Meanings of ME: interpersonal and social dimensions of chronic fatigue / [edited by] Christopher D. Ward, Emeritus Professor, University of Nottingham, UK.

Summary: "Chronic fatigue syndrome (CFS or ME) is a problematic diagnosis, and much of the existing writing on the topic is dominated by questions of biology, psychology and causation. The focus on personal, interpersonal and public meanings in Meanings of ME signals a paradigm shift in thinking about CFS/ME. Contributions from clinicians and academics as well as from those who have personal knowledge of CFS/ME highlight the varied experiences of the illness. Rather than insisting on a specific theory of the illness, the authors provide fresh perspectives on the sometimes conflicting ways in which the diagnosis and symptoms of CFS/ME are interpreted by doctors, patients and others.

The book’s early chapters survey four different ways in which CFS/ME can be presented: as lived experience, as a scientific phenomenon, as a medical diagnostic classification, and as a product of culture. The personal, interpersonal and public meanings of CFS/ME are then discussed before an exploration of stigma and identity from both personal and professional standpoints”—Provided by publisher.

Includes index.

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The aim of this book is to explore how we think and talk about a medical condition for which even the name is controversial. We call it CFS/ME, but it is difficult to define our topic further without, at the same time, being committed to a specific concept of the condition. The meanings of CFS/ME, as a human situation, are constantly influenced by speakers and writers. In this introduction I begin by describing the book’s conception of CFS/ME as a label for a syndrome, a cluster of phenomena that ‘run together’. I then suggest that we can use the label, and be interested in its meanings, without considering what CFS/ME might ‘really’ be. This book does not address the cause of CFS/ME and its symptoms.

Existing ways of writing about CFS/ME are generally unable to accommodate the idea that symptoms and illnesses can have personal or interpersonal meanings. Greater openness to meanings is possible if we assume (1) that any given account of CFS/ME is a particular ‘punctuation’ of complex realities and (2) that the meanings people associated with CFS/ME do not form a fixed code but are developed discursively. For these reasons a multi-perspectival, systemic approach is needed in order to replace preconceptions with curiosity about the many meanings of CFS/ME.

The chapter ends with an overview of the rest of the book.

Many patients, and their doctors, are doubtful whether it is possible for physical symptoms to convey messages (signs) both from the physical organism and also from the patient as a person. If feelings of fatigue are generated by molecules called cytokines,¹ how can they be a reaction to a person’s present or past life? According to a prevalent view there is a stark choice: a psychological description of problems says that ‘the nature and content of your distress is personally meaningful, while a [medical] diagnosis says that it is meaningless. These assumptions cannot both be
Christopher D. Ward

true’. The present book is addressed to patients, clinicians and academics who wish to remain open to both possibilities. In a more didactic mode this book could have been called ‘How to Talk about Chronic Fatigue Syndrome’. We do not want to prescribe what to think, in the manner of a medical textbook. Instead, each of our contributors points towards how symptoms might be thought about and talked about more helpfully.

1.1 The problem of definition

An introduction is supposed to outline what a book is about, but this is not a straightforward task in the borderland between the physical, the psychological and the social. Even the name of our topic causes problems. Some people insist on ‘ME’, denoting ‘myalgic’ (muscle pain) and ‘encephalitis’ or ‘encephalopathy’ (inflammation or other pathology in the brain). Claims about causation are made by other labels that have been used, for example ‘chronic fatigue immune dysfunction syndrome’ (CFIDS) and ‘post-viral fatigue syndrome’. The most widely used medical label is chronic fatigue syndrome (CFS). We use the term ‘CFS/ME’ in this book because our purpose is to explore the personal and social significance – the meanings – of the diagnosis and its associated symptoms. We can do this without promoting any particular theory of causation. Similar issues arise with diagnoses such as fibromyalgia and irritable bowel syndrome, which are often associated with CFS/ME, and with any illnesses described as ‘medically unexplained’ or ‘functional’. Moreover any illness, explained or otherwise, has meanings.

