

The Biopolitics of Chronic Fatigue Syndrome

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Abstract

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This thesis approaches Chronic Fatigue Syndrome (CFS) as a biopolitical problem, that is as a shifting scientific object which needs to be studied, classified and regulated. Assemblages of authorities, knowledges, and techniques make CFS subjects and shape their everyday conduct in an attempt to increase their supposed autonomy, wellbeing and health. CFS identities are, however, made not only through government, scientific and medical interventions but also by the patients themselves, a biosocial community that collaborates with scientists, educates itself about the intricacies of biomedicine, and contests psychiatric truth claims. CFS is a socio-medical disorder, an illness trapped between medicine, psychology and society, an illness that is open to debate, and therefore difficult to manage and standardise. CFS is, thus, more than a fixed and defined medical category; it is a performative and multiple category, it is a heterogeneous world. This thesis studies that performative complexity by assembling different pieces of empirical data that constitute its heterogeneity: medical and psychiatric journals and monographs, self-help books, CFS organisations' magazines, newsletters and websites, illness narratives and social studies of CFS, CFS blogs, and qualitative interviews with diagnosed CFS patients and CFS activists. The thesis delineates different interventions by medicine, science, the state and the patients themselves and concludes that CFS remains elusive, only partially standardised, in an ongoing battle between all the different actors that want to define it for their own situated interests.

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Abbreviations

AfME	Action for M.E.
APT	Adaptive Pacing Therapy
ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
APA	American Productivity Audit
APT	Adaptive Pacing Therapy
ARF	Acute Renal Failure
ASCL	Association of School and College Leaders
AYME	Association of Young People with ME
BA	Benefits Agency
BACME	British Association for Chronic Fatigue Syndrome
BRAME	Blue Ribbon for the Awareness of ME
CAB	Citizens Advice Bureau
CAM	Complementary and Alternative Medicine
CBT	Cognitive Behaviour Therapy
CDC	Centre for Disease Control and Prevention
CEBV	Chronic Epstein-Barr Virus
CIS	Checklist Individual Strength
CFCCC	Chronic Fatigue Syndrome, Fibromyalgia, and Chemical Sensitivity Coalition of Chicago
CFS	Chronic Fatigue Syndrome
CFSAC	CFS Advisory Committee
CFSCC	CFS Coordinating Committee
CFIDS	Chronic Fatigue & Immune Dysfunction Syndrome
CNCC	Clinical Network Coordinating Centre
CNS	Central Nervous System
CLASP	Carers of Leicestershire and Support Project
CSSD	Complex Somatic Symptom Disorder
CT	Computerised Tomography
DDS	Depressive Disorders Study
DLA	Disability Living Allowance
DSC	
DSM	Diagnostic and Statistical Manual of Mental Disorders
DTCA	Direct-to-Consumer Advertising
DWP	Department of Work and Pensions
EDS	Excessive Daytime Sleepiness
EBM	Evidence-Based Medicine
EBT	Evidence-Based Treatment
EBV	Epstein-Barr Virus
EC	European Commission
EMEA	European ME Alliance
ES	Excessive Sleepiness
ESA	Employment and Support Allowance
ESME	European Society for ME
ES	Employment Service
ESR	Erythrocyte Sedimentation Rate

FDA	Food and Drug Administration
FMS	Fibromyalgia Syndrome
FSD	Female Sexual Dysfunction
FSS	Functional Somatic Syndromes
GET	Graded Exercise Therapy
GP	General Practitioner
GWI	Gulf War Illness
HB	Housing Benefit
HE	Healthy Eating
HFME	Hummingbird's Foundation for M.E.
HLA	Human Leukocyte Antigen
IACFS/ME	International Association for Chronic Fatigue Syndrome/M.E.
IB	Incapacity Benefit
ICD	International Classification of Diseases
liME	Invest in M.E.
IS	Income Support
ISS	Insufficient Sleep Syndrome
LP	Lightning Process
LPT	Lost Productive Time
LSLY	Low Sugar Low Yeast
JCP	JobCentre Plus
JSA	Job Seeker's Allowance
MBPS	Munchausen's by Proxy Syndrome
MCL	Mantle Cell Lymphoma
ME	Myalgic Encephalomyelitis
MEA	M.E. Association
MES	Medically Unexplained Symptoms
MEG	Magnetoencephalography
MEG	Monitoring and Evaluating Group
MFMT	Multifunctional Multitargeted
MRC	Medical Research Council
MRI	Magnetic Resonance Image
NDA	New Drug Application
NDDP	New Deal for Disabled People
NEID	Neuroendocrineimmune Deficiency Syndrome
NI	National Insurance
NICE	National Institute for Health and Clinical Excellence
NIH	National Institute of Health
NIRS	Near-Infrared Spectroscopy
NHS	National Health Service
NLP	Neuro-linguistic Programming
NMEC	National M.E. Centre
NOW	Netherlands Organization for Scientific Research
NSAID	Nonsteroidal Anti-Inflammatory Drug
MCS	Multiple Chemical Sensitivity
MCS	Maastrich Cohort Study
ME	Myalgic Encephalomyelitis
MLV	Murine Leukemia Virus
MS	Multiple Sclerosis
MSC	Manpower Services Commission

PACE	Pacing, Graded Activity and Cognitive Behaviour Therapy: A Randomised Evaluation
PANDORA	Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy, Inc.
PI	Principal Investigator
PLDS	Post Lyme Disease Syndrome
PMS	Premenstrual Syndrome
PTSD	Post-Traumatic Stress Disorder
PVFS	Post-Viral Fatigue Syndrome
SAHS	Sleep Apnea-Hypopnea Syndrome
SMC	Science Media Centre
SMC	Specialist Medical Care
SNS	Sympathetic Nervous System
SSAC	Social Security Advisory Committee
RCT	Randomised Clinical Trial
UBO	Unidentified Bright Object
WBC	White Blood Cells
WHO	World Health Organization
WLQ	Work Limitations Questionnaire
WPI	Whitmore Peterson Institute
XMRV	Xenotropic Murine Leukemia Virus-Related Virus

Introduction

After having been removed by force from her house and spent two years in a psychiatric hospital, 32-year-old Sophia Mirza was found dead on 25th November 2005.¹ Sophia was affected by chronic fatigue syndrome (CFS), also known in the UK as myalgic encephalomyelitis (ME). CFS is a debilitating condition with a range of fluctuating symptoms which in its extreme manifestation constitutes patients bedridden. Scientists have for many years struggled to find its cause with no success. Some have suggested that there are physiological causes and in particular viral infections, and others that it is a psychological illness, a view that seems dominant. According to the account of Sophia's mother, she had been told by her daughter's general practitioner (GP) that Sophia had made herself ill and that she was keeping her ill as long as she was looking after her.² Having been advised by Sophia's GP to put her daughter in a clinic, Sophia encouraged her to find out what the clinic had to offer. The clinic, as she was informed, was expensive and would probably not bring long-term benefits because it focused on mental health and used treatments such as graded exercise, although it claimed to be a neurological clinic. Although she fulfilled the necessary requirements for committing her daughter to that clinic, she was not admitted.

By 2002, Sophia's condition had deteriorated. 'She had to eat every 20 minutes, else her symptoms would escalate to even more severe heights', according to her mother.³ At the same time, and after having been visited at her home by a psychiatrist concerned about Sophia's state of health, with whom her mother disagreed about her daughter's condition, the psychiatrist informed her that if Sophia refused to go to the CFS clinic, or if she did not recover within the following six months, she would have to be sectioned under the (new) Mental Health Act (2005). If she tried to stop this, he would go to the courts to have her removed as the nearest relative, and he added that if she did not open the door when they

came to remove Sophia, the police would be called to ‘smash the door down’.⁴ From January 2003, Sophia started to improve and was able to tolerate some light, talk, sit up and have a few visitors. Then, when her mother informed Sophia’s GP about the improvement in her health, the GP told her that he did not care and could no longer remain her doctor. In May 2003, the GP, together with the psychiatrist and a social worker tried to enter Sophia’s house to section her, but her mother did not allow them in. Shortly after that incident, her mother called her GP saying that Sophia was devastated and although she does not want to be sectioned, she is willing to go into a different clinic. However, according to her mother, ‘the die has been cast’; Sophia was finally removed from her house and hospitalised.⁵

After Sophia’s death, an official inquest was conducted to determine the cause of death. Brighton’s Coroner Court ultimately recorded it as acute renal failure (ARF) due to dehydration caused by CFS, while a neuropathologist testified that Sophia showed evidence of dorsal root ganglionitis.⁶ Finally, a neurologist who was consulted on the inquest stated that the changes in the spinal cord may have been the cause of the symptoms Sophia experienced as part of her CFS. Though initially reported by the *New Scientist*, and other public media, as the first death worldwide ascribed to CFS, the magazine later acknowledged that CFS had been put in other death certificates in the US and Australia.⁷ Nonetheless, it was the first death attributed to CFS in the UK. CFS advocacy groups, such as the ME Association (MEA), claimed that the verdict of Sophia’s inquest showed that CFS is a neurological illness. Sophia’s body became the *cause célèbre* of the medical community, the mass media, and the CFS community internationally. Despite, or because of, Sophia’s personal tragedy, hopes that the illness would finally attract the attention and legitimacy it deserved were raised by many people with CFS.

On 5th September 2010, the *Journal of Clinical Pathology* published a paper which explored the possibility of establishing a disease-specific post-mortem tissue bank in the

UK.⁸ Two of the four authors of the paper were members of CFS advocacy groups, of the MEA and of the Action for ME (AfME). The call for establishing tissue banks was not new as similar calls, and more precisely for ‘brain banks’, have been reported in the US and Australia.⁹ Just a few months later, on 1st November 2010, the day people with CFS were banned from giving blood in the UK, CFS activists protested at the UK Department of Health in London in order to raise awareness of the seriousness of the illness, to condemn the National Institute for Health and Clinical Excellence (NICE) CG53 Guideline and demand parity with other serious diseases such as HIV/AIDS and multiple sclerosis (MS).¹⁰ According to the MEA, NICE’s CG53 Guideline is primarily concerned with the clinical assessments and management of the illness, and not with its causation, and primarily supports treatments such as behavioural therapies. Almost six months later, on 25th May 2011, CFS sufferers demonstrated at the US Health and Human Services (HHS) in San Francisco, condemning the lack of support, treatment and research, and demanding clinical trials.¹¹ In both cases, the news of the ‘discovery’ of the XMRV virus, the third known human retrovirus after HTLV and HIV, and its assumed relation to CFS, had raised new hopes and anxieties for people afflicted with CFS.¹²

On 21st August 2011, *The Guardian* published an article entitled ‘Chronic fatigue syndrome researchers face death threat from militants’.¹³ According to the police, CFS ‘militants are now considered to be as dangerous and uncompromising as animal rights extremists’, the paper stated. CFS ‘extremists’ attack scientists who suggest the syndrome has psychological origins, bombard researchers with freedom of information requests, make complaints to university ethical committees about scientists’ behaviour, send letters falsely alleging that individual scientists are in pay of drug and insurance companies, and campaign against cognitive behavioural therapy which can purportedly help sufferers, according to the paper. Almost a month later, sick and disabled claimants took to the streets nationwide to protest

against Atos Healthcare, a French company that provides ‘independent’ medical advice to the UK Department for Work and Pensions (DWP) and is authorised to test who is able to work. Some activists picketed Atos’ offices and others occupied JobCentre Plus (JCP) offices, demonstrating against the £9 billion cuts to disabled benefits.

While the chronological unfolding of these events gives the sense of some underlying continuity of purposes and desires, they are really only a few building blocks of a larger, more complex, and non-totalisable architecture. The habit of portraying single ‘objective’ accounts of events and scientific objects is strong, yet my story about CFS is only one of the many possible stories that can and will surely be told. I will nevertheless try to tell a story that is rich enough to problematise what is usually believed about this illness.

The story I want to tell is full of ambivalence, social stigma, hopes and anxieties. It is a story populated by multiple institutions, discourses, narratives, practices, and technologies. It concerns social actors (or, more precisely, human and nonhuman actors) that have different aims and purposes, but which through their intermingling create and re-create each other. In other words, these actors are formed and transformed by their connections, connections which may be partial and temporary. Each actor or force is, however, not separate from the rest, as if it exists in silence, side by side with other forces in a primordial vacuum, as atoms in Lucretius’ account of the creation of the world, waiting for the *clinamen* to make them relate to each other. Rather, all forces are always already interrelated in an ever-changing palimpsest of relations. This world is, despite its ‘fatigue’, full of mobility; mobility of scientific facts and categories, medical technologies, social institutions, and subjectivities. It is a world composed of many social worlds, a world that is biopolitical (Foucault, 1976/1979) because our knowledge of ourselves as living beings is a central object of rationalities of power.

Sophia Mirza's body became a field of conflict between different scientific disciplines and social authorities. Without denying its insoluble materiality, the human body is a field of conflict between different discourses such as the law, biomedicine, and economics, and each one of them promotes a different subject. The chronically fatigued subject is caught up in between these various discourses that constitute it in the process of knowing it, and in between social authorities, such as scientific research, medical doctors, social workers and occupational therapists, that try to regulate it.

The main thrust of this thesis is that CFS subjects are not only 'made up' from above by government, scientific and medical authorities but also from below by the patients themselves who work to contest psychiatric truth claims. That is why I claim, following Dumit (2000), that CFS patients constitute a 'biosocial' community, that is a new collective identity, no doubt with its own factions, gathered through various means around central shared vulnerabilities, beliefs and aims. What makes the case of CFS unique, in my view, is that there has been no 'closure' in the scientific controversy surrounding its pathophysiology, aetiology, diagnosis, prognosis, treatment and prevention. In fact, I had to re-interpret my theoretical and methodological orientations several times, as the discursive and non-discursive strategies which attempt to stabilise CFS into a coherent object, were evolving.

This thesis, thus, examines the evolving assemblages of authorities, knowledges, and techniques that construct CFS subjects and try to shape their conduct in order to increase their supposed autonomy, health, and wellbeing. It is an enquiry into the ways CFS constitutes a problem to be governed and the governmental technologies, that is the mechanisms, instruments, and programmes, that are being used. It is an enquiry into the ways CFS bodies, identities, and ways of being are made. The persisting 'idleness' of the chronically fatigued subject and the lack of scientific consensus about CFS, continue to pose problems to social authorities. CFS's nebulous 'nature', its uncertain epistemic status, continuously generates

new forms of examination, surveillance, and intervention. As Callon and Latour (1981) have shown, through various negotiations, calculations, acts of persuasion and violence, diverse agents try to ‘translate’ each other’s interests as their own, that is to speak or act on behalf of others. Actors or forces separated in time and space are enrolled into a network when they understand their situation and goals according to a certain language and logic. Hence, what have to be studied are the diverse actors involved in the definition and management of CFS. What has also to be examined is whether and how CFS patients’ activism challenges or reinforces particular ways of seeing and knowing the chronically fatigued body. CFS advocacy groups and associations actively construct CFS with their discourses and practices, with their mobilisation of sources, materials, and facts, with their contribution to clinical trials or with their sharing of experiences and information about CFS, adding in this way to the overall complexity of the picture. Although health movements and activism are not particularly new, the entanglement of public agencies, industries, and private organisations, of scientific research, public policies, and activism can indeed be considered a relatively recent development.

As it currently stands, CFS is a heterogeneous object caught up in between different and competing regimes of objectivity and its fate is unknown. Although the contents of some chapters overlap, for analytical reasons each chapter deals with a different level of the same object, e.g. the medical objectification or the work regulation of people with CFS. In addition, although this thesis focuses more on the regulation of CFS in the UK context, it tries to examine the construction of CFS from an international perspective and in particular by taking into account the US context, which together with the UK are the countries where the prevalence and research of CFS is the greatest. In this way, the national specificity of the UK, in terms of medical, legal, economic and political frameworks, is preserved.

Chapter 1 develops the conceptual arguments and framework through which to carry a broad enquiry into the chronically fatigued subject, a framework by which the intertwining of social, political, scientific and epistemological problems can be approached and analysed. To do so, I draw on biopolitical and governmentality studies and on history and social studies of science and more particularly of medicine. What is gained is an understanding of the historicity of classifications, scientific objects, and knowledge, but also an appreciation of how humans become subjects to and of medical technologies and social institutions, and, in turn, change classifications, scientific objects, and ultimately themselves.

Chapter 2 provides an account of my ‘research journey’ into the CFS world. It discusses the disparate materials and methodological tools that were used in order to research CFS, to understand both the scientific and popular representations of CFS and the meanings and experiences of people with CFS. These tools are the genealogical approach to the study of history as developed by Michel Foucault, the online research of CFS discussion lists, and qualitative interviews of CFS patients. I discuss how I designed my research, the methodological and practical problems I faced during my study and the fine and complex ethical considerations I had to resolve.

Chapter 3 develops a sketch of a genealogical account of fatigue. The aim of this chapter is to situate the historical production of the fatigued subject. I trace how new clinical medical practices and scientific enquiries in the late nineteenth century developed a knowledge of fatigue. While Anson Rabinbach’s (1992) study has shown how fatigue emerged as a social problem to be controlled in the late nineteenth century, I try to complement that history by providing an account of the epistemological transformation in medicine that led to that development. I also look at the evolution of other illnesses of the time, showing how the ‘vitality’ of the body constituted a major concern for modern western societies.

Simultaneously, I trace the diminishing interest in fatigue and the way CFS emerged as a new medical and social problem in the mid-twentieth century.

In chapters 4 and 5, the making of CFS objectivity is explored. We enter the worlds of medical clinics, biomedical charities, patients' organisations, regulatory organisations, laboratories, and biotechnology companies. Chapter 4 shows how CFS is dispersed among often competing discourses and practices of health, normality, risk, and disability. I try to show how the governmental apparatus seeks to transform the experience of fatigue into a field of relations and objects it can potentially govern. When positive knowledge of CFS subjects has been acquired, authorities try to shape CFS subjects and, in turn, CFS subjects try to shape their capacities and conduct. At the same time, the chronically fatigued subject is constituted from below by the patients themselves who contest psychiatric truth claims. The community of CFS patients is a major force in the making of CFS. The making of the chronically fatigued subject comes, however, with a heightened epistemic uncertainty which requires even more relentless surveillance and examination. Discourses, facts, and categories are taken by, negotiated, rejected or transformed by CFS sufferers.

In chapter 5, the examination of the making of CFS objectivity is continued by focusing more on the ways categorisations, classifications and standardisations order and structure the social lives of scientists, institutions, and patients. It tries to show, in more detail, the interlinkages between classifications, concepts, objects, boundaries, practices, understandings and subjects, and more specifically the ways classifications and categorisations have material force and produce the social worlds within which CFS, both as a scientific object and as an experience, takes place. It demonstrates the attempts to produce a single objective account of CFS and the social labour and techniques that are required for something like that to be achieved.

Chapter 6 turns to the construction of CFS as a welfare problem and the governmental techniques that are being employed to regulate it. It focuses on the work regulation of CFS and the ways CFS subjects respond to that. What are investigated here are the political rationalities, mechanisms and programmes through which CFS is managed as an economic problem. Institutions, practices, and processes such as the Work Capacity Assessment (WCA), the JobCentre Plus, the confession of medical problems in the workplace, and the medicalisation of work and unemployment, are examined. CFS can be read as signalling the rejection of capitalist productivism. CFS is, on the one hand, caught up in discourses of national productivity and exhaustion and, on the other hand, in a way, expresses a desire which rejects work and its corresponding subjectivities. Along with the rejection of work's apotheosis, however, come struggles. People with CFS have both to sustain themselves, something that is becoming increasingly difficult given the systematic assault on welfare provision and the financialisation of life, and to struggle against their stigmatisation of their illness.

In the last chapter, I review the main arguments presented throughout the thesis and try to show how they contribute to the various fields and literatures that influenced and supported the thesis. In that way, the contributions of my study to the biopolitical study of illness as well as to the making of scientific controversies will be demonstrated. I conclude that CFS is a heterogeneous world, a performative and multiple category that eludes standardisation, an illness trapped between biomedicine, psychology and society and that the growing activism of CFS advocacy groups is and will in many ways continue to be a major force in the making and management of this disorder.

Chapter One

The Biopolitics of CFS

The purpose of this chapter is twofold. On the one hand, it serves as a general introduction to the problematics of biopolitics, and, on the other hand, it outlines the areas of enquiry that this thesis will focus on. A close look at CFS will be delayed until chapter 3, and, instead, what is provided in this chapter is a theoretical framework through which CFS can be understood as a scientific, economic, cultural, and juridical complex. After briefly discussing Michel Foucault's notions of biopolitics and biopower, I move on to examine some of the transformations of biopower in contemporary western societies. In the next section, I bring the issue of scientific objectivity into our discussion with the aim to integrate its own problematics with the previous discussions on biopower. At the same time, I offer some thoughts on politics in trying to distance myself from the assumption that it is a separate field of life as well as from governmentality's liberal horizon and from essentialist conceptions of history. Instead, we can understand politics as multiple, as operating in all fields of social life, with no overarching telos, and as a process that disrupts identities and domination. In this way, trying to explore the power relations and desire invested in the social field, the individual and collective processes of subjectification that are involved in making and unmaking of CFS may also provide us with some understanding about the effects these might have for the lives of people with CFS.

Biopower and Biosociality

Biopolitics and biopower are crucial terms in Foucault's genealogies of 'governmentality', i.e. the ways in which power regulates the life of the population, for example through marriage laws. According to Foucault, modernity 'brought life and its mechanisms into the

realm of explicit calculations and made knowledge-power an agent of transformation of human life' (Foucault, 1976/1979: 143).¹ Biological existence is no longer the neutral foundation upon which political existence is superimposed but a matter of intervention and regulation. 'Western man [*sic*] gradually learns what it means to be a living species in a living world, to have a body, conditions of existence, probabilities of life, and individual and collective welfare, forces that could be modified', Foucault (1976/1979: 142) writes. Biopolitics signals a major event of modernity.

Foucault developed the notion of biopolitics to displace, or rather to complement, his earlier formulation of disciplinary power (Foucault, 1975/1979). Sovereign power, the power to seize things, bodies, and ultimately the life of subjects, was displaced by disciplinary power which was invested in the 'social body'. Discipline was a form of power that arises on the basis of diverse practices and power mechanisms such as the precise time schedules of the monasteries, the recording of behaviour and symptoms in hospitals, and experiments in military discipline. These elements came together into a particular form of power that was then reapplied to hospitals, prisons, the military, schools, and factories. For example, the observation of humans in prisons and hospitals gave rise to criminology and medical science. Discipline is an 'abstract machine' that overcodes society's molar lines, as Gilles Deleuze and Félix Guattari would say (Deleuze and Guattari, 1980/2004). It operates by unrelenting surveillance, minute observation of the behaviour of bodies and human desires, a normalising judgement, and penalties and rewards. Discipline is 'centered on the body as machine' (Foucault, 1976/1979: 139); it tries to bring people to conform to the norm by training, *dressage*, rewards and punishments. It defines ideal models and paths of movement and development which should be followed.

Having demonstrated that disciplinary power tends to increase the utilitarian force of the individual body, Foucault tried to develop the idea of a non-disciplinary technology of power

that does not exclude the disciplinary technology but is superimposed on it. This technology of power, which he calls biopower, a 'power over life', was developed in two series: in the beginning, in the direction of 'anatomo-politics' which aimed at introducing practices of discipline and education in individuals, and later on, in the mid-nineteenth century, in the direction of 'biopolitics' which aimed at controlling populations as machines to produce wealth and other individuals. Anatomo-politics individualises and biopolitics massifies. Anatomo-politics is the series 'body-organism-discipline-institution' and biopolitics is the series 'population-biological processes-regulatory mechanisms-State' (Foucault, 2003: 250). Biopower no longer addresses itself to the body but to the 'population' which is conceived as a scientific and political problem (Foucault, 2007). The state undertakes the administration of bodies and labour-power according to the needs of the economy.

The disciplinary methods and techniques had to incorporate lower classes' bodies in society as functional bodies armed with the required social qualities (docility, time discipline, precision, etc.). Capitalism required major transformations in individual and social temporalities. The habit of worrying about efficiency and punctuality was, as Norbert Elias has shown, enforced after a long, multilateral process (Elias, 1987/1992). The 'new universe of disciplined time' described by E.P. Thompson (1967) might be considered a prelude to labour's subsequent biopolitical regulation. In France, for example, 'the worker's record book [that was] 'introduced in 1803 and abolished in 1890, was a prototype for police control over labour', as Bourdieu and Reynaud (2002: 2) observe. The power of institutions such as the family, the education system and the police intersected with each other, producing a tight surveillance of space and control of working time. Timetables, schedules, work rate, break times and the conditions under which work might be interrupted became major concerns for employers. Of course, labour's resistance to factory discipline was very much prevalent, to which the response of capital was often drastic. The closing-off of factories and the setting up

of company stores enforced long working hours or precipitated workers into debt, or starve if they went on strike, thus gaining complete control over them.

Until the mid-nineteenth century, through the direction of poor people's and families' lives (e.g. philanthropy, medicine), the absolutist state attempted mainly to reduce the social cost of the reproduction of the social body, securing at the same time the needed number of workers. The state in its biopolitical phase instead undertook the responsibility of society's reproduction. Social policy became biopolitical and connected tactics and strategies of control by regulating the 'natural' substrate of bodies but also by dismantling and recombining lifeworlds, or by standardising the body which reached its apogee in Taylorism. The newly concentrated populations during a period of industrial revolution and urbanisation and the uncertainty they produced demanded new ways to foster and regulate the circulation of people and goods. Populations as 'natural' processes pertaining to collections of bodies are uncertain, unpredictable and difficult to direct and regulate. They call for quite specific modes of knowledge and intervention if they are to be constantly accessible to techniques of transformation. Statistics (the 'science of the state') provided that accessibility since they formalised what behaviours and characteristics were acceptable (Hacking, 1990; Porter, 1995; Mader, 2007).

The new human sciences like demography, criminology, epidemiology, and sociology and the new administrative institutions associated with the establishment of the nation-state produced a mode of power-knowledge that analysed, defined, and regulated bodies. Biopower intervenes in different processes such as birth, death and illnesses, which are considered to be factors in the reduction of force, in the processes of old age, in accidents, in everything that requires mechanisms of assistance and insurance, or even in the relation between the human species and the environment. Importantly, biopower 'addressed the one problem to which the disciplines could propose no solution: that of the fatigue and death of

the productive individual' (Gougelet, 2008-2010: 63). For example, Louis René Villermé, an ex-army surgeon and friend of Adolphe Quélet (the inventor of 'social physics'), conducted elaborate studies in France on the differential mortality of the rich and poor and the health conditions of the working class, which he published in 1840 (Ackerknecht, 1948). For the first time, it was established that the working class endured very long working days and lived in extreme poverty. Villermé compiled mortality tables by occupation and measured the volume of air per person in factories. These profound findings, however, did not stimulate political action. Villermé warned against the involvement of the state in health reform and suggested that the remoralisation of the poor would eliminate epidemic disease and premature mortality. In his report, he called for a reduction in working time for children only, as he judged that the condition of adult workers had improved. Immediately after the publication of the report, in 1841, the French state passed the first piece of legislation seeking to limit children's working hours.

Biopolitics was an 'indispensable event in the development of capitalism' (Foucault, 1976/1979: 43). 'Society's control over individuals was accomplished not only through consciousness or ideology but also in the body and with the body. For capitalist society, it was biopolitics, the biological, the corporal, that mattered more than anything else', Foucault (1974/2001: 137) writes. Capitalism was not patiently waiting for biopolitics, but biopolitics became capitalism's necessary and sufficient condition. Biopolitics begins at the moment *economy* (the government of family) and *politics* (the government of polis) intersect and form political economy. Biopower was capable of optimising human capacities and life without making them more difficult to govern. Foucault asserts that biopower does not intervene in a therapeutic way nor does it seek to individualise and modify a given person but instead functions at the level of generality with the aim to identify risk groups and factors (Foucault, 2003: 246). Security-type normalisation, 'normalisation in a strict sense' (Foucault, 2007:

63), regulates a population on the basis of purely statistical techniques. Security does not so much prohibit or prescribe, though it possibly might make use of ‘some instruments of prescription and prohibition’ (Foucault, 2007: 47), but ‘lets things happen’. In contrast to discipline, which subjects human bodies to an external norm (*normation*), biopower ‘governs’ populations by starting from their inner norms (*normalisation*). Biopower tries to prevent the emergence of physical or psychological anomalies by gathering and collating statistical knowledge which identifies ‘risks’ within given populations (Castel, 1991). There is a move from the disciplines that were based on enclosure and the dyadic system of the observer and the observed, e.g. the doctor and the patient, to a system that functions statistically. Biopolitical techniques tend to create a setting in which the population can optimally regulate itself. Biopower incites, supervises, and increases living forces; normalisation might no longer be the way power tries to regulate the population (Lemke, 2001). This type of power organises the conditions of development of a population: the health system, the pension system, and the habitat.

To summarise what has been discussed thus far, the eighteenth and nineteenth centuries saw the emergence of scientific disciplines that focus on the body as machine, seek to maximise its productivity and render it ‘docile’, and institutions that intervene and regulate populations rather than individuals.

The concept of biopolitics is complex and multi-layered (Lemke, 2011). It denotes neither the ‘politicisation of life’ nor the ‘biologisation of politics’ but rather the inseparability of ‘life’ and ‘politics’. ‘Life’ and ‘politics’ are not independent but coexist in a dynamic relationship. The ‘and’ conjunction is more important than the *relata*; it is prior to the ‘is’, as Deleuze would say. As the biological and the social interpenetrate each other in multiple, complex, and historically bounded ways (Cromby *et al.*, 2011: 224), so do life and politics. Biopolitics ‘makes visible the always contingent, always precarious difference between

politics and life, culture and nature, between the realm of the intangible and the unquestioned' (Lemke, 2011: 31). The border between life and politics is unstable and that is why both terms have to be examined in their relationality and historicity.² For instance, the state racism of National Socialism was not simply biopolitical in the sense that medical discourses transformed the anthropological and political underpinnings of 'race', as Foucault believed, but was instead very much based on a metaphysical tradition of 'race' (Forti, 2006).³ Also, we should not consider the emergence of biopolitics as a chronological succession of modes of power since different modes of power co-exist (Foucault, 1980b/1991: 264; Brown, 1995; Revel, 2009). Sovereignty, discipline and control are not mutually exclusive but interwoven together within the social fabric of everyday life (Rose, 1999: 238). The state is no longer the sole agent of control but individuals and communities themselves participate in their own self-monitoring. The state is, of course, not some reified notion and should be analysed in the complexity of its actions (Saminmian-Darash, 2011: 285-289). These practices of self-monitoring are part of the instrumentalisation of freedom and the responsabilisation through which individuals are made in charge of their own competence, security, and 'well-being'. Today, it is less a question of the internalisation of social norms by subjects but the modulation of 'moods, capacities, affects, potentialities statistically assembled in genetic codes, identification numbers, rating profiles, preference listings, risk statuses' (Clough, 2004: 14).

Moreover, it should be emphasised that biopower is not as benevolent as is at times implied. It is fundamentally ambivalent. While some bodies are optimised, other bodies, which threaten the viability of the social body or which are not easily 'restorable' are left to deteriorate. Biopower exercises the right to 'make live and let die', Foucault famously noted. Biopower is paradoxical because it strives for security and the amelioration of the vicissitudes of life and at the same time threatens it with previously inconceivable means of

destruction. Improvements in health and quality of life go side by side with surveillance and medical discrimination. While some human (and nonhuman) lives are protected and enhanced, others are destroyed and damaged. Undermedicalisation is not mutually exclusive with overmedicalisation. Biomedicalisation is multifariously stratified, including both inclusionary and exclusionary processes and effects (Clarke *et al.*, 2010). To the question of how biopower can be resisted no abstract answer can be given but only concrete answers from particular groups in specific sites of struggle.

Contemporary medicine is very different from what it used to be in the past (Nettleton, 2004; Clarke *et al.*, 2010). Epstein (2008: 502) provides a summary of contemporary biomedicine's distinctive characteristics: innovations in molecular biology, genomics, and bioinformatics; new medical technologies; intensification of clinical research practices and huge increases in public and private funding for biomedical research; growing rationalisation in medicine expressed through the dominance of evidence-based medicine (EBM); privatisation of health care; and, lastly, rapid expansion of a global pharmaceutical industry constantly searching for new markets and engaging in new ways with consumers. Importantly, Foucault's concept of biopolitics, which was based on the notion of an integral body, can no longer hold (Lemke, 2011: 94; see also Martin 1992/1997). The biosciences and biotechnology dismantle and recombine the body. Biopolitics no longer deals with bodies only but intervenes instead in the shaping of life itself. It is less a question of separating ill and healthy populations than the optimisation of our corporeal existence increasingly at a molecular level (Rose, 2007a; cf. Raman and Tutton, 2010). Biopolitics, or 'vital politics' as Nikolas Rose calls it, may be more 'concerned with our growing capacities to control, manage, engineer, reshape and modulate the very vital capacities of human beings as living creatures' (Rose, 2007a: 3). Biomedical advances such as genetic screening and xenotransplantation are rapidly transforming our material and existential horizons.

