he also is having problems so that we can ... there is hmm ... I don't feel that I am letting him down that often when I am too tired or that I am that bad a wife. Because he too has days when he's too tired. He has times when he is just out of it for whatever reason. But I would say that ... ja the irritability, and the tearfulness and the moods, and the swings, and the feeling that he sometimes has to step into the home situation to keep things going, has been different in our lives. But he has just stepped in. And when he'd needed a meal he will go and cook it. Or somebody to be fetched or things to be done or shopping to be done, he will go and do it. So he's always been able to...to fill up where I haven't been able to cope.

Have you been able to do the same for him?

Yes I think so. I think so. I hopeI hope I can come to terms with the fact that he is ageing, you know he is ten years older than I am. And I hope I've come to terms with the fact that he is ageing. I sometimes find myself resisting his tiredness and his ailments if you like, and the results of his medical history and problems. And I then have to work that through because I get a bit guilty, because he is so patient with me. And he really is. But I do try laughs to be as generous with him as he is with me.

Do you think he copes better with his illness?

Ja I do. He is less complicated. He's not as complicated a person as I seemed to be. He's either having a good day or a bad day. He's either angry or he is not angry. He's either irritable or he is not. And he will either talk about it or he won't. Laughs. I'm complicated. I hassle over things and I try and find the best solutions and the best answers, and that really often draws things out. You know where I could just make a choice or have a cut off time or whatever, and he can't always see that. He's a lot more cut and dried than me. Works things through quicker in that way. He does cope better with being ill, or I should say having medical problems. They don't seem to hassle him. Maybe they do deep down, but anyway I don't see it in his lifestyle as much as I do in mine.

Do you think that's because of the different conditions? You mentioned that his was easier to deal with in the sense that it was more cut and dried and more obvious.

Right, I think so. Everybody knows about heart problems and it is easy to talk about. If you say you've got a pacemaker everybody knows what it is. And if you start bringing into the conversation that you have chronic fatigue people will say: hmmm. Like one friend of mine said the other day: do you still find yourself falling asleep at the dinner table? Well I don't know that I've ever done that, laughs but I mean that's how people see this thing you know. They see that you do ... okay maybe that's her way laughs talking about it. But people don't really know much about chronic fatigue, and if they do they've got some idea that you want to sleep all the time. Which is partly true, but the whole picture of chronic fatigue is not as known as something like heart problems. People know about that; they feel safe talking about it; they don't have a problem recognising that this guy has got whatever. And maybe it's me that just doesn't know how to put across the fact that I still have this thing or how to talk about it, or how to relate to it in a normal way. I just try and keep it under wraps all the time.

What do you think people should know about it?

I would love for people to know that it's real. Somebody once said to me early on, one of the doctors I first went to: why do you need to know that you've got this thing? And I still today need to know that I've got this thing because it's real! Because it's happening around the world. There are... I would like to know that there are other people like me. With the same frustrations and the same coping mechanisms or non-coping mechanisms. I would like for the world to know that this is a genuine, legitimate reason. As legitimate as having diabetes or whatever. And as multiple sclerosis once upon a time was a fairly undiagnosed non-treatable thing, it now is a diagnosed and a treatable thing as far as I know. If chronic fatigue could be put in the same category as having as much research done, as much ..umm...input into this whole picture, so that people who **have** chronic fatigue are **not** just labelled as depressed people - neurotic people. umm.. In other words it's not just under that kind of mental umbrella, where the mental manifestations are treated like the depression and the tiredness and so on that goes with it, those **are** part of the chronic fatigue pattern. But the other side, the physical side, if those things could be actually taken seriously and treatment found for them. Then the whole person would be treated. The whole person would be approached. And you would not just be approaching your chronic fatigue patient with your anti-depressants or your whatever. Not that there isn't a place for that. There is a place for that. I would dearly love to find a course of anti-depressants that would not have all the side effects that I've had to work through. And that is why I don't take them. But I know there is a need for them. If I could find one that would take me through my days I would **gladly** take it. Because I know there's a place for that. But at the same time I would like to **not** negate the physical side of things which is just as real. So that the whole picture comes across, not just the ... would you call it psychomatic symptoms?

Psychosomatic.

Psychosomatic symptoms. Those are perhaps the most obvious. Or the most easily recognisable, or the only ones you could treat. But to only treat that side of the person I think is only half the story. That's what would help me a lot; is to have the whole of me discussed as a legitimate, medical problem.

You've mentioned that word legitimate quite a few times.

laughs. I know, I feel strongly about it. I feel I would like to be legitimised. If somebody were to say to me, as this doctor perhaps eight years ago, if he could have said to me: look, this is a real medical problem. And we recognise it, we know it's real. And here are the symptoms and you qualify. I wouldn't have gone away and made myself sicker, or... speaking for myself, maybe there are those who would go back and hug this information to themselves and say: good. Now I'm sick. Now I can be sick. Personally I wouldn't have done that. It would have just helped me to know that I was right. I was allowed to feel ill.

You were not actually looking for a reason to be sick

No. I still am not. I'm looking to get well. I'm desperate to get passed what this thing does to me. And on to being able to maintain my lifestyle. I don't mind that I've had to cut it back. But I just wish I could maintain it a bit more. And I wish I could... just ...keep going with my life. Be able to meet my challenges and commitments.

And you don't think at the moment that those are unrealistic challenges or commitments?

Some of them are maybe. But it's my life. My life is full. umm...There's not much more I could change in it. I can't **only** do a morning's job. I have to do the rest of my life. Because that's important to me as well. And umm...so I often feel that I've done enough cutting back in my life. I would like to be able to add to my life more, rather than cut away.

How has the chronic fatigue affected your sense of who you are?

Well I have lost quite a bit of self-worth maybe. And I find now that in a social situation, like a dinner party or some function involving people and conversation and so forth, I reach a limit quicker than I used to. In other words I find I reach a ceiling of being able to concentrate quicker than I used to. So that limits me when we go somewhere or are involved in a social thing. I can function, hopefully normally, up to a point. And then I get tired -- my mind just won't make conversation any more. So then I just find myself listening. I can't partake any more, at a certain point. So I find that I've grown limited in social things. It's affected me in my sense of adventure. My sense of being able to achieve. The first thing to go very often is my sense of humour. I find I take life far too seriously, because I'm caught up in this kind of internal struggle. And I've lost a little bit of ..who I am and my confidence I think has taken a bit of a knock.

Who are you?

I'm a middle-aged woman laughs...struggling to find...

Who am I? Well I know the obvious things are that I am a mother of two wonderful children and I'm a wife of a wonderful man. I am a person who achieves quite a lot in terms of my job. Strangely enough, even in the midst of all of this and at this late stage in my life, I'm acquiring skills, which I know other people would find daunting. Somehow I'm still able to do that. I run a very successful office where I work. umm...It just seems that on the home front that I am a bit negative. Where I seemed to have had this role change. With my mind that's not a problem -- maybe deep down it is a problem. And then there's this struggle to come to terms with myself as an emotional human being. And I think probably that's the level that I am struggling on. On a practical level, on a job level and largely on a mother-wife level - I think I'm okay. I think I would match up with anyone else of a similar age. umm...my friends ... all of us have hassles. I mean I am no different to anyone else. But it is on an emotional level that I think I've taken a lot of knocks and I haven't really found how to function in that kind of ... in a wholeness approach to accepting myself, and being able to function within that. I've lost a picture of who I am I think on that level. Maybe that's just what I'm searching for.

Do you know where you were -- when you say you've lost it. Who were you?

I was laughs...a fairly together, functioning person. And I am talking a long time ago. With a lot of dreams and desires ... quite a lot of them got hit on the head. So.. I was ...an achieving person...umm... Confident enough, and largely in control of my life. And I would think I was fairly well rounded ...and fairly happy. But it has been a progression over the years of ... I think when one has worked through a failed marriage or ...coming to terms with being a single parent and looking at financial insecurity for an extended number of years, it takes its toll so that you would perhaps wind up like I have; just not too sure of where you're going or what you really want any more. Maybe it's a thing that most people have to work through.

And how has the fatigue impacted that? Do you think that what you're experiencing is normal for your age and circumstances? Or do you think that the fatigue has in anyway changed what might have been?

I somehow feel I've been robbed of ten good years. That a chunk of me has been lost, so that nowI've perhaps aged quicker than I would have otherwise. Or ..I've come to a time in my life where it's too late to redeem any of those years. So I'm not just too sure if I have the right even to be frustrated about what's been lost, because it's lost - those years have happened. But I know that ...one reads a lot about people who come to this time of life and they move on through it very successfully and very positively. And I think I could, on the levels that I've mentioned, where I feel I do achieve. It's just that there's this, maybe it's grief or something like it, where I feel I've lost good years of my life. And I can't go back or redeem them. And it's almost like I'm carrying into my older years (my old age) an addedan added burden. Or...I've inherited age a bit sooner than I would have liked. My body seems to have let me down maybe, or my mind or a combination of both. So that as much as I want to go on into my life and still be fruitful and creative, it's almost as if I have to work through quite a lot to get there. I still have the same desires and the same dreams. It just frustrates me ...that as I approach each of these challenges I have to sort of work through quite a bit of negativity first.

Negativity towards what?

Because I feel ...tiredness is such a part of my life, that I first have to address that - work through it - and then keep going. I can't just get up in a day and go into the day. I have to work through how I'm feeling; whether it's acceptable or not acceptable, whether I go to work or don't go to work, whether I speak about it or don't speak about it, and then I get into the day, if you know what I mean. And other things that crop up in the day, it's almost as if I have to work through what my body is saying, before I can get on into whatever I need to do. If I could just go through my day.

I suppose other people do that -- I'm just assuming that they do. Little laugh. I assume that people get up in the morning and just go to work. More laughter.

Without having to work through this whole extra load. Maybe they don't.

[contemplative] That's the battle for me, because I have no ... I don't know how to compare myself to other people; whether they have other problems, not necessarily chronic fatigue, but whatever. I always seem to have to work through that no-man's land to get to where I'm going. Once I'm at work I pick up. And once I'm at a function or once I'm at a meeting or wherever I'm going, then I kind of kick-in and go for it until I get tired again.

It almost sounds like you almost... what energy is there ...

Use it and then it's finished.

Use it - and you collapse. Okay.

That's a good picture.

Ja. And has that been fairly consistent over the last ten years?

Yes I can see that's how it is. I sort of gather myself and go for it, and then there are the days where all the gathering in the world doesn't help. Then that's the pa... the thing I've described to you, where either Bill or myself will just...

Are there days when you in fact gather all those reserves together and you know that they're not going to be enough for what is lying ahead anyway?

Yes. And then I have to work through that awful feeling of.... failure I suppose ... and anger. Because... because it's still even now not a simple thing of "you are ill and allowed to be ill." It still with me is a problem of: is this a mental thing that I can talk myself out of or not?

Do you think you'd ever be able to answer that question?