But is there one kind of CFS/ME to talk about? The diagnosis continues to provoke controversy, which makes it a difficult topic to speak and write about coherently. Whatever one says about CFS/ME tends to become polarised by emotionally charged questions such as: ‘Is it real?’; ‘Is it a physical illness?’; ‘Is it a psychological disorder?’; ‘Is it neurological?’. Those who prefer the term ‘ME’, with its biological overtones, communicate belief in a fundamentally physical cause and also perhaps resistance to the notion that psychological factors generate symptoms. Conversely, ‘CFS’ is interpreted by some as undermining the assumption that symptoms are physically based; and for many, only physical symptoms are real.

It seems sensible to begin with a definition of CFS/ME, but any definition we choose will align us with a particular version of reality. This would be unhelpful here because we cannot assume that all the personal and social meanings we wish to explore can be attached to a specific disease entity. ‘Flu’, for example, is a useful word for many people but
our wish to understand what a patient or a doctor or a website might mean by ‘flu’ requires us to have a flexible attitude to our own presuppositions. The problems associated with naming CFS/ME, along with the difficulties raised by terms such as ‘medically unexplained’ and ‘functional’, demonstrate the circular relationship between what we are writing about and the way we write; the name we choose pre-defines the object under discussion, as will become clearer later. ‘Medically unexplained chronic fatigue’, ‘CFS’ and ‘ME’ are not identical topics, and the way CFS/ME is framed determines what is conceivable and what is inconceivable. A clinical text necessarily creates a CFS/ME that matches medical parameters, and a piece of social science writing creates something rather different. In order to be open to all these meanings – all these ‘CFS/MEs’ – we are going to set questions of causation aside in this book.

In what follows I will describe the kinds of writing we are attempting within a confusing array of medical, psychological, and sociocultural perspectives; this is neither a medical text, nor a psychosocial critique of medicine. Subsequent chapters will offer multiple perspectives on CFS/ME. What binds them together is the notion that meanings arise from contexts. Ideas from ‘systemic’ (human systems) theory provide one way of expressing this.

1.2 Dimensions of ‘meaning’

The word ‘syndrome’ denotes phenomena that ‘run together’. Patients, doctors and others have used different words at different times to describe a syndrome in which fatigue is combined with other symptoms in the absence of an alternative medical diagnosis. CFS and ME are two of those names and neurasthenia (see Chapters 4 and 5) is another. Identifying a syndrome such as CFS/ME acknowledges that certain sets of human circumstances have what Wittgenstein called family resemblances, without presupposing what the nature of the relationships might be. We speak of a syndrome when, for one reason or another, we wish to identify a collection of phenomena without identifying their cause. Malabsorption syndrome, for example, describes a range of problems that have several different causes.

The way we chunk experience up into syndromes is provisional. The meanings attributed to syndromic labels such as ‘Asperger’s syndrome’ have come and gone in the history of medicine, with different parts of them absorbed into other categories. Rates of diagnosis of neurasthenia in the United Kingdom, for example, rose sharply in the late nineteenth
century, and then petered out in the twentieth. These changes reflected changing attitudes to symptoms rather than variations in the frequency of symptoms⁴ (see Chapter 5). The cluster of symptoms that we currently call CFS or ME can be found among most communities that have been studied in the modern world but the frequency with which they are identified medically as a distinct condition is highly variable. Among 90 people meeting research criteria for CFS in a community-based survey in Wichita, Kansas, only 14 (16%) had been diagnosed as such prior to the survey.⁵ The authors of this study concluded that ‘most cases of CFS in the [US] population are unrecognized by the medical community’. It would be no contradiction to put this differently; only in a minority of Wichita citizens are the meanings of CFS-like symptoms interpreted as a distinct medical illness. The two interpretations channel our curiosity in different directions. By focusing on meanings, the present book triggers questions such as: How might the undiagnosed Americans in Wichita themselves have thought about their fatigue? What would have been the meaning for these individuals, or for the public health system, of their receiving the diagnosis of CFS/ME?