Neurochemistry and neurobiology are gaining importance at the expense of the mind and psychology. As we gain access to the brain and its internal processes, our perception of ourselves changes. The neurosciences raise many serious social, ethical, and philosophical problems (Meloni, 2011). Social identities are increasingly defined through biology. New relations between politics, identity and biology are emerging. New biopolitical technologies are transferred into regimes of governmentality and the production of subjectivities. Carlos Novas and Nikolas Rose observe a ‘general ‘somaticization’ of personhood in an array of practices and styles of thought, from techniques of bodily modification to the rise of corporealism in social and feminist theory and philosophy’ (Novas and Rose, 2000: 491). Indeed, there has recently been an interesting interface between the biological sciences and the humanities and the social sciences which, however, raises its own problems as there is often an uncritical borrowing of biological concepts from the humanities and the social sciences (Papoulias and Callard, 2010; Leys, 2011). In any case, these attempts try to read the body as both socialised and socially embodied, and not only as an effect produced in and through discourse. For example, the brain’s materiality is as much biological as it is social; the choice between biology and culture is deceptive and unproductive. The distinction between nature and culture has become blurred (Latour, 1991/1993; Rheinberger, 2000; Fausto-Sterling, 2005; Fox-Keller, 2008).⁴

Furthermore, the management of chronic disease is no longer confined in the clinic – though it would be wrong to speak of the clinic’s disappearance (Bharadwaj, 2006) – but is instead diffused across the numerous patterns of individual behaviour enacted and reproduced day after day, which are themselves both constrained and enabled by broader societal factors (Wasserman and Hinote, 2011: 42). Wasserman and Hinote note that the tremendous uncertainty that surrounds chronic illnesses, that is the variety of conflicting evidence about the success of each treatment or drug, leads to individuation among those who are

nonetheless forced to make choices about what health is and how to achieve it. There is a plethora of often opposing ‘lifestyle’ practices that cannot be convincingly disconfirmed by biomedicine. The epidemiological shift moves away from infectious diseases (i.e. germ theory) towards chronic, sometimes manageable but rarely curable, illnesses like diabetes. While population analyses yield clear trends, from an individual’s perspective chronic illness risks are invisible and unpredictable. The new epidemiological model tends to be characterised by a policy emphasis on ‘health promotion’ and individualistic concerns with notions of behaviour, education and ‘lifestyle’ are more prominent within this discourse, instead of focusing on the social and structural factors leading to illness and disability (Nettleton, 1996). The burden for keeping one’s self healthy has, to a significant extent, been transferred back to individuals.

Biopolitics is no longer mainly state-led but this does not mean that it does not still work on a molar level, as governmentality literature, which focuses too narrowly on individualisation, seems to suggest (Frandsen and Triantafillou, 2011). Biopolitics is a concern of multiple actors mobilising around health, medicine and the promises of science. Patients and concerned groups take an active part, claim their own responsibility, and try to firmly establish their citizenship. To satisfy their aims, they create and draw on usually limited funds, establish organisational structures and seek to influence the political and scientific agenda. Patients’ organisations fight against restrictions in biomedical technologies and knowledge. At the same time, as we have already alluded, our biology is increasingly becoming artificial, something that the anthropologist Paul Rabinow (1992/1996) has described as ‘biosociality’. Biological life is no longer viewed as an immutable destiny but rather as a flexible object of epistemic planning and administration – though Rabinow (2008) now appears more cautious about his original thesis. Rabinow and others (e.g. Rabinow, 1999; Gibbon and Novas, 2008) have shown how new forms of biosociality are being assembled

around the proliferating categories of corporeal vulnerability, somatic suffering, and genetic risk. Actual and potential patients have become ‘passionately curious about their health, happiness and freedom’ (Rabinow, 1994: 63). While there is an imperative ‘to find biological, but above all genetic, underpinnings for all things human’ (Hacking, 2006a: 81) and while concerns or fears of new forms of biologism and eugenics have been raised (Habermas, 2003; Roberts, 2008-2010; cf. Skinner, 2006), these concerns and fears are overstated or, much more, misguided. It is no longer a matter of finding some transcendent essence trapped in the body, the ‘soul’ or the ‘gene’ (Rabinow, 1999). This does not mean we are becoming ‘post-human’; we have never been only human (Rose, 2007a: 80; Pyyhtinen and Tamminen, 2011). Genetics’ critics fail ‘to recognize the creative impact of the new technologies [such as xenotransplantation and genetic screening] in transforming our very categories of thought’ (Greco, 2004: 7). Epigenetics and epigenomics are radically transforming old ideas about genetic determinism, showing that gene expression is a tremendously complex process. The genome and the milieu, the genotype and phenotype, are in a dynamic relationship. The very distinction between the organism and the environment has in fact become problematic.

A host of notions similar to biosociality have been developed, all trying to capture these radical changes of biology and society. Petryna (2002) has developed the notion of ‘biocitizenship’ to describe the individual and collective welfare claims made by the biologically damaged population of Chernobyl, as well as the political exploitation of those injuries in Ukrainian nationalism. Similarly, Biehl (2004) speaks of ‘biomedical’ citizenship in trying to define AIDS patients in Brazil who submit themselves to state health surveillance, as opposed to people on the margins who die without leaving a trace in the official statistics.⁵ Lastly, Rose and Novas (2005) use the term ‘biological citizenship’ to describe the same emerging connections between biology and self-identity. Biological

citizenship signifies a radical departure from the nationally located model of social citizenship predominant in western Europe since the mid-twentieth century. Rose and Novas argue that contemporary biotechnology makes possible new ideas of what it means to be a human being and a citizen. Biological beliefs such as 'race', blood line, degeneracy, intelligence and so on, were important for the politics of the two previous centuries, but these were rarely explored through citizenship. So, while people may still view themselves as parts of families and lineages, communities, 'races', and as a species, our age differs significantly from the age of eugenics, Rose and Novas argue. The relation between biology and human worth equally differs from that age: selective abortion, pre-implantation, genetic diagnosis and embryo selection, or hopes that genes of particular groups have different 'biovalue' (Waldby, 2000) testify to this. According to Novas and Rose (2000), biological citizenship is both individualising, in that individuals have to know their 'somatic individuality', and collectivising because individuals increasingly form social collectivities around corporeal vulnerability and genetic risk. As has already been mentioned, this creates new forms of activism and contestation around recognition, access to knowledge and claims to expertise, and reshapes the way in which persons are understood and managed by 'political authorities, medical personnel, legal and penal professionals, potential employers or insurance companies' (Rose and Novas, 2005: 445). A kind of biomedical 'care of the self' is now practiced, which involves taking personal responsibility for one's condition by immersion in and activist deployment of a wide range of documents, not only medical, but those pertaining to services, legal instruments, the details of insurance company contracts and claims forms, and the documentary apparatuses of that are required to combat stigma, including those of popular culture and mass media. The concept of biological citizenship also implicates a 'bioethics' which takes the form of practices of ethical self-formation guided by norms of behaviour governing proper attention to and management of one's condition, both with

respect to oneself and to one's relations with others. It involves 'a disciplining of calculations and choices regarding diet, lifestyle and habits in the name of the maximisation of health, and in the light of knowledge of [one's] present and future biological makeup' (Rose and Novas, 2005: 451). At the same time, pharmaceutical companies engage in 'direct-to-consumer-advertising' (DTCA) or use television advertisements and the Internet for the benefits of different brands of psychiatric (or other) drugs. The Internet's role in the formation and spread of these new socialities (e.g. Levina, 2010) as well as the potential exploitation of patients' agony and hopes by pharmaceutical companies (Novas, 2006) should be stressed.

The body has been dismantled and is increasingly perceived at a molecular level. Health care has been to a significant extent corporatised and privatised and biopower mainly uses statistical means to gather knowledge about and regulate the population. Identities and forms of sociality based on biology are emerging, and patients and concerned groups form organisations and mobilise resources and facts in trying to influence the political and scientific agenda. It is exactly the fight over what constitutes good science and for whom to which we now turn our attention. The issue of scientific objectivity will be crucial to the analysis of CFS later in the thesis because CFS constitutes a scientific object that defies a clear objective status.

The Politics of Scientific Objectivity

Truth, or objectivity, has its own 'conditions of possibility', to put it in Kantian terms. According to Foucault, truth is produced through discourses and *dispositifs* and at the same time constitutes the conditions of possibility of its own critique. Truth has its own historical and social conditions of possibility. While Foucault speaks of the mutual constitution of the object and the subject, of the indistinction between the material and the ideal, and while he breaks with any metaphysical understanding of truth and with relativism, as truth is just the

universalisation of localities, of local events (although universality is, in reality, always out of reach), he does not go far enough with the question of materiality and does not resolve the relationship between discursive and non-discursive practices – which is not say that he was in favour of some sort of linguistic constructionism, as it is, unfortunately, often assumed (Heckman, 2009). Therefore, we have to follow a different but, I think, complementary path; a path that avoids both biological and discursive forms of reductionism.

Scientific objectivity is a thorny question for social sciences. As is known, social sciences are usually trapped between social constructionism and objectivism. This creates various sorts of problems that we cannot discuss here. What is of importance for our argument is that objectivity is neither monolithic nor immutable. As the prominent historian of science Lorraine Daston put it, objectivity should not be regarded as a ‘trans-historical given’ (Daston, 1992: 598). Our current usage of objectivity ‘is compounded of several meanings – metaphysical, methodological and moral – and each meaning has a distinct history, as well as a history of fusion within what now counts as a single concept of ‘objectivity’’ (Daston, 1992: 597). For instance, our current understanding of the scientist as detached, impartial, even self-effacing, is a particular kind of objectivity, which Daston calls ‘aperspectival objectivity’. Again, the notion of objectivity raises very complicated questions that we cannot address here (see Douglas, 2004; Arabatzis, 2011).

Although objectivity falls into the realm of epistemology, I want to assert that objectivity is not an epistemological question but an ontological one. Objectivity is not a matter of representation but of intervention. There is no object ‘in itself’; objects do not pre-exist representation as there is no ontological distinction between the object and representation (Woolgar, 1988). Actor-network-theory (ANT), emblematic of the so-called ‘ontological turn’ in social sciences, in a sense, builds on Gaston Bachelard’s materialism which had already sensed the ‘end’ of metaphysics with the advent of quantum physics (see de

Beistegui, 2004: Ch. 6). Quantum physics paved the way for a more fluid, performative ontology (Barad, 2003). Even for scientific objects that might be considered indisputable, 'reality is a matter of degree' (Daston, 2000: 1). With ANT, objects are 'decentred' and nonhuman entities acquire agency. Socio-material entities, be they viruses, measuring devices, journals or institutions, interact with each other and play an active role in the production of scientific objectivity. Agency, and power, is a relational effect; all actors are at the same time enacting and enacted forces, although not all actors have the same power to influence others. There is no 'inevitability of scientific findings' (Star, 1991: 31) but they always emerge in a historically bounded 'style of thought' (Fleck, 1935/1979). Facts are temporary results of long complex social processes, temporary and localised stabilisations of epistemic closures. The universality of a scientific 'discovery' depends on the ability of facts to travel, to act 'at a distance', and its strength is its ability to withstand deconstruction. Objectivity is a matter of protocols, procedures and metrics, a matter of categories, definitions and standards, something achieved when some voices can speak with greater volume and authority than others, standards whose 'objectivity, universality, and optimality' (Timmermans and Epstein, 2010: 74) have emerged after long-lasting battles between various actors in diverse sociotechnical networks. However, it should be emphasised that much more than individual laboratories and professional journals are at stake here. In technoscientific controversies, construction takes place through 'law, money, political influence, enforcement capability, regulatory authority, media access, the power to make and unmake institutions' (Jasanoff, 2011: 5).

The relevance of this understanding of objects and the world for conceiving CFS lies with the changing conception of disease. In contrast to essentialist conceptions of disease (disease understood as natural kind), still to be found in medical sociology and biopolitical studies, diseases are technoscientific arrangements enacted in particular, historically situated

practices, performed in day-to-day sociomaterial practices (Mol, 2002; Latour, 2004a; Styhre, 2009: 28). Diseases not only die, are superseded, and fall into disrepute, but change over time (Bowker and Star, 2000: 75). Here it is very important to note that CFS, as with any other disease, cannot be treated as an ideological or cultural construct. The dichotomy between science, on the one hand, and culture, politics and so on, on the other hand, is untenable, as Science and Technology Studies (STS) have demonstrated. Demonstrating the construction or making of a disease category ‘does not make it invalid, unreal, or unscientific per se’ (Knaapen and Weisz, 2007: 121).

Now, as already implied, contrary to claims of ‘medicalisation’ or ‘objectification’ of patients, we know that patients often actively participate in shaping biomedicine (Epstein, 1995; 1997; Rabinow, 1999; Callon and Rabeharisoa, 2003a,b; Rabeharisoa and Callon, 2002; Rabeharisoa, 2003; 2006). The paradigmatic case of health activism is that of HIV/AIDS activists becoming lay-experts and re-defining the protocols of clinical trials (Epstein, 1995; 1997). Thus, as Papadopoulos puts it, objectivity refers ‘to the efficacy of knowledge practices to transform the materiality of existence’ as

‘[d]esires, hopes and investments in the objects under study – be they individuals, social groups, animals or things – mingle with the constraints these objects impose on the researcher, as well as interest groups, ethics and beliefs, affected social actors, and state institutions’ (Papadopoulos, 2011a: 4).

Instead of objectivity, we might better speak of ‘regions of objectivity’, Papadopoulos adds. That is because all these forces interact with one another and transform the ontological composition of a ‘region of objectivity’. Reality’s ‘conditions of possibilities are not given’ (Mol, 1999: 74) and knowledge is produced through the intersection of different forces

interacting in the world. It makes no sense to speak of a pre-discursive reality which can be viewed from many perspectives. There are multiple realities arising from heterogeneous discursive and material relations, and their enactment excludes others realities. The enactment or exclusion of certain realities is a fundamentally political question.

Fuller (2005: 76) sarcastically argues that '[n]owadays just about everything is "political" *except* the practices conventionally associated with politics'. While there might be some truth in that comment, it is not unproblematic. First of all, is 'politics' itself a unified and incontestable category? Moreover, to stay within the boundaries of science and medicine, it might be argued that there is a (not always clear) line separating the mere study of science, technology, and medicine without any emancipatory effects, from the emancipatory politicisation of these domains, like with the case of HIV/AIDS activism which managed to change the direction and focus of scientific research on HIV/AIDS (Epstein, 1995; 1997). On the contrary, while Bruno Latour – being prominent among the social theorists and social scientists who have problematised science's supposed purity – turns our attention to the nexus epistemology and politics form and to how 'matters of fact' should be 'matters of concern' (Latour, 2004b) involving hybrid networks of humans and nonhumans, among other problems (for a political critique of Latour's work, see Noys, 2012: Ch. 3), he does not address the issue of how the categories of 'race', ethnicity, class, and sex/gender emerge and constitute subjects (Watson, 2011). Again, the 'and', this time between 'politics' and 'science', is more important.

While the discourse of the 'objectification' of patients both as a theoretical and practical problem is based on a humanist and ultimately narrow understanding of the body, medicine and technology, biopower's effects are of great importance. Questions around the optimisation of bodily capacities and the modification of the body, as has already been mentioned, cannot be answered abstractly as they involve concrete problems and struggles.

For example, the question of whether the deaf community should wear hearing aids so that they are supposedly ‘normal’ (something they oppose) is an issue that concerns a specific group of people (Friedner, 2010). The conception of a pure body, unaffected by technology and science is indeed problematic but the optimisation and modification of bodily parts and behaviours through technology raises problems around the notions of illness, disability, and ‘normality’ (Lupton and Seymour, 2000).

CFS subjects exist in a complex web of power relations. Health is both a matter of personal worth and political order. In an age of technoscientific fantasies of expanded capacities, improved bodies and selves, but also of ‘financial crises’, being chronically fatigued goes against dominant bodily ideals. Yet, CFS subjects’ desire to experiment with medical treatments that might improve their state of health, their ways of affirming life, are not for us to dismiss. What kind of demands people with CFS might raise and what kinds of solutions they might come up with is not possible to know nor is it for us to evaluate. That is because, to follow Stephenson and Kippax (2006: 410), the role of social research is not to make moralising judgments on the ways CFS people address their ‘problems’ but to understand how these inform all participants in this scientific controversy.

The Multiplicity of Politics

What is usually referred to as politics is, to borrow an expression from Saint-Simon, the ‘administration of things’. Viewed from this angle, politics is the actions of parliaments, bureaucracies, and courts. On the other hand, though not really separate from it, politics may be considered as what centres on issues of class, ‘race’, sex/gender, ethnicity, and nationality, and their inter-articulation. The combination of these two conceptions of politics is what Jacques Rancière (1995/1999) names ‘the police’, a near-homonym of polis denoting any order of social hierarchy. Thus, politics is a matter of policy-making and of cultural and

economic arrangements.⁶ Society is the configuration of divisions in groups, modes of action, places, occupations, and modes of being, and police keeps everything in its place (Rancière, 2001). Politics as policing has to do with what Rancière (2004) calls ‘the distribution of the sensible’. The distribution or partition of the sensible defines the modes of perception in which politics as police must operate, while police has the ability to continually deny the contingency of its partition of the sensible. It establishes an order of distribution and correspondence and determines who has a voice and who is voiceless, who is legitimate and who is illegitimate, who is reasonable and who is unreasonable. For Rancière, politics only happens when those not ‘counted’ in a given ‘count’ engage in an active disidentification with these regimes. Contrary to political philosophy, according to Rancière’s particular understanding of the term, politics cannot be eliminated as it ‘exists simply because no social order is based on nature, no divine law regulates human society’ (Rancière, 1995/1999: 16). Some commentators have discerned a purely formalist conception of politics and a somewhat Manichean division between the police and politics in Rancière’s writings (in some cases for their own political-philosophical purposes), however Rancière does not take politics to be ultimately separate from and in utter opposition to all police orders and in fact rejects the very idea of pure politics (Chambers, 2011: 308-309). Thus, while politics ‘has no “proper” object’ (Rancière, 1995/1999: 4), it is precisely what makes visible what is invisible and in this way undermines the purity of the given and the idea that the other can ever be fully incorporated into the social order.

Rancière is close to Foucault who provocatively claimed: ‘Nothing is fundamental. That is what is interesting in the analysis of society’ (Foucault, 1980a/1996: 341; see also Oksala, 2010). Rancière, the antiphilosopher and archivist of popular struggles, might well be considered one of Foucault’s greatest ‘followers’.⁷ What Foucault and Rancière share first and foremost is the denaturalisation and politicisation of ontology, the idea that reality, the

ontological order of things, is itself the outcome of political struggle.⁸ A second commonality between Foucault and Rancière, though with some reservations, can be found in the notion of police which is close to Foucault's notion of governmentality. Rancière shares Foucault's concern with regimes of visibility and intelligibility, with modes of doing, saying, and seeing. Politics is the play of freedom and equality (May, 2007), although the goal of politics is not freedom. Rancière is also close to Foucault's Nietzschean understanding of freedom. Freedom corresponds to the structure of constraints (Couzens Hoy, 2004: 1). The motivation for resistance emerges when freedom is encountering constraints. Constraints cannot be absolute and resistance would be impossible unless some degree of freedom remained. Of course, resistance can also be domination's resistance to emancipatory efforts. Freedom is not a metaphysical condition, it exists when we act, think, and experience differently, when we change our selves (although not at will) and the world from which we are inseparable (May, 2005). Freedom, the 'power to', is not attained through laws, rights, and rules; this kind of freedom should not be conflated with the 'metaphysics of separation' of liberal freedom (Brown, 1995: 6). Individual and collective freedom are inseparable, something that Foucault, with his emphasis on the ethics of the self (McNay, 2009) and, at least in his writings, his disinterest in social movements, seems to have ignored.

Freedom and politics might, on the other hand, be considered as 'inhuman'. That is what Deleuze and Guattari (1980/2004) seem to enigmatically be suggesting when they write: 'politics precedes being'. In contrast to Foucault and Rancière (and others), Deleuze does not abandon ontology. Deleuze's metaphysics is peculiar as it has nothing in common with what is usually understood as metaphysics. Ontology cannot tell us what there is. 'Life' is without primary qualities, without pre-given subjects or objects (Thoburn, 2003). What exists, at the most elementary level, are 'things' but only as they are constituted in specific, diverse, and mutable relations of force (the similarities of this philosophy with ANT have been noted).

Politics, for Deleuze and Guattari, is the process whereby matter is cut and assembled by a particular series of forces. Politics may be conceived as ‘an art that affirms the variation and creation of life’ (Thoburn, 2003: 5). What the world is to become is an undetermined project. Politics is the politicisation of the totality of social relations. It is the process that frees stratified forms of identity and equivalence. It is a creative and inventive process that disrupts identities, languages, practices, oppressions and exploitations. Politics takes place in art, science, everywhere. Politics is ‘minor’. Politics is the continual problematisation of any politics that promises the end of politics and of the novelty of ‘life’. Politics is, ultimately, the ‘politics of life’ (Bergen, 2010).⁹

Thus, politics is multiple. It does not have a place or *telos*. It is a disruptive process which challenges dominant discourses, practices, and identities. In this way, it goes against biopower’s normative power and understandings of the human, and it is from this angle that the formation of scientific objectivity, the contestation of experts’ power to define the bodies and lives of people with CFS, is shown to be irrevocably and fundamentally political. Intentionally or not, and with contradictory effects, people with CFS resist or demand their medicalisation, create spaces outside medicine, and transform their relationships with themselves, with the public and private institutions that regulate their lives.

Research Questions

In order to examine some of these intricacies, the intricacies of the inter-articulation of institutions, discourses, and technologies, but also of the desires, resistance, and ambivalence invested in CFS, this thesis will explore the following questions:

1. How did fatigue and CFS emerge as scientific-medical categories? What were the truth effects of those emergences?
2. What scientific experts and disciplines have the authority to tell the truth about the CFS population and how do scientists studying fatigue and CFS construct different models of fatigue and CFS?
3. What types of intervention into the CFS population get legitimised and in what ways? What kinds of bodies and subjects do the discourses and practices of scientists studying fatigue and CFS construct?
4. What are the forms of resistance against the normalisation and biomedicalisation of the experience of fatigue? Do CFS people, instead of merely opposing biomedicine, try to appropriate it for their own aims?
5. How do CFS subjects relate to recent transformations of social provision and to work? Do the medical discourses of fatigue provide space for the rejection, or critique, of productivism and labour?

These types of questions will provide us the necessary constraints through which we can think about the 'origins', evolution, and socio-political implications of fatigue and CFS.

Chapter Two

Researching CFS

Genealogy

After Nietzsche (1887) the notion of genealogy has taken on a different meaning. Nietzsche's thesis is that the 'subject' is a convenient grammatical fiction which gives a deceptive sense of agency. Instead of some unifying centre for the self, there is a multitude of contradictory and competing unconscious impulses that constantly struggle to overcome one another (Smith, 2007: 69-71). Nietzsche (1887) criticised the idea of an eternal and ahistorical subject by showing that the origin of the 'moral prejudices' of his time, i.e. contemporary accepted ideas about good and evil, lay in past struggles. For Nietzsche, the human being is a contingent product of history and the 'subject' is a bundle of contradictory drives. Genealogy was later on adopted by Foucault (1971/1977; see also 1980b/1991) who sought to expose the supposed unavoidable character of concepts, institutions and practices which structure our lives as historically contingent.

For Nietzsche (1887: n.p.), the

'cause of the origin of a thing and its final utility, actual employment, and place in a system of purposes lie worlds apart; ... something existing, having somehow come-into-being, is always again and again appropriated by a power superior to it and interpreted from new viewpoints, reorganized and redirected toward a new use'.

Any interpretation of a thing or an event is one of the forces that change it (Thoburn, 2003). Our interpretations of things unavoidably produce some realities and exclude others. Realities are enacted and contested. As there is no eternal truth, there is no immutable reality either.

Foucault does not deny truth as is often assumed; rather, he problematises truth as an ideal and claims that it is worldly, historical. According to Foucault, truth is produced through discourses and *dispositifs*. But, as argued in the previous chapter, truth is not an epistemological question as knowledge is produced through the intersection of different forces interacting in the world. It is the enactment of materially and discursively heterogeneous relations that produce the world.

Instead of studying the conditions of acceptability for true interpretations on the level of the discursive rules of formation, as in his 'archaeological' period, Foucault embraced Nietzsche's thesis that things only have the meaning that the dominant interpretation gives them. According to Foucault, power relations emerge within a given field of knowledge which is itself constituted by power relations (Foucault, 1975/1979: 200-201). Genealogy goes against the essentialist search for origins which has traditionally dominated history. Genealogy wants to bring 'a breach of self-evidence. It means making visible a singularity at places where there is a temptation to invoke a historical constraint, an immediate anthropological trait' (Foucault, 1980a/1996: 277). Rather than searching for origins, the genealogist sets out to study 'numberless beginnings' (Foucault, 1971/1977: 145). Permeated by theology or rationalism, traditional history aims at dissolving the singular event into an ideal permanence as a teleological progress. *Wirkliche Historie* (real history), however, deals with uniqueness in its intense manifestations. The origin is not sought; rather an analysis of descent is carried out on a 'profusion of lost events [that] permits the discovery of unique aspects of concepts, traits, and the events through which they were formed' (Foucault, 1971/1977: 146). Thus, genealogy tries to separate the various forces and their effects on each other. It shows that the effects of the struggles between these forces is the emergence of a form of life that is durable and uniform and can prevail in the perpetual struggle against other forces.

Traditional history ‘pretends to base its judgments on an apocalyptic objectivity’ (Foucault, 1971/1977: 152) while, for Foucault, genealogy does not assume that words keep their meaning, that desires point in a single direction, or that ideas retain their logic. Through time, words, practices, institutions take new significances and serve different, and even opposed, purposes. According to genealogy, there is only chance, just a ‘profusion of tangled events’ (Foucault, 1971/1977: 155). Whilst Foucault does not deny the importance of economic forces and class struggle, he does not accept the notion of a primary causal necessity. Instead of linear cause-effect determinations, Foucault opts for contingency and complex causality that goes against what he calls ‘total history’ (Foucault, 1969/1972: 9-10). Genealogy is neither a writing of the past in terms of the present, nor a search in the past for the kernel of some present reality which is then presented as if in its evolved form. Rather, it is a meticulous history of how the present came to be and seeks to reveal new possibilities by illustrating past and present struggles over the ownership of truth.

The appreciation of this approach in the study of history is important in my study of fatigue and CFS as what will be sought is not a definitive account of the emergence of fatigue and CFS but an attempt to account for the creativity of history, the play of forces and chance that have determined our present understandings of fatigue and of CFS. It will try to bring to the surface past struggles, subjugated knowledge and desires. The search for the origins of fatigue and CFS has to be replaced by sensitivity to the multiple beginnings, to the multiple forces that have brought them into history. The need for representing, for recovering what ‘really’ happened, has to be replaced by genealogical interventions into history with the aim to leave room for different understandings of the body and fatigue.

The result of my enquiry into fatigue and CFS will help us understand not only their emergence but also their development through time because, as already mentioned, the discursive and non-discursive practices that have brought them to light, as well as the

institutions that try to control and regulate them, change through time. What has to be emphasised is the fact that fatigue and CFS are not immutable entities. Not only might the significance of fatigue and CFS change, often serving different purposes, but both should be regarded as historical singularities, categories materially and discursively performed in different ways in different historical periods. Therefore, fatigue and CFS's discursive presence in different historical moments should not distract us from the fact that we are not speaking about the same entities.

Research Design

In order to approach CFS genealogically I had to collect a broad variety of data that could inform a complex, non-linear picture of CFS. I relied on a combination of secondary and primary data. Throughout the whole period of my research, I immersed myself in gathering a vast number of different kinds of textual materials: medical and psychiatric journals and monographs, research publications, policy documents, self-help books, CFS organisations' magazines and newsletters, publications of CFS patients groups and activists, illness narratives and social studies of CFS, and publications in the popular media (i.e. newspapers, Internet sources, and films) about CFS. In terms of primary data, I conducted interviews with individuals who are currently diagnosed with CFS and gathered material from one CFS blog. I collected data by observing the discussion groups of various UK CFS online communities and virtual environments, although these communities are not restricted by geographical barriers due to the Internet's transnational character.

Besides the need to find archives and historical studies for my genealogy of fatigue and CFS, due to the significant complexity of CFS as a medical category, assembling all the diverse and disparate materials mentioned above was, as I progressively realised, a necessity. The complexity and uncertainty over what CFS is and how it should be best managed, is what

forced me to gather a significant amount of data from the multitude of scientific disciplines and social authorities try to define and regulate it.

I strongly agree with Rabeharisoa (2008b: 227) when she says that biopolitics should be analysed 'not only as a concept, but also as an empirical object', as have for example studies like Epstein's (2007) examination of the 'inclusion-and-difference paradigm' in contemporary US medical research and Klawiter's (2008) research of US breast-cancer activism. Epstein, for instance, drew data from a remarkable number of reports, medical research projects and clinical trials, media reports, laws, and numerous interviews with researchers, health officials, policy-makers and representatives of advocacy groups.

My own project was limited by the fact that I was not able to participate in the meetings CFS patients have among themselves or with therapists, by not being able to reach as many CFS patients as I wished in order to interview them (as I discuss later on). By collecting as many publications and as much information from CFS patients' organisations and activists and from medical researchers, health-officials, and policy-makers as possible, I tried to compensate for these limitations. In addition, by observing and gathering data from one CFS discussion group, I tried to enhance my understanding of the experiential dimension of CFS patients.

Primary Empirical Study

Interviews are mutually constructed social events in which both the interviewees and interviewer determine interactions and in which their relationship is perceived as fluid and dynamic. Contrary to the positivist understanding of interviews which considers them 'unscientific' and 'subjective' and 'biased', qualitative interviews try to 'obtain description of the life world of the interviewee with respect to the meaning of the described phenomena' (Kvale, 1996: 5).

Interviews are one of the few research instruments that are sufficiently complex to comprehend and learn about human existence (Lave and Kvale, 1995). In-depth interviews allow people to describe their own lifeworld, their opinions and acts, in their own words. On the other hand, semi-structured interviews, such as the ones I conducted, are similar to in-depth interviews but more formal and structured. A semi-structured interview ‘comes close to an everyday conversation, but as a professional interview, it has a purpose and involves a specific approach and technique; [...] it is neither an open everyday conversation nor a closed questionnaire’ (Kvale and Brinkmann, 2009: 27). However, as Kvale and Brinkmann (2009: 27) add, ‘[t]echnically the qualitative research interview is semi-structured: It is neither an open conversation nor a highly structured questionnaire’.

Instead of determining the relation between phenomena and categories already isolated and defined prior to the research, the researcher conducting a qualitative interview isolates and defines them during the process of the research in order to comprehend and learn. Interviews may not lead to ‘objective’ data but they capture many of the interviewees’ views on something. This is something I began to realise as my interviews progressed. My interviewees often provided me inaccurate information and contradictory points of view but that helped me to better appreciate how they try to assimilate diverse and contradictory scientific facts about CFS, how they try to make sense of them, and how they deal with them and the social authorities that try to regulate them. The aim of interviews is, therefore, the interpretation of meaningful relations. Interviews are (or should be) characterised by a methodological awareness of question forms, a focus on the dynamics of interaction between the interviewer and the interviewee, and a critical attention to what is said (Kvale, 1996). Interviews provide flexibility, interactive depth and the potential for the scope of enquiry and are one of the best methods to give voice to groups or individuals which have remained predominantly silent.

My semi-structured interviews were designed according to Kvale (1996), consisting of three distinct phases: the briefing and warm up phase at the beginning, the main phase, and the debriefing phase at the end. The briefing and debriefing phases (of the two interviews that were actually recorded) were not tape-recorded. In the warm up phase, I defined the subject to the interviewees, told them about the use of the tape-recorder, and asked them if they had any questions before we started the interview. In the main phase, answers to the research questions were sought. CFS patients were asked about how and when they were diagnosed, their main symptoms and how they try to deal with them, their opinions about CFS therapies, about how they view themselves, about the relations to their previous or current jobs, and other issues and were also invited to comment on various issues such as the current medical research and clinical trials on CFS. During the debriefing phase, they were given the opportunity to comment both on the content and the procedure of the interview.

There are, of course, limitations in using interviews as a research method, as in every other method. The accuracy of the data produced by interviews has been criticised; it has been suggested that one weakness is that there is a gap between what people say and what people do (Silverman, 2000). Also, its use of retrospective accounts has been considered problematic because of the distortion of reality that is presumed to occur with re-telling a story. While Silverman's note is important, this criticism is not sufficient because it assumes there is a single meaning to the experiences of individuals, that when later recalled is distorted through flaws of memory or social forces. However, people are likely to have multiple meanings attached to an experience (that are expressed or not) and they can change over time as new experiences make individuals reinterpret them.

In addition, interviews are not without their own power asymmetries. The power dynamics in the interview, and the potential oppressive use of interview-produced knowledge, are rarely mentioned in literature of qualitative research (Kvale, 2005). Dialogical interviews are

not always egalitarian and progressive, despite being warm and caring. There are complex power relations, dominance and resistance, in such forms of interviews. What is said and how it is said, as also the subsequent circulation of the knowledge produced in the interviews, are very important issues that researchers have to take into consideration. Another question is about who participates in the interviews. Are they people or groups who can easily express their ideas, beliefs, and experiences to a larger audience and participate in public debates? Or are they largely marginalised groups, as for example when Bourdieu *et al.*'s (1993/1999) interviews of French immigrants brought forth their situation of suffering to a wider public. However, it should be stressed again that there is a myth that dialogical interviews in themselves are regarded as good and emancipating (Brinkmaan and Kvale, 2005). Although the feminist tradition has emphasised experiences and subjectivity, and the close personal interaction and harmony between the researcher and the researched that qualitative depth interviews bring, it has been realised that caring interviews may involve an instrumentalism of human relations (Brinkmaan and Kvale, 2005).

All of my interviewees participated because they wished to contribute to the knowledge on CFS, but also because they wanted to reduce the negative attributions and stigma it has received and, mostly of them, to help others with CFS. One of my participants considered her involvement as a cry for help. Most of them expressed the belief that their experiences and knowledge would provide a truer representation of the reality of CFS. At times, the dynamics of the interview process were complicated. I presented myself as a PhD student researching CFS and perceived them as experts regarding their CFS experiences. My participants often changed roles between research participant, expert, and advocate. On the other hand, I was often perceived as a collaborator as I could convey their stories to people with power; the very fact that I was willing to conduct this study confirmed that. I would like to believe that I did all I could to respect their opinions and give them 'voice' and to minimise their fatigue

(as far as my face-to-face interviews are concerned) and the instances where I dominated the interview process.