No, because this chronic fatigue is just such a medical thing - full of questions. And nobody presented it to me ever as a cut and dried thing. I came to the knowledge that this is what I had over a period of years, over many doctors, over much reading and soul searching. So that's never been given to me as an acceptable thing.

Do you think that you've accepted that's what you got?

Well I either **have that** laughs...or I am a neurotic, depressive personality. Laughs. So I hope I've got chronic fatigue. Yes, I think I have, but only 80 percent. There's 20 percent of me that say I'm not fully allowing myself to be labelled.

Do you think if chronic fatigue were a more acceptable label that it would be more comfortable for you?

Ja. You know a part of me yearns to be ...classified if you like - maybe that's the word. And then I'd just put it to one side and get on with my life. To be classified and treated would be the ultimate. laughs.

Hmm, hmm.

But classified would be half the battle.

But it would almost seem like classification of CFS is not a comfortable classification yet.

Not yet no. You mean for me, or generally?

For both.

Ja.

Because if it was a good diagnosis in the sense that it could be treated, or at least better understood, or the people accept that it was real. Maybe you'd accept that it was real.

Hmm. Yes I would. There would be a relief. In the course of the last ten years there have been other things. You know people have come across my path and said: 'this is what it is'. And with relief I've tackled that approach. Hasn't been that of course. You know people have said it's a viral thing and this and that. There's been relief in accepting that, because with that clear diagnosis in inverted commas, comes the promise of treatment. So that's relief! That really is relief. But of course it hasn't been that.

Ja.

So then I'm still finding myself in that ambivalent (if that's the right word) position of the possibility that this is just a straightforward mental problem. Can I live with that? I say to myself. I don't know. Because I would like to think that what I know deep down inside of myself is true - that this is a combined picture of physical problems, with ... the ... out-workings - the fruit of it is definitely depression.'

Hmm. Hmm.

Definitely.

So you see the depression as coming subsequent to the fatigue?

Ja. I know it has been a parallel in my life for a number of years, but I wouldn't say that that was the cause. It's definitely an effect. And it's a very real thing. I don't negate it at all. As I've said earlier I would love to have it treated. If I could have it treated and still keep going with my life. It's a very real and a draining and a problematic side effect. I really is ait's a horrible side effect. It eats into your confidence and your self-worth and everything. If I could deal with one thing I would like to deal with the depression and the anxiety that are spin-offs to this whole... confusion that has come - as to what's happening in my body - my mind.

What do you think your quality of life is at the moment?

Half. Some days three quarters. But I would say that I work largely on half. And I have come to terms with that and I'm not complaining. It's when it slips below that,

that I feel it. Because then it takes its toll on other people in my life and who I mix with, and I'm not able to meet work commitments nor home commitments. But I operate on about maybe fifty- percent output and I've come to terms with that.

Hmm. Hmm. Is there anything positive that's happened as a result of the chronic fatigue? It may sound a strange question.

Ja. No definitely. I mean I have ... I've had to have long looks at myself. I've been driven to look at my whole picture of who I am as a woman, as a mother, wife, career person. And I can see that there are still good things in me; that I **am** still able to function, regardless of what's happening. That there are still so many people out there who have no idea what goes on in me, because I still function on enough levels to run my life. And there are many out there who have no idea what I go through or cope with. I'm positive on many days because I find I can still achieve a good workload in the morning at work. And I'm glad of that; I'm still able as I've said to pick up skills and in spite of many things I am still running a fairly productive lifestyle. ... I miss though what I was. And I miss the stickability and the endurance and the energy that I used to have. But I still feel if I search or I sit long enough with this thing, and if I can get just over the hurdle of accepting what's happened to me, I will be a much quieter, happier person.'

What does acceptance mean for you?

Just letting things happen I think. It's almost within my grasp, if I could just allow my life to be what it is, and not fight. And just be what I am without these sort of internal conversations all the time. I could just be. I think that would be a lot easier than trying to match up or stick to certain levels, or try and be what I was. Come to terms with where I am. Laughs. Whatever that is.

It was difficult for you to describe earlier when I asked you to describe who you are.

Ja.

And whether the fatigue has impacted who you are.

Ja, it definitely has. But I still don't know quite who I am. I think that's the major question. It's definitely impacted, but I can't put all the blame at that door. Because I am at a stage of life where things would make me question who I am anyway - regardless of my fatigue. But it definitely has impacted and made me less able to cope. Not just on a physical level, but as I've said and I may be repeating myself, it's the underlying threat that any stress or tension is a trigger. Any decisions that I have to make at a time when I'm wavering or running low on reserves. At that point if I'm called to make decisions, or put in a stressful position, or I feel circumstances just are ..are weighing in, and that's it. That's the snapping point. So that's a fine line to walk. It's not anybody's fault, but I just do find that my coping mechanism at that point is very thin. Whereas perhaps somebody who doesn't have chronic fatigue would just be more realistic, or just let things happen without that sort of anxiety tussle all the time.

It seems to be a constant struggle.

mm. I very seldom switch off, laughs ...except when I'm reading a good book. There's always this ... it seems to be this tussle to ...to keep going, to keep coping ... to keep saying the things people want to hear

To keep being you in all of that?

Ja, whoever that is. laughter. Some days it doesn't worry me, but when you ask the question and I stop and think, and I don't have an answer..... But I sometimes feel that it's just within my grasp.

What's within your grasp?

Who I am you know, and the fact that I could just grasp a solution there. I can almost see myself levelling out you know, and just not allowing... or not allowing so much - but for me to be happy would be just to have this sort of momentum; like almost a plateau in my life, without these dreadful swings you know. Of fatigue with accompanying depression and anxiety, back up onto a normal level and then the occasional peak into real productivity, and add happiness that goes with it... Or maintenance programme or maintenance level, is one of my goals. That shouldn't be too difficult. Laughs.

Maybe it is at this point that we should stop that for the day.

Okay.

University of Cape Town

APPENDIX D: PROTOCOL ONE

EXAMPLE OF ANALYSIS TRANSFORMATION: GENERAL UNITS OF MEANING – TRANSFORMED UNITS OF MEANING

The transcript in its original form, delineated into general units of meaning [left column], and transformed units of meaning [right column]

General units of meaning	Transformed units of meaning
<p>How are you feeling today? Today especially? 'Not that good today. I don't know why. This combination as I've said to you of things that..that come - you know with the best will in the world, and as much as I've tried to reschedule my days, and how much I do in a day, it's always that I come to a place where there's an accumulation of things. umm..And then I physically don't.. stop coping. And has this been a pattern? Ja. I've tried so ... you know it has been about 10 years now I suppose, and I've got into a way of coping, but it's such a pattern. And even though I recognise it and I can see where things are going, it still..gets to me. I think perhaps because, even after all this time I still fight what is happening to me.</p> <p>Hmmm. I can't quite accept it and I struggle to accept it when I'm having a bad day.</p> <p>When you first started to feel like that (you said that was about 10 years ago), and ..what happened for you then? I didn't know what was happening. I had no idea. I worked through the fact that umm..I was possibly developing into a hypochondriac.</p> <p>I was single at the time and I felt maybe this was one way of..of getting attention for myself, or finding some sort of subconscious weird way of getting people to help me in my..in my circumstances. I didn't really know why I was ill without reason, and it didn't help me that the doctors couldn't find anythingto work with. So you went to a lot of doctors?</p>	<p><i>P1 has tried to reschedule her days and the activity of her days, but despite this, still comes to a place where she physically stops coping</i></p> <p><i>This pattern has gone on for about ten years, but it still gets to her</i></p> <p><i>Despite recognising how things are going, she still fights what is happening to her</i></p> <p><i>She can't quite accept this and struggles to accept to when she's having a bad day</i></p> <p><i>When it first started she didn't know what was happening to her She worked through the possibility that she was becoming a hypochondriac She felt that this was an attention seeking mechanism as she was single at the time</i></p> <p><i>She wanted there to be a reason for the illness The doctors couldn't help her find a reason and something to work with</i></p>

General units of meaning

I did you know. Initially I should say it was just a question of the odd er..bouts of what felt like a flu attack, or days where I just couldn't get out of bed and face the world. And I felt ..umm.. it took me a while to get to go to people for help. But eventually I did. I started with my GP at the time. And it was always just a question of: well take ..take a few days; and it's tiredness or it's depression, it was usually those two! And it **was**, I mean that's what I was manifesting, but it didn't ever, not even in the early days, begin to touch on WHY and what could possibly be wrong.

How did that make you feel - when people just couldn't give you answers?

It was a horrible place to be in, because I knew myself that I wasn't like that. I know even today, I'm not like that.

I am someone else on a good day and I cope extremely well, and I do all that I am supposed to be doing.

And yet there is....there was that part of me that just suddenly couldn't physically cope. And people were not addressing that; they weren't **able** to see past what I was showing physically. To that person underneath - that was still trying to cope.

And it it..hurt me a lot, not being heard. And I think right then I began this cover-up-thing which I still do today.

You talk about not being heard. How does that feel; not to be heard?

Horrible.

I must say in the last year or two, I have found more people willing to listen than in all the years that I've I've..had this

... whatever you want to call it! I still don't know what to call it, if it's an illness or not. I hate even to label myself with that word,

but now in the last year or two, I found people who are willing to listen. But in the early days there wasn't anyone.

And it hurt a lot because it made me. ...it made it necessary for me then to go along with what they were saying to me: that in fact I might just be neurotic. I might just be a depressant. I could just be one of those hypochondriac people that I personally have no time for! And I had to consider that I was like these two people.

Transformed units of meaning

She went to a number of doctors for flu like symptoms, starting with her GP. The GP response was - it's tiredness or depression, take a few days off

No one dealt with why or what was wrong

*It felt horrible because she knew herself a someone different [not a tried, depressed person]
She sees herself as someone else on a good day, who copes extremely well, and can do all that she is supposed to be doing
There was however, a part of her that just suddenly couldn't cope.
People were unable to see past her physical symptoms.*

Not being heard was very hurtful. It was the point at which her cover-up strategies began.

*It feels horrible not to be heard
She has experienced more willingness of people to listen to her over the last year or two.
She still doesn't know what to call this condition. She hates to label herself with that word[ME/fatigue]
In the early days no one would listen to her*

*It hurt a lot
It was necessary for her to go along with what others were saying - that she might be neurotic or depressed. She has no time for these types of people, but had to consider that she herself might be one*

General units of meaning

And yet I knew myself deep down; I knew that if somebody would just help me cope with this thing I ...I would keep going. But I didn't find that in the early days.

And so not only were you being heard, but you were very scared of being labelled as something that you didn't want to be.

Yes over the years I've had all those labels.

As much as I have tried to present myself as a well-balanced person. And I think having come through the nursing side of things more than others maybe ... than anyone else maybe, I have been.. I've been nervous of labels

And while you've been nervous of labels, what has happened? Do you think that you've in some way adapted the way that you feel?

Ja. I would think in a lot of instances I have adjusted myself to what people expect.

Hmmm.