These questions call attention to the negative and also the positive consequences of labels, a topic to which we will return in Chapter 13. Naming a syndrome can certainly be a positive achievement, not solely for science but also for communication. A scientific viewpoint encourages us to speculate about what CFS/ME ‘really is’ but these are not the only questions that are worth asking. We can also explore the way the concepts of such syndromes operate in ordinary life. One benefit of a focus on meanings is that we grow to understand one another better, and another is that we become more resistant to mystifications put about by competing interest groups in relation to a medical diagnosis.

Having unpacked some difficult issues raised by the book’s title (‘CFS’, ‘syndrome’, ‘interpersonal and social’) I can no longer postpone addressing that other tricky word, ‘meanings’. As I implied earlier, clinicians and researchers and also those diagnosed with CFS/ME seem to be confronted with a choice: either the illness is biological and therefore meaningless, or else it is ‘psychogenic’ and therefore meaningful. Both sides of this dichotomy are concerned with the same question: how can we explain CFS/ME? Psychologists and psychiatrists have explanatory models in mind when they refer to ‘cognitions’ or ‘attributions’ as factors that predispose to illness or perpetuate it (see Chapter 8). When we use this sort of language we are certainly in the domain of meaning, but with a particular picture in mind. An individual whose thoughts are making her ill is seen as deviating from a norm: her cognitions and attributions
are conceptualised as pathogens. This perspective provides a rationale for cognitive behavioural psychotherapy (CBT) as a means of shifting thoughts and feelings towards a healthier – more ‘normal’ – direction.

In this book we do not consider that meanings are normative and we are therefore wary of words such as ‘cognitions’ and ‘attributions’. Even a word such as ‘fatigue’ lacks a single meaning (see Chapter 6). We think of meanings as created between people. Meanings are thus keys to the way CFS/ME is talked about and thought about within intimate, professional, and other relationships, and in the wider world. We must constantly take account of ‘the peculiar way in which any part of a discourse, in the last resort, does what it does only because the other parts of the surrounding, uttered or unuttered discourse and its conditions are what they are’. Meanings, in this sense, are a function of context.

1.3 How can ‘meanings’ make sense in CFS/ME?

We wish to maintain an interest in meanings but this raises theoretical and also ethical problems. A physician who focuses primarily on the ‘meaning’ of a failing heart rather than on a practical remedy is not likely to be getting to the heart of the matter: more probably she or he is abusing power. Using TB and HIV/AIDS as examples Susan Sontag warns against endowing pathophysiological events with moral and cultural significance. Surely (bio)medicine concerns diseases that cannot contain messages about, or for, the victim?

The ‘medical model’ symbolises impersonal, mechanistic attitudes that everyone deplores, and that has little interest in meanings. Real twenty-first-century doctors are mostly somewhat to the ‘left’ of this classic notion. The medical co-authors of the UK’s NICE Guidelines, for example, would probably describe their formulation as biopsychosocial. This term indicates an awareness of non-physical factors in the generation of symptoms but not necessarily an interest in the meanings of illness. It is as well to remember that the biopsychosocial model originated within psychiatry and that its function was not to discount the concept of mental illnesses but rather to clarify their dimensions. A biopsychosocial lens does not prevent CFS/ME from being defined normatively and measured and managed as an object of the same general kind as, say, thyroid disease.

If biopsychosocial medicine is somewhat to the ‘left’, there is another species of medical theorising that lies to the ‘right’ of orthodox medicine. A vocal part of the CFS/ME community occupies a parallel universe of medical theorising, for example about the role of subcellular
organs called mitochondria. Such theories attract those who for one reason or another suspect mainstream scientific medicine of failing in its duty to help patients diagnosed with CFS/ME. There may be a sense that the power of science is being held back, as suggested by the magazine and website ‘What the Doctors Don’t Tell You’. Here, personal meanings are not the issue at all. Medical interpretations of illness are strongly promoted, and doctors are urged to stick to (biological) science rather than indulge in psychologising. Hostility to mainstream medicine thus leads some patients and practitioners to build an alternative orthodoxy in which the biomedical identity of CFS is absolute.