My second source of primary data was blogs and a variety of textual materials like medical and psychiatric journals and monographs, research publications, and policy documents. Doing social research through the Internet, and especially ‘cyber-ethnography’ (Ward, 1999), is increasingly becoming more familiar (Hine, 2004). The rapid spread of Internet technology in recent years offers new possibilities for research, ‘particularly when working with hard to reach groups’ (Brownlow and O’Dell, 2002: 685) as in my case. There are various methodologies that can be used, varying from analyses of web pages to complex discourse analyses of ‘electronic conversations’ (Denzin, 1999). The use of online questionnaires has been very common but also that of on-line focus groups and real-time interviews. Other research methods that have been used are those based on observations of online communities and blogs. These often involve online discussion forums where messages are posted asynchronously, exactly as in my case with CFS discussion groups. Mann and Stewart (2000) cite various advantages of such a methodology, most notably the benefit of being able to silently observe online discussions (which, of course, raises serious ethical concerns that I discuss shortly). One of the main ways to do Internet research is passive analysis of online data such as studies of information patterns on websites or interactions on discussions groups without the researcher actually involving himself. An example of this would be Emily Martin’s (2010) ethnographic study of the ways different forms of subjectivity are being constructed by non-experts in relation to neurological explanations of human behaviour. Besides the ethnographic material she collected, Martin also observed the online discussion groups devoted to bipolar disorder. I followed a similar approach in my research.

Employing the Internet as a field to conduct research raises a series of practical, technical, and ethical issues. Doing online or Internet-based research raises questions

concerning consent and privacy as the borders between what is public and private become problematic (if they were ever unproblematic) and probably also those between ‘the physical and the virtual’ (Ward, 1999). This is even more so when it comes to particularly sensitive issues like health and illness, and disability, as again with my study of CFS. While some hold that all online research should seek the informed consent of its subjects, others consider this unnecessary where the research topics are not particularly sensitive. The ethics of observing and analysing online interactions have been the subject of considerable debate in recent years (Cavanagh, 1999; Ward, 1999; Pleace *et al.*, 2000; Bassett and O’Riordan, 2002; Capurro and Pingel, 2002). Concerns regarding the ethical basis of online research have been voiced by researchers (Schrum, 1995; Sharf, 1999; Mann and Stewart, 2000). To date, no universally accepted ethical guidelines exist, although several researchers have provided grounding for the development of ethical guidelines specific to such work (e.g. ESOMAR, 1999; Sharf, 1999). Because this is an unclear situation I decided to use only one blog which was open for public viewing and access. That is the reason I did not use other blogs. I paid particular attention not to include any materials that could compromise privacy and confidentiality by using non-sensitive data and by presenting them in a way that makes them non-identifiable. All the names of my participants and CFS blog users were completely anonymised in order to protect the privacy and confidentiality of the discussions. Furthermore, I responded to the problem of narrative appropriation by trying to pay attention to the context in which they emerged and by trying to reproduce this context in my thesis.

Collection of Data and Analysis

As mentioned above, my data collection was broken down into two parts: the secondary data from sources such as books, journals, policy documents, etc. and the primary data which

consisted of interviews and the data I gathered by observing online discussions by individuals with CFS. The secondary data were comprised of the following kind of materials:

1. Historical studies of fatigue and CFS and of medicine, psychology and psychiatry. These include studies such as Shorter's *From Paralysis to Fatigue* (1992) and *History of Psychiatry* (1997) and articles such as the ones published in *History of the Human Sciences* and in *Advances in Physiology Education*.

2. Papers on CFS published in medical journals such as *Dynamic Medicine*; *European Neurology*; and *Occupational Environmental Medicine* and medical monographs on CFS such as the interdisciplinary and important one published by Ciba Foundation in 1993.

3. Psychiatric books such as the DSM-III (1980) and psychiatric papers published in academic journals including *Philosophy, Psychiatry & Psychology* and *Applied Neuropsychology* concerning CFS, 'medically unexplained symptoms' (MUSs), depression, etc.

4. Research publications on CFS in fields such as virology, immunology, and brain studies, published in journals such as *Journal of Clinical Pathology*; *American Journal of Medicine*; *Science*; *PLoS ONE*; *Retrovirology*, etc.

5. Self-help books such as *From Fatigue to Fantastic* and *Overcoming Chronic Fatigue*.

6. Illness narratives and social studies of CFS such as Travers' (2004) doctoral study on the process of self-renewal associated with CFS, Tucker's (2004) discourse analysis of how CFS patients rhetorically construct CFS as a legitimate organic illness, Dumit's (2000; 2006)

studies of CFS patients' struggle for recognition and legitimacy, and articles concerning issues such as the diagnosis and treatment of CFS in clinical settings, published in academic journals including *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*; *Social Science & Medicine*; and *Social Policy & Administration*.

7. Publicly available documents concerning Work Capacity Assessment (WCA) and Atos Healthcare.

8. Various CFS organisations' magazines and newsletters such as *Breakthrough*, *InterAction*, and *ME essential*, kindly provided to me by two of my participants, all published in 2010.

9. Newspaper articles on CFS and JobCentre Plus (JCP) published in different daily British newspapers.

10. A broad range of policy documents concerning fatigue and CFS published by regulatory bodies such as the National Institute for Health and Clinical Excellence Guidelines (NICE), the World Health Organization (WHO), the Centre for Disease Control and Prevention (CDC), the Department of Work and Pensions (DWP), the Medical Research Council (MRC), and the Food and Drug Administration (FDA). In addition, I collected the various clinical case definitions of CFS.

11. A wide range of Internet sources including:

a) CFS patients' publications, often in collaboration with medical researchers, such as William and Hooper's (2008) 'Wessely's Ways: Rhetoric or reason?'.

b) Organisations and companies' websites (e.g. Hemispherx and Whitemore Peterson Institute for Neuro-Immune Disease (WPI)).

c) Popular news websites such as www.bbc.co.uk and www.CNN.com.

d) Health websites such as <http://www.chronicfatiguetreatments.com>.

12. Publicly available films and documentaries on CFS such as the *MECFS Alert* (http://www.youtube.com/watch?v=M4Jj6S0_06A) and the DVD copy of an immunologist, and supporter of CFS, talking in a local self-help group, again kindly provided by one of my informants.

My primary data originated from ten interviews and the close observation of one UK CFS discussion group which has to remain anonymous. Although initially I started gathering material from a number of CFS blogs and discussions groups, I had to finally restrict my focus to this one because it was the only one open to public access.

To my great satisfaction, as it turned out, it was a very significant source of data as it consisted of a vast number of threads on various issues relevant to CFS patients. I observed that online CFS forum from November 2010 to May 2011.

As far as my interviews are concerned, as has already been mentioned, reaching my participants was at times extremely difficult, and although I would have liked to expand my sample size, which was not pre-determined, that was not possible. My two sample criteria for someone to participate in the research were the following: s/he had to be over 18 years old and currently diagnosed with CFS. As far as assessing my participants was concerned, initially I got in touch with a specialist clinic near Leicester. My original plan was to interview the patients and doctors of the clinic and to conduct participant observation. However, although the negotiations with the 'gatekeeper' were at a good stage and we had

almost agreed to proceed with the study (he provided me with a number of journal articles on various subjects concerning CFS, as well reference lists on some CFS issues, and I would like to thank him for that), the 'gatekeeper' decided to withdraw for reasons unknown to me, and so I had to abandon this course of action and find alternative ways of accessing participants. This happened halfway through the thesis, therefore creating enormous problems because I had to redesign my strategy for my primary data collection.

My first option was to find a couple of individuals with CFS and then, by using snowball sampling, hope to be introduced to more as a result. In addition, I tried to recruit people from local CFS associations and self-help groups, such as ME Support Leicestershire, M.E. Positive East Midlands, Ashby M.E. Group, Carers of Leicestershire and Support Project (CLASP), and the local association of mosaic: shaping disability services in Leicester. That involved getting in touch with the managers of these associations, either by visiting them or by telephone or through e-mails. Usually, these associations are not very willing to help because they are suspicious of CFS research as they think it discredits and minimises the legitimacy of this illness. Although the managers of these groups and associations did not give the personal telephone numbers or e-mail addresses of their members nor asked anyone personally to take part in the research, they allowed me to visit a few of these associations and support groups and distribute brochures which informed them about the nature and scope of my study, making clear that all data would be made anonymous and treated as confidential. Finally, another recruitment strategy that I used was to send e-mails to online forums, again, explaining my position and the nature and purpose of the study and stating that anonymity and confidentiality would be protected. I sent e-mails to three online fora but that strategy did not bring any results. However, in the end all these efforts resulted in arranging, as already mentioned, ten semi-structured interviews with individuals currently diagnosed with CFS. That was accomplished with the help of the leader of a CFS self-help group near

Leicester who asked me to send him a letter informing them about the nature and scope of my study. The number of the individuals who agreed to participate in my study was originally 12, but due to the chronicity and unpredictability of their symptoms, and their vulnerability, two of them decided to withdraw.

Six of my interviews were face-to-face, two of them were telephone interviews, and two of them 'e-interviews'. One face-to-face interview and one telephone interview were followed by one 'e-interview' respectively. Face-to-face interviews were used for a number of areas in order to provide direction and generate discussion. The participants were asked open-ended, non-directive questions in order to avoid imposing my own concerns and beliefs. My face-to-face interviews were conducted at my participants' homes, with the exception of one that was conducted in a coffee shop. Only two of the face-to-face interviews were recorded, which were transcribed in full. In the remaining four face-to-face interviews, I limited my note taking so as not to impede the flow of the conversation.

The data, both from all the various textual resources I collected and from my interviews and observation of the CFS online discussion group, were analysed through a basic thematic analysis. That is, I tried to identify some patterns in the data by means of thematic codes. Themes gradually emerged as a result of the combined process of becoming intimate with the data and considering what was learned during the initial review of the literatures I used (although that was not a very linear process). At successive stages, themes moved to a higher level of abstraction and became overarching themes rooted in the concrete evidence provided by the data. I stopped analysing my data when no new themes were found. However, I decided not to present these themes as standalone findings of the study but to develop a narrative strategy that would do justice to the genealogical approach that drives this study. I put the findings of the thematic analysis in discussion with the textual materials which allowed me to see these findings as part of the broader discourses and to locate them in

different positions in what CFS and how it should be regulated. Finally, it also allowed me to order and organise my vast amount of secondary data into different topics that each one of them can be considered as one of the possible beginnings to approach CFS. These are the genealogy of fatigue, the making of CFS, and the regulation of the CFS subjects' labour-power. The textual style I deployed was not of reporting but creating a story for each one of these possible beginnings and in this story you included theoretical considerations as well as primary and secondary empirical data. The next four chapters are driven by a genealogical approach and not a realist presentation of facts and findings.

Chapter Three

Towards a Genealogy of Fatigue and CFS

In the Old Testament, God creates the world in six days and rests on the seventh, the *sabbath*. In Homer, fatigue is described as an exhaustion reaction after war. In the Hippocratic corpus, even though ‘spontaneous fatigue’, i.e. fatigue that arises after no work or exercise, is described as a disease, it does not constitute a major social problem (Smith, 1979/2002). In Hippocratic-Galenic medicine, disease arises from an imbalance in natural conditions (e.g. weather), as it does from an imbalance in the constitution of the individual’s body. The human being is filled with four bodily humours, i.e. phlegm, blood, yellow bile and black bile, and health is achieved when these four humours are in perfect balance (*isonomia*) or perfect blend (*krasis*). When one humour is in excess, there is a bad mixture (*dyskrasia*), and disease, illness or disability come as a result. Temperaments dictate behaviour and provide different types of *characters*, i.e. sanguine, choleric, melancholic and phlegmatic.

For Theophrastus (2003), lassitude or fatigue is a sort of melting (*suntexis*) and excess of liquid or moisture in the sinews (*neura*) which can be alleviated, for example, by a long hot bath. Those who are fatigued feel heaviness in certain parts of the body and especially the limbs which have borne the impact of the work. This sensation is very distinctive in the joints because during movement there is an afflux of moisture to the joints from other parts. Some physicians argue, however, that the feeling of heaviness is apparent in the flesh, bones and even throughout the entire body. Weariness seems to be due to the taking up of moisture or of some humour by the fatigued parts. There is no clear answer to the question of where weariness resides as it can be, as Epigenes declared, in the vessels and the *neura*, or in the *neura* alone (Cardwell, 1904). Galen (c. 170 BC) also provides us with dietetic details relating to exercise and fatigue, such as the preparation of exercise, the treatment of fatigue

after exercise (*apotherapeia*), massage, food (e.g. someone should drink more wine and less water), and bathing that one should receive (Smith, 1979/2002: 109). Such beliefs about the body, disease, and personality persisted for a long time in western culture.

Vapours and Nerves

So I tell you: My body is awash in many of the weaknesses of my sex; it is affected very easily by the troubles of the soul and doesn't have the power to restore itself when the soul is restored. [. . .] In people who can't get much exercise, it doesn't take long for sadness to obstruct the spleen and infect the rest of the body by its vapours. I imagine that that's the source of my low-grade fever and dry throat; I still have them despite the warmth of the season, though the walks I take bring back my strength a little. This is what made me agree to follow the doctors' advice to drink the waters of Spa here for a month . . . as I have found by experience that they get rid of obstructions.¹

Thus writes Princess Elisabeth of Bohemia to René Descartes in a letter in 1645. In England, there are frequent complaints of 'the vapours' which are characterised by great fatigue and unexplained general malaise and are often described as a result of the effects of the thickening of the blood. In 1698, in his *A Collection of Chronical Diseases*, the English physician and moralist John Pechey describes the vapours as the 'most frequent of all Chronical Diseases . . . wonderfully various that they resemble almost all the Diseases poor Mortals are subject to' (quoted in Stubhaug, 2008: 19). The vapours and its male equivalent hypochondria, as hysteria and melancholia, are also very prevalent in the second half of the seventeenth and first half of the eighteenth centuries. Significantly, madness and hysteria replaced the catch-all description of 'witch' as a label that patriarchal discourse applied to sexually and politically deviant women (Gilman *et al.*, 1993). Early capitalism required widespread restraints on female sexuality, especially among bourgeois women, to secure the

stability of the system of property distribution (Turner, 2001). Working women rarely suffered from melancholia, while bourgeois women were commonly affected by the malady. The large numbers of women who suffered from hysteria were due to the fact that 'being vapourish or hysterical were roles ... which women themselves sometimes adopted – as, of course, did men – to give vent to their feelings and to cope with life's demands' (Porter, 1987: 106). Thus, in assuming the role of hysteric, as feminist scholars have noted, women were able to express their frustration with their lives in a culturally acceptable form, 'a far safer alternative than agitation for legal, political, and economic rights' (Becker, 2010: 37).

The medical system operating in Europe until the Enlightenment was founded on a belief in the similarity between the microcosm and the macrocosm, between the bodily order and the cosmic order (Canguilhem, 1988; Foucault, 1966/2002) and the principles of humoral theory mentioned in the beginning of the chapter. Before the emergence of the clinic (Foucault, 1963/2010), diseases are conceptualised like Platonic forms that are somehow independent of particular bodies. Diseases are apparent through their visible symptoms, but visibility is not dominant in the identification of disease. Sickness of the body and mind is directly related to the sickness of the soul and is maintained by the presence of vapours and the stabilisation of humours. The 'English Malady', as the vapours were termed later, is an invention of the Scottish physician George Cheyne in 1733. It is an affliction of civilisation, initially of the upper classes. The causes of that malady are moist air, fickle weather, and the exhibition of luxury and abundance through idleness, in particular, the excessive consumption of meat and wine. England is becoming wealthier but not healthier. '[W]hen mankind was simple, plane, hones and frugal, there were few or no diseases. Temperance, Exercise, Hunting, Labour, and Industry kept the Juices sweet and Solids brac'd', Cheyne writes (quoted in Porter, 2001: 32-33). Health, for Cheyne, 'hinted not upon humoral equipoise but upon nervous tone (Porter, 2001: 35). Being very delicate, the nerves could easily become sluggish. Following William

Harvey's 'discovery' of the circulation of blood, Cheyne argues that the body is merely a series of canals and that pathology can be properly studied mathematically (Turner, 2001). Influenced by the Christian tradition, Cheyne advocates a sort of medical asceticism, diet, moderation in drink, and light exercise for healthy living and mental stability. Although his regimen probably aimed at the elite who were suffering, through these medical guidelines it became part of the Methodist discipline for a much wider section of the community. In a period of expanding industrial production, the government of the body becomes not only a sign of social standing but an outward indicator of spiritual virtue. In the eighteenth century, pietist asceticism merges with the medical regimen of healthy living to produce a moral code which is compatible with the capitalist's interest in a disciplined work force. The duty to be healthy becomes a part of a calling to world mastery and self-control. Disease is redolent with moral implications; it is a part of the disequilibrium between body and environment, resulting from abuses of diet, poor hygiene, and immorality.

The origin of illnesses such as mania, hysteria and hypochondria changes which is believed to be due to the movement of 'animal spirits' (i.e. the body's fluids) is replaced by the image of tension in nerve fibres (Foucault, 1961/2000). Hysteria and hypochondria are united to form the concept of a 'disease of the nerves'. Secondly, they were integrated into 'diseases of the mind'. But classical physicians could not discover the particular qualities of hysteria and hypochondria. Hysteria progressed and assumed its dimensions in the space of the body, and that is why for physicians the problem was how to identify the system through which disease dispersed itself. By the eighteenth century nothing remained of the idea of the mobility of the womb, except the theme of corporeal space. One explanation for the long popularity of the wandering uterus as the cause of hysteria was the widely held belief in the one-sexed body. Prior to the eighteenth century, the Galenic, one-sex model dominated both medical and social discourse (Laqueur, 1997). The idea of the woman as a flawed man was proven by

woman's inverted male genitals. In the eighteenth century, however, 'as the natural body itself became the gold standard of social discourse, the bodies of women ... became the battleground for redefining the ancient, fundamental relation ... of woman to man' (Laqueur, 1997: 150). It was when women's ovaries became medically recognised in their own right as unique reproductive organs, instead of female testicles, that the differentiation occurred. That new pathology was apparent in the move to blame hysteria as a 'defect of the nerves' being 'chiefly and primarily convulsive, and chiefly depends on the brain and the nervous stock being affected' (Porter, 1987: 48). The new concept of hysteria was that of a disease of the female nerves rather than of the body. It was because of this shift in the root cause of hysteria, from caused by the womb to caused by 'a chemopathology of the spirits and nerves' that men could also become victims of the disease (Porter, 1978: 48). In the eighteenth century, the idea of the dynamics of corporeal space gave way to that of a morality of sensibility. The penetration of the body by various spirits assumed that the body was essentially open inside. The shift from the idea of movement and space to that of moral judgment came through the notion of sympathy. Sympathy implied a certain sensitivity of the nervous system. By over-stimulating the emotions and nerves, a drastic response could follow.

As already mentioned, the disordered movement of hysteria and hypochondria is the result of the disordered movement of 'animal spirits'. Hysteria is a deceptive disease because it has various symptoms. Doctors believe that it affects women more because of their 'softer' bodies. The idea that the womb 'rose' above its place was replaced by the belief that spirits moved chaotically within the body. A body penetrated by disease must also be continuous. This problem haunted eighteenth century medicine. It made hysteria and hypochondria diseases of the general agency of all sympathies. The nervous system was used to explain the body's sensibility with regard to its own phenomena. The sympathetic sensibility of women

predisposed them to the vapours and nervous disease. To understand classical conceptions of sympathy, it is essential to understand the idea of irritated nerve fibres. It was believed that too much sensibility resulted in unconsciousness or nervous shock. One could fall ill from too much exposure to outside stimulation. As a result, people were both innocent and guilty; they were guilty because their lifestyle and passions irritated their nerves and their innocence was seen as evidence of a deeper guilt and its punishment.

Neurasthenia and Da Costa's Syndrome

Neurasthenia was a term used to refer to a mechanical weakness of the actual nerves, before the American neurologist George Beard introduced it in the medical literature for the first time in 1869 and popularised it.² Neurasthenia is considered a male equivalent to hysteria and the somatic explanation offered for neurasthenia is based on the 'hypersensitivity' of the nervous system. Beard considered that the growing modernisation and speed of life was responsible for neurasthenia's rise, and identified six factors in this: steam power, the periodical press, the telegraph, the sciences, the mental activity of women, and the erosion of religious faith. What Beard described is, in Heidegger's terms, a world of 'acceleration' (Aho, 2007). For Beard it is not civilisation per se that causes neurasthenia, but rather the unique social forms of modernity itself: 'The Greeks were certainly civilized but they were not nervous, and in the Greek language there is no word for the term' (quoted in O'Malley, 2005: 385). Neurasthenia soon proves an attractive explanation for a range of unexplained conditions of the age (e.g. chronic fatigue, mild melancholia, general nervousness, and evolving psychosis) and throughout the following decades its prevalence increases dramatically (Shorter, 1992). Neurasthenia was a 'cacophony of complaints that replicates 'real' illness without any observable organic lesion' (Rabinbach, 1992: 154). Some

physicians interested in social reform began diagnosing neurasthenia among working class men whose health complaints (e.g. overload), until then, were considered non-medical.

Before the 1870s there were almost no studies of fatigue (Rabinbach, 1992; 1996).³ Work was either considered a spiritual activity, as in the Judeo-Christian *Weltanschauung*, or as pain (*arbeit, travail, lavoro*), as it was for the ancient Greeks, or otherwise as a poetic activity not confined to satisfying needs. From maladies of the will like torpor, melancholia and apathy prevalent during the Middle Ages, the trend switched to apathy and then to fatigue. If torpor or melancholia were linked to religious and moral ideas (i.e. the sin of *acedia*), fatigue underwent a materialist reassessment that presupposed the conceptualisation of energy (*Kraft*).⁴ What in the late eighteenth century was referred to as *the fatigues*, meant the ‘extra duties of a soldier’. The moral-religious view of fatigue was replaced by a scientific understanding of fatigue, which was considered both a physical and moral disorder. The body became conceived as a motor capable of sustaining the increase in production, thereby lessening the effects of debilitation. The motor, unlike the previous metaphor of the machine, referred ‘not simply to the mechanical generation of movement but to the industrial model of a calculable and natural channeling of energy converted from nature to society and back again’ (Rabinbach, 1996: 97). That was due to the ‘discovery’ of the first law of thermodynamics and the shift from a Newtonian universe to a Helmholtzian one. Labour came to be viewed in terms of labour-power (*Arbeitskraft*), as something purely quantifiable and devoid of purpose and meaning. By the end of the nineteenth century, the routinisation of work and the extraction of value from labour were understood in terms of the first law of thermodynamics. According to this law, energy can be neither created nor destroyed in its transformation from one form to another. This made it possible to think of labour abstractly as labour-power and the transfer of energy through work from the labourer to the product without loss of energy.

In Rabinbach's opinion, even the 'later' Marx, who wanted to emancipate humanity *from* labour and not *through* labour, fell into the trap of productivism because he borrowed ideas from the early nineteenth century French engineers and the concept of labour-power from the German physicist and physician Hermann von Helmholtz. Despite the significant complexity of Marx's understanding of labour (Caffentzis, 2007), as Étienne Balibar points out, he had retained 'a narrow, perhaps utilitarian, view of labor' (Curcio and Örselçuk, 2010: 318). Marx understands labour as at once 'a quantitative, material, and socially constituting core and [as] the decisive creative, expressive, self-constituting human activity' (Rabinbach, 1993: 49). Of course there were some currents which tried to resist that ideology of productivism. While imprisoned in Sainte-Pélagie prison, Marx's son-in-law, Paul Lafargue, famously wrote:

'Work, work, proletarians, to increase social wealth and your individual poverty; work, work, in order that becoming poorer, you may have more reason to work and become miserable. Such is the inexorable law of capitalist production' (Lafargue, 1883: n.p.).

However, the majority, liberals and socialists alike, were under productivism's spell. 'Political physiology as a variant of political economics was the consequence of an unstable combination of chemistry, physics and medicine, manipulated by political tools of social and economic management' (Roldán, 2010: 2). The productive optimum had to match with the social optimum. That particular constellation of knowledge, the European science of work (and Taylorism), rationalised the working body (see also Corbett, 2008). Taylorism and the science of work were competing approaches to rendering workers more productive and efficient. While both shared the same productivist aims, work science was 'a struggle over energy and fatigue rather than time and money' (Rabinbach, 1986: 506).⁵

Of course, that *idée fixe* with body's idleness and capacities did not arise from the 'discovery' of the laws of thermodynamics. There was already an immense attempt to understand and regulate bodily energies. Manuals such as Marc-Antoine Jullien's 1808 *Essai sur l'emploi du temps: ou méthode qui a pour objet de bien régler l'emploi du temps* offered a plethora of practical solutions designed to combat bodily and intellectual fatigue (van Zuylen, 2008). Jullien believed that by measuring and cutting up time in rhythmical and orderly sequences, one could get rid of the dangerous idleness that resulted in mind-numbing weariness. For Jullien, as civilisation progresses we rely less and less on the body to perform daily tasks and fatigue is transferred to our souls. Cold showers, large quantities of tea and coffee, programmed meals and praying sessions and many other solutions were offered as antidotes to the upsetting and antisocial manifestations of fatigue. Writing at about the same time as Jullien, his compatriot Charles Fourier saw idleness (*l'oisiveté*) as a symptom of work not yet adequately organised (Morgan, 2011: 36). Measures like those Julien proposed were too mild and one had to wait for more drastic solutions, like those of utopian scientists who dreamt of eliminating fatigue completely. However, the utopia of unlimited production was challenged with the 'discovery' of the second law of thermodynamics, because the second law of thermodynamics points to the dissipation of energy and the inevitable increase of entropy in a closed system. The threat of bodily fatigue posed a danger not only to the labouring body as such, but to capitalism itself since fatigue was 'a natural barrier to the efficient use of the human motor' (Rabinbach, 1992: 133). By the late nineteenth century, as already mentioned, the scientific and medical discourse of fatigue had largely replaced the moralism and religious proscription inherent in the earlier rhetoric of idleness, sloth, and ennui (of course, thieves, vagabonds and prostitutes were motivated solely by the avoidance of productive labour). Nevertheless, fatigue was a major problem and the expectations society placed on its citizens, the expanded leisure time, and the monotony of mechanised work were

to blame. The decrease in the hours of the workday or days off from work was not (so much) the result of social justice but a means of rationalising industrial labour in order to manage productivity through regulating the activities of the working class. The victory of the eight-hour workday was the result of the work scientists proposal for the reduction of fatigue, labour's call for shorter hours, and industrialists' ideal of scientifically determined productivism; all these factors combined to establish the notion of an 'optimum' (as opposed to Taylor's maximum) duration of work.

By 1891, the Italian physiologist Angelo Mosso, author of *La Fatica*, had already popularised the idea that fatigue could not only be objectively described, but analysed and controlled. Mosso was distressed by the detrimental effects of work on the bodies of children, sulphur miners, and Silician farmers and by the physical changes experienced by immigrants seeking to work in the United States. His desire to help workers by easing their fatigue led him to experiment with muscular mechanics and inspired him to invent the *ergograph* (register of work) (Figure 1), in order to understand the principles of endurance and energy. Mosso's importance in modern physiology cannot be underestimated.

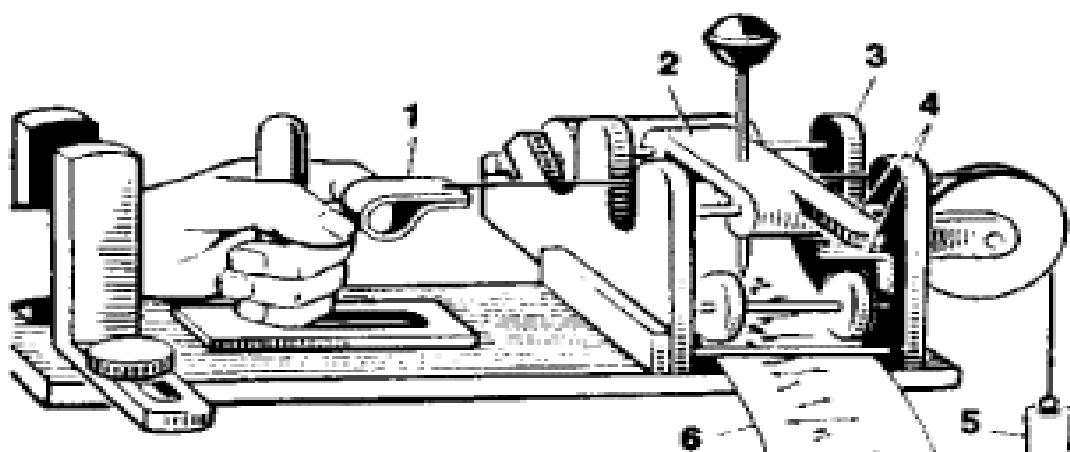


Figure 1. Mosso's finger ergograph. Ergographs vary according to the muscles to be studied and may be classified as finger, hand, leg, trunk, etc. (1) movement sensor, (2) recording unit, (3) carriage, (4) components that move the strip chart, (5) weight, (6) strip chart for recording an ergogram.

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During his anniversary lecture at the University of Turin in 1875, Mosso stated that '[t]he evolution of mechanics is reducing man's muscular work, which improves, while sparing strength, the abundance and the effectiveness of intellectual work' (di Gulio *et al.*, 2006: 52).

Using tracings from the ergograph (concentric contractions of the flexor muscles of the middle finger that were volitionally or electrically stimulated), Mosso was able to characterise muscle fatigue and to associate its occurrence with central or peripheral influences. He demonstrated that exercise would increase muscular strength and endurance while prolonging the occurrence of fatigue, which he postulated was a chemical process that involved the production of toxic substances such as carbonic acid. The ergograph produced 'fatigue curves' which could represent the fatigue of different individuals. Mosso's results showed strong differences even between subjects of relatively equal strength, age, sex or occupation. But, still, fatigue was unpredictable, displaying a great variety from individual to individual. 'Muscle fatigue and brain, or mental, fatigue were sometimes mutually constitutive, but just as often they were mutually exclusive' (Rabinbach, 1992: 135). That made Mosso more convinced that although exhaustion's laws are dynamic, they remain constant. To prove that he had to eliminate any subjective dimension of fatigue by quantifying it even more. Experimenting with electrodes that produced involuntary spasms, he concluded that while each individual fatigues uniquely, each individual's curve displayed the same regularity independently of the causes of fatigue or the work performed. For example, as those who fatigue gradually in physical labour, those who fatigue in intellectual labour also fatigue gradually. Fatigue had a central (the will) as well as a peripheral (muscular) component. Moreover, because it was possible with the ergograph to demonstrate muscular fatigue by volitional means (e.g. central, the will, psychic, or mental) as well as by electrical stimulation, Mosso concluded that central fatigue could be distinguished from peripheral fatigue. However, Mosso acknowledged the inherent difficulties in measuring

purely central fatigue. As he put it: 'It is not will, not the nerves, but it is the muscle that finds itself worn out after the intense work of the brain' (di Giulio *et al.*, 2006: 55). Finally, Mosso came to believe that fatigue was a toxin after having injected the blood of a fatigued frog into a rested one.

That fatigue crusader hoped that fatigue could be, if not completely eliminated, at least conquered and controlled, and certainly he was not the only one. In an attempt to find a 'cure' for fatigue, experiments of all sorts were conducted to determine the relationship between mental and physical exhaustion (Rabinbach, 1992; see also Turner, 2008). Perhaps the apogee of those crusades was Wilhelm Weichardt's 1914 invention of a sprayable vaccine for German classrooms that would combat harmful fatigue toxins that built up in students' bloodstreams (Rabinbach, 1992: 142-143).⁷ The *fin-de-siècle* spirit was obsessed with fatigue; one just has to read the literature of the time. The protagonists of Flaubert, Proust, Gide or Melville, are all weary and exhausted. The 'rest cure' was at the time a popular method of defence against the dangers caused by neurasthenia's fatigue. Beard, the famous psychiatrists Jean-Martin Charcot, Emil Kraepelin and Jean-Pierre Janet, and a host of other scientists, including Sigmund Freud, saw neurasthenia as a serious problem which had to be investigated. Is neurasthenia hereditary? Is it an illness of the working class or of the middle class? Does it affect men more than women? These were some of the questions that preoccupied them. That neurasthenia eventually lost its importance was probably due to a combination of changes in psychiatric nosology and a shift in class bias (Zorzanelli, 2009), and the fact the metaphor of the human motor progressively lost most of its compelling power helped, according to Rabinbach, to decrease the preoccupation with fatigue. For this reason, Rabinbach problematically asserts that we have transcended the 'work-centered' society (cf. Best, 1994). Rabinbach believes that because we are no longer in the industrial era, the question of labour has somehow become obsolete or, to say the least, of little

importance. The significance of material commodities for social reproduction may not be as important as they were at the height of industrialism but there is no reason for arguing that labour has lost its power and, therefore, the political consequences that Rabinbach draws are misleading. As Best (1994: 592) put it: 'Although metaphors certainly help to define our sense of reality, it is unimaginable how a shift in the metaphor of work suffices to change the totalitarian nature of the modern workplace and promises "the obsolescence of the body"'. However, in ironically, Rabinbach may be correct. Value can also be extracted from dead bodies (literal 'dead labour'), as the trend of commodifying dead bodies by turning them into gimmicks illustrates (Sanders, 2011).