And so I present to them what I think they want to hear. I will present a good, almost like a case history, if I go for an interview to a medical person. Or to an employer I will present a coping person - which I am - a lot of the time. That is not necessarily a false thing that I present, but I find myself wanting to err..give this good impression of someone who isn't ill.

I don't know if that's true you know on a day like today, when I am sort of fuzzy anyway. I am not sure who the real person is sometimes!

But because of the labels that I've had; of being a depressed person; of being a neurotic, which is one label that a doctor once gave me. I fought tooth and nail to present something different. You know to ..to myself and to others

Haven't always succeeded in that, and sometimes maybe that's why it's a struggle to put that down and just acknowledge that on certain days I am just ill.

I suppose it's because I've never had the freedom to actually be ill. Either I haven't allowed myself, or I don't want to admit that that's still happening in my life.

Who has not given you the freedom?

Probably me.

Transformed units of meaning

She knew that if someone would help her she could keep going

*She has had all the labels
She has tried to present herself as a well balanced person, may because of her nursing background, and has been wary of labels.*

She has in a lot of instance adjusted herself to what others expect of her

She presents to them what she thinks they want to hear - to a medical person, a good case history; to an employer, a coping person.

She doesn't think of this as false but as wanting to give a good impression.

She is not sure who the real person is sometimes

Because of the labels that she has had -depressed, neurotic, she has fought tooth and nail to present something different to herself and others

She hasn't always succeeded in presenting something different, that is my be why she has such a struggle to admit that on certain days she is ill

She thinks that it may be because she has never had the freedom to be ill. Either she has not allowed herself or does not want to admit to what is happening in her life.

She sees herself as not having given herself freedom [in response to I's question]

General units of meaning

You know for instance my circle, my immediate family circle, never question when I have a bad day. My husband doesn't question it. He very rarely will argue with the fact that I am having a bad day. My children - neither.. of them will. They will be most supportive. My circle of friends are supportive -- my work situation, my current work situation anyway, not all my work situations have been sympathetic. But my current one is

But it's ingrained in me now...not to admit something.

In case maybe I come back in under some sort of condemnation I suppose.

Condemnation?

It's a strong word! laughs... As I say, it's a strong word. I build up quite a bit of anger I think over the years for the non-understanding from the medical people, because from the doctors that I went to I had hoped if not to have a cure offered, or a programme offered that would benefit or help me, at least I went asking for understanding and I didn't always get it. And I took that as a form of condemnation or a judgement or a criticism, or whatever you want to call it. So that's been an extra burden

And have you perceived that as coming from them? They've placed a judgement on you?

Ja. I suppose again having worked through umm...years of working with doctors as a member of the medical profession I feel somehow betrayed, as I think about it. I had hoped that they would find something. And..and not having found any way of coping with M.E. is **one** side of the picture. But not willing to take me seriously over many years is another issue that affected me personally. I always tried to present myself as I've said, as an honest umm..person. I've never hidden what I've been feeling. And so with that honesty very often what I got back was just like a superficial judgement of who I was as a person. So, something like this now, is probably the first time that umm..who I am as a whole person is being looked at. Not just this person who may or may not be sick **And that is actually quite important.**

Transformed units of meaning

Her immediate family circle don't question when she has a bad day. Her husband and children are supportive. Her current work situation is supportive

She feels that the behaviour of not admitting something is ingrained in her

She thinks that it may cause her to come under condemnation

She has built t up a lot of anger as a result of the non-understanding of the medical people. She had hoped to have, if not either a cure or at least a programme which would benefit her, then understanding form them.

She didn't get this, and taken this as a form of judgement or criticism, which has placed an extra burden on her.

She feels betrayed.

The fat that the medical profession have no found a way of dealing with the condition is only one side of the picture - that she was not taken seriously has had far more impact on hr personally. She has always tired to present herself as an open and honest person, and so the superficial judgement that she received was taken as person. This interaction with the researcher is the first time that she is being looked at as a whole person, not just as someone who may or may not be sick

General units of meaning

It is very important to me, that is why ... one of the reasons I didn't phone today and say: don't come. It's because I thought: there are days you know, when I am like this. Where I don't have two thoughts in my head. But come to the push, I can actually do it! Laughs And I need to know that I can go through a day like this, even an interview like this. Because it's important that I say what I need to say. And I am seen as I am. In the context of a whole person, instead of just presenting what other people expect. And always having to find what they expect. If that makes sense. Uncertain laughter. I think most of my life I have been a person who has tried to match people's expectation, even as a child. And even as a nurse, and even as a career person. It's..it's part of my nature just to meet expectations.

Did you ever feel that you were having to meet expectations of what people thought you should be when you were sick?

Yes, even being sick I feel there is a limit to how much I can be sick; how long I can be sick; when I can be sick; how I can be sick! Laughs It's almost as if I sometimes see that as a thing that I must still control. I must still control, when it happens and how much it happens, and what it does to my circle. The hardest thing is to ..is to acknowledge, that as much as I've tried to control it and contain it, it still happens. It's still a part of my life. And I obviously don't have control over it.

How do you try and control it?

By ignoring it; by keeping going when I am aching from head to foot; by trying to keep as many appointments as I make. Occasionally I cancel. By just ... I don't talk about it. If people say: how are you? I will try and be honest, but I won't go into detail. I very seldom talk about it. Not even to my family. Maybe that's denial, and it probably is, but it's ...umm.. I'm afraid that if I focus on it I'll be acknowledging that it is still part of my life -- after all these years. So maybe that's not to helpful or honest, self-conscious laughter.. but it's part of my struggle I think

Transformed units of meaning

*Being seen as a whole person is important to her, instead of just presenting what other people expect. And always having to find what they expect.
I think most of my life I have been a person who has tried to match people's expectation, even as a child.*

*Even when she is sick she feels that there is a limit to how much she can be sick, when and how long she can be sick.
Its sickness is almost as if it is something that she must control. She must still control, when it happens and how much it happens, and what it does to her circle
The hardest thing for her has been to acknowledge, that as much as she has tried to control it and contain it, it still happens, and is still a part of her life. She feels that she doesn't have control over it*

*She tries to control the condition by ignoring it, y keeping going when aching from head to foot, and by trying to keep all her appointments. Also by not talking about it
She is afraid that if she focuses on it she will be acknowledging that it is still part of her life -- after all these years.*

General units of meaning

What other aspects of this struggle do you have?

I think that it makes me ... umm..it still has the ability to make me fall apart, if that's not too ...too vague. I have a real sort of desire to keep going with my life with as much momentum as I can. And then on a day when I can't, it makes me angry. And I struggle because of the suddenness of it you know. In a day I can... I can start well and kind of fall apart by lunchtime, or I can pick up and keep going till late at night. It is such an unpredictable thing. And so.. I don't always put all the blame at the door of chronic fatigue, because I still don't have very well contained menopause either, but that combination makes me very ... it makes me swing between being fairly rational and just depressed, unable to cope. So I struggle with the unpredictability of it. Again it's something I can't control or contain. I don't have a handle on it

And it seems like, for you as a person who likes to have some sense of order and control in your life, this has been a big thing.

Yes I think so. You know I ... it's like most people; I suppose you work through your childhood insecurities, and you go through your marriage and so forth. I haven't had a very sort of secure lifestyle in a number of ways. Which is not unusual to other people's stories, but it just happens to be mine. I've worked through many, many years of ..of circumstantial stuff which has brought its heartache and its insecurities and its fears maybe. So that if I could contain and control this illness, I feel somehow I would regain something of what life has done to me. Or the fruit of what's happened in my life, which I sometimes feel is partly to blame - if I'm right. I don't know if anyone knows why one ends up with chronic fatigue. But I know stress is related -- stress is a trigger. And it must..it must have laid the foundations for it you know. And not being able to control it means that these circumstantial things that I've worked through are still having some effect. And I wish they didn't have.

What circumstantial things are there?

Do you mean currently, or what I look back on.

When you look back on particularly the last ten years of dealing with the chronic fatigue.

Transformed units of meaning

The struggle for her is that the condition has the ability to make her fall apart, as she desires to keep going, and when she can't she get angry. Part of the struggle is dealing with the suddenness of the symptoms which can mean that she starts a day well and falls apart by lunchtime. The struggle is with the unpredictability, which she cannot handle or contain. She doesn't blame the chronic fatigue entirely because she is menopausal, but feels that the combinations causes swings between being rational and depressed..

She has worked through childhood insecurities, sees herself as having not had a very secure life style.

She feels that if she could contain and control this illness, she could regain something of what life has done to her.

She feels that her life is partly to blame, because stress is related to chronic fatigue, and must have laid a foundation for her condition.

Because she is unable to control the fatigue, the other things are still having some effect, which she wishes were not the case.

General units of meaning

I've had to deal with not only my own illness, but I've worked through remarriage and with the joy of remarriage - and it has been. There are always many things to work through. And the adjustment of two lifestyles, and the two children that were brought into it. And then because of illness in my husband there's been a sort of role change. So that over the years.... as he has been progressively unable to maintain a full-time job - and then not anything at all - the roles have changed, so I continued in..in working. And I don't mind it, I have a lovely job. But I think subconsciously and deep down... I know that there's been a role change.

. And our lifestyles have changed too. We've gone into full-time ministry - which is unpaid. I work through a lot of the fact that umm ..it's financially insecure in one way, and I've had to sort of let go of a lot of things that have been a form of security in terms of my own home and umm...structures that one came to rely on. I don't....in my mind I don't have a problem with this. It's just occasionally I think that that structure shook me more than I knew -- losing that shook me more than I knew. And I think as a woman, even if you make those decisions with your mind, your emotions may not always keep up with your decisions. And I didn't regret, and I still don't regret making those choices. But I do have to be honest that there has been cost along the way.

And just running like a thread through all of this has been the tiredness. Wanting to do so many things with my life, with my new marriage and the opportunities that have come. And I catch glimpses of myself wanting to run with all these new challenges, and not ever being able to maintain long enough without coming to a screeching halt, laughs every so often.
How do you know that you're not going to be able to maintain? Is there anything that tells you in your body, the way you feel- that something is beginning to happen?

Transformed units of meaning

She has had to deal with her illness, her remarriage, the adjustment of two lifestyles, and with her children. As her husband has got progressively less able to maintain a full time job there have been role changes

. She has continued working which she doesn't mind, but thinks that this has affected her subconsciously and deep down. Their lifestyles have changed - have gone into full-time unpaid ministry. It has been difficult to let go of things that had been a form of security for her.

Although she doesn't have a problem with this in her mind, she feels that it may have shaken her more than she knew - the loss of financial security

. As a woman, she feels that emotions don't always keep pace with one's mind. Although she does not regret the choices made, there has been a cost. The tiredness has run like a thread through her life. Wanting to do so many things with her life, her new marriage and new opportunities. She has glimpses of herself being able to run with all the challenges, but not ever being able to maintain long enough without coming to a halt.