If biomedical models are as far as one can imagine from an interest in meanings, psychoanalysis would surely be their antithesis. Psychodynamic interpretations view symptoms as primarily the carriers of meaning. There have been few attempts to describe CFS/ME in this way; some are mentioned in Chapter 8. CBT is a more frequently applied interpretative approach, in which feelings and cognitions are central. Despite their apparent distance from medical explanations both the psychoanalytic and the cognitive-behavioural paradigms follow a medical model in treating CFS/ME as a disorder that can be defined normatively. In both cases, norms are linked to standardised notions of objective reality.

The psychological and medical models of illness we have considered so far are all normative, and they all generate theories about internal mechanisms of symptom generation. These perspectives discourage an intersubjective perspective on meaning. When we shift our attention from the internal mechanisms of a syndrome we become open to alternative ways of understanding it. As I indicated earlier, from a phenomenological point of view a syndrome is a totality, something that is just there. This is how CFS/ME tends to be viewed by complementary and alternative medicine (CAM). The literature of CAM generally focuses more on treatment than on pathogenesis, and is mainly written for patients rather than professionals. Often describing itself as holistic, CAM challenges some of the reductionist explanations of illness that are associated with orthodox medicine. CAM’s challenge is to generate a description of CFS/ME that not only makes emotional sense but that also reaches beyond itself as a resource for making sense of symptoms. Orthodox medical accounts have the virtue of being able to connect with our understandings of the physical world in general: we all know that we can become ill if we get an infection. Biopsychosocial accounts of CFS/ME also connect with how we explain behaviour to each other; to most of us it does not seem strange that we might be more likely to get a
cold, or lose weight, if we are stressed, and that our social environment affects our health. CAM, on the other hand, tends to rely on less mundane concepts. It often refers to less salient notions such as toxins\(^{13}\) and ‘energy’.\(^{14}\) Energy as a metaphor helps to make sense of approaches to treatment but is a ‘dormitive’ concept: if you are less energetic then you lack energy. The concept of energy does not carry you or anyone else towards a broader understanding of what your state amounts to, or what it might mean. CAM favours global factors such as energy when it is orientated towards explanations that are ‘holistic’. It is difficult to express holistic ideas in language, a point I will return to in Chapter 5. CAM is certainly helpful in fostering a concept of illness that is not embarrassed by humanness, but its holism is not sufficiently thought through, and is not realisable as a description of people’s everyday experiences or of the meanings attributed to them.

Sociocultural accounts of CFS/ME, also, treat syndromes as totalities, focusing on the context as a whole rather than on the inner mechanisms of illness. CFS/ME is among the ‘medically unexplained’ conditions that have often interested social scientists. They are less interested in biomedical abnormality than in individuals who have been labelled as ‘CFS/ME’. This perspective opens up avenues for the exploration of meanings in terms of factors such as gender, social class, and economic or professional power. A problem that needs to be avoided, certainly in this book, is that a sociological or anthropological perspective can come to be thought of as cancelling out other ways in which illness is understood. The notion of illness as a ‘social construct’, for instance, encourages people to infer that personal experience is a mere symptom of wider social forces, as though fatigue or pain could be deconstructed at will. Writers in this vein do not necessarily mean to imply this but they do sometimes get carried away. Accounts of people diagnosed with neurasthenia a century ago sometimes have a whimsical tone, enhanced by engravings of ladies on divans or moustachioed customers for nerve tonic,\(^{15,16}\) and on occasions one gets a whiff of something similar in contemporary writings about people diagnosed with CFS/ME. The implication is that some supposed illnesses are not illnesses at all.