Another fatigue-like illness of the time was 'Da Costa's syndrome', often also referred to as 'general exhaustion' or 'neurocirculatory asthenia', a syndrome originally identified in men in wartime, a syndrome that Paul (1987) identifies as similar to current psychiatric terms such as 'anxiety stress' or 'anxiety neurosis'. In 1871, Jacob Da Costa, an American physician, publishes a paper entitled 'On irritable heart: a clinical study of a form of functional cardiac disorder and its consequences' in the *American Journal of Medical Sciences*. Some of the symptoms he identifies are palpitation with a rapid pulse (with and without effort), chest pain, shortness of breath, and digestion problems (Paul, 1987: 306). The British authorities try to rectify the problem and alter the weight and strapping of the soldiers' pack and later alter training drills in an attempt to prevent the recurrence of the symptoms.⁷ Discharges from the British Army for 'diseases of the circulatory system' became a serious cause for concern in 1864 following a presentation at the Royal United Services Institute by the British William Maclean, surgeon, general, and professor of military medicine at the Army Medical School, Netley (Jones, 2006). Although Britain was not then at war, such soldiers broke down either under the rigours of training or as a result of earlier overseas service in the Crimea and India. To shed light on this problem, Maclean

investigated 5,500 soldiers admitted to the medical division of the Royal Victoria Hospital, Netley, who had served abroad between 1863 and 1866, and found that 8% of the soldiers had been invalided from the forces with what appeared to be heart disease. At Fort Pitt, where ‘invalids’ serving in the UK were treated, he estimated that 15% were discharged with heart disease. Having excluded rheumatism, excessive alcohol consumption, heavy smoking or overexertion as causes, Maclean considered that the weight and distribution of the soldiers’ equipment were responsible:

‘The pack-straps press on important muscles, arteries, veins and nerves to a degree which only those who have carried the loaded pack can appreciate. The weight, especially when the greatcoat is strapped on, falls, to a great extent, without the line of the centre of gravity. You can well imagine how impossible it must be to make severe exertion under so many disadvantages without suffering’ (quoted in Jones, 2006: 535).

That concern with soldiers’ physique continued and increased after the First World War. British and American doctors were increasingly concerned with what Thomas Lewis, a leading British cardiologist of the time, characterised in 1919 as the reduced ‘vital capacity’ (*capacité vitale*), i.e. the lung capacity, of soldiers (Paul, 1987: 309). In just the previous year, Lewis made some recommendations published in *The Lancet* and pointed to the screening and rehabilitative value of a graded recreation and exercise programme conducted in a hospital. Of 558 men discharged over a six-month period in 1916 (with an average follow up of 11 months), approximately half could be returned to some duty capacity. The programme included ‘setting up exercises, marches with the band; ... round games and tennis, golf and cricket; athletic competitions, lectures and picture shows’ (Paul, 1987: 309). In the nineteenth century, large numbers of the peasantry preferred self-mutilation rather than service which, as the historian Eugen Weber (1976) notes, ‘was seen not as a duty owed to

some larger community or nation, but as a heavy tribute exacted by an oppressive and alien state' (quoted in Naqvi, 2007: 21). Rabinbach (1992: 226-227) argues that, at the end of the eighteenth and the beginning of the nineteenth century, there were many such attempts to change the training and length of military service because it was exhausting the soldiers and diminishing their morale. Troops were 'hypertrained' and thus militarily useless, while '[p]roper training had to be energetically sound, that is, accomplished by the least effort' (Rabinbach, 1992: 226). Otherwise there would be a 'regression' of 'social energy'. A 'rational course of military training demanded the scientific calculation not only of the time required, but also of the rhythm, and the intensity of the most favourable conditions' (Rabinbach, 1992: 226). But soldiers did not have to mutilate themselves to avoid military service as they could malingering while in service and be discharged. In 1838, Hector Gavin, a British military surgeon, reports that 'soldiers are often actuated by the same wayward fancies, so perplexing to the physician, which influence hypochondriacal or hysterical patients in the middling or upper ranks of life' (quoted in Kanaan and Wessely, 2010: 76).⁸ In 1843, Gavin coins the term 'factitious disorder' (often referred to as Munchausen syndrome) to delineate a particular malingering subtype where the clinical evidence is faked. The Freudian model absolved hysteria from malingering because of the role of subconscious or unconscious motives in malingering by identifying them through the notion of 'secondary gain', that is the conscious motives of a patient could have for remaining ill (Kanaan and Wessely, 2010). The emergence of that category resulted in a distinction between being ill or just criminal (when no neurological or psychological aetiology was to be found).

Da Costa did not believe the syndrome was to be found solely in military surroundings; rather, much of what he wrote, he believed he 'could duplicate from the experience of private practice' (Paul, 1987: 307). Lewis also held that the syndrome was common in 'civilian' life and that fatigue 'was universal as a complaint' (Lewis, 1987: 309-310). In fact, as Wood put

it, it 'is possible that the curious lack of recognition of Da Costa's syndrome in civilian life is due to the fact that it is commoner in women', adding that although the War Office has not provided 'reliable control figures', the 'matter is receiving attention' (Wood, 1941: 767, 768). Wood also notes that it must be a matter of 'race' because 'although no race is immune, the emotional races are more susceptible than the stolid' (Wood, 1941: 768). Wood refers to a study conducted by Brooks in 1924 that describes the frequency of the syndrome in different 'races': 'the Jews, especially the Russian Jews; next ... the Italians, then the Irish, then Americans, Scandinavians, and lastly the negroes [*sic*]'. In addition, after he has examined various theories about the cause of inframammary pain, he refers to his own research in which he investigated the method of respiration 'by means of *x* rays' (Wood, 1941: 771). After the First World War, but also between and after Second World War, extensive long-term studies were carried out both in the UK and the US, such as the famous Harvard Fatigue Studies (Figure 2) in the US (e.g. Folk, 2010).

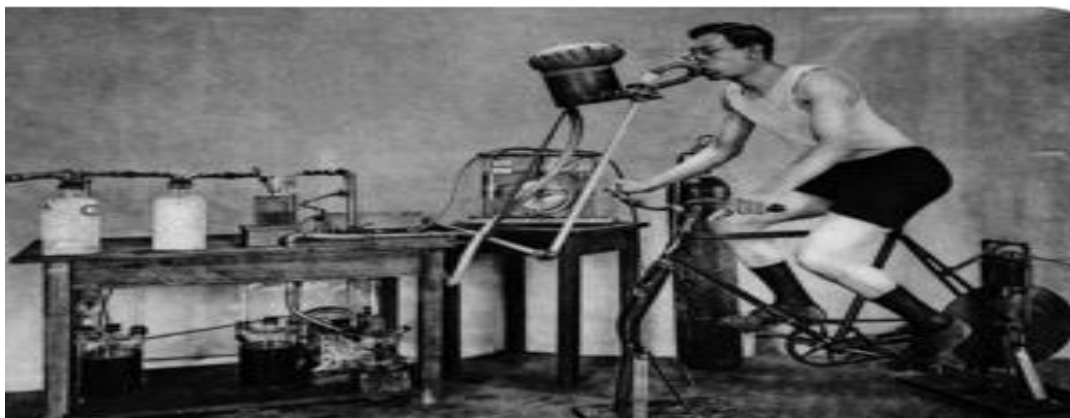


Figure 2. Photograph of one of the many fatigue experiments conducted in the Harvard Laboratory between 1927 and 1952. Reproduced from <http://www.scienceofsocceronline.com/2010/12/nutrition-and-performance-look-back.html>

In 1941, Ward conducted a fatigue study of 600 male and female workers and found that 4

percent were chronically fatigued, and concluded that ‘anyone who works beyond 100 percent of his capacity is bound to develop fatigue-related symptoms, and overwork was a primary cause of chronic fatigue’ (Torres-Harding and Jason, 2005: 7).

Immunology and Stress

The emergence of CFS as a medical category would not have been possible without a change in the discourses of biology and medicine. Luthra and Wessely suggest that at a certain point ‘immunology replaces neurology’ (Luthra and Wessely, 2004: 2364). During the 1900s and until 1934, ‘fatigue-like illnesses were remarkably quiet’ (Luthra and Wessely, 2004: 2364). As Ware (1992) points out, the emergence of CFS was possible only because of the re-‘discovery’ of infectious and post-infectious mechanisms and the influence of mass media.

Following Jewson (1976), Nettleton (2004) argues that in our age a new ‘medical cosmology’ (akin to a paradigm or discursive formation) has emerged that she calls ‘e-spaced medicine’. Nettleton argues that today’s medicine is fundamentally different from the past and even from a good part of the twentieth century. According to Jewson, from the 1770s to the 1800s medicine operated under the cosmology of *bedside medicine*. The doctor had an intimate relationship with the client who was his or her patron and therefore had to take into consideration his or her opinions. Then, from 1800s to the 1840s, there was a move to *hospital medicine* where patients were located in the hospital and a coherent theory of a disease was developed due to the localisation of pathology. Next, there was *laboratory medicine* where scientists control the production of knowledge. As Nettleton (2004: 662) writes, ‘[p]rogress in physiology was critical in this period, and the origins of diseases were to be understood primarily in terms of cellular processes rather than anatomical science’. Finally, the developments in cybernetics and information theory and then those of ‘chaos theory’ and non-linear dynamics are what brought ‘e-scaped medicine’. In this new medical

cosmology the Internet plays a profound role at the level of social epistemology because the proliferation of information and communication technologies influences the means by which knowledge and information are generated and sustained, though it seems not able to change the patterns of structural inequality. Significantly, information has become the dominant motif of biology. For instance, whereas Harvey's 'discovery' of blood circulation took the heart as a pump, recent advances describe it as a pump and a 'communicator' at the same time.

The immune system has become one of the sources of bodily energy and vitality, and the ways to protect and bolster it are diet and nutrition, exercise, and stress reduction. Immunology was made possible by the 'discoveries' in information theory and microbiology. While 'immunity' emerged as a biological fact at the end of the nineteenth century, immunology did not attain a formal theoretical construction until after First World War, when the notion of the 'self'/organism was introduced to provide a ready and convenient metaphor for deciphering immune activity (Tauber, 2009). Here it is important to note the socio-political implications of some discourses of immunology. Martin (1990) has shown that in the field of immunology, the body is typically viewed as a nation under siege by hostile forces, where metaphors of attack, invasion, war and defence are dominant.⁹ However, this is only one way to understand the immune system processes; other metaphors, such as the 'food chain', in which macrophages ingest microorganisms, would direct researchers' attention toward different aspects of how the immune system works. Nonetheless, as Martin suggests, the 'nation at war' model of the body is so taken for granted in immunology that many scientists find it hard to talk about the body in any other way. Thus, while what scientists know about the body is not false, it is limited by these metaphors that constrain both observation and interpretation. Furthermore, Cohen (2009) has shown

how the supposed characteristics of the modern political subject (i.e. autonomy and individualism) are related and transferred to biomedical and immunological discourses.

What about fatigue, which played such a big role in the past? One answer would be that developments in science and technology have lessened fatigue. Indeed, by 'the 1920s, as work in the chemical and electrical industries depended less and less on physical effort, the disabilities of work shifted away from fatigue to new problems of stress, from physiology to psychology' (Rabinbach, 1996: 105). Stress has been investigated by a number of scholars (Haraway, 1991; Martin, 1990; Anderson *et al.*, 1994). Stress is difficult to define as it can refer to physiological or psychological factors, to an emotion or to an environmental condition. Stress has become so popular and difficult to define that it is being used as a quick and convenient explanation for many health problems these days, from a heart attack to pimples. It has been described by anthropologists and other scholars as a discourse, a modern metaphor or a collective representation.

The notion of stress is historically entangled with concerns related to shock, trauma, emotions, and memory. It emerged in the nineteenth century and was elaborated further in the aftermath of the Second World War experience with 'shell shock' (Pohlman and Becker, 2006). British doctors working in military hospitals noticed patients were suffering from tiredness, irritability, giddiness, lack of concentration and headaches. Eventually the men suffered mental breakdowns making it impossible for them to remain in the front-line. Some doctors came to the conclusion that the soldiers' condition was caused by the enemy's heavy artillery. These doctors argued that a bursting shell creates a vacuum, and when the air rushes into this vacuum it disturbs the cerebro-spinal fluid and this can upset the working of the brain. Stress was later on developed in the 1930s by endocrinologist Hans Selye, and was only later co-opted by psychology. Stress denoted the physiological adaptation of an organism to environmental influences. During the interwar years, researchers from both

physiological and social science disciplines were concerned with stability, which is to say finding stability in an unstable world caused by industrialisation, the Great Depression, and the emergence of fascism in Europe (Viner, 1999). Selye would go as far as to suggest that ethics and human life can be reduced to intercellular behaviour which supersedes all religious explanations, something that created quite fierce reactions. Later on, due to its flexibility as a concept, stress became the concern of alliances between the US military and corporations. The military was concerned with battle fatigue and using stress as a weapon, and, on the other hand, the idea that work constituted positive and necessary stress for humans was of interest to those who wanted a more efficient workforce. Stress also became associated with conservatism and personal ambition – so characteristic of the American society of the time – but also came to be seen as a critique of modern life. Thus, stress's relation to modernity is as ambivalent as modernity's relation to fatigue. The anthropologist of medicine Alan Young (1980) has argued that stress researchers have grounded their enquiries in a notion of a fundamentally asocial and abstract individual (see Pohlman and Becker, 2006). According to Young, scientific research resembles the current social relations and division of labour and, thus, the dominant ideology is reproduced, which sees society as merely the sum of individuals who belong to it and health or other problems as just personal. Haraway (1991) has shown how the popularity of stress grows in times of serious threat to the prevailing social order. In addition, stress has often, but not necessarily, been seen and presented as a problem of women (evolutionary science suggests that women have different 'bio-behavioural' responses to stress), and more specifically of middle class women. According to this discourse, what stresses women is motherhood, and that is because it is difficult to balance work and motherhood. Becker (2010) suggests that stress has in a way replaced the role hysteria had in the past. Stress is now being used to place middle class women at home again. As Becker (2010: 39) puts it: 'The 19th-century rest cure has been supplanted by

scented candles and pastel yoga mats'. Furthermore, by being not only a problem for women, many would identify work stress as the main work health problem in our age.

By the 1930s, and even more by the 1960s after the introduction of polio vaccines, most contagious diseases had been either eliminated or controlled (Albertini, 2009). The success of therapeutic medicine since Pasteur's 'discovery' of microbes had been immense (Vaz and Bruno, 2003). The multiplication of vaccines, hygiene observance in interventional surgery, the 'discovery' of blood compatibility that made surgery more efficient, and the invention of antibiotics were all events that accounted for a huge success in combating infectious diseases. This success allowed for both an increase in the average life expectancy and for a consequent increase in the percentage of chronic-degenerative illnesses among the totality of causes of death in developed countries. Until the end of the First World War, and the invention of the concept of risk factor (from research carried out on lung cancer), epidemiology was centered on infectious agents such as viruses and bacteria.

Chronic brucellosis was one of the first outbreaks of fatigue, in the 1930s, to be reported. Chronic brucellosis is a bacterial infection, 'discovered' by Sir David Bruce in 1887, spreading from animals to humans, with characteristic signs of an infection, such as high fever, pains, malaise, and long-lasting fatigue. That served as an accepted explanation for chronic fatigue in the 1940s and 1950s (especially in the US), even for people who had never been infected but had those or similar symptoms. Chronic brucellosis never became a widespread illness, sharing its destiny with the theories of chronic fatigue that appeared and disappeared in the decades to follow (e.g. total allergy syndrome in the 1970s). At about the same time, epidemic outbreaks of mysterious fatigue were reported in 1934 in Los Angeles General Hospital, among the employees at the hospital, which was labeled 'neuromyasthenia' because it was presumed to be an 'atypical poliomyelitis infection' (Shorter, 1993). Other labels used were 'Icelandic' disease, due to the local occurrence in Iceland. The term Benign

Myalgic Encephalomyelitis was introduced in the UK in 1957 in order to describe a peculiar outbreak of a paralytic illness that swept the nursing establishment of the Royal Free Hospital in London (Ramsay and O'Sullivan, 1956), but had little public prominence (the prefix 'benign' was later dropped because patients found nothing particularly benign in their experiences). The majority of these outbreaks were first believed to be poliomyelitis but were later differentiated on clinical and epidemiological grounds. It seems that one of the major problems is that, in half of the outbreaks, the hospital staffs were affected (Acheson, 1959). As is known, from the emergence of the institution of the clinic, a consistent problem has been the fact that bringing bodies together and confining them in a single place in order to cure them of disease has frequently the opposite effect, that is, of spreading disease.

'Most curious of all the epidemic's features is the apparent susceptibility of the nursing medical and ancillary professions. Seven of the fourteen outbreaks have occurred in the staffs of hospitals. In the other [i.e. in Punda Florida] a high attack rate among nurses, doctors and their helpers was noted. Thus the attack rate among medical personnel was 40 per cent (sixteen of thirty-eight) as opposed to 6.1 per cent (62 of 1,010) in the community as a whole. In the Los Angeles and Royal Free Hospital outbreaks the attack rates were higher in nurses than in the other hospital staff. In the Middlesex, Coventry, Bethesda and Durban epidemics the disorder was virtually confined to nurses' (Acheson, 1959: n.p.).

Furthermore, the problem of securitising the population is in all these cases crucial. That is why, in each single case, 'the whole population at risk was under close medical supervision throughout' (Ackeson, 1959: n.p.). How can such a disease become a city epidemic? Are urban populations affected more than rural or semi-rural communities? How is the disease spread if the source is not food or water? Is the disease more frequent in women? Why? Is there really a sex susceptibility or might the higher attack rate in women on the staff of a

hospital indicate occupational hazard? Is this the same with men in military barracks? Does it affect black men and women more? These were some of the questions that preoccupied the medical establishment at the time. But more importantly, what seems to be really crucial in most cases (the total number affected by those epidemics was nearly 1,000 people), is that, first, the symptoms appeared abruptly and, second, that these diseases do not correspond to some organic or virologic aetiology. These, in turn, created a new series of problems for the medical establishment. Are these diseases some form of mental illness? Are they, for example, forms of mass hysteria or psychoneurosis? Can there be some bias in the diagnostic process (which was done by internists, orthopaedists, and neurologists in different instances, thus having little homogeneity)? This is how Acheson (1959), and we have to quote him at length, concludes his report in the *American Journal of Medicine* on the various epidemic outbreaks of the time:

‘Clinical laboratory studies have on the whole proved unhelpful. With the exception of two outbreaks in which a mild lymphocytosis was found, the cerebrospinal fluid has been normal in 95 per cent of cases investigated. An unusual electromyogram has been found in two outbreaks in some sporadic cases. No deaths directly attributed to the disease have occurred and the pathology remains unknown. In spite of the sidest investigations, no known bacterial or viral pathogen has been incriminated. In particular, there is no evidence that the poliomyelitis Coxsackie or Echo groups of viruses have been responsible. Evidence is adduced that the outbreaks can be distinguished on clinical grounds from poliomyelitis, encephalitis lethargic, the anthropod-borne encephalitides, epidemic myalgia and infectious mononucleosis. The disease is not a manifestation of mass hysteria. It is concluded that the disease is recognizable on its epidemic grounds and therefore may properly be considered a clinical entity. In its sporadic form, which is now well documented, the diagnosis should be reversed at present for severe cases with definitive neurological signs including paresis and the characteristic fluctuating course. The disease is

probably due to the *infection by an unknown agent or group of related agents*' (Acheson, 1959: n.p., emphasis added).

There were also several reports of similar outbreaks of epidemic fatigue in the US, although few are described in detail. In 1984, in Lake Tahoe in the US, a severe outbreak of fatigue illness is reported. In many patients affected, Epstein-Barr virus (EBV) antibodies are detected and a causal explanation of definitive organicity by post-infectious mechanisms is claimed. Post-viral fatigue syndrome (PVFS), chronic fatigue immune dysfunction syndrome (CFIDS), chronic fatigue, chronic fatigue & immune dysregulation syndrome (CFIDS), chronic Epstein-Barr virus (CEBV) and chronic fatigue syndrome (CFS) are the different terms given to 'that' condition over the years. By the late 1980s, an illness of severe and prolonged fatigue was becoming known to the public – the media named it the 'yuppie flu' – and an increasing pressure was exerted on the medical authorities to recognise the illness as an entity of its own. In 1988, the Center of Disease Control and Prevention (CDC) in the US suggested a working case definition of CFS, later to be revised and replaced by the 1994 CDC case definition. In that case definition, CFS is defined as an unexplained, persistent or relapsing chronic fatigue of new or defined onset; it is not the result of ongoing exertion; it is not substantially alleviated by rest; and, it results in substantial reduction in occupational, social or personal activities. Additional requirements are the concurrent occurrence of four or more specified symptoms like impairment in short-term memory or concentration, sore throat, muscle pain, headaches, non-refreshing sleep, and post-exertional malaise lasting more than 24 hours. There is no specific diagnostic test and routine medical investigations do not usually find significant abnormalities. Therefore, CFS is diagnosed when other conditions associated with chronic fatigue have been excluded (Fukuda *et al.*, 1994). Since then, the term CFS has been accepted as the most common term for unexplained, severe chronic

fatigue, and the CDC case definition has been the most widely used case definition internationally. Still, other, broader, case definitions have been suggested, as the British or the F case definition that favours fewer symptoms. Despite efforts to reach consensus about case definitions and research criteria, the discussions between scientists and medical bodies are ongoing. Advocates of CFIDS and PVCF in the US and ME in Britain have fought for more exclusive case definitions, emphasising the explicit organicity, the extensive functional impairment beyond fatigue symptoms alone. Patients who were familiar with the then current biomedical research on the illness, later introduced the term CFIDS in an effort to reduce the psychiatric stigma associated with the term CFS. In 1994, in cooperation with an international study group, the CDC revised the diagnostic criteria for CFS. That case definition created a certain amount of medical legitimacy for CFS and allowed researchers to identify more patients for their studies.

Taking the body as the surface of inscription for the struggle of forces that drives history, this genealogy has tried to show how religious-moral understandings of idleness were transformed by the scientific-medical discourses of fatigue and exhaustion. Fatigue was long understood as some deviation of the body's balance, as a spiritual state, until it was re-inscribed as a medical category in the eighteenth century with the emergence of clinical medicine. It is only with capitalism that fatigue becomes a social problem. Fatigue emerges at the point where industrial capitalism requires productive, calculable and docile bodies. When the ascetic morality, that seems to leave the body in its quietude, is superseded, the body becomes a productive machine, the surface upon which economy's needs are invested. When capitalist accumulation becomes biopolitical, the body's energy and fatigue become production's motor and limit. Furthermore, it might be argued that fatigue is simultaneously the index of capital's regulation of the body and of labour's desire for flight from work. The saving of labour time, however, is for capital a necessary requirement, and does not

necessarily lead to the expansion of 'freedom'. Political economy not only knows the worker 'as an animal reduced to the minimum bodily needs'; it also knows him/her as a machine. The limits placed upon labour time are one response to the demands for a more productive and not over-exhausted workforce.

CFS, or ME as it was originally called, was the term given to a series of strange epidemics with no organic aetiology, with questionable 'objectivity'. At a time when contagious diseases seemed to be largely eliminated and discourses of technological and social progress were quite prevalent in western societies, the disturbing power of those epidemics was clear. They were threatening social harmony and medicine's supposedly overwhelming power to define and control life.

Chapter Four

Making CFS Objectivity

CFS: A Heterogeneous Object

The ‘nature’ of CFS is passionately debated by psychiatrists, medical scientists, and patients’ organisations. As with all illnesses, CFS is infiltrated, supported or hindered by various socio-cultural beliefs and values and by economic rationalities. CFS constitutes an economic problem, an educational problem, possibly a contagious disease that needs to be securitised, a scientific mystery, an ‘enigma’ (Pearce, 2006) that needs to be solved, and, finally, a moral problem as the persisting inactivity of these bodies is troubling. CFS bodies are ‘unruly’ and ‘underperforming’; they are bodies that have ‘failed’ to be productive, or to keep up with the frenetic work rhythms many of them previously had (Ware, 1992; Clarke, 2003). It is hard to be unproductive in a ‘productive world’ (Hay, 2010). In western societies, idleness and inactivity are considered a moral failure. An individual’s moral worth can be judged by his/her productivity, and ill bodies that strive to become, once more, productive, are applauded by family members, friends, physicians, and mass media. Tiredness ‘is medicalized and transformed into a syndrome, albeit a very vague one’ (Filc, 2004: 1279). CFS is, in a way, the negative copy of attention deficit hyperactivity disorder (ADHD) because while the former is characterised by the ‘expenditure and waste of energy’ (Lowe, 2002), CFS is characterised by ‘energy shortage’.

Explanations for chronic fatigue have been sought, among others, in viral infections, in the immunological system, in dysfunctions of the nervous system, in sleep patterns, and in genetic composition, but none has been conclusive. CFS was once considered the ‘yuppie flu’, the disease of the upper middle class, but not anymore. CFS was, and is probably now even more, considered a ‘female disease’ because women have taken up ‘many roles’ – one

of the reasons for this is that women seek medical help more readily than men. CFS is more often identified in white, middle class women. Shorter (1986) argues that the nature of ‘medically unexplained syndromes’ (MUSs) has changed, shifting from apparently neurological symptoms such as paralyses, tremors and fits, to more ill-defined and subjective symptoms such as fatigue and pain. Showalter (1997; cf. Dumit, 1997) takes CFS to be a contemporary form of hysteria like Gulf War syndrome (or Gulf War illness (GWI)) or alien abduction. Morris (1998) finds a biological dimension in CFS, but views it as a ‘postmodern illness’ because culture plays a significant role (see Zavestoski *et al.*, 2004: 168). Richman *et al.* (2010) claim that the failure of western biomedicine to provide a viral aetiology for CFS led to largely psychosocial explanations that encompass a flight to a ‘sick role’ in order to escape cultural expectations such as burdensome social roles. As they point out, unlike CFS, multiple sclerosis (MS), which also disproportionately affects women, lacks identified organic aetiology but has managed to overcome its early psychogenic explanation which took stress linked with oedipal fixations as the root. Professor of Immunology and principal medical advisor for Action for ME (AfME), Antony Pinching, states that, unlike CFS, ‘with HIV/AIDS, we were fortunate to have the necessary tools in immunology and virology, as well as the conceptual framework we needed’ (Pinching, 2003: 79). Pinching is concerned with showing that the current lack of ‘interest, enthusiasm, energy, sense of emergency, and – above all – the resources of pharmaceutical medicine’ is unjustified (Pinching, 2003: 78). But, as he goes on to add,

‘biomedical solutions are insufficient in themselves, whether for AIDS/HIV, or any other condition. What they can do is provide some anchorage against shifting social constructs of illness, of which perhaps CFS/ME is one of the most evident current exemplars’ (Pinching, 2003: 79).

Some of the reasons Pinching gives about why CFS has not attracted much attention include the lack of aetiology, the marginalisation of patients, its small market size, but also, at times, patients' 'unproductive' activism (e.g. personal attacks on scientists or complete rejection of biomedicine).

When it comes to ethnicity and socio-economic status, in community-based studies in the US, for example, there appears to be a higher prevalence of CFS in people of lower socio-economic groups, and in African-Americans and Latino populations (Luthra and Wessely, 2004). However, Luthra and Wessely (2004) note that, first, these populations are not frequently referred for diagnosis and, second, that it perpetuates the myth inherited from neurasthenia which takes CFS to be an illness of the 'developed' countries. Neurasthenia, influenced by evolutionism and 'race' thinking, was supposed to be a disease of 'brain workers' and of the 'civilised races', and only later became one of the 'American Negro [sic]' (Luthra and Wessely, 2004: 2364). Europeans and Americans were more 'developed' and 'sensitive' than other 'races'. In anecdotal fashion, Beard argued that 'although white people could not work all day like black people, they could channel their energy into specific tasks and had a sophistication that black people lacked' (Luthra and Wessely, 2004: 2364). Luthra and Wessely criticise lay accounts, such as those of the UK patient group Action for ME (AfME), for their racist language (e.g. 'less civilised' and 'primitive cultures'). The over-exposure of non-western countries to viruses is supposed to have strengthened them. In the UK, and in other countries, CFS seems to affect all social classes equally.

In terms of economics, in 2003, according to a BBC report, the AfME estimated that the annual cost of CFS in the UK was £3.5 billion, almost £15,000 for each person diagnosed with the syndrome.¹ A report, also conducted in 2003, by researchers at Sheffield Hallam University, suggested that there is significant cost in terms of

‘the loss of tax revenue from [CFS] people who have to stop working because of the condition and the ... paying incapacity and other benefits. The cost of treating patients with ME is estimated at £210m per year or £900 per person. Most of this money represents the costs of medical consultations and tests to exclude other illnesses and money spent on drugs aimed at managing the condition’.

Another issue of concern is that in studies of chronic fatigue, the symptom pattern observed in child and adolescents samples has been found to be similar to that observed in adult presentation with a few exceptions. Most children with CFS also display an impaired school performance and a decrease in social activities. According to a 1994 report in *The Sunday Times* (Van Hoof *et al.*, 2006: 46), the impact of this illness is profound as one survey suggested that it is responsible for 50% of long term absences from school in the UK. Widespread scepticism among medical professionals increases when confronted with child CFS. As a result, CFS organisations argue, after routine examination the child is frequently dismissed as suffering from a psychogenic illness. The core problem of this scepticism is that it spreads to educators and possibly to members of the family. Consequently, patients and parents must fend for themselves, arranging school accommodation and fighting allegations of child abuse and neglect for truancy from school, they add. ‘The lifelong potential for harm in this scenario is enormous as it occurs during an important period of identity formation’, Van Hoof *et al.* (2006: 46) write. This alarmist discourse brings to mind ADHD. A good number among the CFS community assert that because of the beliefs of the ‘Wessely School’ (i.e. the psychiatrists affiliated with the psychiatrist and life-long ‘denyalist’ of CFS Simon Wessely, whom I discuss later on) children with CFS have been diagnosed as having ‘pervasive refusal syndrome’ and have been forcibly removed from their distraught parents, who themselves have been labelled as having Munchausen’s by Proxy syndrome (MBPS), a rare syndrome which involves the exaggeration or fabrication of illnesses or symptoms by a

primary caretaker and a damaging label that is never deleted from their medical records. Of course, this situation generates further concerns. As Bryant writes on the website of the UK CFS organisation The One Click Group:

‘What is Peter Lachman, an expert in child abuse, doing running a ‘CFS/ME’ Centre for children bearing in mind the massive controversy and scandal that has for many years surrounded false Munchausen Syndrome by Proxy accusations levied at the parents of ME/CFS children? Precisely what experience has this man got in the field of ME/CFS?’²

The growing involvement of CFS patients in the management and care of themselves and of their children is clearly illustrated in the above example. Rose (2006) has provided an account of how such ‘disorders without borders’, as he calls them, come into existence. Somatic symptoms ‘at least as a part pool of malaise available to be recoded as physical illness [are] also available to be recoded in psychiatric terms’ (Rose, 2006: 480). The recoding of this ‘pool of malaise’ can be done in various ways. It may be recoded ‘by those carrying out public health surveys with a gaze attuned to the symptomatic’ (Rose, 2006: 480). It may be recoded by ‘proto-patients’ themselves, once categories like pre-menstrual dysphoric disorder or panic become available to them, and by medical market research agencies seeking to define potential markets for their products. Finally, it may be recoded by psychiatrists and general practitioners (GPs). The recoding depends on a norm against which experience can be judged as abnormal and a discourse to enable it to be understood and communicated. As Rose notes, these disorders ‘are experienced and coded, by individuals and their doctors, in relation to a cultural norm of the active, responsible, choosing self, realizing his or her potential in the world through shaping a lifestyle’ (Rose, 2006: 480). These processes are associated to a great degree with the expansion of psychiatry in everyday life. It is now a few years that an

alarmist discourse has been in circulation, according to which around half of the population will meet the criteria for mental disease at some point in their life, and which will unavoidably affect national productivity. According to one report for the European Commission (EC) Green Paper, *Improving the mental health of the population*, ‘mental ill health costs the EU an estimated 3%-4% of GDP, mainly through lost productivity’ (quoted in Rose, 2006: 469).

If CFS is a scientific conundrum, as I suggested in the beginning, the question then becomes who has the power to define it. Psychiatrists, immunologists, virologists, geneticists, neuroscientists, and patients’ organisations, all engage in multiple conflicts and collaborations to construct the truth of CFS. As we will see, nosology and diagnosis, closely connected as they are, become battlefields of intersecting and competing economic and scientific interests and moral beliefs. Diagnosis becomes a field of contestation not only on a local scale, where, for instance, psychiatric symptoms are redefined as neurological, and vice versa (Horton-Salway, 2002), but on a larger scale too because state and welfare institutions are concerned with the ‘excessive’ welfare claims being made by parts of the population. As long as there is no ‘objective’ diagnosis, there is a space for ‘malingering’.

On the other hand, there is a different set of problems, not unrelated to the diagnosis and treatment of this disorder. If biology is no longer fate but something malleable and improvable, then why are problems social in nature described as simply biological, as in the case of panic disorder (Orr, 2005)? The increasing dissolution of the nature/culture divide leads to interesting and at times quite perplexing questions. Indeed, biosociality might be a contestable concept because it can be argued that biology is ‘already, in an important way, social?’.³ As already pointed out, the new types of sociality and citizenship that are being assembled around the proliferating categories of somatic suffering, and genetic risk and susceptibility create new forms of activism and contestation around recognition, access to

knowledge and claims to expertise, and reshape the way in which illnesses and diseases are understood by authorities. The notion of biosociality has similarities with what Brown *et al.* (2004) call ‘embodied health movements’ (EHMs). An important, if not the most significant, precursor of these movements is the Women’s Health Movement with its attempts and successes to de-medicalise women’s bodies and health (Halfmann, 2012). Here some brief remarks about biomedicine and its significance in western societies are required in order to fully appreciate CFS partial biomedical existence and its potential effects for CFS patients.