General units of meaning

It's hmm, as I've said before, often unpredictable. But I can be working well at a morning's work and suddenly -- it is as if somebody pulls a plug, and I just realise that I just haven't got the momentum any more. umm..My head sort of ... it goes fuzzy, that's all I can say. My brain sort of ... it gets more and more difficult to concentrate and to put things in sequence. I start shuffling my papers, I start realising that I'm not able to concentrate as I was up until that point. My body starts to ache, my throat starts to hurt and **suddenly**, out of the blue, I will feel I'm coming down with something. So ..at that point that I'm faced with a choice ..I suddenly feel it. Out of the blue. I mean I'm not sitting thinking about it or feeling sorry for myself or anything -- I'm having a good morning. So physically I will pick it up; that my reserves have gone. And whatever was..I was using to go through my workload, it's either not there or cut in half.

So then at that point I have a choice. And I usually get myself tea or a snack, or something that will kind of just bring up my energy levels a bit. And it may do so, but physically then there is a change. Sometimes it will settle down if I sleep, or if I talk it through with someone, or if I take a Med-lemon. laugh.. But some days it just doesn't pick up. And I will just tail off into the end of the day and wait for a new day.

And in the new day, what happens?

Very often I'm ...I'm able to find some more good hours in the new day. Mornings are never good. It takes me an hour or two to really get my body going and my mind together. Then I will find a place in ... I usually find in every day a few good hours, before this thing hits.

And then it's not everyday that I can't pick up again - some days like today I don't. I don't pick it up again. But very often I do. I just have ..that time where things dip and I feel **so** tired. Part of me would love to just go and crawl into bed, but circumstances don't allow for that. So, I more or less talk myself back up into a place of coping. And then I take something as I've said - whatever it is, and on I go. Probably not with the same energy or momentum. But I do keep going.

You mentioned earlier you don't often cancel appointments, but sometimes you have to. How does that work for you? How does it make you feel when that happens?

Transformed units of meaning

*She describes feeling well and then suddenly someone pulls a plug and she realises that she hasn't got momentum any more. Her head goes fuzzy, it gets more difficult to concentrate and put things in sequence. Her body starts to ache, her throat starts to hurt and **suddenly**, out of the blue, she begins to feel she is coming down with something. "I suddenly feel it"..... She picks it up physically; that her reserves have gone.*

At this point she has a choice, to do something to get her energy levels up a bit. She may get a cup of tea or a snack, take a Med-Lemon, or talk it through with someone. But sometimes all of these don't help, and she has to wait for a new day.

The new day may brings some good hours. Mornings are not good. In every day she usually finds a few good hours, before the fatigue hits.

Some days she can pick up again, but somedays she can't. There are time when she is so tired that she would love to crawl into bed, but her circumstances do not allow for that. Then she talks herself back into a place of coping, and keeps going.

General units of meaning

I **hate** it. If I get up in the morning and I am actually so sore or so fuzzy in my head that I can't put things together, then I actually have to let my husband pick up the phone and say: she's not coming to work today. But I agonise over it until I get to that place -- usually with a lot of remorse and umm..guilt.

And then once a choice is made **for** me usually, then I can relax into the freedom that I then have to actually feel the way I'm feeling.

You say the choice is made for you

I know it's strange. I **hate** to make that confession that I'm ill. So if I can I will get my husband to do it. He's not always here obviously, that was just an early morning example. But during the day if I can't make something then I'll phone a friend or make a call in the evening. I try and leave it as late as I can just in case I perk up - and I know I can manage it.

But it is a combination of the physical, what's happening in my body physically and what it does to me mentally. There's kind of two threads. The physical I can sometimes override; that example I gave you of an office situation. Where I can override it -- I've still got two hours to go or whatever it is. So I override the discomfort and what I'm feeling and I keep going till it's time to go home. But sometimes when it comes to a function in the evening or I know that I don't have it mentally. I don't have what it takes to carry on a conversation, or be bright socially, or handle whatever I will be called upon to handle. And then I just have to cancel. And I do.

A lot of people just ..know where I'm coming from. And as I've said, they don't seem to mind. It's me that minds. laughs

What do you mind most?

I don't mind the not going to wherever it is. I mind having to make that admission I think. I mind having to acknowledge that I'm still fighting this thing. Maybe it's an admission of failure? Maybe I don't like to give in. It could be even more complicated than that. A little laugh.

Transformed units of meaning

She hates not being able to meet her appointment. She lets her husband notify her employer. She agonises over this before getting to that point, and has a lot of remorse and guilt.

The choice is made for her -and then she is able to relax into the freedom to actually experience the feelings

I **hate** to make that confession that I'm ill. So if I can I will get my husband to do it. She will call a friend during the day if she unable to make an appointment. But she leaves it as late as possible in case she perks up and is able to manage it.

She feels that there are tow kinds of threads - the physical she can sometimes override, but when she feels she doesn't have mentally, to carry on a conversation, or handle things, then she has to cancel.

A lot of people know ere she is coming from, and don't seem to mind. She minds.

It is not the fact of not being able to go to an appointment/function that she minds, it having to acknowledge that she still has to fight this thing[CFS] she thinks that this may be an admission of failure, or of not being able to give in.

General units of meaning

There's this pattern in my life of coping, coping, coping. And then there comes a time when I don't want to cope any more. And so.. there is this tiredness and this feeling ill. So I would like to take refuge in it and I would like to acknowledge it, but then part of me says: well no, you actually can't do that. So there is this conversation that goes laughs..on sometimes in my mind. Until I eventually -- I just give in.

Quite a lot of ambivalence there

Ja. It's not as straight forward as it sounds sometimes, because there's this programming that goes on in each of us maybe - where you have levels of expectation - others and your own. And you try to match that, and you're trying to be honest with what's happening in your life. And maybe I'm different to others -- I don't know. But I do... I do go between back and forth. Little laugh.

What do you mean by saying that maybe you are different to others?

I don't know how others cope. Maybe that's what I'm trying to say. I don't know how anyone else copes with this. Whether they have the same internal struggles with what they feeling, or whether they just come out and say. Maybe it is me as a person who makes things more difficult than others. I maybe ...not as honest as I've said I am. I still do find I cover-up and then.....

End of side one.

There are times when you seem to be quite hard on yourself as a person.

I know. It's probably the thing that my friends and family will say most about me. I am hard on myself. I don't know where it began. As a child maybe. These expectations that I've always put on myself to match up to. From an early age it has been there. And I will allow a certain leeway. a little laugh. I'm very generous with everyone else, but not with myself. I don't know quite how to change that, but it is who I am.

How do you think in any way this has impacted on the fatigue that you had? The fact that you are that kind of person, do you have..do you sense that there's any connection at all?

Transformed units of meaning

There is a pattern in her life of coping, coping, coping. And then there comes a time when she doesn't want to cope any more. She would like to take refuge in the illness feeling, but a part of her says no. She has a conversation in her mind until eventually she gives in.

She feels that she has levels of expectations - others and one's own, maybe she is different to others

She does not know how others cope with this condition - whether they have the same internal struggles with what they are feeling, or whether they come out and tell others.

Thinks that maybe she isn't as honest as she thinks that she is, as she still finds that she covers up..

She is hard on herself, and says that friends and family will also say that about her. She has to live up to these expectations. While she is very generous with others, she is hard on herself. She doesn't know how to change this.

General units of meaning

I would think so, I would think so in one way. I think a lot of people would agree that the chronic fatigue comes from ... or it's ..there's a common denominator between those who are achievers, or people who push themselves to meet goals -- to keep commitments and to meet their responsibilities. Those kind of people; there seems to be a common denominator there. And with that then there is the feeling that you must keep going. If you kept going when you were not ill, then you must keep going even though you are ill. So at a certain point there's ... certainly in my case, I just don't acknowledge half the time. And so I still keep pushing myself and I know it could ... I wonder though. I don't know if it would have perpetuated it as long as it has done. I often ask myself if I am self-perpetuating this thing. And I haven't got an answer. Slight laugh. If I were kinder to myself would it go away -- is a question. Laughs.

That is a good question.

It's a good question. Well, on a day when I just am a bit selfish in terms of taking time for myself when I want to, I have a more peaceful day. If it were just that it were that simple, and it was an either or situation.

There's just so many threads running through - certainly my life. Circumstantially and also what I see is kind of the fruit of this thing. Which part of what I have found in myself over the years, is this fretfulness. You know this anxiety. This inability to make choices. Unable to at a certain point just to be real and say: This is it, end of the road, end of the story. It's who I am and there's no more arguing. I find myself unable to be that cut and dried. So as much as I see all of this, I don't actually know the answers; to how to improve who I am ... who I've become.

Do you see yourself as different from who you were?

Transformed units of meaning

She thinks that a lot of people would agree that there is a common denominator in chronic fatigue, a common denominator between those who are achievers, or people who push themselves to meet goals -- to keep commitments and to meet their responsibilities. She describes a feeling of having to keep going, because if one can keep going when one is not ill, then one should be able to even when ill. Therefore she keeps pushing herself, but wonders if she is possibly self-perpetuating the condition. Asks the question If I were kinder to myself would it go away

When she does act in a selfish way, and take time for herself, then she has more of a peaceful day, but wishes that it was that simple.

Finds that over the years she has developed a fretfulness and anxiety, as well as inability to make choices, doesn't know the answers, and how to improve who she is.

General units of meaning

I wonder. I suppose underneath who I am over all the years I have been a fairly anxious personality in some ways. But I look back on myself and I do remember myself certainly being more carefree. More able to.. just laugh at things. Not take things so seriously. Not be so caught up in who and what I am or have become. So again I hesitate to put all the blame at the door of chronic fatigue, although I think that's the major.. major thing in my life. But I do know that I am fifty-two and at a questionable age anyway. Where a lot of things are in question - a lot of things are not as they were. And I am seeing myself as someone different anyway. So I do try and keep the bigger picture.

Who is that person that you see yourself as now?

Now? Ha. little laugh. Not very nice. My daughter has just gone overseas and she had a long talk with me. Trying to impress upon me that I was still a person of worth and all the rest of it. I just somehow feel **now** that I am searching for the person I was - in..in a couple of ways. And I do see myself as someone who has grown too intense, too introverted, too hard on herself. Unable to laugh as much as I used to, and just find a bit of freedom and **fun really**. So it's as if my life has got a bit narrow in some ways

Do you think that fatigue has done that?

I certainly think it had a role to play. But I don't want to lay everything at the door... I do know though that if I didn't have to cope with feeling tired so much of the time and having so much physical sort of pain and umm drawbacks then, it would be one less thing to cope with. A major part of my life would just be a little less complicated. I have a feeling that my mind would be able to make better choices - better decisions. And ja, it would be a big chunk of my life that I wouldn't have to have a look at all the time you know. I could do without that.'

Ja.

And just have menopause for instance, laughs. But no, I do see it as a real drawback in my life.

What is the tiredness like for you? If you had to describe that tiredness, what is it?

Transformed units of meaning

Although she sees herself as having been an anxious personality over the years, she remembers being more carefree before the onset of the fatigue. She hesitates to put all the blame on CF, as she is at a questionable age when things are changing.