The idea that CFS/ME or any other diagnostic category might be nothing but a cultural fiction is obnoxious when it is used to invalidate the illness experience of individuals. On the other hand, we would fall into an opposite trap if we excluded the possibility that a diagnostic label were ever capable of constructing illness: illness can be influenced by social contexts. When writers either make free with people’s claims of illness, at one extreme, or when they accept them unquestioningly at the
other, we should ask who is speaking or writing, and for what audience. One occasionally observes academics having what they think is harmless fun deconstructing the illnesses of people they are never going to have to meet. Historians have this possibility; clinicians do not. Among doctors whose patients and whose reputations are alive and current, one more often sees clinicians showing an exaggerated reverence towards concepts of illness that ought to be subjected to critical scrutiny.

In summary, writers on CFS/ME can often only accommodate notions of personal meaning with difficulty. When they do so, they are often writing from a polarised position, for example that of social constructionism. In this book we do not take a single position on the question of causation because we want to remain as open as possible to multiple interpretations of CFS/ME.

1.4 Multiple perspectives

This book takes a critical approach towards all explanatory frameworks – the academic disciplines of medicine, clinical psychology, and the social sciences, along with the less theoretically rigorous formulations of CAM. Identifying with any one perspective would be to claim something that I at least do not believe, that it is possible to look at an objective reality called ‘CFS/ME’ from an external, expert position. We would thus force questions of meaning into a specific mould, and I have hopefully already made it clear why this would be inappropriate here. A core aim of the book is to respect authentic human experience and to recognise the multiple languages or frameworks used by individuals to communicate their understandings of illness. Understandings developed by people with symptoms, by professionals, and by others, derive their coherence and their usefulness from diverse contexts and the task of this book is to explore contexts rather than to arbitrate on facts or values.

The position that I have been developing to this point can be summed up in a number of principles:

1. If we think of illness as a human reality, then no single account of it is paramount. Each interpretation is a particular ‘punctuation’ of relationships among an infinite range of elements that influence one another within a situation. Bateson makes this point in a famous essay on alcoholism. For example, a physiological explanation provides a useful punctuation of the fatigue experienced by people diagnosed with CFS/ME but neglects the links a particular person may make between current or past life and feelings of exhaustion. These
latter may be better understood through a different punctuation of the situation as a whole.

2. Meanings, including those used by doctors, are arrived at discursively, through the contexts in which they operate. They do not form a fixed code. Understandings of ‘health’, ‘illness’, and ‘disease’, as of ‘fatigue’, ‘exhaustion’, and so on, have varied through history. So also have the definitions of diagnostic categories such as CFS/ME. Current meanings continue to be influenced by their cultural and social contexts.

3. Consequently, the way in which we speak (and the way in which a book is written) always participates in the creation of meaning rather than being an inert vehicle for objective interpretations. If we choose to use language that reifies CFS/ME as an exogenous ‘disease’ we construct an entity that it is possible for a patient to acquire, contain, be controlled by, be rid of, and so on. Alternatively we can view ‘CFS/ME’ as the name for a concatenation of relationships between processes, traits, or histories that are no less real but that we hesitate to think of as a ‘thing’. We could still call it a syndrome. This latter kind of language is more conducive to systemic thinking than is language that reifies CFS/ME. A systemic description does not discount biological theories of causation. Whether we choose to think of alcoholism as a discrete, genetically determined disease or as a systemic phenomenon we will still have to include realities such as the liver, chromosomes, and so on in our account.

4. The above three characteristics of a systemic perspective imply that speakers and writers, along with audiences, are active participants in the co-creation of human realities. This is necessarily so first because individuals punctuate reality in different ways; secondly because meanings are influenced by our individual contexts; and thirdly because we embody our meanings in the way we communicate them. A human situation such as CFS/ME simply cannot be described impersonally.

5. Awareness of one’s self as a constructor of meanings brings to mind the question of power. Power is derived from the cultural contexts that influence what we say and how we say it. Emotions surrounding controversies about CFS/ME are often triggered by challenges to professional power, or by other political issues such as gender.