Although biomedicine is a remarkably slippery concept, it has been identified with western scientific medicine that emerged in the mid-nineteenth century as a hybrid branch of the biological sciences and which had by the beginning of the twentieth century demonstrated its value as an effective tool for the diagnosis, treatment, and prevention of disease (Baronov, 2009). Biomedicine has been, not without good reasons, heavily critiqued and contested for being too narrow, mechanistic, disembodiment, and politically biased (Baronov, 2008). As is known, starting in the 1970s, biomedicine was subjected to considerable critique for its scientific reductionism and alienating effects (e.g. Engel, 1977). Feminism, medical sociology and the sociology of health and illness are some of the traditions and disciplines that have pointed out the ways biomedicine ignores broader social, cultural and institutional contexts and is thus an individualising and depoliticising institution. It can be argued that biomedicine operates as a ‘regime of truth’ (Clarke *et al.*, 2003: 166) which subjugates other discourses. This does not mean there is no resistance within (and against) biomedical discourses. It is ‘too readily assumed that discourses translate into practices and that discursively constituted subjectivities evoke the subjects they seek’ (Clarke *et al.*, 2007: 140). The move from medical sociology – which is, however, not as a-theoretical and policy-driven as is often assumed – to the sociology of medicine to the sociology of health and illness has helped in taking matters of health, illness and healing beyond the strict biomedical remit

(Williams *et al.*, 1998). The difference between the sociology of medicine and the sociology of health and illness is that while the former focuses on the role of health professionals and the patient-practitioner relationship, the latter examines health and illness in relation to institutions such as family and employment.

Timmermans and Almeling (2009; see also Lupton, 1997; Halfmann, 2012) argue that medical sociology has historically seen objectification, commodification, and standardisation as pointing out pathologies of modern medicine such as depersonalisation of care and bureaucratic control, while this is not necessarily the case. Medical sociology has by and large perceived medicalisation as dehumanising (medical sociology and related disciplines draw upon the ultimately problematic phenomenological distinction between the ‘objectified body’ and the ‘lived body’ and, concomitantly, between disease and illness). A classic work in this conceptualisation of health care as dehumanising is Ivan Illich’s book *Medical Nemesis* (1976). For Illich, health care is a system of social control charged with iatrogenic effects. Timmermans and Almeling (2009), however, argue that recent work in science studies, economic sociology, and sociology of health have explored how objectification, commodification, and standardisation produce a variety biomedical achievements. One of the examples they use is Thomson’s (2005) ethnographic work in an infertility clinic. Thomson undermined the opposition between agency and objectification which leads either to viewing a woman as helpless and saved by infertility technologies or victimised by them, by showing that, on the contrary, women actively participate in and demand their own objectification. Women in infertility clinics are objectified multiple times over, but this does not imply loss of individuality and autonomy. Women just exercise their agency in their active participation in each of these forms of objectification. This resonates well with Mol’s (2002) work on atherosclerosis. Mol has also shown that medicine interacts and shapes its objects in various ways. Atherosclerosis is enacted as an object in a range of overlapping and interrelated

practices: the vascular laboratory; the consulting room; the lecture theatre of the medical school, and so on. In each case, the meaning of atherosclerosis is enacted in practices by an assemblage of material and human actors, but this does not mean there are different atheroscleroses. Mol's argument is that ontology is multiple, that atherosclerosis is multiple in its enactment (see also Law, 2004; Latour, 2004a). Berg and Akrich (2004: 3) point out that the body is 'fundamentally both discursive and material, both historical and real'. Therefore the body is both constantly constituted by various discourses and performed in various ways without ever being a finished 'product'. I would now like to turn our attention to biomedical objectivity in order to have a better understanding of the ways biomedical evidence for illnesses such as CFS are made.

We have already seen in chapter 1 that scientific objectivity is the product of conflict and negotiation between various actors in given sociotechnical networks. Cambrosio *et al.* (2006; 2009) argue that the evolution of western medicine since the Second World War can be described as a realignment of biology and medicine that has resulted in the emergence of new distinctive biomedical practices that have been accompanied by the production of a new type of objectivity that they call 'regulatory objectivity' (see also Moreira *et al.*, 2009). By this they mean a novel form of objectivity that is based on the systematic recourse to collective production of evidence. This form of objectivity and its concomitant evidence are produced by inter-laboratory studies, multi-centre clinical trials and research consortia that develop devices such as clinical and laboratory guidelines. 'Regulatory objectivity' consistently results in the production of entities and protocols that combine biology and pathology in new ways that are most often produced through concerted programmes of collective action. These actions incorporate high degrees of reflexivity in the sense that biomedical practitioners take into account, in their debates and discussions, the conventional nature of their actions. Cambrosio *et al.* (2006: 193) write that:

‘[w]hen a patient consults a hospital practitioner or is admitted to hospital, s/he sets out on a non-linear trajectory divided into diagnosis, treatment, and evaluation stages where the results of one stage may feed back into a previous stage, as when the results of therapy modify the initial diagnosis or prognosis’ (Cambrosio *et al.*, 2006: 193).

The importance they give to the ‘non-linear trajectory’ of a patient in the stages of diagnosis, treatment and evaluation points out the increasing ‘complexification’ of modern biomedicine. As already argued, the role of the contemporary clinic should not be underestimated. Rather than being marginalised and merely applying knowledge produced elsewhere (i.e. the laboratory), as Latimer *et al.* (2006: 620) argue, ‘we are witnessing the rebirth of the clinic as a site of production of medical knowledge’. There is, in fact, an ‘intersection of the laboratory, the clinic, industry, and mechanisms of regulation in networks of interdependence’ (Latimer *et al.*, 2006: 606).

Let us go back to CFS. Currently there is no conclusive, ‘objective’, account of what causes CFS. In other words, CFS still lacks ‘disease specificity’, i.e. a conceptualisation of diseases as a ‘stable entities that exist outside of their embodiment in particular individuals and that can be explained in terms of specific causal mechanisms that are located within the sufferer’s body’ (Lakoff, 2008: 744). CFS is often described as a complex or multi-system illness (e.g. Johnson and DeLuca, 2005; Ulvestag, 2008; Ortega-Hernandez, 2009; Holgate *et al.*, 2011), as other illnesses like multiple chemical sensitivity (MCS) or Alzheimer’s (Lock, 2007). CFS is also considered as one of the so-called ‘emerging functional syndromes’ at the end of the twentieth century, such as fibromyalgia syndrome (FMS), premenstrual syndrome (PMS), and MCS. All these syndromes can also be grouped under what Dumit (2000; 2006) denominates ‘new socio-medico disorders’. Although these disorders are quite different from each other, their common denominator is that they are found on the border between the

mental and the biological, and are open to debate. De Wolfe (2009: 5) points out that ‘discourses on CFS are diverse and sometimes contradictory’. The uncertainty and openness to contestation in the field of medicine affects the understanding patients and their organisations have of the illness and of themselves and, subsequently, the different ways they may seek research, treatment, and welfare benefits. CFS is a heterogeneous object; heterogeneous in the ways it is classified, diagnosed, treated, researched, and lived.

If CFS is not considered as a psychosomatic illness but instead precisely as something that borders the mental and the biological, then not only is there nothing that excludes the possibility of its re-definition in purely biological terms, but this seems quite plausible if we consider the growing biomedicalisation of psychiatry. According to the majority of psychiatrists, extreme anxiety is somatised and manifested as fatigue and/or other symptoms. Here we have to briefly look at the notion of ‘psychosomatic’. There is really little agreement over what precisely ‘psychosomatic’ refers to, and it is necessary to simplify a complex history of terminological conflicts and debates. The word ‘psychosomatic’ can be traced back to 1818, in the writings of the German psychiatrist Johann Christian August Heinroth (Lipowski, 1984: 155). Our understanding of that notion is of course tied to two well known, closely connected forms of dualism, greatly important for modern western thought, commonly considered to originate in Descartes’ philosophy: the ontological dualism between mind and body and the epistemological dualism between subject and object (cf. Colebrook, 2000). In this perspective, ‘the most natural way of interpreting the expression ‘psychosomatic’ is a type of illness where psychological factors constitute a specific cause, to be distinguished from illnesses that supposedly are not ‘psychosomatic’ (Greco, 2001: 474). That is why conditions like irritable bowel syndrome or hypertension have followed an uneasy path between psychiatry and organic medicine, according to Lipowski (Greco, 2001).

It is in this context, perhaps paradoxically, that the CFS community can be seen as a biosocial community in search of the ‘bio’, of a clear ‘biomarker’.

A biomarker is ‘a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes or pharmacologic responses to a therapeutic intervention’ (quoted in Singh and Rose, 2009: 204). Biomarkers were introduced in the 1970s, although their use in medical literature has expanded tremendously only since the beginning of this century. They have rendered the diagnostic practices more ‘objective’, and have given modern medicine its scientific standing (Metzler, 2010). The ordering of diseases is no longer focused on patients’ narrations of their experiences and the clinician’s interpretation of observable clinical symptoms. Most early biomarkers were either physiological markers (e.g. blood pressure) or were based on laboratory parameters (e.g. cholesterol levels) but the current generation of biomarker technologies ‘tends to measure ever increasing molecular substances’ (Metzler, 2010: n.p.). Biomarkers can be used for various purposes: to diagnose a condition; to predict the outcomes for an individual with the condition; to predict whether the individual will benefit from a particular treatment; and to assess an individual’s response to this treatment (Singh and Rose, 2009: 204).

The CFS community’s search for a biomarker can be understood as a struggle against the psychiatrisation of CFS, although, as we are going to see, this struggle is characterised by tensions, ambiguities and uncertainties with regard to psychiatry’s role in explaining and treating this condition. Psychiatric power still trains, improves and reforms bodies. The re-biologisation of psychiatry is normalising CFS sufferers differently because now the brain is emerging as the possible objective explanation of the illness. The brain is increasingly considered the locus of ourselves, of our ability to plan and control ourselves. While to talk about neurocognitive determinism and reductionism would be far-fetched, the imperative of ‘taking care of one’s brain’ (Brenninkmeijer, 2010) is quite a different matter.

The epistemic uncertainty that surrounds the illness creates a relentless process of surveillance and intervention, and multiple forms of subjectification and (self-)objectification, aiming at the extraction of optimal capacities from CFS bodies. What is common in all these forms of subjectification is the discursive positioning of CFS patients as ‘autonomous’, ‘self-determined’ and ‘active’ citizens. The imperative of ‘self-management’, of ‘accepting responsibility for those parts of our illness that are under our control’, to use the words of a CFS self-help health site, is widespread in popular health sites, occupational therapy manuals, and patient organisations’ discourse.⁴ Therefore, we have to examine the ways CFS subjects are constructed through meticulous surveillance and examinations. Are CFS subjects ‘just tired’ or also ‘sleepy’? (Neu *et al.*, 2008). Can a low sugar low yeast (LSLY) diet or healthy eating (HE) improve their quality of life? (Hobday *et al.*, 2008). Were they traumatised in early childhood?⁵ These are but a few of the numerous, and at times conflicting, interpretations of how risk is conceptualised in CFS studies. Let us now turn our attention to the nosology and diagnosis of CFS and the aims and operations of CFS advocacy groups.

The Nosology and Diagnosis of CFS

Nosology deals with the classification of diseases. Diseases may be classified by aetiology, by the pathogenesis by which the disease is caused, or by symptom(s). Alternatively, diseases may be classified according to the organ system involved, though this is often complicated since many diseases affect more than one organ. A common difficulty in nosology is that diseases often cannot be defined and classified clearly, especially when aetiology or pathogenesis is unknown. Thus diagnostic terms often only reflect a symptom or cluster of symptoms, i.e. a syndrome. We could give many examples of how a scientific ‘discovery’ re-classifies a biological condition. For instance, after the synthesis of estrogen (the main female

sex hormone) in the 1940s, menopause became a central issue in the matter of women's aging and was classified as an 'estrogen deficiency disease' by the World Health Organization (WHO) in 1981 (Coney, 1995). Because biomedicine is based on the notion that disease is deviation from a 'biological norm', the positioning of pregnancy as the 'normal' state for women led to the development of classifications that reflected menopause as 'living decay' (Coney, 1995: 1). Sulik (2009: 1059) points out that after 'a condition has been medicalised, it can be re-medicalised through domain expansion; as new knowledge alters the medical definition, new interventions are developed, or new diagnostic tools are identified or improved'.

In the case of CFS it has been observed that several working definitions and diagnostic protocols, some complementary, some contradictory, exist defining it as a category of disease. As Moss put it:

'Because both the identifying features of the constellation of symptoms forming an ill body with ME/CFS and the parameters of the distinguishing characteristics going to categorize ME/CFS fluctuate, the interpretations of the disease and ill body are contestable' (Moss, n.d.: n.p.).

Again following Moss, in its international classification of disease (ICD-10, 1996), the WHO categorises Benign Myalgic Encephalomyelitis (a term not in use since the 1970s) under the general heading of 'Disorders of the Nervous System (G00-99)', the sub-heading 'Other Disorders of the Brain (G93)', and under the specific heading of 'Post-viral Fatigue Syndrome' (PVFS) (G93.3). CFS is categorised under the heading of 'Symptoms, Signs and Abnormal Clinical and Laboratory Findings, Not Elsewhere Classified (R00-R99)', the sub-heading of 'General Symptoms and Signs (R50-R69)', and under the specific heading of 'Chronic Fatigue, Unspecified (R53.82)'.⁶ The WHO also categorises fatigue syndrome, a

term sometimes synonymous with CFS, under the general heading of ‘Mental and Behavioural Disorders (F00-F99)’, the sub-heading of ‘Neurotic, Stress-related and Somatoform Disorders (F40-F48)’, and under the specific heading of ‘Neurasthenia (F48)’. The category ‘Somatoform Disorders’ includes ‘Functional somatic syndromes’, which denote physical symptoms that cannot be attributed to organic disease and appear to be psychogenic. The ambiguity over the definitions of ME and CFS is clear. Of course a number of attempts have been made to define ME and CFS but none has been universally accepted. For instance, the English Report of the 2002 *Chief Medical Officer CFS/ME Working Group* called for a consensus on terminology and definition, and while awaiting this, suggested that a composite term should be used and that CFS/ME should be considered as one illness or a spectrum of disease. The compound ‘CFS/ME’ or ‘ME/CFS’ is sometimes preferred instead of CFS as it is believed that it implies a more serious illness than CFS which focuses simply on fatigue.⁷ For its part, the National Health Service (NHS) recognises CFS, or ME, as a real disease associated with altered neural functioning, causing significant and, in some cases, profound disability.⁸ The ambiguity increases as different institutions and classification systems define ME and CFS in different ways.

The ICD is very important in the making of CFS objectivity. The ICD, which originated as a means for describing causes of deaths, is used by medical insurance companies, epidemiologists, government health officials, statisticians, clinicians and managers, and functions as a creator of inscriptions that can travel unchanged and be combinable and comparable (Bowker and Star, 2000). As Bowker and Star point out, all classificatory work practices involve politics, and ICD, which should be considered a classification system or scheme, is a text or product reflecting a long and diverse history of bureaucratic struggles, differences in world-view among health officials, medical specialists, etc., and systematic erasures of such struggles.

One of the leading researchers in CFS is Simon Wessely, professor of epidemiological and liaison psychiatry at the Institute of Psychiatry at King's College London. Wessely is also Vice Dean for Academic Psychiatry, Teaching and Training at the Institute of Psychiatry, as well as Director of the King's Centre for Military Health Research. He is, in addition, honorary Consultant Psychiatrist at King's College Hospital and Maudsley Hospital, as well as Civilian Consultant Advisor in Psychiatry to the British Army. Wessely has published a great number of papers on various subjects including epidemiology, post-traumatic stress disorder (PTSD), CFS, somatisation, military health and terrorism. Wessely has consistently and repeatedly denied there is any 'objective', pathological evidence in CFS patients, and can hence be regarded as the strongest 'denialist' of CFS. Wessely believes that CFS is basically the same as neurasthenia: 'Neurasthenia would readily suffice for ME', he has written (David and Wessely, 1993: 1247-1248). Wessely believes that attribution by patients to a virus is somatisation par excellence. The relation between Wessely, and psychiatry more generally, and the CFS community can be described in polemic terms. According to Emeritus Professor of Medicinal Chemistry at the University of Sunderland, Malcom Hooper, whose views have gained much currency in the CFS community, and his collaborative work with the ME Association UK (MEA) (Hooper, 2010), the 'Wessely School' takes CFS to be a condition of 'medically unexplained' fatigue that is perpetuated by 'inappropriate illness beliefs', 'pervasive inactivity', 'current membership of a self-help group', and 'being in receipt of disability benefits', and that it should be managed by behavioural interventions (PACE Trial Identifier, section 3.9).⁹

To make better sense of this conflict we have to revisit the notion of 'somatisation'. According to a paper Wessely published in the *Scandinavian Journal of Work, Environment & Health*, somatisation has many meanings (Wessely, 1997). It can either refer to a process

or to a discrete disorder (the DSM-III view) and, following Sharpe *et al.*, (1995) it can refer to:

‘(i) symptoms (number and type), (ii) psychiatric diagnoses (depression, anxiety, panic, etc), (iii) cognitions (fear or conviction of disease) and attributions (illness belief), (iv) behavioural and functional impairment, and (v) pathophysiological disturbance (hyperventilation, inactivity, etc)’ (Wessely, 1997: 19).

According to psychiatric discourse, as Courjaret (2009: 14) points out, ‘CFS subjects have a tendency to minimize psychological contributions to their illness and to view the causes for bad events as external, stable, and global’. They suffer from depressive attributional style or ‘learned helplessness’. According to some researchers, CFS subjects have a ‘maladaptive perfectionist personality style, which involves severe criticism and is associated with dissatisfaction with aspects of oneself, with personal relationships, and with life in general’ (Courjaret *et al.*, 2009: 14). They are ‘action-prone’, that is ‘oriented toward direct action and achievement, putting themselves at risk of acute or chronic physical overload and/or sleep deprivation’ (Courjaret *et al.*, 2009: 14). CFS subjects are deemed to be ‘more cautious, careful, fearful, insecure, or pessimistic even in situations that do not worry other people’ (Courjaret *et al.*, 2009: 14). In contrast, according to Ortega-Hernandez (2009: 600), CFS is a complex disease ‘in which several risk factors might interact to cause its full expression’. Ulvestad (2008) proposes the dissolution of the ontological separation of the body and the mind, so well maintained in psychological medicine, suggesting that CFS can be properly understood only by taking an integrated perspective in which evolutionary, developmental and ecological aspects are considered. That integrative approach, supplemented by complexity theory and psychoneuroimmunological research, is capable of explaining why

there are so few structural aberrations to be found in CFS and why specific treatment is so difficult to establish, Ulvestad argues. All individuals with CFS are diseased in their own way, according to Ulvestad, and that is why he emphasises the need to study the development of personalised life histories.

The ‘Wessely School’, according to Hooper (2010) and to a large part of the CFS community – although there is no great homogeneity in the CFS community, it seems that it shares a common distrust for psychiatry – claims there are no physical signs of disease and assert that there is no pathology causing patients’ symptoms, simply that patients are ‘hyper-vigilant’ to ‘normal bodily sensations’; that is why they classify CFS among functional somatic syndromes (FSS) – ‘functional’ here denotes ‘non-organic’. According to the CFS community, whilst ‘Wessely School’ psychiatrists continue to believe, teach and advise government agencies that CFS is a behavioural disorder that must be managed by behavioural interventions and incremental aerobic exercise, and with two of the Principal Investigators (PIs) asserting it can be ‘cured’ by those interventions, CFS affects every system in the body and many physiological abnormalities have been documented over the years, which Wessely and other psychiatrists disregard, including: abnormalities of the nervous systems, cardiovascular dysfunction, respiratory system dysfunction, a disrupted immune system, virological and neuroendocrine abnormalities, defects in gene expression profiling, abnormalities in HLA (Human Leukocyte antigen) expression, and gastro-intestinal, reproductive system, and visual dysfunction. CFS organisations claim there have been almost 5,000 papers since the first outbreak in 1957. As Professor of Harvard Medical School, Antony Komaroff, put it in the 2006 Centers for Disease and Prevention (CDC) press conference,

‘there are now over 4,000 published studies that show underlying biomedical abnormalities in patients with this illness. It’s not an illness that people can simply imagine that they have and it’s not a psychological illness. In my view, that debate, which has waged for 20 years, should be over’ (Komaroff, 2006).

Similarly, Professor of Medicine and Immunology at the University of Miami, and one of the world’s foremost HIV/AIDS and CFS physicians, Nancy Klimas, has been quoted in the *New York Times* saying:

‘I hope you are not saying that ME/CFS patients are not as ill as HIV patients. I split my clinical time between the two illnesses, and I can tell you that if I had to choose between the two illnesses I would rather have HIV’ (quoted in Hooper, 2010: 1).

As other health activists had done, CFS organisations collaborate with, or employ, ‘sympathetic’ scientists, and try to educate themselves about the intricacies of biomedicine. CFS organisations have a widespread disbelief of the psychiatric community (Figure 3), and,



Fig. 3. Cartoon by Trish Campbell of the Warwickshire Network for ME. Reproduced from ME Research UK (<http://www.mereseach.org.uk/information/publications/niceguideline.html>).

at times, even the profession as a whole, and accuse it of deliberately ignoring and misinterpreting all these sources of biomedical evidence (Hooper, 2008), something which has been confirmed to a considerable extent by my online research. Many CFS patients lament that they are not being provided with special facilities other than psychiatric clinics; they are not being offered appropriate medical care; doctors are not being offered special training; they are not being offered state benefits; and finally that insufficient biomedical research is being conducted. Psychiatrists marginalise individuals with CFS by a number of tactics and practices, such as: they attempt to subvert the international classification of this disorder from neurological to behavioural; they propagate ‘untruths’ about the disorder; they build affiliations with corporate industry; they denigrate those with CFS; they suppress published findings; they refuse to see or acknowledge the multiplicity of symptoms and attempt to ‘make ME disappear in a sea of chronic fatigue’. As I have suggested, not everyone agrees that ME and CFS are the same condition; instead many, especially in the UK, only view ME as a ‘testable’ and ‘scientifically measurable’ disease. CFS is the term often preferred by doctors, while ME is often the preferred term of people with CFS. On the other hand, the term chronic fatigue immune deficiency syndrome (CFIDS) is often used instead of CFS in the US. Doctors prefer the term CFS because in most cases the main symptom is chronic fatigue. The results of psychiatry’s ‘war’ against CFS are: the arresting and sectioning of protestors; the silencing of CFS patients through being given a psychiatric label; the labeling of CFS patients as the ‘undeserving sick’, as ‘malingerers’, and the forcible removal of sick children and adults from their homes.

Indeed, although incarceration is not common practice any more in western societies, there are two cases of patients with CFS in the UK that were committed to psychiatric units, a treatment that is considered by many in the UK CFS blog community and the general CFS

community, as barbaric and inhumane. One of the two cases was, as we have already mentioned, that of Sophia Mirza who died in November 2005, having been forcibly incarcerated in a mental institution on the basis that she was exhibiting illness behaviour.

‘I know that in today’s society that we have to put up with a lot of negativity and disbelief from others but I honestly was not aware that this barbaric treatment was still happening to people’, Judy writes in the CFS blog. As she goes on to add:

‘I honestly hope that through the current research that is going on at the moment [referring to the research on the XMRV virus]... that their findings will at one point resolve the mystery behind the current situation that many sufferers are in today... and that the current research does not prove to be unfounded and placed in a database like the rest’.¹¹

Samantha, another user of the CFS blog, believes that it is ‘upsetting[,] it doesn’t take a genius to see all the patient sy[mp]toms are real and the body[’]s obviously fighting some things[,] it’s pure arrogance’. She thinks that the ‘testing is out of date’. The medical professions have not researched enough, which is why they rely on a test that does not respond to the ‘reality’ of CFS. New tests would be able to show and guarantee the biological abnormalities in their bodies.

That is what diagnosis does. It ‘provides a structure to a narrative of dysfunction ... and imposes official order, sorting out the real from the imagined’ (Jutel, 2009: 278-9). Diagnosis is about ‘segmenting and ordering corporeal states, valorizing some, disregarding others, and in any case, exerting an important material force’ (Jutel, 2009: 278); diagnosis is about ‘making up people’ (Hacking, 2006). Ian Hacking has investigated the history of numerous illnesses such as Alzheimer’s and multiple personality disorder (e.g. Hacking, 1986/1995; 2005; 2006b). For instance, as Hacking suggests, as a diagnosis, Alzheimer’s ‘is a product of

advocacy groups' (Hacking, 2005: n.p.). For Hacking, while Alzheimer's is an 'absolutely objective' neurological condition, it might not have been remembered had it not been for the vigorous lobbying of associations of families whose elderly members had dementia. 'The history of late 20th-century medicine will not only be a history of truly breathtaking triumphs but also a history of advocacy groups', he writes (Hacking, 2005: n.p.). This can be explained by the not too rigid distinction Hacking (1986/1995) makes between 'natural kinds' and 'human kinds'. 'Human kinds' refer to the social groups whose description depends on knowledge produced by the 'human' sciences, and which differs from the 'natural kinds' sciences like physics claim to 'discover' because humans interact with their descriptions, change their self-perceptions and behaviour, forge group identities, and often struggle to changes to the classifications about them. As Hacking (1986/1995: 369) puts it, 'classifying people works on people, changes them, and can even change their past'. Scott's (1990; see also Brown, 1995) account of the incorporation of PTSD into the DSM-III is a good illustration of the considerable individual and collective effort required by numerous Vietnam veterans to obtain acknowledgment that their psychological distress is different from psychosis, cowardice, or malingering.¹² Homosexuality's demedicalisation in the DSM-III after challenges from the gay community is another good illustration of the way medical categories are linked with social problems and social movements (Bowker and Star, 2000: 101).

CFS is recognised as being heterogeneous and as probably consisting of a number of sub-types, but these have not yet been specifically categorised. Currently there are no specific tests available to confirm the presence of the illness and routine medical investigations usually do not find significant abnormalities. Therefore, CFS is defined clinically and diagnosed when other conditions associated with chronic fatigue have been excluded (Fukuda *et al.*, 1994), what is known as 'differential diagnosis'. A series of negations is what leads to

a determination. There are many conditions with the same symptoms but differential diagnosis, if carefully applied, should enable CFS to be accurately identified, according to the NHS. As the NHS suggests, it follows that care of patients with CFS must be specifically and carefully 'tailored' to the symptoms, needs and circumstances of the individual patient. Also according to the NHS, many people consult their GP because they think they have CFS, but only a small minority is diagnosed with it.¹³ CFS is not diagnosed in people who simply feel tired all the time. There are other symptoms that help to confirm the diagnosis. The GP asks the patient about his/her medical history and carries out a physical examination. The patient may then have blood tests and scans to rule out other conditions like Adrenal insufficiency, 'Malignancy', HIV/AIDS and Liver Disease. Other laboratory studies that often take place and may indicate CFS in the patient are thyroid test and the Erythrocyte Sedimentation Rate (ESR) and White Blood Cells (WBC) tests. The last two are markers that can show that there is some 'abnormality'.

Diagnosing CFS is therefore a process which selects and orders corporeal states while it excludes others. Being a cluster of symptoms, the diagnosis of CFS is quite a complex procedure, especially according to the international consensus case definition reported in Fukuda *et al.* (1994) which, as already mentioned, has more symptoms than the Australian or the British. That case definition of CFS is as follows:

1. Fatigue lasting for six months or longer where other known causes have been excluded from history, physical examination, mental state assessment and appropriate tests.
2. Four or more of the following present concurrently for six months or longer:
 - Impaired memory or concentration
 - Sore throat

- Tender cervical or axillary lymph nodes
- Muscle pain
- Multi-joint pain
- New headaches
- Unrefreshing sleep
- Post-exertion malaise

According to Shepherd (2006: 666), the following basic investigations should always be carried out before a diagnosis of CFS is confirmed:

- Full blood count and differential
- Erythrocyte rate (ESR) or acute phase protein changes
- Blood chemistry: calcium, sodium, potassium, urea, etc.
- Creatine kinase (to help exclude muscle disease)
- Thyroid and liver function tests
- Urine tests for renal disease and diabetes

Second line tests, which may be appropriate in certain circumstances, include:

- Antibody screening tests for specific infections, e.g. hepatitis B/C; Lyme disease; parvovirus
- Screening for coeliac disease if there are irritable bowel-type symptoms or unexplained anaemia
- Autoimmune and rheumatology screening if joint pains are prominent
- MRI scan if another neurological illness seems possible on the basis of symptoms and signs
- Pituitary and endocrine function if there are symptoms and signs of an endocrine disorder

According to the *Scottish Good Practice Statement on ME-CFS*, '[p]atients should be encouraged about establishing the correct diagnosis and may need to be reassured that listing those other conditions for the purposes of differentiation does not imply any judgment about the nature of ME/CFS'.¹⁴

Professional factors are very important in the diagnostic process. An individual having symptoms that fall in the range of CFS can be diagnosed by a GP, a consultant psychologist, a general medical physiologist, or a private doctor consultant in infectious diseases. In other words, there seems to be considerable professional conflict over the diagnosis of CFS. For instance, the question of whether the diagnosis of CFS should be applied in patients with co-morbid psychiatric disorders has been hotly debated. As Evengård *et al.* (1999: 457) put it: 'In the current case definition, bipolar disorder, 'melancholic depression', and several comorbid psychotic disorders disallow the diagnosis of CFS, whereas major unipolar depression, dysthymia and various anxiety disorders do not'.

Diagnosis is also an important site of contestation and compromise in clinical settings because different parties come with different understandings, values and beliefs. Cooper's (1997; cf. Deale and Wessely, 2001) account of CFS patients' 'illness careers' provides a nice illustration of the difficulties in obtaining a 'correct' diagnosis and achieving legitimate 'sick role' status. Problems of miscommunication, dismissal and disbelief are quite common. As one of my informants, Robert, put it: 'GPs are consciously uninformed' (Interview 1). As a result, these individuals often change their attitudes towards either particular doctors or even the medical profession in general. When sufferers start to take a more active role in the diagnostic process, sometimes diagnosing themselves and pushing for other consultants or doctors who could give a more definitive diagnosis, they recount that doctors could not accept this threat to their professional knowledge and power, and attempt to retain control not

only over the patient but also over their claim to knowledge, often becoming angry and abusive. Furthermore, when confronted by patients who had obtained a diagnosis from elsewhere, or gone to self-help groups for advice, again doctors may become abusive. The discursive construction and contestation of CFS in the diagnostic process is significant as several studies have shown (Åsbring and Närvänen, 2003; 2004; Horton-Salway, 2001; 2002; 2004; Swoboda, 2008).

This resonates well with the increasing trend of the ‘informed’, ‘empowered’ patient, whereby the patient is positioned as a ‘health consumer’. Various studies have pointed out that the trend towards ‘patient empowerment’ is not unproblematic (e.g. Paterson, 2001; Aujoulat *et al.*, 2008). The traditional patient-doctor relationship has changed and what has emerged is often described as ‘new medical pluralism’. Whether this can be of help to patients or lead to new forms of ‘quackery’ is a question of debate. Also, as Wasserman and Hinote (2011: 46) note: ‘While alternative medicine in the form of folk-treatments has historically been a refuge of the poor [...], a new, expensive alternative treatment industry tends to exclude the poor’. Complementary and Alternative Medicine (CAM) is increasingly included in medical institutions who offer courses in acupuncture and other Eastern medical traditions. Nettleton (1996) asserts that the contemporary growth in unconventional therapies has been accompanied by the development of a new ‘psycho-social-environmental-epidemiological’ paradigm of health care, which has also pushed mainstream medicine in a more preventative and holistic direction. This growth seems to reflect a growing rejection of the dualistic divisions like nature/culture and individual/society, which have traditionally characterised clinical biomedicine. Nettleton argues that although the new model of health care has enabled conventional medical practitioners to act more holistically, a result of the success of the feminist and community health movements, it has had mixed implications for women and other marginalised social groups.

The Internet is emblematic in the transformation of the traditional patient-doctor relationship. As already mentioned, medicine has ‘e-scaped’ (Nettleton, 2004). Many lay people believe that doctors are not literate in some areas. ‘Only my allergist and the immunologists helped me at all’, William writes on a health site about CFS.¹⁵ On the other hand, doctors often worry that their privileged roles and status are being challenged by the proliferation of Internet health sites. The reliability of Internet health material is thus crucial and that is why health professionals, most often, are the ones who are responsible for these Internet sites. From a different point of view, this ‘democratisation’ of health care can be problematic because it can reinforce biomedical normalisation. For instance, Fox *et al.*’s (2005; see also Fullagar, 2008) study of an Internet forum on obesity shows that the users perpetuate the biomedical model which views obesity as undesirable. Fox *et al.* argue that these changes are problematic in that they do not account for the fact that not all patients wish to take responsibility for their health nor the vested professional power which constrains certain individuals with chronic illness from having access to resources. Rather, these changes can be seen as an extension of the ‘medical gaze’ which makes all aspects of the patient’s life visible. A different line of argument is developed by Broom (2005) who did in-depth interviews with prostate cancer specialists and found that the so-called ‘deprofessionalisation thesis’ is inadequate to capture the different and complex ways in which specialists respond to the growth of lay expertise. In fact, Broom’s research suggests, specialists may be happy and willing to share their knowledge and ‘empower’ patients. In many cases specialists might find new ways to discipline the actions of their patients, retain their control and reposition the patients as the passive receivers of expertise through their ‘enlistments’ on the Internet. This can be done through a variety of strategies such as ‘promoting certain websites, setting up regulatory bodies, warning patients away, [and]

teaching [them] to assess quality and discouraging certain forms of usage' (Broom, 2005: 335).

Over the last couple of years, especially via the Internet, UK CFS patients have been petitioning the government to reinstate ME as the proper diagnosis. They believe that such a return to the ME diagnosis dropped by the CDC in 1988 would imply a viral aetiology for the disease and place it in mainstream medicine. In addition, with CFS there is little evidence that inflammation of the brain and spinal cord occurs, as it does with ME. ME is thought to be too specific to cover all the symptoms. This is because patients feel 'fatigue' is too general, and does not reflect the severity and different types of fatigue. They feel that even though fatigue occurs in most cases, it is not the only, or the most serious, symptom they experience.

Thus far we have seen some of the ways CFS patients' groups take up, change, or oppose biomedical and psychiatric discourses. Now I would like to describe some of these patient groups' aims and operations.