She does not see herself as a very nice person at this point. Her daughter tried to impress upon her that she was still a person of worth, but she feels that she has grown too intense, introverted and hard on herself, unable to laugh, to find freedom and fun and her life has become a bit narrow. She is searching for the person that she was.

She does not blame the fatigue for all the problems, but feels that if she did not have to cope with pain and tiredness a major part of her life would be less complicated, and she would be able to make better decisions.

She would only have to deal with menopause

General units of meaning

Well, just before you came I was sitting in the chair there ... and it is partly a purely physical thing. Where you are actually so tired you feel you can't move properly. You can't use your limbs properly. You just want to lie down. Your head feels so heavy, so empty. In my case the muscles are all hurting. There's very often a headache and a sore throat. That would be the physical side of things. And then ..there are very definitely mental things as well. Where the mind gets cloudy and unable to concentrate as I've said. You can't connect things.

And then when you faced with a choice, or a decision that you have to make, you actually could snap. That combination, certainly with me. Faced at that time with something that I have to decide one way or the other, it doesn't matter what it is. About brushing my teeth, to going to work, or cancelling an appointment, or acknowledging that I need whatever I need at that time, it's almost beyond me. It sounds ridiculous, but that's how bad it can get.

On your very worst days do you get out of bed?

Most days now. I certainly ... having a job I need to get up everyday. So then I find myself at work, even on a day when I would rather not go to work. That is quite a good thing. If I need to I will come back and go back to bed - in the afternoon. umm..It doesn't often happen that I stay in bed, unless I develop a real cold or something on top of what I am already feeling. I don't nowadays spend much time, like days, in bed. I usually get up everyday.

Was there a time when you would spend days in bed?

Transformed units of meaning

A description of the tiredness:

Physically

it is partly a purely physical thing. Where you are actually so tired you feel you can't move properly. You can't use your limbs properly. You just want to lie down. Your head feels so heavy, so empty. In my case the muscles are all hurting. There's very often a headache and a sore throat. That would be the physical side of things.

Mentally

definitely mental things as well.

Where the mind gets cloudy and unable to concentrate as I've said. You can't connect things. And then when you faced with a choice, or a decision that you have to make, you actually could snap. Choices can cause her to snap. Even relatively minor decisions are beyond her.

She gets out of beds most days at present, even when she would rather stay home, she goes to work. She may come home and go to bed in the afternoon.

General units of meaning

Ja. Several years ago. I would find especially when I wasn't working. If I felt in that day that this thing had really closed in on me, I would just spend the morning sleeping or reading. I would just stay there until I felt I could get up. It was ...it was good, I sometimes longingly think. I would still like to have that option, but as I'm working I don't have that option. Except over the weekends and then I usually find that things need doing anyway, so I get up.

And it seems like.. you've continued to try and fight it even at your worst days.

Ja, it looks like it. I think ... if I think about it, I'm fighting what I see happening in me as much as I'm fighting what I see happening in my husband.

I hate acknowledging that there are umm..these things happening in our lives; that drain us of energy and take us away from being productive, and keep certainly myself so caught up in me. I would rather that I didn't have to face all of that.

You mentioned your husband. How do you think that your having chronic fatigue has affected your relationship and him?

Now and again I find that he will voice something which shows his concern. And perhaps, umm..I don't want to say anger, but regret that there is this thing. If he was a fit, active man who needed a wife alongside of him.. for you know, three office functions a week or travelling, then it would be more noticeable than it is. He's not in a fixed employment and he's also slowed down a lot in the last three years with his pacemaker. but..So I suppose the fact that I am often tired or taking time out doesn't have that much of an affect on him, but it does mean very often that I'm not there when we could just have an evening together, chatting or going somewhere, or meeting all our commitments or something. So he is aware of it.

But I have very, very seldom had anything from him either than support. So I'm so grateful for that. He just entered in right from the beginning to trying and to understand what was happening. And I very seldom have seen him angry or disappointed in me.

Transformed units of meaning

Several years ago she would stay in bed, especially when not working. She would spend the morning in bed sleeping or reading, until she felt good enough to get up.

She is fighting what she sees happening in herself as much as I'm fighting what she see happening in my husband. She hates to acknowledge the process happening in her and her husband's life that drains them of energy and lessen their productivity. I keeps her caught up in herself.

CFS has impacted on her relationship with her husband - he sometime voices his concern, and not anger, nut regret. She feels that it is less noticeable because he is no a fit active man, and has slowed down due to his heart problems. Her slowing down has not had that much of an effect on her husband, but they are not able to spend time together in the evening

She has always had support from her husband, for which she is very grateful

General units of meaning

Do you talk about it much?

Yes especially now since I went to the chronic fatigue for a few sessions - the clinic I mean. And he has been willing to chat and I've been able to say a little bit of what I was able to talk through, and I think for us the frustration - both of us feel the frustration of not knowing what it is or how to actually deal with it. And the knowledge that there isn't anything one can do about it is a frustration for both of us I think. If we could practically work **at** it, it would help some of the frustration. It's just here - just part of our lives..

At least with his pacemaker you know they review it from time to time, and so on. You kind of feel... small laugh. umm..And in any case, something like that is more of a medically acceptable thing you know

I come back to the fact that this chronic fatigue is somehow not a medically acceptable thing - or acknowledged thing. Very few as I see it are willing to look at it as an entity. As a ...as a recognisable thing.

But he's been largely very supportive for the times that it has taken its toll on our marriage or our relationship. We've just been able to talk and keep going through it.

When you say taken its toll on your marriage and relationship, what has it done? How has it impacted?

Well, I'm often irritable. Tiredness and the ...and the pain that goes with the fatigue sometimes makes me very irritable and fretful. And I find myself having to take it out on someone. Not consciously, but I just find myself snapping or tearful, and then he bears the brunt of that.

Laughs a little.

umm...And then I suppose on a closer level, although that has affected him too. I mean physically, well,... ja I suppose, over the years his libido and mine have sort of tapered down to..to a level. But it's common ground. I mean I'm often, I shouldn't say this, but I'm grateful in one way that his health is ..is also at a sort of um....not a comparable level to mine, but he also is having problems so that we can ... there is hmm ... I don't feel that I am letting him down that often when I am too tired or that I am that bad a wife. Because he too has days when he's too tired. He has times when he is just out of it for whatever reason.

Transformed units of meaning

They do talk a but CF, after having attend the CF clinic. The frustration comes from not knowing what it is and being able to do anything about it. If they could practically work at it, it would ease the situation.

Her husband's pacemaker is reviewed form time to time, and it is more medically acceptable.

CF is not a medically acceptable - or acknowledged thing. Very few people re willing to look at it as a recognisable entity

Her husband has been supportive during the times when the /CF placed a strain on the relationship.

She is often irritable. The tiredness and the associated pain makes her irritable and fretful. And she find herself taking this out on someone, at an unconscious level. Her husband bears the brunt of her frustrations.

The CF has impacted on their physical[sexual]relationship. She is grateful that her husband's libido has tapered off due to his health, so that she doesn't have top feel that she is letting him down or being a bad wife

General units of meaning

But I would say that ... ja the irritability, and the tearfulness and the moods, and the swings, and the feeling that he sometimes has to step into the home situation to keep things going, has been different in our lives. But he has just stepped in. And when he'd needed a meal he will go and cook it. Or somebody to be fetched or things to be done or shopping to be done, he will go and do it. So he's always been able to...to fill up where I haven't been able to cope.

Have you been able to do the same for him?

Yes I think so. I think so. I hopeI hope I can come to terms with the fact that he is ageing, you know he is ten years older than I am. And I hope I've come to terms with the fact that he is ageing. I sometimes find myself resisting his tiredness and his ailments if you like, and the results of his medical history and problems. And I then have to work that through because I get a bit guilty, because he is so patient with me. And he really is. But I do try laughs to be as generous with him as he is with me.

Do you think he copes better with his illness?

Ja I do. He is less complicated. He's not as complicated a person as I seemed to be. He's either having a good day or a bad day. He's either angry or he is not angry. He's either irritable or he is not. And he will either talk about it or he won't. Laughs. I'm complicated. I hassle over things and I try and find the best solutions and the best answers, and that really often draws things out. You know where I could just make a choice or have a cut off time or whatever, and he can't always see that. He's a lot more cut and dried than me. Works things through quicker in that way. He does cope better with being ill, or I should say having medical problems. They don't seem to hassle him. Maybe they do deep down, but anyway I don't see it in his lifestyle as much as I do in mine.

Do you think that's because of the different conditions? You mentioned that his was easier to deal with in the sense that it was more cut and dried and more obvious.

Transformed units of meaning

She sees him as always being able to step in when she hasn't been able to cope - cooking a meal, fetching things or doing shopping

She likes to think that she does the same of her husband.

She hoes that she can come to terms with his again, and his tiredness and ailments. She feels a bit guilty about this, because he is so patient with her.

She feels that her husband copes better with his illness, because he is not such a complicated person. He's either having a good day or a bad day. He's either angry or he is not angry. He's either irritable or he is not. And he will either talk about it or he won't. She is more complicated, hassles over things, and does not make choices easily.

General units of meaning

Right, I think so. Everybody knows about heart problems and it is easy to talk about. If you say you've got a pacemaker everybody knows what it is. And if you start bringing into the conversation that you have chronic fatigue people will say: hmmm. Like one friend of mine said the other day: do you still find yourself falling asleep at the dinner-table? Well I don't know that I've ever done that, laughs but I mean that's how people see this thing you know. They see that you do ... okay maybe that's her way laughs talking about it. But people don't really know much about chronic fatigue, and if they do they've got some idea that you want to sleep all the time. Which is partly true, but the whole picture of chronic fatigue is not as known as something like heart problems. People know about that; they feel safe talking about it; they don't have a problem recognising that this guy has got whatever. And maybe it's me that just doesn't know how to put across the fact that I still have this thing or how to talk about it, or how to relate to it in a normal way. I just try and keep it under wraps all the time.

What do you think people should know about it?

I would love for people to know that it's real. Somebody once said to me early on, one of the doctors I first went to: why do you need to know that you've got this thing? And I still today need to know that I've got this thing because it's real! Because it's happening around the world. There are... I would like to know that there are other people like me. With the same frustrations and the same coping mechanisms or non-coping mechanisms.

I would like for the world to know that this is a genuine, legitimate reason. As legitimate as having diabetes or whatever. And as multiple sclerosis once upon a time was a fairly undiagnosed non-treatable thing, it now **is** a diagnosed and a treatable thing as far as I know. If chronic fatigue could be put in the same category as having as much research done, as much ..umm..input into this whole picture, so that people who **have** chronic fatigue are **not** just labelled as depressed people - neurotic people. umm..

In other words it's not just under that kind of mental umbrella, where the mental manifestations are treated like the depression and the tiredness and so on that goes with it, those **are** part of the chronic fatigue pattern.

Transformed units of meaning

She sees her husbands medical problems as more clear cut, because his heart condition is understood by others. People know about that [heart/pacemaker]; they feel safe talking about it; they don't have a problem recognising that this guy has got whatever.