6. If the above principles are taken seriously then preconceptions about CFS/ME have to be discarded. A taken-for-granted attitude must give way to a multi-perspectival, systemic perspective.

Multiple perspectives generate what systemic family therapists call curiosity.¹⁸
Our hope is that this book will foster an attitude of curiosity about meanings for people with symptoms, for clinicians, for academics – and for us as readers.

1.5 Overview of the book

The raw material of clinical experience and professional discourse is the book’s starting point. Chapter 2 (‘Personally Speaking’) presents personal descriptions of illness in words that are not filtered by any medical interpretation, because an exploration of meaning requires us to make personal experience rather than textbook dogma our point of reference. The brief extracts from mainstream medical literature that form Chapter 3 (‘Scientifically Speaking’) are treated similarly. They enable CFS/ME to appear in the guise either of ‘disease’ or of ‘illness’, but without editorial interpretation.

Chapters 4 and 5 consider CFS from a conceptual point of view. In Chapter 4 (‘Diagnostically Speaking’) a psychiatrist highlights weaknesses and contradictions in current classifications of psychiatric and medically unexplained disorders. Is CFS a neurological condition? Does it belong with infectious diseases or immunology? Or is it psychiatric? In short: What is the medical meaning of CFS? Chapter 5 (‘Historically Speaking’) describes the intertwined histories of medicalisation, medical theorising and medical specialisation over the past two centuries and suggests that our current ‘knowledges’ of CFS/ME owe much to the particular professional structures (such as medicine and psychiatry) in which we happen to find ourselves today. An exchange between the authors of Chapters 4 and 5 highlights some of the controversies implied by our two positions.

Chapters 6–8 are all based on empirical investigations relevant to the way in which meanings are developed by people diagnosed with CFS/ME in the personal, interpersonal, and public domains. At the personal level, Chapter 6 (‘Symptoms into Words’) describes an investigation of the language used among individuals with CFS and other long-term conditions to describe fatigue. We interpret the findings in terms of inter-subjectivity, and end by suggesting that people with CFS/ME may have particular difficulties in making their experiences intelligible to others. The interpersonal level is central in Chapter 7 (‘Meanings of CFS/ME in the Lives of Couples’) which is based on a qualitative investigation of couples. So far as possible the couples speak for themselves here, rather than being used as exemplars for general theories. A more academic approach is taken in Chapter 8 (‘The Self and Others: Reinterpreting
Research Evidence’), where quantitative research, as well as qualitative studies such as the one described in Chapter 7, is reviewed from an interpersonal perspective. The public domain is explored in Chapter 9, which considers internet material as a producer of knowledge of CFS/ME and as an influence on how people with that diagnosis come to see themselves and be seen by others.

The remaining chapters (10–13) maintain a personal perspective but with attention to physicians along with their ‘patients’. Chapter 10 (‘The Challenge of CFS/ME in Primary Care’) describes the ups and downs of doctor–patient relationships. Although written from a GP’s point of view the chapter is another point in the book where the voices of patients are also heard. The complex emotions evinced by CFS/ME are explored further in Chapter 11 (‘The Said and the Unsaid’). Chapter 12 (‘Stigma, Unspeakable Dilemmas and Somatic Symptoms’) combines an analytical with a subjective perspective, being jointly presented by a psychiatrist and his patient. They together focus on the effect of stigma in stifling communication in medical consultations and elsewhere, and as a source of suffering. They describe strategies for combating stigma. Chapter 13 (‘What Does the Diagnosis Say?’) examines labelling from a relational point of view, building on the doctor–patient perspectives of preceding chapters and showing how labelling intersects with themes that run through the book as a whole. Chapter 14 (‘Ways of Not Knowing’) reviews the ways of knowing CFS/ME that have been emerged in the preceding chapters and suggests that there is room for more writing from an interpersonal perspective.

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