CFS Patients' Organisations

Action for M.E. (AfME) is the UK's leading charity dedicated to improving the lives of people with CFS. Established in 1987, it has been, as they mention, at the forefront of the campaign for more research, better treatments and services and providing information and support to people affected by this condition. In 1987, Sue Finlay, the founder of AfME, wrote an article about ME in a national newspaper and received 15,000 letters in response. This expression of frustration and suffering was to be the start of what was then named 'The M.E. Action Campaign'. In 2002, they merged with the charity Westcare UK, based in the West country, to combine its respective strengths of campaigning and information provision with direct services and training for people with CFS and professionals. The AfME's vision calls for respect, access to appropriate health and social care, education and employment and the

opportunity to lead a ‘fulfilling’ life. The AfME campaigns for the widespread recognition of the severity of the condition which merits appropriate diagnosis, treatment, services and support. They ‘empower’ and support people with CFS, their carers, family, friends and professionals, and facilitate information and disseminate services, so that they can make ‘informed choices’. The provision of support for individuals comes through independent local support groups, a support service including telephone helplines, a dedicated young people’s website, and a range of information and publications (e.g. a quarterly magazine to members of AfME that shares experiences, news and views) to help them understand the illness and ‘take control of their lives’. Their supreme objective is to act as ‘a catalyst for the development of research into the treatment and causes of ME’. To achieve this, they have to promote, monitor, analyse and disseminate research into all aspects of the illness. They campaign to influence national policy improve standards of care and increase research into CFS. The AfME tries to lobby the government and Parliament to recognise CFS as an ‘urgent health priority’. They work together and collaborate with professionals to inform and support them. They represent the needs of the affected people to positively influence the development of NHS services and support people that want to help raise funds for this illness. Another strategy the AfME tries to employ is what they call ‘company giving’. Many companies, the AfME says, have recognised that CFS affects their staff, customers, friends and family and have chosen to support them. A working partnership helps to ‘motivate staff’, ‘strengthen customer loyalty’, and adds a vibrant charitable dimension to the companies’ marketing strategies. They state they need to raise £1 million each year to fight CFS. Interested companies can help by ‘cause-related marketing’, ‘staff and charity of the year’, donations, payroll giving, corporate events and sponsorship. Corporate events, which can be tailored to the company’s particular needs ‘are a great way to have fun, build teams, improve morale and attract media interest’, the AfME says. Donations can come in the form of a percentage of a

company's product's retail price to the AfME or a donation for every online order placed over a specific period of time.

ME Association (MEA) is the oldest and second biggest CFS association in the UK and has local support groups all over the UK. It was formed in 1976 and is a non-governmental organisation – almost all CFS organisations are – which aims to fund and support biomedical research. Besides funding and supporting biomedical research, they provide information, support and practical advice for people affected by ME, their families and carers. The MEA offers telephone support, has its own magazine, and makes use of social media like RSS and Twitter (generally, the larger and more 'tech-friendly' CFS organisations make use of social media).

ME Research UK was established in 2003 and is a charity with the principal aim of commissioning and funding 'scientific (biomedical) investigation' into the causes, consequences and treatment of CFS. Their mission is to 'Energise ME Research', which involves: raising awareness of the need for biomedical research into CFS globally, and providing high quality information on all aspects of the illness to a wide audience. The latter involves, among others things, summarising and appraising scientific literature on CFS to informing the policy agenda and hosting conferences on CFS biomedical research such as their 'New Horizons 2008: International Conference on CFS Biomedical Research' which took place at the Wellcome Trust Conference Centre, Cambridge. ME Research UK recognises that much of the existing research into ME has concentrated on psychological interventions designed to 'manage' the illness, and therefore believes that a programme of biomedical research is what is needed, and is what most patients and carers want to see.

Formed in 2005, Invest in ME (IiME) is another independent UK charity campaigning for biomedical research into ME. It has links nationwide and internationally, being one of the founding members of The European ME Alliance (EMEA). Its aim, similar to those the

aforementioned organisations, is to establish a national strategy of biomedical research into ME by bringing together ‘like-minded individuals and groups to campaign for research and funding to establish an understanding of the aetiology, pathogenesis and epidemiology of ME/CFS’. This should lead, they claim, to the development of a universal ‘thumb-print’ test for the diagnosis of ME and, subsequently, medical treatments to cure or alleviate the effects of the illness.

So far I have described only the large-scale and relatively well known UK CFS organisations. There are other such organisations, smaller and less exposed to the media, and, consequently, less effective in achieving their goals. Among those we could mention are Anglia for ME Action (which is not really small!), the British Association for Chronic Fatigue Syndrome/ME (BACME), The 25% ME Group, Tymes Trust, the Association of Young People with ME (AYME), the Blue Ribbon for the Awareness of ME (BRAME), and The Hummingbirds’ Foundation for M.E. (HFME). Similarly, there is a plethora of CFS and associated patients’ organisations in the US and internationally.

Among the US CFS organisations we could mention the CFS/Fibromyalgia Knowledge Organization of Georgia, Inc., CFS Knowledge Centers, Phoenix Rising, and the Chronic Fatigue Syndrome, Fibromyalgia, and Chemical Sensitivity Coalition of Chicago (CFCCC). All these associations and four more are part of the US umbrella organisation Coalition 4 ME/CFS (also a charity organisation).

On an international level, there is the European ME Alliance (EMEA) which was formed in 2008 by national charities and organisations in Europe and which has representatives in Belgium, Denmark, Germany, Ireland, Norway, Spain, Sweden, Switzerland and the UK. It aims at improving awareness of CFS, providing a ‘correct and consistent view of ME’ for healthcare organisations, healthcare professionals, government organisations, the media, and patients and the public, and campaigning for funds for biomedical research to provide

treatments and cures for CFS. Having been classified as a debilitating neurological illness by the WHO under the ICD-10 G93.3, the EMEA claims that the organic ‘objectivity’ of the illness has already been found. So by lobbying, it also hopes to establish an understanding of the aetiology, pathogenesis and epidemiology of ME which should lead to development of a universal ‘thumb-print’ test and to the development of treatments to cure or better manage the illness. In 2010, after Canada and Australia prohibited individuals diagnosed with ME from donating blood, the EMEA wrote to European health ministers and Chief Medical Officers requesting that a similar ban be put in place in European countries. The EMEA has also requested more funding for biomedical research into CFS and again invited Health ministers and Chief Medical Officers in Europe to a meeting in London on 23rd May 2010 to discuss ME. They invited all European support groups, patients, carers, healthcare staff and others who wish to see progress support them in that initiative. Its attempts should be considered successful considering the subsequent ban of people with CFS from blood donation in other countries including the UK.

Another European CFS organisation is the European Society for ME (ESME). Their mission is ‘to create a Think Tank where top scientists from relevant fields can discuss current ME knowledge in order to determine the most crucial direction of future research, and to provide a reliable source of cutting-edge ME information that the ESME will incorporate in the education of medical professionals’. The ESME’s ‘Think Tank’ includes, among others, specialists in virology, neurology, pediatrics, and CFS clinicians. The ESME organised a XMRV/MLV seminar on 28th November, 2010 in Oslo, Norway, and the speakers were Dr Judy Mikovits, Research Director for the Whittemore Peterson Institute (WPI) for Neuro-Immune Disease in the US and Dr Mette Johnsgaard, Medical Director of Lillestrom Helseklinikk – Center for the Treatment of Chronic Diseases in Norway (we will come back to this issue later on, in chapter 5).

Lastly, there is the International Association for Chronic Fatigue Syndrome/ME (IACFS/ME), formed in 1990, with similar goals and operations to those of the EMEA and of the ESME, but having greater scope as it is a global organisation.

As has been suggested more than once, in the current medical landscape, medical knowledge spreads easily and medical authorities have lost much of their traditional power. Now individuals and groups, at least those with a certain cultural capital – those Greenhalgh and Wessely (2004) would classify as middle class ‘health-for-me’ individuals – try to educate themselves about the developments in biomedicine or other issues of concern. My informant Thomas, a self-help group leader, verified this by saying that the ‘ME/CFS community is quite familiar with computers’. For example, patients often also try to collaborate with ‘sympathetic’ or more ‘knowledgeable’ scientists. We have already seen the case of Malcolm Hooper who has collaborated with members of the CFS community to produced documents like ‘The Mental Health Movement: Persecution of Patients?’ (2003) and ‘Magical Medicine: How to Make a Disease Disappear’ (2010). Another example would be the case of the immunologist and principal medical advisor for the AfME, Antony Pinching. In addition, in 1997 the IiME produced a forty-page document with ‘quotable quotes’ on the history, biomedical specificities of, and controversies around the illness since 1956.¹⁶ As this document is available on the Web, making the exchange of information much easier, it could be argued that CFS patients are in a way privileged compared to health activists of the past. Similarly, CFS patients can find online a document like ‘THE CFS FAQ’ which, as the title implies, includes a collection of frequently asked questions regarding CFS as well as lists of medical and computer and other common abbreviations related to CFS.¹⁷ Other examples would be the summary and dissemination of studies related to the XMRV virus (Table 1) and of the distribution of unfunded biomedical research by the Medical Research Council (MRC) (Table 2) – which is responsible for specific guidelines for studies

on vulnerable people – provided by ME Research UK. All these examples demonstrate the importance of CFS activism in the making of CFS. Far from being ‘objectified’, CFS patients actively engage with the making of biomedicine and in the classification of themselves.

Table 1. Published studies related to XMRV virus between October 2009 to June 2011. Reproduced from ME Research UK website (<http://www.mereseach.org.uk/information/publications/xmrfind.html>)

First author	Country, Journal, Date	Patients positive for XMRV?
Lombardi	USA, <i>Science</i> , October 2009	Yes (67%)
Erlwein	UK, <i>PLoS One</i> , January 2010 & March 2011 (re-analysis)	No
van Kuppelweld	Netherlands, <i>British Medical Journal</i> , February 2010	No
Groom	UK, <i>Retrovirology</i> , February 2010	No
Swizer	USA, <i>Retrovirology</i> , July 2010	No
Lo	USA, <i>Proc Natl Acad Sci</i> , August 2010	No
Hong	China, <i>Virology Journal</i> , September 2010	No
Henrich	USA, <i>J Infect Dis</i> , November 2010	No
Hohn	Germany, <i>PLoS One</i> , December 2010	No
Satterfield	USA, <i>Retrovirology</i> , February 2011	No
Furuta	Japan, <i>Retrovirology</i> , March 2011	No
Schutzer	USA, <i>Ann Neurol</i> , April 2011	No
Shin	USA, <i>Journal of Virology</i> , May 2011	No
Knox	USA, <i>Science</i> , May 2011	No

Table 2. Unfunded applications to the MRC between 2002 and 2008. Reproduced from ME Research UK (<http://www.mereseach.org.uk/information/publications/casetoanswer.html>)

Time frame of applications	CFS/ME subject area
2002 to 2005 (11 total)	Neurophysiology of fatigue; Population-based/epidemiological studies (4 applications); Neurotransmitters and stress; Neuroimaging; Clinical and

	laboratory characterisation physiology/diagnosis); Dietary intervention – RCT; Facilitated self-help – RCT; Psychosocial and genetic factors in young people
2005 to 2006 (12 total)	Pathophysiology, including studies regarding genetics/biomarkers, immunology and neuroimaging (7 applications); Population-based/epidemiological studies (3); Primary care study; Experimental medicine study
2006 to April 2007 (7 total)	Cognitive outcomes in children – pathophysiology; Epidemiological studies – epidemiology; Biomarkers; Pathophysiology (2 applications); Molecular pathogenesis – pathophysiology; Molecular and genetic characterisation – pathophysiology; Neuroimaging – pathophysiology
May 2007 to June 2008 (3 total)	Biomarkers – pathophysiology; Management and treatment – intervention; Management and treatment – observational study

Other ways in which CFS patients try to make their illness more ‘visible’ and persuade state institutions to increase research funds and welfare benefits are documentaries, films, campaigns and petitions. According to Barbara, a leader of a ME self-help group with whom I had conversations, not only does the AfME have no members but just subscribers (meaning that by being just subscribers they only communicate with other ME patients and access archives about CFS), it also supported the PACE trial (more on this in chapter 5), as did its ‘sister group’, the Association of Young People with ME (AYME), and is ‘aligned to the state’ (Interview 5). Barbara believes that the only ‘grassroots’ activist organisations are the liME, The Young ME Sufferers (Tymes) Trust, and the 25% Group – this dissatisfaction with the charity character of CFS organisations is quite common, as I have realised from my own research into UK CFS blog communities. In fact, these are the only organisations that are supported by the self-help group she leads. However, it is not true that these organisations do not collaborate with state institutions, as for example with The Young ME Sufferers (Tymes) Trust. The Young ME Sufferers (Tymes) Trust – also a charity organisation – is the largest UK CFS organisation dedicated to children and young people diagnosed with ME. As they

say, they ‘work constantly with doctors, teachers and other specialists, and played a major role in producing the children’s section of Dept of Health Report on CFS/ME (2002)’. They also promote interactive virtual education for children diagnosed with ME and provide the Tymes Trustcard, i.e. a pass card for children in school, which is endorsed by the Association of School and College Leaders (ASCL). In addition, they co-funded, together with ME Research UK, Search ME and Tenovus Scotland (an organisation that supports innovative research across the full spectrum of medical sciences), a study on the physical and functional impact of CFS in childhood (Kennedy *et al.*, 2010).¹⁸

Barbara believes that the three most important problems CFS organisations face are their fragmentation, funding problems, and the fact that CFS patients’ physical condition does not allow them to become very much involved. As far as the former is concerned, the current fragmentation of CFS patients’ organisations – despite their attempts at collaboration and even unification under umbrella organisations as in the US – has also been observed and discussed by members of the US CFS online community. One of the attempts to unify CFS and other neuroendocrineimmune deficiency syndromes (NEIDs) under bigger organisations is, as we have seen, that of the CFS/Fibromyalgia Knowledge Organization of Georgia. It might be worth quoting the aim of this organisation:

‘Our vision is to create a network of U.S. 501 (c) (3) [i.e. charity] organizations to support the ME/CFS and other NEIDs community. This network will aim to strengthen its individual member organizations and guide them to collaborative efforts and effective resource-sharing. This includes mentoring current and future patient advocacy leaders to augment their leadership skills. This coalition will push for local, state and federal legislative strategies’.¹⁹

For both Barbara and the CFS blog users mentioned above, the division of CFS patients' organisations undermines the ability of the CFS community to act in an effective way. The same CFS blog users discussed whether they need one more international CFS association and, if so, what new would that have to offer. What the aims of such an association would be was the heart of the problem in that discussion. On the other hand, but relatedly, the first two problems refer to the need to be financially independent and to have some sort of delegation. According to Barbara, currently only the patients themselves fund the organisations while, ideally, they should have private sponsors, as happens with other health related campaigns where specific people are paid to attract funds (as with cancer research campaigns). With regard to the issue of delegation, she does not see any real, efficient alternative. As she bluntly told me, 'I'm too exhausted to do activism!' (Interview 5). Of course, as the member of chronic-fatigue-community.com, a US online CFS community, Sue Jackson said, the attempts of a CFS patient to 'educate the world about CFS, even if [s/he] can't leave [his/her] house' can also be considered a form of activism.²⁰ However, the fact that CFS is often debilitating seems to make many CFS patients favour some form of representation. If that is unavoidable, then the question becomes what form of representation. In the aforementioned online discussions, CFS blog users expressed their dissatisfaction with, for example, the administrators of a CFS organisation who were, according to them, alienating scientists and especially retrovirologists who were looking for answers by possibly accusing them of being either biased or ignorant (this refers to the 'discovery' of the XMRV virus and the debates over its possible relation to CFS, that, again, we will approach in chapter 5). Another issue of discussion and debate in the UK CFS blog community, as my research has revealed, is that there is not a lot of transparency in the running of UK CFS organisations. There is no information about how the committee of the charity trustees (i.e. the directors of the charity) is constituted, about how these organisations operate, and about how donations are to be

handled. As with other illness, the running of CFS organisations is and will continue to be a very important issue in the making of CFS.

Chapter Five

Standardising Through Intervening

This chapter continues the examination of the construction of CFS and focuses on the current attempts to standardise its definition, diagnosis, and treatment. As was made clear from the outset, this is not a retrospective account into how a contested disease was standardised but an examination of an open scientific controversy. Therefore, this chapter's title may not be fully appropriate. Perhaps a more precise way of putting it would be to say that CFS is continually constructed, reconstructed, and standardised. In this sense, the Fukuda *et al.* (1994) criteria for diagnosing CFS are amongst the various partial standardisations of CFS. Standardised categories are, for different reasons, an imperative for medical researchers, health officials, pharmaceutical and insurance companies. So, while researchers need clear diagnoses to justify applications to funding agencies that increasingly demand comparable and reproducible results, pharmaceutical companies need standardised diagnostic categories to develop and sell their products (Knaapen and Weisz, 2008: 127). The second purpose of this chapter is to expand on how patients diagnosed with CFS experience and deal with their condition. This is, however, not a phenomenology of patients diagnosed with CFS, something that other studies have successfully done (e.g. Travers, 2004; Büllow, 2004; Whitehead, 2006; Edwards *et al.*, 2007; Aroll and Senior, 2008; Moss, n.d.), but an attempt to incorporate their understandings, ways of coping, and demands insofar as they relate to the developments in the scientific world into the study of making and managing CFS.

In Search of Energy

Besides being in search of biomarkers that would render their condition measurable and 'objective', CFS subjects are in search of energy; energy to work, to keep up with the

‘busyness’ of the world, to devote care to themselves, to their families and friends. Energy is a floating signifier which can specify, among other things, ‘muscles’, ‘bioenergy’ or even the discontent prevalent in today’s uncertain economic environment. Everyday reality is ‘vague’ (Miller, 2006) and CFS is part of that vagueness. Although in many cases energy means the functional capacity to do things, it should not be conceived in strictly physical terms. CFS bodies lack energy or find it difficult to control their remaining energy. Describing the steps to her gradual, if not complete, recovery, my informant Sarah told me: ‘I still had to plan for my reduced energy bank’ (Interview 3). Perhaps the ‘energy bank’ metaphor signifies the struggle she had to go through to secure a minimum of energy.¹ Some individuals diagnosed with CFS believe that a cure can be found, a cure which would restore their ‘original selves’ or, at least, significantly improve their state of health, often resorting to clinics. Part of the CFS population is self-medicated. These individuals try to increase their energy levels by experimenting with, and combining, different sorts of treatments and medications. Some people diagnosed with CFS could be regarded as ‘neurochemical subjects’, as areas or processes of their brains (e.g. cells or waves) have become an integral part of their identities, and others claim that their bodies are ‘attacked’ by viruses, while, as we have seen, for psychiatric authorities these are inappropriate beliefs which are precisely causing their functional disabilities and that is why behavioural therapies are best suited. Finally, some give up hope altogether of restoring their original energy levels or of overcoming their ‘spoiled identities’ (to use Goffman’s term) and create new and often better ‘selves’. Some individuals diagnosed with CFS directly blame their previous or current stressful and over-demanding work and criticise employers for mostly caring about productivity. The last point was plainly expressed in a post by Mark: ‘Employers (governments & public sector) are all about productivity ... no matter how warm and fuzzy they may app[ear]’. It is therefore

clearly inadequate to homogenise the variety of CFS subjectivities. Processes of subjectification often coexist or collide, giving rise to new processes of subjectification.

Before we examine the treatments CFS patients in the UK receive, we should first look into how access to health care services takes place. The National ME Centre (NMEC), based in the Disablement Services Centre (DSC) in Essex, is one of the few ways people diagnosed with CFS can access health care. Another one is the CFS service at King's College and the Maudsley Hospital in London, one of the first ever NHS services dedicated just to CFS, the place where Wessely spent most of his CFS career. Created in the early 1990s by microbiologist Dr Betty Dowsett and neurologist Professor Leslie Findley who were concerned by the lack of guidance and support available to the increasing number of patients diagnosed with CFS that they were seeing, NMEC offered a multi-disciplinary team consisting of clinicians, an occupational therapist, a physiotherapist, a nutritionist and a counsellor. The clinical service was suspended in May 2007 but occupational therapy, physiotherapy, nutritional input and counselling are still available, and the accessing of these services for CFS patients is normally done by a referral route via their GP.² The provision of these new services was announced in 2004 by the then health minister, Stephen Ladyman who, as *The Guardian* reported, said that this condition 'poses a challenge to medicine and the NHS' (Shirfin, 2004). As *The Guardian* further reported:

'The teams will provide specialist rehabilitation programmes for patients to help increase energy and activity levels and develop local domiciliary services covering health, education and social care needs for more severely affected patients who may be housebound or bedridden' (Shirfin, 2004).

These teams were to ‘offer backup to GPs and other help professionals and work with self-help groups to develop “expert patient” and self-management initiatives’ (Shirfin, 2004). The announcement, which was already delayed given that it came two years after a 2002 report by an independent working group was submitted to the Chief Medical Officer who recommended that ‘services be set up “with some urgency” to address the lack of treatment and care provision’ (a separate report in 2003 had estimated that funding to set up the new services would amount to £8.5 million). Individuals called ‘clinical champions’ provide their doctors with details of their nearest service. There are 13 Clinical Network Coordinating Centres (CNCCs) across the UK which are championing the development of services and improved clinical care in their area, and each CNCC has a ‘clinical champion’ or network coordinator who advises patients, GPs and carers about services. Two of them belong in the field of immunology and one in that of infectious diseases; the rest specialise in neuropsychiatry, psychology, occupational therapy, medicine, neurology, and rheumatology.

While there is a range of mainly non-pharmacological treatments or ‘rehabilitation strategies’, only two have demonstrated reproducible evidence for their efficacy in non-severely affected CFS patients: cognitive behaviour therapy (CBT) and graded exercise therapy (GET). Based on evidence from multiple randomised clinical trials (RCTs), a systematic review claimed that CBT and GET interventions showed promising results, appearing to reduce symptoms and improve function (Chambers *et al.*, 2006). Chambers *et al.* claimed that the evidence of effectiveness was inconclusive for most other interventions, with some interventions reporting significant adverse effects. The wide variety of outcome measures used in CFS research is a fundamental problem for assessing the effectiveness of interventions and none of the interventions had proven to be effective in restoring the ‘ability to work’ (health’s confluence with the ability to work seems characteristic of western societies, something that we will explore in chapter 6). One review concluded that depression

was the only factor associated with unemployment and that only CBT, rehabilitation and exercise therapy interventions were associated with restoring the ‘ability to work’ (Ross *et al.*, 2004).

The aforementioned reports are based on the premises of evidence-based medicine (EBM), and its correlative, the health care trend of evidence-based treatment (EBT) according to which specific treatments for symptom-based diagnoses are recommended. Although the term EBM is quite recent, there has been a trend of increasing standardisation in the history of medical research and therapeutic practice. EBM’s purpose is to ‘reshape biomedical practice by creating an organising presence for clinical research within medical decision making’ (Mykhalovskiy and Weir, 2004: 1059) and there are many who view EBM as ‘cookbook medicine’ (e.g. Holmes *et al.*, 2006; cf. Mykhalovskiy and Weir, 2004; Timmermans and Mauck, 2005). The rationalisation of medicine, i.e. the exclusion and suppression of the clinician’s expertise, tacit knowledge, and judgment in the name of ‘effectiveness’ and ‘cost-cutting’, that is supported by EBM, is, according to its critics, the destruction of medicine. Nonetheless, it should not lead to fatalism. As Timmermans and Almeling (2009: 26) note: ‘[a] meta-review of physicians’ adherence to standards estimates that in only 50% of the cases do clinicians follow clinical guidelines endorsed by national and professional medical organizations’. As far as mental health issues are concerned, EBM has favoured CBT over other approaches such as psychodynamic treatments. In the UK, the National Institute for Health and Clinical Excellence (NICE), an independent organisation responsible for providing treatment guidelines to doctors, recommends CBT as the treatment of choice for illnesses like bulimia nervosa and depression (for a general account of EBM in the UK, see Harrison, 1998). Now we should turn our attention to the standardisation of CFS through various forms of interventions, starting with the treatments offered for CFS.

Cognitive Behaviour Therapy (CBT)

CBT has been used to treat, among others, ‘problem drug users’ (Coyles, 2009) and ‘shyness’ (Scott, 2006), and now there is even Internet delivery of CBT for treating panic disorder (Advocat and Lindsay, 2010). According to the cognitive-behavioural model of illness, the patient’s interpretation of symptoms plays an important role in perpetuating the illness (Wessely *et al.*, 1989; Sharpe, 1991). CBT aims to help the patient change the negative beliefs that s/he has with the goal being either to reduce the symptoms and help the patient cope with the illness or to fully recover. By training CFS patients to stop their ‘automatic negative thoughts’ and replace them with more ‘realistic’ attitudes, the CBT practitioner aims to return them to a more ‘normal’ level of social functioning. This is how Robert described his feelings about CBT:

‘I had one appointment with a respected local CBT practitioner and found that I had already developed (by trial and error) several of the approaches that CBT involves. [For example,] I had been keeping a diary of my actions and feelings, I had experimented with doing some things differently and recording the effects of my actions on my morale and effectiveness. I chose not to continue seeing the practitioner. The principles of CBT seem to be sound and as long as the practitioner has a good understanding of what ME/CFS is, it should help some people with the illness to regain some control of their wellbeing. However, it may not suit everyone and good quality CBT practitioners seem to be in short supply (and can be expensive if people choose to seek help from the private sector)’ (Interview 1).

In the case of CFS, there is moderate evidence of benefit for CBT but its effectiveness outside of specialist settings has been questioned and the quality of the evidence seems ‘low’. A systematic review of CBT concluded that ‘CBT is more effective than usual care for reducing fatigue symptoms in adults diagnosed with CFS, with 40% of participants assigned

to CBT showing clinical response at post-treatment, in comparison with 26% assigned to usual care control' (Price *et al.*, 2008: 23). However, that review also held that the benefits of CBT in sustaining clinical response at follow-up are inconclusive and that there were no conclusive improvements to physical functioning, depression, anxiety or psychological distress at either post-treatment or later follow-up. Data on adverse effects were not systematically presented by any included study. The review concluded that while the quantity and quality of the evidence has grown in recent years 'there is a surprising lack of high quality evidence on the effectiveness of CBT alone or in combination with other treatments to inform the development of clinical management programmes for people diagnosed with CFS' (Price *et al.*, 2008: 23). An uncontrolled study with no follow-up found that CBT could facilitate full recovery in some patients, with 69% of the patient cohort no longer meeting the CDC criteria for CFS, and full recovery occurring in 23% of CFS patients after CBT using the most comprehensive definition of recovery (Knoop *et al.*, 2007), while one review found that 'CBT was associated with a significant positive effect on fatigue, symptoms, physical functioning and school attendance' (Chambers *et al.*, 2006: 509) but had not proved to be effective in restoring the 'ability to work'. The reviewers claimed that many recent trials on CBT are 'lower-quality' RCTs or trials that did not involve random allocation (Deal *et al.*, 2001), though one recent 'good' quality trial of CBT in children and adults supports the effectiveness of CBT. According to a recent review of trials that measured physical activity before and after CBT, although CBT effectively reduced fatigue, 'activity levels' were not affected by CBT and changes in physical activity were not related to changes in fatigue (Wiborg *et al.*, 2010). The review concluded that the effect of CBT on fatigue is not mediated by a change in physical activity. The effectiveness of CBT for adolescents was supported by one 'high-quality' RCT, although it had only 69 participants (Chambers *et al.*, 2006). Currently there is no research into the effectiveness of CBT for the severely affected which

may be effectively excluded from trials due to the need to attend a clinic (Chambers *et al.*, 2006). Moreover, some CBT trials suffer from large dropout rates, up to 42% in one study, with a mean dropout rate of 16%, and there seems to be a degree of publication bias present in CFS literature as a whole.

CBT has been criticised by patients' organisations, across multiple patient surveys, because of the negative reports from some of their members which have indicated that it can sometimes make them worse. The point of contention is that CBT is too often the primary treatment and that some therapists think that a 'change in thought' can alleviate CFS's major symptoms. One survey conducted by the MEA in 2001 found that out of the 285 participants who reported using CBT, 7% reported it to be helpful, 67% reported no change, and 26% reported that it made their condition worse.³ A survey conducted by the AfME in the same year reported that 50% of patients found CBT helpful, 38% reported no change, and 12% felt that it made their illness worse, though it remained among the lowest-rated treatments in the survey despite the significant increase.⁴ Finally, a survey of 437 severely affected patients by the 25% ME Group in 2004 reported that CBT was helpful to 7% and unhelpful to 93%.⁵

On the other hand, according to Wessely, CBT is almost always affective for treating fatigue in general and needlessly stigmatised as 'psychiatric'. Following a similar line of argumentation, the director of Neuroscience Research at the Kessler Medical Rehabilitation Research and Education Corporation in the US, John DeLuca (2005), believes that CFS patients exaggerate and are aggressive at psychiatry; 'anything but psychiatry' (ABP) might well be the motto of the CFS community, he writes (see also Deal and Wessely, 2001). DeLuca calls CFS 'secondary fatigue' because patients diagnosed with CFS report greater cognitive effort and cognitive impairment than is detectable on objective assessment. For DeLuca, modern psychiatric research has made great progress. The revolution that took place in psychiatry cannot be underestimated. Symptom is now different from disease, and

neurology is not only ‘muscles and nerves studies’. DeLuca does not appreciate the expression ‘medically unexplained syndromes’ (MESs) and finds the notion of somatisation problematic and is against the ‘psychologisation’ of fatigue (which is connected with depression and anxiety) that he takes to be an effect of the spread of psychology in the popular culture – he is undoubtedly correct on the latter (see Madsen and Brinkmann, 2011). Commenting on MEDs, Jutel similarly thinks that the discursive approach of both medical literature and practice is paradoxical because medicine ‘fails to note the limitations of its episteme, creating a catch-all psychogenic diagnosis in the absence of a suitable existent label’ (Jutel, 2010: 230; see also Loughlin, 2010; Sykes, 2010a,b). The ‘psychologisation’ of fatigue, therefore, enacts a reality in which CBT is almost the only possible treatment for CFS.

Graded Exercise Therapy (GET)

GET is a physical activity that starts very slowly and gradually increases over time. This method avoids the extremes of the ‘push-crash cycle’ of over exercising during remittance or not exercising at all due to concern of relapse. Despite some limitations with the evidence and the generalisability of the findings, two reviews cautiously concluded that some patients may benefit from GET (Edwards *et al.*, 2004; Chambers *et al.*, 2006). Edwards *et al.* found statistically significant improvements to self-reported fatigue severity and physical functioning. Benefit was sustained after six months, but became non-significant compared to the control group who did not receive GET. Withdrawals were noted in some studies but were difficult to interpret due to the poor reporting of adverse effects. The protocols for many clinical studies may have biased the sample towards those with less severe symptoms and severely affected patients were not included in the studies of GET. Edwards *et al.* further argued that research is needed to ‘define the characteristics of patients who would benefit

from specific interventions and to develop clinically relevant objective outcome measures’ (Edwards *et al.*, 2004: 506). Finally, one review found that ‘functional work capacity’ was not significantly improved with GET (Edmonds *et al.*, 2010). GET had a tendency towards higher dropout rates and although there was no evidence that it worsened outcomes on average, no data was reported for adverse effects. The authors stated that the evidence base and the precision of the results are limited and encouraged ‘higher-quality’ studies ‘that involve different patient groups and settings, and that measure additional outcomes such as adverse effects, quality of life and cost effectiveness over longer periods of time’ (Edmonds *et al.*, 2010: 7). Many commentators believe that in order to avoid detrimental effects from GET, care must be taken to avoid the exacerbation of symptoms while catering the programme to individual capabilities and the fluctuating nature of symptoms. Patient organisations’ surveys commonly report adverse effects, with the AfME reporting in a 2008 survey that 35-50% found GET made their condition worse, and with the 25% ME Group reporting that 95% found GET unhelpful with some members ‘not severely affected before trying GET’.⁶

CFS organisations have often lobbied in favour of particular types of research or, alternatively, protested against studies they considered unethical or useless. An example of this would be when in 2008 the High Court in London held a judicial review of NICE guidelines for treating CFS after protests from both patients and the medical profession.⁷ NICE issued their guidelines for CFS in August 2010 amid protests from patients and medical researchers that they had not followed correct protocols in producing the guidelines. Patient groups feared that some patients could be pressured into accepting treatments which at best may be useless and at worst could cause real harm. Lawyers for two individuals diagnosed with CFS argued that by recommending either CBT or GET, but also advocating ‘activity management’, the guidance issued by NICE restricted the range of treatment

available. Eventually, the judge dismissed their allegations that current therapies were harmful to some patients diagnosed with CFS. Professor Peter Littlejohn, NICE's public health director, welcomed the decision by saying '[w]e are pleased to have won convincingly on all counts in this case – this judgment is a welcome endorsement of the rigorous methods we use to produce our guidelines', adding that these are 'very good news for the thousands of people with ME, who can continue to benefit from evidence-based diagnosis, management and care for this disabling condition'. Once again, by intervention of the High Court helped in producing a certain form of reality in which, despite the protests of CFS activists, the possible treatments for CFS are restricted.

Pacing and Lightning Process (LP)

Pacing is probably the most accepted form of treatment after CBT and GET. Pacing techniques encourage behavioural change, but unlike CBT, they acknowledge the typical patient fluctuations in symptom severity and delayed exercise recovery. Patients are advised to set 'manageable' daily activity goals, 'balance' their activity, and rest to avoid possible over-exertion which may worsen their symptoms. Those who are able to function within their individual limits might then try to gradually increase activity levels while maintaining pacing methods. Pacing's goal is to increase over time the level of 'routine functioning' of the individual. A RCT concluded that pacing with GET had statistically better results than relaxation therapy (Wallman *et al.*, 2004; see also Deale *et al.*, 2001), and a 2008 patient survey by the AfME found pacing to be the most helpful treatment.⁸ According to an occupational therapist's assessments and observations of patients diagnosed with CFS over time, daily activity in response to the symptoms experienced appeared to have a common pattern across all patients (Cox, 1999). Cox, an occupational therapist, identified a pattern of 'peaks and troughs', meaning that patients do more when they feel able (peak), then often do

too much, which pushes them into exhaustion so they have to rest (trough) until they feel more able again. Thus, the pattern of ‘peaks and troughs’ is established (Table 3). This pattern occurs not only on a weekly or monthly basis but also a daily basis, with patients often sleeping in the afternoon to regain energy. This pattern, Cox claims, not only assists in perpetuating the illness but increases the sleep disturbance often described.