CF is not well understood, and there are false impressions about it. She quotes a comment from a friend do you still find yourself falling asleep at the dinner-table?

She wants people to know that this condition is real. A doctor she consulted asked why she needed to know that it was a real condition. She would like to know that there are others like her, who have the same frustrations and coping or non coping mechanisms

She wants the world to know that CF is legitimate - as legitimate as having diabetes and multiplesclerosis, which is diagnosable and treatable.

If CF was put into this category, as much research would be done, and people with CF would not be labelled as neurotic, depressed

CF would then not be put under a mental umbrella.

General units of meaning

But the other side, the physical side, if those things could be actually taken seriously and treatment found for them. Then the whole person would be treated. The whole person would be approached. And you would not just be approaching your chronic fatigue patient with your anti-depressants or your whatever. Not that there isn't a place for that.

There is a place for that. I would dearly love to find a course of anti-depressants that would not have all the side-effects that I've had to work through. And that is why I don't take them. But I know there is a need for them. If I could find one that would take me through my days I would **gladly** take it. Because I know there's a place for that.

But at the same time I would like to **not** negate the physical side of things which is just as real. So that the whole picture comes across, not just the ... would you call it psychomatic symptoms? **Psychosomatic.**

Psychosomatic symptoms. Those are perhaps the most obvious. Or the most easily recognisable, or the only ones you could treat. But to only treat that side of the person I think is only half the story. That's what would help me a lot; is to have the whole of me discussed as a legitimate, medical problem.

You've mentioned that word legitimate quite a few times.

laughs. I know, I feel strongly about it. I feel I would like to be legitimised. If somebody were to say to me, as this doctor perhaps eight years ago, if he could have said to me: look, this is a real medical problem. And we recognise it, we know it's real. And here are the symptoms and you qualify. I wouldn't have gone away and made myself sicker, or... speaking for myself, maybe there are those who would go back and hug this information to themselves and say: good. Now I'm sick. Now I can be sick. Personally I wouldn't have done that. It would have just helped me to know that I was right. I was allowed to feel ill.

You were not actually looking for a reason to be sick

'No. I still am not. I'm looking to get well. I'm desperate to get past what this thing does to me. And on to being able to maintain my lifestyle. I don't mind that I've had to cut it back. But I just wish I could maintain it a bit more. And I wish I could... just ...keep going with my life. Be able to meet my challenges and commitments.

And you don't think at the moment that those are unrealistic challenges or commitments?

Transformed units of meaning

If the physical symptoms were taken seriously, and treatment found for them, then the whole person would be treated.

She recognises that there is a place for antidepressant even though she has not been able to find a suitable one, and she would take them if side effects were not such a problem for her.

For her the physical symptoms though are just as real. The condition needs to be seen as a whole picture.

If only the psychosomatic symptoms are treated then that is only half the story. It would help her to be treated as a whole person, with a legitimate, medical problem.

She feels strongly about the term legitimise and feel she would like to be legitimised. For her this would mean that the condition was recognised as a real medical problem. She then would not have gone away and made herself sicker or taken on a sick role. It would have helped her to know that she was right in feeling so ill and that she was allowed to feel ill..

She denies looking for a reason to be sick, and describes herself as desperate to get past the effects of the condition. She would like to be able to maintain her life style - keep going with her life, even though she has had to cut back

General units of meaning

Some of them are maybe. But it's my life. My life is full. umm..There's not much more I could change in it. I can't **only** do a morning's job. I have to do the rest of my life. Because that's important to me as well.

And umm..so I often feel that I've done enough cutting back in my life. I would like to be able to add to my life more, rather than cut away.

How has the chronic fatigue affected your sense of who you are?

Well I have lost quite a bit of self-worth maybe.

And I find now that in a social situation, like a dinner party or some function involving people and conversation and so forth, I reach a limit quicker than I used to. In other words I find I reach a ceiling of being able to concentrate quicker than I used to. So that limits me when we go somewhere or are involved in a social thing. I can function, hopefully normally, up to a point. And then I get tired -- my mind just won't make conversation any more. So then I just find myself listening. I can't partake any more, at a certain point. So I find that I've grown limited in social things.

It's affected me in my sense of adventure.

My sense of being able to achieve.

The first thing to go very often is my sense of humour. I find I take life far too seriously, because I'm caught up in this kind of internal struggle.

And I've lost a little bit of ..who I am and my confidence I think has taken a bit of a knock.

Who are you?

I'm a middle-aged woman laughs..struggling to find.....[End of side two - tape is turned over]
Who am I? Well I know the obvious things are that I am a mother of two wonderful children and I'm a wife of a wonderful man.

I am a person who achieves quite a lot in terms of my job. Strangely enough, even in the midst of all of this and at this late stage in my life, I'm acquiring skills which I know other people would find daunting. Somehow I'm still able to do that. I run a very successful office where I work.

Transformed units of meaning

She has challenges and commitments which are possibly unrealistic, but she does not see how she could change things, as she can not only do her morning job, but has to do the rest of her life, which is important to her. She feels that she has done enough cutting back in her life, and would like to add more to her life.

The CF has meant that she has lost quite a bit of self worth, and finds that she is limited in social situations as she reaches a ceiling of concentration quicker than she used to, and gets tired - her mind won't make conversation any more.

CFS has affected her sense of adventure

CFS has affected her sense of being able to achieve

She has lost her sense of humour and takes life too seriously

She has lost confidence and a little bit of her sense of self[who she is]

She describes herself as a middle aged woman, mother of two children and wife of a wonderful man

She sees herself as achieving quite a lot in her job, and has managed acquire skills which other people would find daunting, despite the CFS

General units of meaning

umm..It just seems that on the home front that I am a bit negative. Where I seemed to have had this role change. With my mind that's not a problem -- maybe deep down it is a problem. And then there's this struggle to come to terms with myself as an emotional human being. And I think probably that's the level that I am struggling on. On a practical level, on a job level and largely on a mother-wife level - I think I'm okay. I think I would match up with anyone else of a similar age. umm..my friends ... all of us have hassles. I mean I am no different to anyone else.

But it is on an emotional level that I think I've taken a lot of knocks and I haven't really found how to function in that kind of ... in a wholeness approach to accepting myself, and being able to function within that. I've lost a picture of who I am I think on that level. Maybe that's just what I'm searching for.

Do you know where you were -- when you say you've lost it. Who were you?

I was laughs..a fairly together, functioning person. And I am talking a long time ago. With a lot of dreams and desires ... quite a lot of them got hit on the head. So.. I was ...an achieving person.umm.. Confident enough, and largely in control of my life. And I would think I was fairly well-rounded ...and fairly happy..

But it has been a progression over the years of ... I think when one has worked through a failed marriage or ..coming to terms with being a single parent and looking at financial insecurity for an extended number of years, it takes its toll so that you would perhaps wind up like I have; just not too sure of where you're going or what you really want any more. Maybe it's a thing that most people have to work through

And how has the fatigue impacted that? Do you think that what you're experiencing is normal for your age and circumstances? Or do you think that the fatigue has in anyway changed what might have been?

I somehow feel I've been robbed of ten good years. That a chunk of me has been lost, so that now

I've perhaps aged quicker than I would have otherwise.

Or ..I've come to a time in my life where it's too late to redeem any of those years.

Transformed units of meaning

She is negative at home, struggling to deal with the role change at a deep level, and trying to come to terms with herself as a human being.

On the mother wife level she sees herself as okay.

*She thinks that she would compare well with people of a similar age - she is no different from anyone else - they all have hassles
On an emotional level she has taken knocks and cannot function in a wholeness approach to accepting herself, and being able to function - she has lost the picture of who she is.*

She was a fairly together functioning person, with dreams, desires - an achieving person. Confident enough and largely in control of her life; fairly well rounded and fairly happy

the progression over the years of having to work though a failed marriage, single parenthood, financial insecurity over an extended period - it has taken its toll - she is not sure where she is going and what she really wants anymore.

She feels robbed of ten good years - a chunk of her has been lost

*She has aged quicker that she would otherwise have done
The other option is that she has come to a time in her life when it is too late to redeem any of the lost years*

General units of meaning

So I'm not just too sure if I have the right even to be frustrated about what's been lost, because it's lost - those years have happened.

But I know that ...one reads a lot about people who come to this time of life and they move on through it very successfully and very positively. And I think I could, on the levels that I've mentioned, where I feel I do achieve.

It's just that there's this, maybe it's grief or something like it, where I feel I've lost good years of my life. And I can't go back or redeem them. And it's almost like I'm carrying into my older years (my old age) an addedan added burden. Or...I've inherited age a bit sooner than I would have liked.

My body seems to have let me down maybe, or my mind or a combination of both.

So that as much as I want to go on into my life and still be fruitful and creative, it's almost as if I have to work through quite a lot to get there. I still have the same desires and the same dreams. It just frustrates me ...that as I approach each of these challenges I have to sort of work through quite a bit of negativity first.

Negativity towards what?

'Because I feel ...tiredness is such a part of my life, that I first have to address that - work through it - and then keep going. I can't just get up in a day and go into the day. I have to work through how I'm feeling; whether it's acceptable or not acceptable, whether I go to work or don't go to work, whether I speak about it or don't speak about it, and then I get into the day, if you know what I mean. And other things that crop up in the day, it's almost as if I have to work through what my body is saying, before I can get on into whatever I need to do. If I could just go through my day.

I suppose other people do that -- I'm just assuming that they do. Little laugh. I assume that people get up in the morning and just go to work. More laughter. Without having to work through this whole extra load. Maybe they don't. [contemplative] That's the battle for me, because I have no ... I don't know how to compare myself to other people; whether they have other problems, not necessarily chronic fatigue, but whatever. I always seem to have to work through that no-man's land to get to where I'm going.

Transformed units of meaning

She is unsure whether she has the right to feel frustrated about what she has lost

She reads about people who have come through this period of life [around the menopause] very successfully; she feels that she could as well

She grieves for the lost years, which she cannot redeem, and she seems to be carrying and added burden into her old age - or she has inherited age a bit sooner than she would have liked

Her body or her mind, or possibly both seem to have let her down Although she wants to go on with her life and has the same desires and dreams, she has to work though quite a bit of negativity to get there

The tiredness seems to be the overriding thing in her life - almost overwhelming, and she cannot simply get up and get on with her day. She has to work though who she is feeling, how acceptable the feeling is, the options to go to work or not, whether to talk about it or not. When other things crop up during the day, she has to listen to her body before being able to get on with whatever if required

She presumes that others are able to get up, go to work without having to work through the load that she carries. She cannot compare herself to others so and therefore always seems to have to go through a no-,mans land to get to where she is going

General units of meaning

Once I'm at work I pick up. And once I'm at a function or once I'm at a meeting or wherever I'm going, then I kind of kick-in and go for it until I get tired again.

It almost sounds like you almost... what energy is there ...

Use it and then it's finished.

Use it - and you collapse. Okay.

that's a good picture.

Ja. And has that been fairly consistent over the last ten years?

'Yes I can see that's how it is. I sort of gather myself and go for it, and then there are the days where all the gathering in the world doesn't help. Then that's the pa... the thing I've described to you, where either Bill or myself will just...'

Are there days when you in fact gather all those reserves together and you know that they're not going to be enough for what is lying ahead anyway?

Yes. And then I have to work through that awful feeling of... failure I suppose ... and anger. Because... because it's still even now not a simple thing of "you are ill and allowed to be ill." It still with me is a problem of: is this a mental thing that I can talk myself out of or not?

Do you think you'd ever be able to answer that question?

No, because this chronic fatigue is just such a medical thing - full of questions. And nobody presented it to me ever as a cut and dried thing. I came to the knowledge that this is what I had over a period of years, over many doctors, over much reading and soul searching. So that's never been given to me as an acceptable thing.

Do you think that you've accepted that's what you got?

Well I either **have that laughs**..or I am a neurotic, depressive personality. Laughs.

So I hope I've got chronic fatigue. Yes, I think I have, but only 80 percent. There's 20 percent of me that say I'm not fully allowing myself to be labelled.

Transformed units of meaning

She feel better once she gets to work or other commitment

She uses what energy she has until it is finished and then collapses

She notes that se has to gather herself up to get on with her day, but some days, nothings works

When this happens she has to deal with the sense of failure and anger She continues to struggle with the dilemma - is this condition a mental thing which she can talk herself out of -it is not a simple thing of - you are ill and allowed to be ill.

There are many question s related to CF - its not a straightforward entity

The knowledge that she has gained has come from doctor reading and soul searching - but she has never experienced this as an acceptable thing

She realise that she wither has CF or she must have a neurotic and depressive personality

She hopes that she has CF but not completely there is still a part of her that doe not allow herself to be labelled with this condition

General units of meaning

Do you think if chronic fatigue were a more acceptable label that it would be more comfortable for you?

Ja. You know a part of me yearns to be ...classified if you like - maybe that's the word. And then I'd just put it to one side and get on with my life.

To be classified and treated would be the ultimate. laughs.

Hmm, hmm.

But classified would be half the battle.

But it would almost seem like classification of CFS is not a comfortable classification yet.

'Not yet no. You mean for me, or generally?'

For both.

Ja.

Because if it was a good diagnosis in the sense that it could be treated, or at least better understood, or the people accept that it was real. Maybe you'd accept that it was real.

Hmm. Yes I would. There would be a relief. In the course of the last ten years there have been other things. You know people have come across my path and said: 'this is what it is'. And with relief I've tackled that approach. Hasn't been that of course. You know people have said it's a viral thing and this and that. There's been relief in accepting that, because with that clear diagnosis in inverted commas, comes the promise of treatment. So that's relief! That really is relief. But of course it hasn't been that.

Ja.

So then I'm still finding myself in that ambivalent (if that's the right word) position of the possibility that this is just a straight forward mental problem. Can I live with that? I say to myself. I don't know.

Because I would like to think that what I know deep down inside of myself is true - that this is a combined picture of physical problems, with ... the ... out-workings - the fruit of it is definitely depression.'

Hmm. Hmm.

Definitely.

Transformed units of meaning

There is a part of her that want to have this classification, so that she could deal with it and get on with her life

The ultimate for her would to be have a classification and treatment

But classified would be half the battle

Despite this CFS is not yet a comfortable diagnosis

She note that if it were an acceptable diagnosis she would be relieved - but up till now, she has been impacted by other people with definite ides on her problem, because with a clear diagnosis comes the promise of treatment

She is still ambivalent about the fact that this could be a psychiatric condition and doesn't know if she could live with that knowledge

What she would really like to believe is that it is a combined physical-psychological picture, and that depression is the result of this

General units of meaning

So you see the depression as coming subsequent to the fatigue?

Ja. I know it has been a parallel in my life for a number of years, but I wouldn't say that that was the cause. It's definitely an effect. And it's a very real thing. I don't negate it at all. As I've said earlier I would love to have it treated. If I could have it treated and still keep going with my life. It's a very real and a draining and a problematic side-effect. I really is a ...it's a horrible side-effect. It eats into your confidence and your self-worth and everything. If I could deal with one thing I would like to deal with the depression and the anxiety that are spin-offs to this whole... confusion that has come - as to what's happening in my body - my mind.

What do you think your quality of life is at the moment?

Half. Some days three quarters. But I would say that I work largely on half

And I have come to terms with that and I'm not complaining

.It's when it slips below that, that I feel it. Because then it takes its toll on other people in my life and who I mix with, and I'm not able to meet work commitments nor home commitments.

But I operate on about maybe fifty percent output and I've come to terms with that.

Hmm. Hmm. Is there anything positive that's happened as a result of the chronic fatigue? It may sound a strange question.

Ja. No definitely. I mean I have ... I've had to have long looks at myself. I've been driven to look at my whole picture of who I am as a woman, as a mother, wife, career person. And I can see that there are still good things in me; that I am still able to function, regardless of what's happening.

That there are still so many people out there who have no idea what goes on in me, because I still function on enough levels to run my life. And there are many out there who have no idea what I go through or cope with.

And I'm glad of that; I'm still able as I've said to pick up skills and in spite of many things I am still running a fairly productive lifestyle. I'm positive on many days because I find I can still achieve a good workload in the morning at work....

I miss though what I was. And I miss the stickability and the endurance and the energy that I used to have.

Transformed units of meaning

*The depression is real for her and she would have loved to have effective treatment. Depression for her is a draining experience, which eats into self confidence, self worth and everything else
The most important thing for her would be to deal with the depression*

*She states that her quality of life as at about half what it should be, on good day may be three quarters
She feels that she has comes to terms with this level
When she operates at less that 50%, other people in her life are negatively impacted*

She feels that she has comes to terms with this level

CFS has had some positive effects for her - she has been forced to appraise her self as a while - who she is. She sees good things till in her, and feels that she is still able to function

*Because she functions on enough levels to keep her life together, many people do not realise the extent of her situation and what she has to cope with
She is glad about this, as she can still be fairly productive, and on good days can achieve a good workload*

She misses that past self, also her endurance capabilities

General units of meaning

But I still feel if I search or I sit long enough with this thing, and if I can get just over the hurdle of accepting what's happened to me, I will be a much quieter, happier person.'

What does acceptance mean for you?

Just letting things happen I think. It's almost within my grasp, if I could just allow my life to be what it is, and not fight. And just be what I am without these sort of internal conversations all the time. I could just be. I think that would be a lot easier than trying to match up or stick to certain levels, or try and be what I was. Come to terms with where I am. Laughs. Whatever that is.

It was difficult for you to describe earlier when I asked you to describe who you are.

Ja.

And whether the fatigue has impacted who you are.

But I still don't know quite who I am. I think that's the major question.

Ja, it definitely has. It's definitely impacted, but I can't put all the blame at that door. Because I am at a stage of life where things would make me question who I am anyway - regardless of my fatigue.

But it definitely has impacted and made me less able to cope.

Not just on a physical level, but as I've said and I may be repeating myself, it's the underlying threat that any stress or tension is a trigger. Any decisions that I have to make at a time when I'm wavering or running low on reserves. At that point if I'm called to make decisions, or put in a stressful position, or I feel circumstances just are ..are weighing in, and that's it. That's the snapping point. So that's a fine line to walk. It's not anybody's fault, but I just do find that my coping mechanism at that point is very thin. Whereas perhaps somebody who doesn't have chronic fatigue would just be more realistic, or just let things happen without that sort of anxiety tussle all the time.

It seems to be a constant struggle.

mm. I very seldom switch off, laughs ..except when I'm reading a good book. There's always this ... it seems to be this tussle to ...to keep going, to keep coping ... to keep saying the things people want to hear

To keep being you in all of that?

Transformed units of meaning

She fantasises that if she searches enough or waits long enough and is able to conquer the hurdle of acceptance of CF, she will get over it and she will be a quieter and happier person

Acceptance for her means letting things happen. she wonders about the fact that if she could allow herself be what , it would be easier

She remains unsure of who she is

The fatigue has had a definite impact, but again she does not want to blame her situation entirely on CF

*The impact has been reduced coping abilities
Less ability to cope both at a physical and psychosocial level, particularly when having to deal with stress situations*

Her coping mechanisms are very limited under stress, but she surmises that persons who don't suffer from CFS would be more realistic

She finds it difficult to switch off, because there is always the need to keep going ,to cope, to say what people want to hear

General units of meaning

Ja, whoever that is. laughter. Some days it doesn't worry me, but when you ask the question and I stop and think, and I don't have an answer..... But I sometimes feel that it's just within my grasp.

What's within your grasp?

Who I am you know, and the fact that I could just grasp a solution there.

I can almost see myself levelling out you know, and just not allowing... or not allowing so much - but for me to be happy would be just to have this sort of momentum; like almost a plateau in my life, without these dreadful swings you know. Of fatigue with accompanying depression and anxiety, back up onto a normal level and then the occasional peak into real productivity, and add happiness that goes with it..... Or maintenance programme or maintenance level, is one of my goals.

That shouldn't be too difficult. Laughs.

Maybe it is at this point that we should stop that for the day.

Okay.

Transformed units of meaning

It is difficult to keep being herself

She feel that finding out who she is is just within her grasp

It is almost possible for her to stay at a comfortable level

Happiness for her would be more of a constant state without the swings from depression and anxiety on the one side and real productivity on the other - a maintenance level

APPENDIX E

EXAMPLE OF THEME OF ACCEPTANCE AND THE RESEARCHER'S REFLECTIONS ON THIS THEME DURING THE PROCESS OF ANALYSIS, PROTOCOL ONE

Acceptance

The themes emerging from this transcript included the theme of acceptance.

Researcher's reflections:

The issue of acceptance is a source of conflict for this participant. She struggles to accept the diagnosis, the impact that the illness has on her life, her relationships and her belief in herself.

It seems to reflect the reality of relationship – in that we see ourselves in relation to others. We are who we are only because of our relationships to others. If others do not believe our stories and our experiences, our lives and our inner selves are invalidated.

I can't quite accept it and I struggle to accept it when I'm having a bad day.

But because of the labels that I've had; of being a depressed person; of being a neurotic, which is one label that a doctor once gave me. I fought tooth and nail to present something different. You know to myself and to others.

Labels that we are given impact on our acceptance of ourselves. Each label has meaning, and one has the choice of living up to the meaning attached to the label, or fighting against it. P1 tries to fight it – to be different. Yet in that struggle, she loses the right to be ill and have her illness accepted.

*You know to myself and to others. Haven't always succeeded in that, and sometimes maybe that's why it's a struggle to put that down and just acknowledge that on certain days I am just ill. I suppose it's because I've never had the freedom to actually be ill. Either I haven't allowed myself, or I don't want to admit that that's **still** happening in my life.*

Because P1 cannot accept her illness, she cannot allow herself the freedom to be ill – is being ill a freedom? For most persons, I guess that illness is seen as a restriction

one's normal day to day activities and on the choices one has – but for her it seems that because the illness is not accepted by the health professionals she is not free to be ill.