Table 3. Example of a daily activity schedule. Reproduced from Cox, 1999: 60.

Daily programme chart

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

Robert, who prefers mixing different treatments, described his experience about pacing in the following way:

‘I try to stop doing things before I get tired. I limit myself to a maximum of one hour of any kind of activity (physical or mental) and then take a significant break. In the evening I go to bed when I am tired (usually no later than 9.30pm) to ensure I am in bed for at least 9 hours. The quality of my sleep is poor and I usually get up at 6.30am every morning’ (Interview 1).

On the other hand, behavioural interventions like lightning process (LP) do not seem to work very much. Developed by the US osteopath Phil Parker in the late 1990s, LP is a non-medical treatment based on a vague notion of the brain’s neuroplasticity and the interaction of the

body and the mind. LP is a 3-day process that combines neuro-linguistic programming (NLP), a form of psychotherapy, 'life coaching', and osteopathy. 'Life coaching' derives from 'positive adult development' and career counselling. LP's purpose is to help 'clients' determine and achieve personal goals. This is similar to 'ADHD coaching' which helps people with ADHD to 'manage time', 'organise their lives', and so on. To give an example, NLP can purportedly be used 'for helping people who have as yet not reached their potential', argues Global Consultancy Services, a Birmingham-based firm specialised in providing a range of business development consultancy services in small and medium businesses.⁹ Global Consultancy Services' website provides 'testimonials' from universities and other businesses which have 'achieved excellent results, ensuring the entrepreneurs are empowered, encouraged and highly organised' after using its services. These training programmes, as books and manuals for living a life, provided by authorities such as HRM specialists, coaches and mentors, are congruent with the neoliberal discourses and practices which try to inculcate individual responsibility and self-management. Consider the following testimonial: 'NLP has provided me with so many choices and enabled me to create numerous choices for others: I now believe human beings really can be masters of their own destiny'.¹⁰ 'Double bind', 'stress', 'conflict' and 'dissatisfaction' are portrayed as psychological defects that are potential costs to business and in need of therapeutic treatment (Cheal, 2008: 36). An employee's 'personal failure' to keep performing under an environment where the pace and amount of work increases needs to be quickly resolved. Such techniques or forms of intervention position workers as 'pathological' and unhealthy subjects and attempt to reform them for the greater good of society. Through confession and exposure, therapeutic discourses render the 'self' visible and amenable to change. Knowing and managing one's emotions and the quest for one's 'true' self are commonplace in these discourses.

Returning to LP, the programming works by ‘manipulating’ the external ‘signal’ and converting it into ‘useful information’ (the influence of some computer model of the brain is clear here). This is based on the idea that the words we use reflect a ‘subconscious’ perception of our problems. Parker suggests that with ME comes a ‘deregulation’ of the Central Nervous System (CNS) and of the Sympathetic Nervous System (SNS), which LP may be able to address, as it may help to break the so-called ‘adrenaline loop’ (i.e. the production of too much adrenalin in CFS bodies).¹¹ ME affects the body’s capacity to deal with adrenaline and its ‘rebalancing’ is found in ‘modifying the brain’s thought patterns’ to generate endorphins instead of stress-related hormones. LP has been described as treating ME as a ‘psychological manifestation’ rather than a physical illness, although Parker has emphasised that it is a physical illness. CFS patients’ views of LP are surely ambiguous. For example, although a survey conducted by the MEA found out that LP came top of their poll for approaches that greatly improved the symptoms of ME, on 4th August 2010 the MEA and the Young ME Sufferers Trusts issued a joint statement about the forthcoming pilot study of the ‘psychologically-based LP’ on children.¹² That study was planned to involve over 90 children aged between eight and eighteen and their families. LP ‘calls itself a training programme, not a medical treatment’, the aforementioned associations said, adding that the programme claims to be effective for stress, depression, low self-esteem and the like, but ‘ME is a neurological condition, classified by the WHO’. The MRC said that that research ‘should be carried out if it cannot be feasibly carried out on adults’. Nonetheless, on 16th September the aforementioned study was accepted.¹³ Let us now see how CFS subjects relate to other, often not approved, drugs and treatments, in their striving to improve their condition.

Drugs and Complementary and Alternative Medicine (CAM)

Epidemiology is increasingly showing CFS to have a prevalence of about 0.4%, which is well

beyond the projected size of HIV/AIDS in the industrialised world when pharmaceutical interest and investment began (Pinching, 2003: 81). Nevertheless, neurostimulants and antidepressants like Ritalin and Prozac, very profitable in other instances with disorders such as ADHD (Conrad and Potter, 2000; Lakoff, 2000; Singh, 2006; Bray, 2009) or female sexual dysfunction (FSD) (Fishman, 2004) – themselves very much products of the expansion of the so-called ‘new biological revolution’ in psychiatry (i.e. the alignment of psychiatry with mainstream medicine and its focus on empirical findings, the neurosciences, and genetic studies) and the ever-increasing search for new market niches by biomedical companies – have not found fertile ground in the CFS field. Various experimental anti-retroviral drugs have had a similar fate as they have not managed to be granted approval.

Lakoff’s (2004; 2006) ethnographic work on the marketing of antidepressants in Argentina provides us with significant insights into the marketing and distribution of drugs. Lakoff’s work set out to explain the increase in prescriptions of antidepressants when there was no increase in the diagnoses of depression. In Argentina, direct-to-consumer advertising (DTCA) is not allowed and companies use other ways like the sponsorship of illness-awareness campaigns to increase their sales. However, because of Argentina’s patent laws, domestic pharmaceutical companies have a greater share of the market than foreign ones and due to high competition these awareness campaigns are not enough. For this reason, pharmaceutical companies target clinicians directly and try to establish ties through gifts. Because these gifts should not appear as mere bribing, pharmaceutical companies try to engage with the clinicians professionally and intellectually by giving them access to centres of knowledge production. To achieve this, they rely on their sales force, the ‘reps’. The reps in turn rely on information from pharmaceutical data companies that buy these databases and use them to understand the market and provide direction for their reps. For example, reps can buy copies of prescriptions from pharmacies and create profiles for each doctor’s prescribing habits.

Moreover, they try to find ways to influence and monitor doctors; doctors are being monitored by reps and in turn reps are being monitored by managers. When it comes to adapting strategies for the particularities of a local context, knowing that in Argentina psychoanalytic and social explanations of mental disorder are preferred instead of chemical imbalances, and that there are no regulatory bodies to demand specificity of effect, pharmaceutical companies target the widespread anxiety over family relations, job loss, and globalisation.

In a similar fashion, Rose (2006: 479) notes that pharmaceutical companies' campaigns 'point to the misery caused by the apparent symptoms of ... undiagnosed or untreated condition[s], and interpret available data so as to maximise beliefs about prevalence, shaping malaise into a specific clinical form'. Rose adds that such 'campaigns often involve the use of public relations firms to place stories and supplying experts who will explain them in terms of the new disorder' (Rose, 2006: 479). Something similar happened with the daughter of the English journalist and TV presenter Esther Rantzen, Emily Wilcox, who was diagnosed with ME in 1995.¹⁴ In order to support the cause, Emily Wilcox did many press conferences, interviews and photo shoots, arguing that ME is a very real illness.

Although drugs might not be the first or most common choice for CFS patients, this does not mean they abstain from using them. There are many who experiment with drugs, often making cocktails of different drugs. Some of the drugs and treatments being used to alleviate CFS are antivirals, antidepressants, nonsteroidal anti-inflammatory drugs (NSAIDs), and experimental treatments like hormones and immunological therapy. A medication that is sometimes used is the 'NT factor drug', an energy supplement that produces 'healthy mitochondrial membranes and energy levels'. In order to get an 'energy boost', CFS patients may also try vitamins, creatine, minerals, caffeine, lucozade, and Siberian ginseng. 'CFS is not a disease', Graham writes in the CFS blog, it is

‘an energy condition. That energy condition of “homolateral” can be easily normalised with a “homolateral repatterning drill”. That drill takes about 3-5 minutes to do. Since you’ve had it long term you probably need to do that drill 4-5 times a day’.

Besides drugs, a number of individuals diagnosed with CFS use complementary and alternative medicine (CAM) in their effort to manage their symptoms. As already mentioned, CAM is becoming more and more popular and accepted in western societies. It is little wonder then that people diagnosed with CFS try Reiki, Yoga, and Reflexology.¹⁵ Some believe in ‘spontaneous recovery’ because a mechanism of ‘self-diagnosis’ and ‘self-repair’ exists in us at every biological level. Furthermore, there are many self-help books (an old and strong tradition in Britain) that provide guidance to patients. One of them is *From Fatigue to Fantastic* which purports to treat illness such as CFIDS and fibromyalgia by an understanding of ‘bioenergy’.

Experimenting with new drugs has to pass through clinical trials. The assessment of new drugs in clinical trials is an important part of the standardisation of CFS. This is where we should now turn our attention.

Clinical Trials

Clinical trials are research studies that prospectively assign groups of humans to health-related interventions to evaluate the effects on health outcomes. These interventions include drugs, cells, surgical procedures, devices, behavioural treatments, and preventive care. For instance, the use of Sildenafil (Viagra) to alter fatigue, functional status and impaired cerebral blood flow in patients diagnosed with CFS was recently tested in the US. Clinical trials are divided into four categories:

‘Phase I studies rely on roughly 20-80 healthy volunteers and determine the tolerable dose range of a new drug. Phase II studies evaluate efficacy and safety in 100-300 subjects who have the disease

or condition to be treated. Phase III studies generate more safety and efficacy data. They are generally multicentered and can involve up to 10,000 people in 10-20 countries. This base is the most time-consuming and expensive. Phase IV studies provide further safety and efficacy information after the drug has been marketed, and they can involve millions of people' (Petryna, 2007: 26).

Clinical trials can also be divided into non-randomised clinical trials and Randomised Clinical Trials (RCTs). RCT is a type of scientific experiment most commonly used in testing the safety issues attendant upon adverse drug reactions and adverse effects of other treatments, and the efficacy and effectiveness of health care services or health technologies such as pharmaceuticals, medical devices or surgery (on RCTs, see Wahlberg and McGoe, 2007). The key distinguishing feature of RCTs is that after assessment of eligibility and recruitment, but before the intervention to be studied begins, study subjects are randomly allocated to receive one or other of the alternative treatments under study. Random allocation in trials is a complex procedure. After randomisation, the two or more groups of subjects are followed up in exactly the same way and the only differences in the care they receive, in terms of procedures, tests, outpatient visits, follow-up calls and so on, should be those intrinsic to the treatments being compared. The most important advantage of proper randomisation, it is claimed, is that it minimises allocation bias, balancing both known and unknown prognostic factors in the assignment of treatments. Finally, RCTs themselves can themselves be divided according to variables such as time, group or cluster (e.g. a village).

Epstein (1995; 1997; see also Richards, 1988) has shown how, faced with the multiple factors and pressures which structure the conduct and meaning of a clinical trial concerning HIV/AIDS – e.g. methodological and jurisdictional disputes between clinical researchers and biostatisticians, the marketing strategies of pharmaceutical companies, and the complicated role of practising physicians in interpreting the data produced by clinical trials – certain

activists succeeded in being credible speakers about science, representing patients on official policymaking committees. HIV/AIDS activists did so, in part, in the language of biomedicine to demand that molecules be made accessible to them on the basis of their perceptions. In this way they managed to obtain acceptance of the rate of CD4 (i.e. a protocol used for the identification and investigation of cell surface molecules present on white blood cells) as surrogate markers of the disease in order to assure the approval of a new drug (ddC), as well as the implementation of compassion trials.

Currently, the US Food and Drug Administration (FDA) do not approve any drug for treating CFS. However, a number of CFS trials that set out to test the efficacy of experimental drugs have had mixed findings. Furthermore, a considerable number of these studies have been based on only a small number of patients and hence consistent results have been hard to replicate. For example, Ritatolimond (Ampligen), a experimental immunomodulatory drug developed by US pharmaceutical Hemispherx, has been tested as a treatment for a wide array of illnesses including AIDS and, more recently, CFS, with limited success. Being a controversial drug, its critics say that Hemispherx is desperate to make some money on a failed project. Hemispherx reported the completion of a Phase III clinical trial for CFS in 2004 and filed a new drug application (NDA) with the US Food and Drug Administration (FDA) to market and sell Ampligen for the treatment of CFS. Ampligen, many thought, would be the first FDA-approved treatment for CFS. However, it was rejected in December 2009 because the FDA concluded that the two RCTs did not provide credible evidence of efficacy due to their small numbers (a clinical study including 300 or more patients was required).¹⁶ In March 2011, Hemispherx published new data analysis from a previous RCT that showed that Ampligen made improvements in exercise tolerance, one of the major problems for people diagnosed with CFS. Hemispherx had a meeting with the FDA on whether the new data were sufficient to resubmit the drug under the original NDA. The

FDA accepted the resubmission of the drug by Hemispherx and as it claims it expects FDA's decision in February 2013.¹⁷ As long as Ampligen fails to be the first FDA-approved drug for the treatment of CFS the available treatments are narrowed down to behavioural and activity therapies. Let us now examine a UK clinical trial on CFS of considerable importance, a trial that was set out to precisely measure the relative success of such therapies.

The PACE trial

The trial Pacing, Activity, and Cognitive behaviour therapy: a randomised Evaluation (PACE) was a relatively large-scale government-funded CFS trial conducted between 2006 and 2011 in the UK. Its purpose was to compare the efficacy and safety of four treatments: CBT, GET, Specialist Medical Care (SMC), i.e. care delivered by experienced clinicians experiences at treating CFS, and Adaptive Pacing Therapy (APT).¹⁸ It was 'the first in the world to test and compare the effectiveness of four of the main treatments currently available for people suffering from [CFS]'. The treatments offered ways for patients to deal with and improve the symptoms of CFS and its effects on disability. The study hypotheses were the following:

- Are CBT and/or GET more effective than pacing in reducing both fatigue and disability?
- Is pacing more effective than usual medical care?
- Are there differential predictors of response to CBT and GET and does the mechanism of change differ?
- Do different treatments have differential effects on outcomes (i.e. disability versus symptoms)?
- What factors predict a favourable response to treatment in general and with specific treatments?

- What are the mechanisms of change with successful treatment?
- What are the relative cost-effectiveness and cost-utility of these treatments?

The results were published in February 2011, showing that CBT and GET were moderately effective compared to SMT alone. APT was not found to be effective when added to SMT. Out of 3158 potential participants screened for eligibility, 641 patients meeting the Oxford criteria for CFS were recruited. 159 were assigned to the 'APT group', 161 to the 'CBT group', 160 to the 'GET group' and 160 to the SMT group. Compared to SMT, mean fatigue scores after 52 weeks were, on a scale of 0-33, 3.4 points lower for CBT and 3.2 points lower for GET, but did not significantly differ for APT (0.7 points lower). Physical function was also improved by CBT and GET, compared to APT or SMC. A subgroup analysis that compared patients using the Oxford criteria, the international CDC criteria and the London criteria for ME, found no statistically significant differences between the groups. In all cases, CBT and GET resulted in significant moderate improvements compared to SMT or APT. In addition, the trial found that CBT and GET were safe. Serious adverse reactions were recorded in two of the 159 patients in the 'APT group' (1%), three of the 161 patients in the 'CBT group' (2%), two of the 160 patients in the 'GET group' (1%), and two of the 160 patients in the 'SMC group' (1%). Furthermore, CBT and GET were found to be the most cost-effective treatments for CFS. Limitations of the trial included the fact that patients younger than 18 years of age and those not able to attend hospital were excluded. PACE's results were not contested.

Patient groups have criticised the PACE trial for over-simplified and exaggerated conclusions, for using a 'flawed psychosocial illness model' that ignores biological evidence, for testing a 'non-representative' version of pacing, and because the results seriously conflict with their member surveys which showed that pacing is effective and that CBT and GET can

cause deterioration in many patients who use the treatments. UK CFS organisations suggested that bad advice to patients, such as being told to just go out and join a gym, could be responsible for bad experiences that some patients have with exercise therapy. The MEA has had a number of concerns about the way in which the Science Media Centre (SMC) has been presenting CFS to the media. There is a wide spectrum of medical opinion as to what causes this condition and how it should be managed but this is not being reflected in the views of the medical experts in CFS research papers, they said. The most recent example of this debate was SMC's press release covering publication of the PACE trial results in *The Lancet* on 17th February 2011.¹⁹ All of SMC's medical experts who provided quotes for the media were strongly in support of the PACE trial results, and nobody pointed out any of the criticisms of the study, the MEA claimed. The CFS patient community, as well as a section of medical opinion, regarded the design and outcome of the PACE trial with great scepticism. The results for CBT, GET and pacing were not consistent with a large amount of patient evidence that has been published over the past few years, the MEA argued. The MEA was also very concerned about the way in which the results have been over-simplified in the media and in particular the inappropriate and potentially harmful advice concerning exercise. The worst example for the MEA was the headline in *The Independent*, 'Got ME? Just get out and exercise, say scientists'. In 2011, the MEA assessed patient opinion on the PACE trial results and found that over 90% of people diagnosed with CFS who had at the time responded (out of 462) said that the results were going to make the situation regarding the management of their symptoms worse. In its response to *The Lancet* (which *The Lancet* refused to publish), the MEA claimed that only the AYME has shown any support for this trial, with the remainder concluding that the results are flawed, the benefits for CBT and GET exaggerated, and that the negative results for pacing are at serious odds with patient evidence. The MEA argued that SMC would probably not agree with those dissenting views but they believed it is

unacceptable to censor other opinions, and wanted a meeting to be arranged to discuss how the SMC currently covers CFS and whether it was prepared to widen the range of medical expert opinion when covering CFS research in the future.

In its *2007 Clinical Guideline 53* on 'CFS/ME', NICE recommended that the Canadian case definition of CFS, which excludes patients with symptoms of mental illness, should not be used in the UK. According to the MEA, NICE based its decision on a small number of mildly positive clinical trials by the 'Wessely School', while devaluing evidence from scientific studies and patients' own evidence. CFS is the only physical condition for which behavioural modification is the primary management approach in NICE's Guidelines. The MRC declines to fund biomedical studies, yet the cost of implementing the 'Wessely School' regime in the UK is £3.75 million annually, in addition to non-recurrent costs of £26.45 million, the MEA claims. Furthermore, there was criticism of the scientific integrity of the panel of the trial (which apparently consisted mostly of members of the 'Wessely School'), the legitimacy and ability of statisticians, and the aim of the trial in the first place. Between 2002 and 2003 many members of the 'Wessely School' were appointed to MRC boards including Anthony David, Michael Sharpe, and Trudie Chalder, and with Simon Wessely being a recent member (Wessely was a member on three MRC boards: the Health Services and Public Health Research Board; the Neurosciences and Mental Health Group, and the Monitoring and Evaluating Group (MEG)). The panel, it was claimed, had direct affiliations with insurance companies. The PACE trial was the only clinical trial that the Department for Welfare and Pensions (DWP) has ever funded and the only one that patients and their organisation tried to prevent, CFS patients claimed.²⁰ Wessely himself set up and directed *The Mental Health & Neuroscience Clinical Trials Unit* in 2002, which was the first unit in the UK to specialise in mental health and the neurosciences, and which, in its first six years of operation, provided advice and support to a large number of grant applications. Furthermore,

when the MRC, that classified CFS as a mental health problem, was challenged, Dr Robert Buckle, member of the MRC and of the PACE Trial Steering Committee, subsequently stated that CFS was classified as a mental health problem for a ‘pragmatic’ reason ‘related to the MRC grants classification associated with the activities of one section of the office’ (Hooper, 2010: 47). Be that as it may, after a proposal from the interdisciplinary MRC CFS/ME Research Advisory Group, that includes experts from a wide range of disciplines as well as input from the major UK-based CFS patient charities, the MRC has now a dedicated budget for research in areas such as autonomic dysfunction, immune dysregulation, and sleep disorders in patients diagnosed with CFS.

The making of a scientific controversy such as CFS is determined, besides law and media, as we have already seen, on money, political influence, and regulatory authority. While the MRC boards were dominated by exponents of the psychiatric account of CFS, CFS activism has managed to direct the MRC research on CFS on biomedical grounds.

Fatigue’s Cerebralisation?

‘Yes – it’s all in your head’ (the abbreviation IAIYH is sometimes used) writes John, a member of the CFS blog. CFS is not in the mind but literally inside the head, in the brain. Another user, Mike, used the expression: ‘The damn thing is in the Brain’. Although some of my informants talked a little bit about their brains, and a few indeed confirmed Mike’s view, here I concentrate more on the research I did in the CFS blog. For my informant Thomas, the ‘illness is not in the mind but in the brain’ (Interview 2). Thomas was certain that two things are involved in this condition: a virus and the brain (other factors might be influencing it but they are less important). According to Mike, ‘[t]he inherent plasticity of the brain allows people ... to ‘purposefully introduce conscious actions to block the abnormal circuit’ by doing behavioural therapies such as meditation, the Amygdala retraining programme, CBT,

etc'. Mike actually quoted a certain Dr Baraniuk who obviously has a great trust in the brain's capacities. One of the possible and relatively frequent suggestions is that clumps of abnormally folded proteins could be causing small punctures in the blood vessels of CFS patients' brains, something which has been established in Alzheimer's and Down syndromes. It has also been suggested that CFS patients suffer from an 'overactive brain' which is connected with the CNDP1 gene. 'Brain imaging studies...have shown inflammation, reduced blood flow and impaired cellular function in different locations of the brain...(and) they change a person's life', Steve writes. According to brain imaging studies, no change in the human body can be detected except for a few small changes in the functioning of the brain, changes which can only be known through very specialised and expensive brain scans. As Thomas told me, there is an 'objective' way to detect CFS and that is the brain scan (Interview 2). The problem is, according to him, its excessive cost, one of the reasons CFS is 'massively underdiagnosed' (Interview 2). He told me that it costs around £4,000, though he was probably misinformed.²¹

Like earlier practices of confession and diary writing, the practices of posting, reading and replying to messages in such web forums and chat rooms are 'techniques of the self' which entail the disclosure of one's experiences and thoughts according to particular rules, norms, values and forms of authority. Through these practices of disclosure 'individuals develop a language to narrate and reflect upon their genetic identity, seek advice on how to conduct their lives appropriately, and assume responsibilities for the management of genetic illness' (Novas and Rose, 2005: 503). Novas and Rose (2005) coin the term 'life strategies' to name the variable and multiple strategies individuals formulate in relation to particular directions that they would like their life to take. I do not think these strategies concern only the management of genetic illnesses nor that Rose argues that. Although biosocialities are usually associated with diseases of a genetic nature, this does not mean they cannot be associated

with other, non-genetic or complex diseases. Proclaiming oneself a ‘cerebral subject’ is becoming a criterion of social grouping, as can be seen in support groups for bearers of neurodegenerative disorders (Ortega, 2009).

Abi-Rached and Rose (2010) describe an epistemological shift in the brain sciences during the last decade or so which they term ‘neuromolecular gaze’. The current neurological rhetoric claims that the ‘neurosciences hold the key to the management of all manner of human activities and experiences, from psychiatric illness to economic behaviour, from human sociality to spirituality and ethics’ (Abi-Rached and Rose, 2010: 32). New visions of personhood are coming to the fore associated with the growing interest and sophistication in brain-imaging techniques, which localise the features of the personality in particular regions of the brain. The emergence of molecular science and the push for pharmacological solutions are contributing to the discursive formation of new subject positions, such as the ‘neurochemically deficient self’ (Rose, 2007b). There is a growing literature on brain scanning and the uncertainty that exists in its scientific application (Beaulieu, 2001; 2002; Dumit, 2003; Joyce, 2005; Prasad, 2005; Alac, 2008; Johnson, 2008) and on the socio-political implications of different visions of the brain (Abi-Rached, 2008; Martin, 2010; Pitts-Taylor, 2010; Papadopoulos, 2011b; Rees, 2011). The genome might have been a great hope for ‘unlocking’ the secrets of ‘human nature’, but as Maun (2003) put it, ‘the “neural aspects of human nature” seem more directly relevant to many of the philosophical and ethical questions, notably those related to self, raised by the Western philosophical tradition, and by genetics and genomics as well’ (quoted in Vidal, 2009: 6). Recently, it was suggested that PTSD exhibits a distinct pattern of brain activity that can be found with great accuracy by a new brain scanning technique called magnetoencephalography (MEG) (Drummond, 2010; Storrs, 2010). What was once called a ‘soft disorder’ without an objective diagnosis that had to be evaluated psychologically and distinguished from mental illnesses, now seems

to have an accurate assesment. ‘Whereas CT [computerised tomography] scan and MRIs record signals every few seconds, MEGs can do it by the millisecond, catching biomarkers and brain activity that other tests inevitably miss’, writes Drummond (2010: n.p.). Brian Endgdahl, a psychologist at the Department of Veterans Medical Centre in Minneapolis, says that MEG can help people feel less stigma ‘[b]ecause there’s something different with [their] brain’ (quoted in Storrs, 2010: n.p.).

Can the brain provide a conclusive aetiological account for CFS? At least this is what some neuroscientists, with DeLuca (2005) being one of the most prominent, and some people diagnosed with CFS like to think (Figure 4). DeLuca edited *Fatigue is the Window to the Brain*, a book which, by having gathered experts on a wide variety of disorders, wants to consider what the presence of fatigue tells us about how the brain works and tries to identify the neural mechanisms potentially responsible for fatigue. The book considers neurological conditions, including MS and stroke, and psychiatric conditions as well as the overall treatment of fatigue in psychiatry, but also general medical conditions like heart disease.

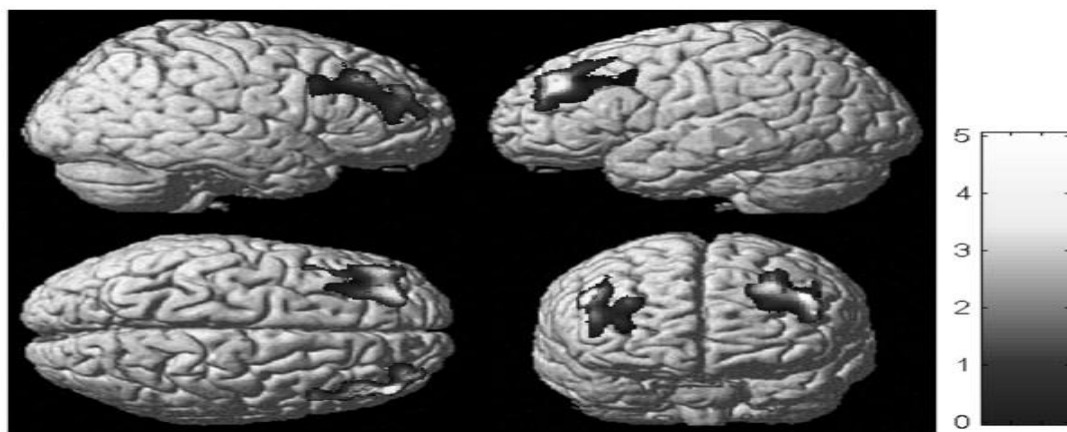


Fig. 4. Regional differences between CFS/ME patients and controls. Areas with significantly reduced gray-matter densities in the CFS/ME patients were located at bilateral prefrontal areas, which were surface rendered onto the high-resolution MRI (Magnetic Resonance Image). The bar indicates the *t*-values (*t*-tests are statistical tests that are used to determine whether there are significant statistical differences between two groups with respect to a given endpoint). Reproduced from Okada *et al.* (2004: n.p.).

Moreover, there are practical reasons for the popular endorsement of equating mental diseases with those of the brain (Ortega and Zorzanelli, 2010: n.p.). In the case of the US, for example, the insurance system favours this choice, since a disease considered to be real is better remunerated than psychogenic diseases or diseases with no medical explanation. In neurasthenia the brain served as a possible explanation (Rabinbach, 1992; Ward, 2003). That was because the brain supplied the individual with nervous energy and was, at the same time, the organ that became exhausted. Although the brain was never really convincing as an explanation for CFS, it was not completely dismissed. As Ward (2003: 126) puts it, '[i]n our times, the medical formulation of CFS/ME ... implies disease of central nervous tissues – including, but not exclusively of the brain'; however, Wessely (1993) has argued that in ME there is an inappropriate use of the word 'encephalic'. Johnson and DeLuca (2005) acknowledge that CFS is a heterogeneous, multidimensional illness and suggest that it *may* be related to brain dysfunction, for which they give considerable evidence from the relevant literature. Abnormalities or differences in the cerebral ventricular volumes can be observed by various brain imaging techniques such as MRI, functional MRI (fMRI), and near-infrared spectroscopy (NIRS). These 'abnormalities', which appear in a variety of diseases and even normal subjects, are frequently labelled UBO's ('Unidentified Bright Objects'). Arguing that CFS is nothing more than 'some other psychiatric condition is too simplistic', Johnson and DeLuca (2005: 148) suggest. There have been numerous studies that try to find some pathology for CFS located in the brain (e.g. Schwartz *et al.*, 1994; Greco *et al.*, 1997; Lange *et al.*, 1999; Cook and Natelson, 2001; Schmaling *et al.*, 2003). The fact that CFS does not have an identified cause provides the space for different competing aetiological hypotheses, primarily motivated by the patients' struggle for the legitimacy of their disease, based on the search for organic factors. Ortega and Zorzanelli (2010) note that '[o]ver half of the studies of CFS between 1980 and 1995 concentrated exclusively on its physical aetiology and in

subsequent years little emphasis was given to research on the psychological and psychiatric factors'. Explanations for fatigue were sought in viral infections, the immunological system, dysfunctions of the nervous system, sleep patterns, and genetic composition, and although many studies pointed out irregularities in the patterns investigated, few found them in a significant number of patients. In CFS, the explanatory hypotheses reinvent the brain as the aetiological locus. Although not completely dismissive of the idea, Ortega and Zorzanelli find it problematic because,

‘even in the ideal case, supposing that the processes and structures responsible for a determined task are implemented in a given part of the brain, it can be argued that the activation in that area while the subject is realizing the task is evidence that these processes were used while the subject did it’ (Ortega and Zorzanelli, 2010: n.p.).

The demonstration that a particular pattern of cerebral activity is related to the performance of particular types of tasks is not, in and of itself, very interesting. The problem is that a given part of the brain can implement multiple processes and, therefore, the results should be considered only as another source of convergence of the evidence. Nevertheless, even though these findings are inconclusive, they can potentially be used to explain the ‘essence’ of the disease. The visual expressivity is rhetorically used to construct what is intended to be shown in the first place. As a result, ‘the use of neuroimages not only leads to the objectivation of individuals ... but also to an objectivation of the disease itself’ (Ortega and Zorzanelli, 2010: n.p.). The following statement by MRC clinical professor of immunopharmacology at the University of Southampton, Stephen Holgate, testifies to this:

‘Technological developments in neuroscience such as functional brain imaging are providing new ways of studying how the CNS is influenced by systemic disorders and vice versa. With such powerful and innovative tools available to explore disease mechanisms, it would be a missed

opportunity and a great disservice to CFS/ME patients if these tools could not be used to enhance understanding of this disease because of the prejudice of relatively few individuals' (Holgate *et al.*, 2011: 542).

People diagnosed with CFS are puzzled about a series of questions such as the nature of the brain, its relation to the mind, and the extent to which CFS can be detected in the brain. Consider the following extracts of a conversation between Patrick and Peter in the CFS forum:

'A recent MRI that was requested by a neurologist who I was referred to by an occupational health doc at work ... revealed lesions in my brain, yet, the diagnosis, is still CFS. My GP however, is unconvinced and is treating me with medication used for MS patients and it has eased some of the symptoms; I am now awaiting a referral to another neurologist ... for a second opinion' (Patrick).

'Personally, I don't think the mind and body are separate entities. The amygdala and the hypothalamus and the sympathetic nervous system are body parts after all!!' (Peter).

Being 'awash in a sea of biomedicalizing discourses' (Clarke *et al.*, 2003: 184), like all of us, CFS individuals try to understand what is happening in/with their bodies. They try to understand the functions of the brain, its relation to the mind, or the specific causality between the neurological systems and the brain. Of course this is not pure intellectual curiosity but stems from the quest for objectivity and energy. They want a cure or at least the knowledge to make their selves more 'controllable'. It would not be an exaggeration to suggest that many people diagnosed with CFS conceive of themselves in neuroscientific terms. The prevalent discourse of brain plasticity, of the adaptive and self-recreating capacities of the brain is, as Pitts-Taylor (2010: 640) argues, 'highly compatible with the

neoliberal pressures of self-care, personal responsibility, and constant flexibility'. Although this should not be considered absolute, it definitely highlights how different understandings about the brain and the body's parts and functions are inseparable from the broader social and political climate. I would like now to talk about the 'discovery' of the XMRV virus and the debates it provoked between scientists and patient organisations. That will further enhance our appreciation of the ways in which the making of CFS is a matter of intervention.

The 'Discovery' of the XMRV Virus

Since 1957, various viruses including Brucella, Epstein-Barr Virus (EBV) and even HIV have been suggested as the possible pathogens of CFS, but to the detriment of the CFS community globally none has conclusively been found to be the cause of CFS. The 'discovery' of a new virus, many believed, was about to change everything. XMRV (Xenotropic murine leukemia virus-related virus) is a gammaretrovirus that was first described in 2006 and was initially linked to prostate cancer. XMRV was 'discovered' by laboratories led by Joseph DeRisi at the University of California, and Robert Silverman and Eric Klein of the Cleveland Clinic. Silverman had previously investigated the enzyme RNase L that is part of the cell's defence against viruses. When activated, RNase L degrades cellular and viral RNA to halt viral replication. In 2002, the 'hereditary prostate cancer 1' locus (HPC1) was mapped to the RNase L gene, implicating it in the development of prostate cancer. The cancer-associated R462Q mutation results in a glutamine instead of an arginine at position 462 of the RNase L enzyme, reducing its catalytic activity. Someone with two copies of this mutation has twice the risk of prostate cancer. Klein and Silverman hypothesised that the putative linkage of RNase L alterations to HPC might reflect enhanced susceptibility to a viral agent, leading to the 'discovery' of XMRV.