It is very important to me, that is why ... one of the reasons I didn't phone today and say: don't come. It's because I thought: there are days you know, when I am like this. Where I don't have two thoughts in my head. But come to the push, I can actually do it! And I need to know that I can go through a day like this, even an interview like this. Because it's important that I say what I need to say. And I am seen as I am. In the context of a whole person, instead of just presenting what other people expect. And always having to find what they expect

So that if I could contain and control this illness, I feel somehow I would regain something of what life has done to me. Or the fruit of what's happened in my life, which I sometimes feel is partly to blame - if I'm right.

This illness has the effect of taking control away from the person. She expresses her loss of control over her life. Control has to do with the sense of self – it creates her sense of meaning for her life. I know when I am ill, particularly if I don't know what the cause is, I am scared and frustrated – because if I know I can do something about my illness, I begin to feel more in control of my situation.

Wanting to do so many things with my life, with my new marriage and the opportunities that have come. And I catch glimpses of myself wanting to run with all these new challenges, and not ever being able to maintain long enough without coming to a screeching halt, every so often.'

P1 has not been able to accept the limitations that her illness has placed on her new marriage and her relationship with her husband. Not only that, but even if her friends say that they understand and accept her situation when she cancels an appointment, she is unable to accept it – almost an admission of failure – as if it is she who can change the illness – once again this is about control.

I know it's strange. I hate to make that confession that I'm ill.

And then I just have to cancel. And I do. A lot of people just know where I'm coming from. And as I've said, they don't seem to mind. It's me that minds.

I don't mind the not going to wherever it is. I mind having to make that admission I think. I mind having to acknowledge that I'm still fighting this thing. Maybe it's an admission of failure? Maybe I don't like to give in. It could be even more complicated than that.

Admitting that she is ill is the struggle. This illness appears to have a different impact on her – is it because it is not perceived to be legitimate?

There's this pattern in my life of coping, coping, coping. And then there comes a time when I don't want to cope any more. And so there is this tiredness and this feeling ill. So I would like to take refuge in it and I would like to acknowledge it, but then part of me says: well no, you actually can't do that. So there is this conversation that goes on sometimes in my mind. Until I eventually – I just give in.

The struggle that goes on - to cope, and go on coping, until it becomes impossible to continue- and then having to accept that she cannot go on any more – to be able to take refuge in the illness. What does this mean? Taking refuge from the struggle of having to keep going? On the one hand she talks about the freedom to be ill, and now it is about refuge in illness. This seems to epitomise the struggle for acceptance that characterises this illness.

...Because there's this programming that goes on in each of us maybe - where you have levels of expectation - others and your own. And you try to match that, and you're trying to be honest with what's happening in your life. And maybe I'm different to others – I don't know. But I do go between back and forth.

P1 is constantly trying to meet others expectation of her, as well as her own. At the same time she is attempting to be honest with herself

[1] There are times when you seem to be quite hard on yourself as a person.

I know. It's probably the thing that my friends and family will say most about me. I am hard on myself. I don't know where it began. As a child maybe. These expectations that I've always put on myself to match up to. From an early age it has been there. And I want ... allow a certain leeway. (a little laugh) I'm very generous with everyone else, but not with myself. I don't know quite how to change that, but it is who I am....If I were kinder to myself would it go away -- is a question (laughs)

It seems as if P1 has set herself high expectations and been hard on herself from an early age. Has this influenced the way she responds to this illness?

.....on a day when I just am a bit selfish in terms of taking time for myself when I want to, I have a more peaceful day. If it were just that it were that simple, and it was an either or situation. There's just so many threads running through - certainly my life..... part of what I have found in myself over the years, is this fretfulness. You know this anxiety. This inability to make choices. Unable to at a certain point just to be real and say: this is it. End of the road. End of the story. It's who I am and there's no more arguing. I find myself unable to be that cut and dried. So as much as I see all of this, I don't actually know the answers; to how to improve who I am ... who I've become.....But I do know that I am fifty-two and at a questionable age anyway. Where a lot of things are in question - a lot of things are not as they were. And I am seeing myself as someone different anyway.

Self-acceptance is difficult – it seems that P1 is looking for any kind of explanation for her anxiety, her indecision, and her inability to accept herself. Maybe it's her age – implying that menopause may explain these feelings. Her experience of her world need to be connected to something familiar – at least then explanations would be rational and acceptable. Her daughter has tried to create in her a sense of worth – but she does not seem able to connect with this.

My daughter has just gone overseas and she had a long talk with me. Trying to impress upon me that I was still a person of worth and all the rest of it. I just somehow feel now that I am searching for the person I was - in

a couple of ways. And I do see myself as someone who has grown too intense, too introverted, too hard on herself. Unable to laugh as much as I used to, and just find a bit of freedom and fun really. So it's as if my life has got a bit narrow in some ways.'

..I hate acknowledging that there are these things happening in our lives; that drain us of energy and take us away from being productive, and keep certainly myself so caught up in me. I would rather that I didn't have to face all that.

This illness has challenged the core of P1's ability to accept herself. It has taken away the control that she needs over her life and her body, it has impacted on her relationships and on her ability to make decisions about her life. She cannot accept the person that she now is, the limitations that are part of her daily existence, and the person she has become.

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APPENDIX F: CATEGORIES AND THEMES EMERGING FROM THE DATA

The table below attempts to track the researcher's categorisation of the themes as they emerged from the data during analysis. As meaningful descriptions were identified, these were given category names and a description was attached to each category. After reading and rereading, ensuring that the description best fitted the category, categories were drawn together, using an inductive process, into central themes.

	Categories	Participants	Descriptions	Central themes
1	Acceptance vs. non-acceptance	P1; P4	Descriptions of aspects of acceptance or non-acceptance of situation	The struggle for acceptance
2	Causes	P4; P2; P5	Possible causes of the illness as seen by the participant	An unpredictable and undependable body
3	CFS impact	P2; P5	CFS impact on person's life, situation, behaviours etc	Illness has power
4	CFS manage	P4	Managing the illness	Creating a meaningful existence
5	CFS symptoms	P4; P3	Description of the various symptoms of CFS	Uncertainty and fear
6	Coping strategies	P1; P4; P3; P2; P5	Descriptions of ways in which person copes with CFS	Creating a meaningful existence
7	Disbelief	P5	Responses to illness and the diagnosis	Uncertainty and fear
8	Discrimination	P2	Experiences of discrimination related to living with CFS; sense of discrimination, judgement, blame	Illness has power
9	Employment impact	P4; P3; P2; P5	The impact that the illness has on relationships at work and ability to do the job	Illness has power
10	Family impact	P4; P2	Impact on family members – dynamics and functioning	Illness in relationship
11	Fatigue experience	P3; P5	The experiences and feelings of tiredness and fatigue	Life draining tiredness An unpredictable and undependable body
12	Feel good	P4; P5	Describe how the participant feels and acts on days when he/she is feeling good	Creating a meaningful existence

APPENDIX F: CATEGORIES AND THEMES EMERGING FROM THE DATA (continued)

	Categories	Participants	Descriptions	Central themes
13	Feel ill	P4	Descriptions of feeling ill	Uncertainty and fear An unpredictable and undependable body
14	Feel like death	P4	Describes feeling as if going to die	Life draining tiredness
15	Feeling ill	P4	Descriptions of the experience of becoming ill	Uncertainty and fear
16	Feelings	P1	Descriptions of feelings verbalised by participant when talking about experience of CFS	Emotions in illness
17	Feelings - depression	P2	Feelings of depression related to living with CFS	Emotions in illness
18	Feelings - helplessness	P2	Feelings of helplessness associated with CFS	Illness has power
19	Feelings of anger	P2; P5	Feelings of anger which are generated by living with CFS	Emotions in illness
20	Feelings - rejection	P2	Feelings of rejection experiences which are related to having CFS	Illness has power
21	Financial impact	P2	The financial impact of living with CFS	Illness has power
22	Future	P4; P2; P5	How participant sees the future	Remission, recovery and hope
23	Guilt	P5	Description of feelings of guilt	Emotions in illness
24	Healthcare	P4; P1; P3; P5	Descriptions of how the person has related to the health care system – medical and/or other professionals	Creating a meaningful existence
25	Helpful	P4	Things that were helpful during the CFS experience	Creating a meaningful existence
26	Illness	P1; P4; P5	Person's experience of illness and its symptoms	Remission, recovery and hope
27	Isolation and loneliness	P5	Descriptions of the isolation and loneliness that were concomitants of CFS	Illness has power

APPENDIX F: CATEGORIES AND THEMES EMERGING FROM THE DATA (continued)

	Categories	Participants	Descriptions	Central themes
28	Label	P4; P1; P3; P5	Person's experience of being labelled	Legitimacy of illness
29	Legitimate	P4; P2	Recognition of the illness and legitimisation are important to the participant	Legitimacy of illness
30	Living death	P2	CFS is described as a living death	Life draining tiredness Living death
31	Losses	P4; P2; P5	Description of participant's understanding of the perceived losses which CFS has caused	Illness has power
32	Neg. feelings	P4	Descriptions of negative feelings in response to CFS experience	Emotions in illness
33	Non-legit	P4	The experience of having a non-legitimised illness	Legitimacy of the illness
34	Not heard	P1	Person's descriptions of the experience of being "not heard" - not being listened to	The struggle for acceptance Legitimacy of the illness
35	Personal Impact	P4; P3; P5	Description of the personal impact of CFS	Illness has power Living death
36	Positive	P4; P2; P5	Positive aspects experienced by the person which could be attributed to the experience of CFS	Remission, recovery and hope
37	Previous health	P4; P5	Description of health status prior to onset of CFS	The struggle for acceptance
38	Relationship partner	P3	Descriptions of how CFS impacts on relationships with partner	Illness in relationship
39	Relationships with others	P1; P3; P5	Descriptions of how other people relate to CFS illness and how this differs with their understanding of other conditions	Illness in relationship
40	Relationship-spouse	P1;P2;	Descriptions of impact of CFS on relationship with spouse	Illness in relationship

APPENDIX F: CATEGORIES AND THEMES EMERGING FROM THE DATA (continued)

	Categories	Participants	Descriptions	Central themes
41	Social impact	P4; P3	Impact of CFS on social life	Illness in relationship Illness has power
42	Social isolation	P2	Participant's experience of social isolation and loss of social contact as a result of living with CFS	Illness has power Losses
43	Suicide	P4; P2; P5	Participant's view of suicide as an option with CFS – feelings and thoughts of wanting to die	Illness has power Living death
44	Support	P4; P1; P5	Person's experiences of support during the CFS experience	Illness in relationship Creating a meaningful existence
45	Test-diagnosis	P4; P2; P5	Descriptions of the tests done and the diagnoses given	Uncertainty and fear
46	Treatment	P4; P2; P5	The kinds of treatment to which the person was subjected or considered and the effects of these	Legitimacy of the illness

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