Subsequently, a study by Lombardi *et al.* (2009) claimed to have found XMRV in the peripheral blood mononuclear cells of patients with confirmed CFS, and a second study by Lo *et al.* (2010) reported that scientists from the FDA's Center for Biologics Evaluation and Research and the National Institute of Health (NIH) have found MLV-related gene sequences in patients diagnosed with CFS and in some healthy blood donors. Those findings, which were published online on 23rd August 2010 in the *Proceedings of the National Academy of Sciences*, added to the evidence that a virus may play a role in some, if not all, cases of CFS, and lend support to Lombardi *et al.*'s study. Lo *et al.*'s study showed that 86.5% of 37 people diagnosed with CFS had evidence of that virus in their blood, as did 6.8% of healthy blood donors, backing up a report by researchers at the Whittemore Peterson Institute for Neuro-Immune Disease (WPI) in the US, which showed similar results. 'There is a dramatic association with CFS, [but] we have not determined causality for this agent', said Harvey Alter, a hepatitis expert and chief of clinical studies and associate director for research in the department of transfusion medicine at the NIH Clinical Center in Bethesda at a news conference.²² 'Other labs have not found this virus, so a dilemma at present is how to reconcile that some labs find the association and others do not', he added. 'These results do raise as many questions as they answer', said Dr Steve Monroe, director of the division of high-consequence pathogens and pathology at the CDC. Monroe went on to add that 'the different findings from different laboratories now that have been reported suggest that there are still a lot of things about this virus that we do not know'.²³ Nevertheless, later studies found no results whatsoever (Erlewin, 2010; van Kuppelweld, 2010; Groom *et al.*, 2010). WPI's role in that emergent reality was significant. WPI describes itself as '[t]he first institute in the world dedicated to neuro-immune disease integrating patient treatment, basic and clinical research, and medical education'.²⁴ As one reads on their website, which I have to quote at length:

‘The spectrum of neuro-immune diseases including: Myalgic Encephalomyelitis (ME/CFS), Atypical MS, Fibromyalgia and Gulf War Syndrome, share common abnormalities in the innate immune response, which result in chronic immune activation and immune deficiency. We have detected the retroviral infection XMRV in greater than 95% of the more than 200 ME/CFS, Fibromyalgia, Atypical MS patients tested. The current working hypothesis is that XMRV infection of B, T, NK and other cells of the innate immune response causes chronic inflammation and immune deficiency resulting in an inability to mount an effective immune response to opportunistic infections. This discovery opens an entirely new avenue of Neuro-Immune Disease related research and our discovery has brought to this field world-renowned immunologists and retrovirologists building our team of collaborators to translate our discoveries into new treatments as soon as possible’.

WPI claimed it was ‘leveraging an international network of dedicated virologists, immunologists, geneticists and other highly skilled researchers’. The virologist and spokesperson of the CFS cause, Judy Mikovits, was one of them. The National Cancer Institute in the US has already started working on a vaccine and clinical trials are expected to begin at the WPI sometime next year, Mikovits said in 2009. The world’s largest pharmaceutical companies, among them *LabCorp* and *Quest*, have been calling the institute asking if they can test their lines of a drug now used to treat patients with HIV to see if their anti-viral drugs can be adapted to treat CFS patients, Mikovits said.²⁵ The drug companies would pay for the Reno Institute’s cell lines, the established cultures that would grow the XMRV retrovirus, so they can test their antiviral drugs on them. ‘They want us to send them [i.e. to the National Cancer Institute] the retrovirus so they can screen huge libraries of compounds and see what they have that could work’, adding that ‘[s]ince they already have FDA approval, they could get something out to people fast.... I think this will bring money into the state right now’. According to the WPI, future research and biotechnology stemming

from the initial study was expected to generate more research and intellectual property, and Mikovits and Dr Ruscetti filed for a patent for an antibody test for XMRV. In its official statement on the paper ‘Failure to Detect the Novel Retrovirus XMRV in Chronic Fatigue Syndrome’ (Erlwein *et al.*, 2010), the WPI stated:

‘WPI does not recommend the use of anti-retroviral drugs that have yet to be proven to be effective in treating XMRV infection. However, several large pharmaceutical companies have expressed interest in developing anti-retroviral and immune modulating drugs that will effectively treat XMRV associated diseases’.²⁶

Suspicion arose that the WPI was supporting the financial interests of certain pharmaceutical companies. The WPI would deny such allegations as they write on their website that none of their staff has ‘any financial interests or holdings in the various pharmaceutical companies who produce drugs used to treat chronic diseases’. However, it should be noted that Mikovits is director of research at the *Genyous Biomed International Inc* (‘Genyous’) and Kenny DeMeirleir a member of *Protea Pharma*.²⁷ ‘Genyous’ has invented a Multifunctional Multitargeted (MFMT™) drug development platform to create multivalent therapies for early intervention and treatment of heterogeneous chronic diseases like cancer. A subsidiary of ‘Genyous’ is *Vitala Therapeutics Inc.* whose mission is to commercialise healthy function and early-intervention MFMT biopharmaceuticals.²⁸ It should also be noted that the WPI is related to Cerus Corporation, a US biomedical company focused on commercialising internationally the INTERCEPT Blood System to enhance blood safety.²⁹ The INTERCEPT Blood System is designed to inactivate blood-borne pathogens in donated blood components intended for transfusion. The FDA requires that blood donors be in good health at the time of donation, and the Advancing Transfusion and Cellular Therapies

Worldwide (AABB) recommends that people diagnosed with CFS be discouraged from donating blood or blood components.³⁰ There was a rumour among users of the online CFS community that the XMRV virus was a trick of the pharmaceutical companies to make profits; otherwise, a drug to cure CFS would already exist. ‘Nobody can beat Big Pharma, they’re much too powerful and much too keen on money’, CFS blog user Nick wrote. Some suspicion existed even in those CFS patients who did not doubt that there was something ‘wrong’ with them. Let us now see what happened with the battle over the publication of findings around XMRV.

In May 2011, the editors of *Science* (Alberts, 2011) asked the co-authors of the Lombardi *et al.* paper to voluntarily retract the paper following other studies that have failed to detect the retrovirus. Mikovits, one of the paper’s key authors, strongly refused to retract, citing the fact that other studies have indeed found evidence of the retrovirus infection, that no study to date has replicated or disproved her original research, and that other major scientific investigations into gamma retrovirus infection are being conducted. In addition, there was a delay of a publication related to XMRV (that also raised suspicion in the online CFS community). This happened in the case of Alter and his team, who identified viruses similar to XMRV in 32 of 37 people diagnosed with CFS and in 3 of 44 healthy people and were preparing to publish their results in the *Proceedings of the National Academy of Sciences* but because scientists at the CDC were about to publish a negative report, they had to delay their publications to assess discrepancies (Callaway, 2011). Moreover, some scientists (Oakes *et al.*, 2010; Kearney *et al.*, 2012) claimed that some studies have used samples contaminated with mice samples and therefore the credibility of those studies was seriously challenged.

What were CFS organisations’ responses to all these? After XMRV was found in some CFS patients’ blood, the IiME, for example, published these findings in their 2010 conference, considering them a major breakthrough in the understanding and treatment of CFS. The IiME

claimed that for 2011 the way forward was to focus on translational biomedical research into CFS with the initiation of clinical trials using ‘homogeneous patient cohorts’ and ‘correct clinical guidelines’. The education of health care staff about CFS needed to break with the past and reflect the new knowledge about the pathogenesis of CFS which high quality biomedical research was providing. The *International ME/CFS Conference 2011: The Way Forward for ME – A Case for Clinical Trials* was oriented toward providing ‘knowledge of the latest research and the biomarkers which allow appropriate treatments to be prescribed’.³¹ Apart from knowledge of the ongoing biomedical research, it was necessary for healthcare staff to be aware of the multiple symptoms exhibited by CFS patients and the possible treatments available. Research data, experiences of treating CFS, and findings from the latest biomedical research were presented. One of the most important aspects of previous international conferences on CFS has been the creation or resumption of the unique networking opportunities available with some of the most renowned experts on CFS in the world. As the IiME mentioned:

‘The conference will appeal to healthcare professionals, doctors, nurses, paediatricians, occupational therapists, researchers, ME/CFS support groups, people diagnosed with ME/CFS and those working in social services, educational support and the media. The conference provides an opportunity for people within government, health departments, social services and education to be able to be informed of the true nature of ME/CFS and of the current status of diagnosis, treatment and current/future biomedical research possibilities’.

Similar attempts to expand biomedical research on CFS have been made. One of them was the NIH’s ‘State of Science’ meetings on CFS.³² The first two ‘State of Science’ meetings were held in 2000 and included just three CFS experts among the speakers, all of whom were psychiatrists. Following objections from members of the Health and Human Services CFS

Coordinating Committee (CFSCC), the predecessor to the CFS Advisory Committee (CFSAC) – which provides advice on issues related to CFS to the Secretary of HHS – and other advocates, the panel was expanded and members of the public were permitted to attend. In 2011, HHS announced that a ‘true’ ‘State of the Science’ meeting would be held later that year, as it was, but that time the planning committee included members of the CFSCC and other patient advocates. The workshop, which was attended by 150 people, concentrated on various areas including infectious diseases, immunology, neurology, diagnosis and biomarkers, treatments, gaps in existing knowledge and opportunities. Significant was the summary of a community psychologist from DePaul University in the US, Dr Leonard Jason. Jason gave emphasis to the importance and pitfalls of the current diagnostic criteria and case definitions for CFS. The selection and application of a case definition has profound impacts on research cohorts and comparability of data. Jason pointed out that CFS can be distinguished from depression but that many research studies do not account for these differences in patient selection and argued that it was time to create ‘gold standard’ criteria. Following summaries by each group of session co-chairs, scientific director of CFIDS Association of America, Dr Suzanne Vernon, presented a comprehensive summary of the gaps and opportunities in CFS research identified during the workshop.³³ Gaps in current knowledge and research studies included:

- Different terminology and case definitions blur the lines between research and clinical medicine and create problems in comparing study results.
- CFS research falls into discipline silos.
- There is a lack of standard operating procedures for studies, a lack of common data elements and a lack of coordination and collaboration.

- Study design must account for subtypes, demographics, disease and healthy controls, biomarkers, time course data, clinical trials, early detection, paediatric vs. adult presentations and outcome measures.
- Many types of studies are needed, including longitudinal, natural history, early detection, paediatric vs. adult CFS, genetics and clinical trials.
- Biomarkers must be reproducible, replicated and validated.
- Animal models are needed.
- There are not enough doctors to treat the millions of CFS patients.
- There are not enough researchers.
- There is not enough money.

However, Vernon added, these difficulties can be addressed and progress made. What is required is collaboration to leverage existing infrastructure, resources and knowledge. Opportunities for advancing the ‘science of CFS’ included:

- XMRV has given the field unprecedented awareness, attention and opportunities.
- Leadership is needed to agree on and embrace opportunities.
- Platforms for collaboration should be silo-transparent and include patient derived/reported outcomes and a clinical network to share information.
- Information standardization and aggregation should help identify and prioritise studies, including biomarker discovery, biomarker replication and validation, preclinical and clinical studies and leveraging existing infrastructure and resources.
- Learning from other research areas and diseases must be incorporated.

On the official website of CFIDS, Vernon argued that in research studies the 1994 definition ‘should be the minimum means by which CFS cases are classified’, which means that particular care should be taken to exclude other causes of symptoms and that subjects be

described as ‘completely as possible, with data collected on duration of illness, type of onset, severity, functional and comorbid conditions’.³⁴ As far as the opportunities for further research on CFS are concerned, Vernon provided a summary of how clinical research on CFS should be conducted, highlighting areas such as the multidisciplinary approaches on researching CFS and the statistical analysis and limitations of studies.

While the hopes of establishing the XMRV virus and the polytropic murine leukemia viruses (MLVs) as the causative agents have been minimised, if not completely abandoned, the Chair of Trans-NIH ME/CFS Research Working Group at the NIH, Dennis Mangan remarks that:

‘this does not alter the evidence of neurologic dysfunction in CFS, and it does not have a bearing on evidence linking CFS with other neurotropic viruses – particularly human herpesvirus 6 and enteroviruses. There are many leads for neuroscientists to pursue in uncovering the pathology and the aetiology of this terribly debilitating illness that afflicts nearly 1% of adults’ (Holgate *et al.*, 2011: 543).

Besides demanding further biomedical research, CFS patients and associated organisations have been fighting the new DSM proposals, which they believe would affect both research and clinical care. The WPI and the Patient Alliance for Neuroendocrineimmune Disorders Organization for Research and Advocacy, Inc. (P.A.N.D.O.R.A) – which is not just a coalition of CFS groups as claimed in some online CFS communities as it addresses other illness, such as FMS, GWI, and post Lyme disease syndrome (PLDS) as well – are two of these organisations in the US. The proposed changes of DSM-V, which is scheduled to be published in 2013, would combine several existing somatic categories into one larger category, the so-called ‘complex somatic symptom disorder’ (CSSD), the P.A.N.D.O.R.A. claimed. In trying to prevent this, the P.A.N.D.O.R.A. sent a letter of concern to the

American Psychiatric Association (APA), saying they were deeply concerned by that potential reclassification which not only may include CFS as a somatoform disorder but also other illnesses such as fibromyalgia.³⁵ The P.A.N.D.O.R.A. claimed that researchers from the both the NIH and the CDC have documented the pathophysiological underpinnings of the illness and that the CDC has launched a campaign of a million dollars within the past few years to underscore that CFS is a multi-system disorder. Similarly, the MEA argued that it is ‘of paramount importance that the [APA] are aware of the dangers inherent in establishing incorrect categories of disorders which are based on poor science, vested interest or which do not serve the patient’. As they went on to add:

‘Who decides when someone misattributes their pain or fatigue? How are these symptoms measured? How long and vigorously is a patient allowed to complain about their symptoms before a doctor can decide to investigate further and determine if a headache is a brain tumour or irritable bowel syndrome colon cancer?’

We have already seen that classification systems are complex and messy. Not only are the proposals of DSM-IV a problem for the legitimacy of CFS as a biological illness but the WHO will be revisiting its system in 2014; the ICD-11, which would reclassify CFS as ‘R53.82 Chronic Fatigue, unspecified’, should also be taken into consideration. As has been noted, the differences in the ICD-10 and DSM-V definitions for the same disorder impede international communication and research efforts, something that the forthcoming parallel development of DSM-V and ICD-11 might overcome (First, 2009). A great opportunity for psychiatry’s development (and for private insurance companies that would find it easier not to give money to CFS patients) can be at the same time a serious threat to the interests of CFS patients, medical researchers, and potentially to pharmaceutical companies. ‘Any illness

lacking a diagnostic test is in danger of being put into this non-specific category which helps no one', the MEA claimed. CSSD is a 'flawed', 'broad unspecified' category. In a similar line of argument, Holgate remarked that: 'The great challenge that faces the field is how to engage scientists to undertake research into the condition that will translate into new diagnostic tests and treatments that go beyond controlling symptoms' (Holgate *et al.*, 2011: 543). In a recent paper dedicated to CFS's future, Magnan together with Wessely concluded that the neurosciences is the field where new insights into the nature of CFS are most likely to emerge, a field which has strong connections with other domains of CFS like infection and inflammation, immune dysfunction, and sleep (Holgate *et al.*, 2011: 543-544). For his part, Wessely believes that the 'discovery' of XMRV will simply join the list of dramatic discoveries in CFS that did not stand the test of replication, and adds that:

'unfortunately, the XMRV story may also have had unintended consequences beyond generating a rush of papers and citations. The ongoing antagonism that has been directed towards so many of the scientists who failed to replicate the original findings and who thus came up with what the extremists see as the 'wrong answer', has alienated yet another group of scientists from getting involved in this arena. This can only be of harm to science and to patients (Holgate *et al.*, 2011: 544)

Magnan claims that the Working Group identifies cross-cutting areas of research and confronts challenges that embrace multiple scientific areas, including the neurosciences. That can be achieved through funding initiatives and educational outreach activities to attract investigators and advance research on CFS (Holgate *et al.*, 2011: 544). What is currently needed is to establish the 'subphenotypes of the syndrome through standardized clinical, laboratory and physiological measurements without constraining the data input with preconceived clustering', Holgate argued (Holgate *et al.*, 2011: 540).

It is clear that there is a remarkable effort by CFS organisations and medical scientists to standardise CFS both in the clinic and in the laboratory and to change the classifications of CFS. The need to have reproducible, replicated and validated biomarkers is the perfect illustration of that. Magnan's proposal for 'new diagnostic tests and treatments that go beyond controlling symptoms' is also crucial as it highlights the pressure that is put on the field in order to finally have an 'objective' diagnosis and the required treatment. One conclusion seems appropriate for the time being. The attempts to standardise the treatment of CFS, which are in a way autonomous from the standardisation of its definition, are stronger. Even if there is a partial standardisation of large-scale RCTs showing a statistical benefit for one treatment or another, this does not translate easily into the complex and heterogeneous world of CFS. That is due to both the increasing demand by CFS patients themselves to find a treatment that could alleviate their fatigue and manage their symptoms and the as yet lack of scientific consensus over its aetiology.

While there is still no generally accepted definition of CFS, the XMRV virus, the continuous struggle of CFS advocacy groups for the recognition and legitimacy of the illness as neurological or organic, and the 'extremist' attempts of CFS activists, have brought considerable results. The history of CFS is marked by periods where psychological explanations dominate the field, and others where organic ones become more and more prominent, as in the last couple of years with developments in neuroscience and the XMRV virus; in between there are proposals for an integrated approach that would overcome the dichotomy between medicine and psychology. Nevertheless, none of the actors in the CFS network has managed to 'speak' on behalf of all others, to force everyone else to accept its own language and logic. CFS constantly escapes standardisation and remains elusive.

Chapter Six

The Work Regulation of CFS

‘Depression Most Costly Illness for Employers’ was the title of a paper published in *Psychiatric News* (Rosack, 2003). Employers across the US are losing an estimated \$44 billion a year in lost productivity because of ‘depression’ and that mainly due to ‘presenteeism’, that is, being on the job but with reduced productivity. Rosack followed the results of the Depressive Disorders Study (DDS) which found that ‘depressive’ workers cost employers more than three times the amount associated with lost productivity from all other illnesses (Stewart *et al.*, 2003). DDS was a part of the American Productivity Audit (APA) run by Walter Stewart, a researcher in Advance PCS Center for Work and Health in Hunt Valley, which surveyed more than 30,000 randomly selected employed individuals in 2002 and estimated the impact of various illnesses on labour costs, including ‘absenteeism’ and ‘presenteeism’, in the US labour force. The APA and the DDS were funded respectively by the private companies AdvancePCS and Eli Lilly and Company. The APA was initiated to better understand the relation between health and ‘lost productive time’ (LPT). The DDS was necessary, Stewart emphasised, because previous estimates of the cost of depression in the US workplace were based on data collected during the 1980s and included assumptions regarding prevalence, duration and impact on work of depressive episodes. The ‘excess’ LPT costs from depression were derived as the difference in LPT among individuals with depression minus the expected LPT in the absence of depression projected to the US workforce. The data were based on the ‘Work and Health Interview’, a telephone interview that included questions in reference to only the previous two-week period and asked about occupation, a self-reported health assessment, the number of days of work missed in the previous two weeks, and how that affected the respondent’s productivity on the job. The

questions elicited information on income, quality of life, treatments obtained, and demographic details. Nineteen percent of the \$44 billion cost of depression was accounted for by ‘absenteeism’, while the remaining 81 percent was linked to ‘presenteeism’. Depressive symptoms were more common in women and people with lower levels of education. This is a ‘major finding’, Stewart noted, because employers believe employees are ‘generally fine’ because they are on the job. What they do not realise are the ‘hidden costs’ of lost productivity due to lack of ‘energy’, ‘insight’, ‘creativity’, and ‘motivation’, all difficult to quantify. Those interviewed estimated that with depression they lost an average of 5.6 hours a week (‘h/wk’) of productivity versus 1.5 hours a week for non-depressed workers.¹ Finally, the DDS estimated that about twenty-five percent of the depressed workers had received treatment, saying that on a scale of a self-reported treatment effectiveness from zero (‘doesn’t work at all’) to 10 (‘complete relief’), the average rating was also at 5.6.

Was that lack of energy and creativity a synonym for depression? Could we suggest that energy is now more ‘affective’? These questions will, in some ways, traverse this chapter. It is commonplace that workers’ health and emotions have become capital’s main targets. Capital has long moved beyond the optimisation of body movements and is concerned with the psychological well-being of workers. Workers have to continuously monitor themselves for any deviation from the norms that define the healthy body. Additionally, a doctrine of creativity has entered psychology vocabularies, economics, education, and other domains of life, and is connected with compulsory individualism and productiveness (Osborne, 2003: 507).² Creativity and energy potentially reside in each one of us even though we might be at rest. It would not be an overstatement to assert that under such a regime ‘slow-down’ can be pathologised. How else could we interpret what in fatigue and sickness absence studies is referred to as ‘motivational fatigue’ (Janssen *et al.*, 2003: 71)? This medicalisation of fatigue, as of feelings of distress more broadly, can have dangerous consequences. That relates to the

‘psychologisation of work’ (Crespo and Serrano, 2011). As other social matters, work has been individualised too. The gradual trend towards the autonomisation of the individual and the concomitant demand for the individual to become responsible for oneself has been a central characteristic of modernity. One has rights as a ‘citizen’ and is responsible for his/her destiny. Psychologisation refers to an ‘asocial’ way of understanding the modern individual, in contrast to a certain type of individualism which, it can be argued, can be positive because it breaks from traditional social ties and leads to new networks of solidarity.³ Thus, individuals can be held responsible for situations that are out their control (e.g. keeping their jobs). While the discourse of autonomy boosts individuals’ capacity to take responsibility for their own life, it also undermines the collective conceptual and institutional resources through which they could control the conditions that make them vulnerable. Vulnerability expresses the subjective position of the individual worker in the current labour market. But here we need to turn to the labour market itself.

CFS and Precarity

According to estimations, there are currently around 250,000 individuals in the UK who suffer from CFS. In the US, the number seems to be around 1 million, and on a global scale around 17 million, a number which seems to be increasing. Although numbers vary, over half are unable to work and nearly two-thirds are ‘limited’ in their work. More than half are on disability benefits or temporary sick leave, less than a fifth work full-time, and although there are no precise numbers, unemployment in patients diagnosed with CFS seems to be high (Ross *et al.*, 2004). To be classified as having disability, patients should have a severe impairment making them unable to work. According to the Social Security Administration in the US, the impairment:

‘must result from anatomical, physical, or psychological abnormalities which can be shown by

medically acceptable clinical and laboratory diagnostic techniques. A physical or mental impairment must be established by medical evidence consisting of signs, symptoms, and laboratory findings, not only by a statement of symptoms' (quoted in Ross *et al.*, 2004: 1099).

That is also the case for the medical system in the UK. Now, as already mentioned, because CFS has no established organic aetiology, as no diagnostic laboratory biomarker has been identified, and because its core complaint, fatigue, is considered entirely subjective, CFS lacks the 'objectivity' that would legitimate it as disability (see also Hammond, 2004). That despite the fact that most CFS patients, but also the CDC and, in the UK the NHS describe their condition as severely disabling (e.g. limited motion). '[W]hatever one presumes CFS to be, people suffer with it and because of it' (Strauss quoted in Ross *et al.*, 2004: 1104). Ross *et al.* (2004), finally, argued that neither are standardised measurements of impairment in patients diagnosed with CFS available nor the impact on employability.

In 2003, it was estimated by AfME that the annual cost of CFS in the UK was £3.5 billion.⁴ Reynolds *et al.* (2004) estimated that the illness caused about \$9.1 billion per year in lost productivity in the US, while Jason *et al.*'s (2008) estimation was higher, at approximately \$18.7 to \$24.0 billion. 'Patients with CFS are more functionally impaired than those suffering from type II diabetes mellitus, congestive heart failure, multiple sclerosis, and end-stage renal disease' and therefore 'there is a need to find ways to develop effective intervention strategies' for 'energy modulation' (Jason *et al.*, 2009a: 237). Ross *et al.* (2004: 1104) had already expressed such an opinion, arguing that is better to focus 'less on the medical mystery per se and more on the functional consequences'. It is true that when work is either a moral ideal or, as we will see, compulsory and unavoidable, people with chronic illnesses often encounter problems upon returning to work. Doctors can obviously help them return to work, but in patients with chronic illnesses there is a lack of support. 'A reason for the perceived

lack of support of patients might be that most doctors of patients feel unsure how they could be involved in “return-to-work issues”, something they could and should overcome, is one of Verbeek’s (2006: 315) ‘best practice’ suggestions on this matter. Doctors’ conduct and beliefs have to be shaped to intervene to ‘reintegrate patients into the workplace’ (Verbeek, 2006: 315). In CFS, as we have seen in chapter four, ‘no specific demographic, clinical, or psychological traits have been shown to be consistently predictive of the ability of patients with CFS to return to work’ (Ross *et al.*, 2004: 1104). Tiersky *et al.* (2001) studied neuropsychological functioning and employment status in CFS patients, indicating that ‘objective and subjective attention abilities, mood, level of fatigue and disability’ improved over a mean time of about four years, but these findings could in no case claim to be valid and reliable. On the other hand, medical insurance systems are increasingly in need of more ‘accurate’ tests that show who is able to work and who is not. As Coetzer *et al.* (2001: 170) worryingly state: ‘It is vital for every insurer to have fair and objective criteria to distinguish invalid claims and those with merit’. We will come back to medical insurance and disability benefits later on.

As is known, in an earlier stage of capitalism, illness came to be viewed as a thing that ‘shortened the working week, wasted energy, and cost money’ (Foucault, 2003: 244), and medical science improved health in order for an large and efficient labour force to be available. However, it could be argued that due to a series of political, economic, and technological developments, a large labour force at full employment and working full time is not required anymore. People diagnosed with CFS are conceived as a burden on the state, as were disabled people in the nineteenth century, or, rather, they are viewed as ‘underperforming’, as not having taken care of their own well-being. After the neoliberal turn of the 1980s, and the demise of the Keynesian welfare-state (and now with the ‘debt crisis’), a new order emerged. The state’s provision of health care, education, etc., has been

diminished. In other words, the state provided a ‘social wage’ (that was gained after intense struggles by the organised labour), it organised the reproduction of the conditions of the working classes. In parallel, the life-long, stable jobs that were common in industrial capitalism and welfare-state economies have been replaced by temporary, insecure and low-paying jobs. The socio-economic guarantee of wage that was tied to health care, housing, paid time off, pensions, and so on, has been removed in the last thirty years or so. Individuals are released from state control and are treated as ‘clients’ of the opportunities offered by the market. These changes, on the one hand, make it both necessary and difficult (perhaps at times impossible) for workers to reproduce their labour-power on their own, and, on the other hand, make regular exploitative jobs look attractive. Workers often undergo a breakdown of the ability to distinguish life from work due to constant demand to be available for work and feel depressed although they try to hide it because they are ashamed (Robinson, 2011).

This kind of ‘depression’ however can be considered more as a sort of existential vulnerability. This condition of generalised instability and vulnerability has been described as ‘precarity’ (Vishmidt, 2005; Neilson and Rossiter, 2006; 2008; Papadopoulos *et al.*, 2008; Southwood, 2011; cf. Ross, 2008).⁵ It would be wrong however to suggest that precarity is directly associated with depression or other psychological problems, as it would be wrong to claim that it describes a homogenous population. Indeed, the terms precarity and ‘precariat’ have a variety of meanings in different countries. As Standing (2011: 9) puts it, ‘[i]t is not right to equate the precariat with the working poor or with just insecure employment, although these dimensions are correlated with it’. Precarity might be better understood as a combination of lack of different forms of security associated with industrial citizenship: income, protection against arbitrary dismissal, representation through trade unions, protection against accidents and illness at work, opportunities to gain skills, etc. (Standing, 2011: 10). It could be argued (but again this is a generalisation) that in neoliberalism life becomes

contingent on capital. This is even more so for precarious workers with health and disability ‘problems’ (let us for the moment put the word problems in brackets). Fordism, of course, never really included migrants, people from extremely poor backgrounds and single women, who did not belong to the small number of highly skilled workers (Neilson and Rossiter, 2008: 57). Furthermore, the Fordist model was only fully realised in the rich Northern countries and can thus be considered as an exception to capitalist history. Finally, exactly because of their vulnerability, precarious workers have been seen as carrying transformative possibilities because many voluntarily choose precarious works seeking to escape rigid forms of labour organisation. Such theories are in contrast to accounts of ‘immaterial’ labour that see the eventual reduction of work and exploitation through the role of socialisation in work (often through overoptimistic accounts of media and artistic labour) and privilege certain variants of precarious labour as the most politically significant (Federici, 2006).

While there are workers working under irregular labour conditions, being constantly on call, other workers, in relatively regular jobs, face work intensification (e.g. Green and McIntosh, 2001; Burchell, 2002). These two do not have to be considered contradictory at all; rather, these two changes in the labour market should be considered complementary. Indeed, illnesses related to tiredness and exhaustion, e.g. burnout and stress, have increased in most western countries (Widerberg, 2006: 105), though it is not strictly a western phenomenon. In Japan, for instance, overwork (*karoshi*) sometimes drives people to commit suicide. Of course, there are individuals who cannot work or are unable to get a job. The growing populations of undocumented workers and the working poor ‘are denied the political right to health, or ... lack the resources that might enable them to ‘choose’ as ideal neoliberal subjects’ (Braun, 2007: 12). Finally, if we take Holmqvist’s (2009; see also Holmqvist *et al.*, 2012) findings from the Swedish welfare state to reflect a broader, European trend toward the medicalisation of unemployment, then one more dimension is added in our schema.

Unemployment gets medicalised through the classification of the ‘job seeking’ unemployed as ‘occupationally disabled’ by certain work programmes. Whereas self-governing individuals are governed as an active and high-performing segment of the working population, work programmes position individuals as passive and dependent and tend to govern them not just as parts of an underperforming segment of the working populations, but also as a disabled segment.

All these parts of the population have their own temporalities and rhythms. Everyday life is itself a mosaic of different temporalities and speeds. It is ‘composed of various social fields of practice that are articulated, codified and normalized to different degrees and in different ways (either officially or unofficially)’ (Burkitt, 2004: 211). However, some dominant trends can be noted. As E.P. Thompson, Lewis Mumford, Henri Lefebvre and others have shown, the ‘cyclical’ and ‘task’ times, dominant in the periods before the rise of industrialisation and capitalism, were violently displaced by linear, clock time; the ‘organic’ rhythms of life were organised and compressed with schedules and plans and the day broken down in terms of the productivity of hours and minutes. In spite of narratives of technological and social progress, since the advent of modernity, most societies have been experiencing a sense of ‘irritation’ and ‘insecurity’ (Rosa, 2003; Widerberg 2006; Aho, 2007). Nostalgia aside, old dualisms as those between *Gemeinschaft* and *Gesellschaft*, have begun to crumble and the imaginary of ‘network sociality’ has come to the fore (Brinkmann, 2008: 93; see also Vandenberghe, 2008). Clock time has itself been displaced by ‘network time’, i.e. a digitally compressed clock time which is beginning to displace other temporal relationships in work, home and leisure environments (Hassan, 2003: 235; cf. Westenholtz, 2006; Dennis, 2007). Interconnectedness and asynchronous networks accustom us to living in a constant present. We can see this in academics’ struggle with the increasing demands and time pressures to manage conflicting organisational and temporal priorities which adversely affects the quality

of their teaching and research (Menzies and Newson, 2007; Ylijoki and Mäntylä, 2003). Different temporalities intersect and overlap in complex and contradictory ways as when working mothers, despite work intensification, manage to ‘accumulate’ care for their families through their capacity to draw together and synthesise work across diverse temporal orders (Maher, 2009).

But much more than a feeling of living in a constant present, the current biopolitical regime makes people morally responsible to ‘anticipate’ and optimise the future (Adams *et al.*, 2009). That requires that citizens inhabit a state of uncertainty, of living between in ‘preparation for potential trauma’ and hopefulness. ‘Preparedness’ can be seen in the ways governments and media make citizens adjust themselves to the likelihoods of possible or ‘inevitable’ events (e.g. ecological disasters or ‘financial crises’). Irrespective of whether they might be ‘actualised’, these disasters serve as ‘reference points’ around which people can organise their lives. Finally, it is interesting that Adams *et al.* suggest that living in such a regime ‘affects physical, mental and emotional well being in ways that are only beginning to be understood as long-term chronic disorders’ (Adams *et al.*, 2009: 251).

Our analysis of fatigue should be expanded. Negri (2006) rhetorically asks whether the fatigue of a call centre operator is less, albeit absolutely different, than that of a steel worker a century ago. Call centres, which some see as neo-Taylorist, demand what is often, problematically, referred to as ‘immaterial’ or ‘cognitive’ labour. Bifo (2009a,b,c) argues that capital is now concerned with the workers’ ‘neuro-psyche energies’ which are stressed to their limits. Following, at least to some extent, Ehrenberg (1998/2010), Bifo (2009a) suggests that depression is a social pathological syndrome specifically depending on situations characterised by competition.⁶ Bifo (2009a: 98) observes, depression ‘is deeply connected to the ideology of self-realization and the happiness imperative’ and it is of little wonder that many people have to take fluoxetine (Prozac), sertraline (Zoloft) or other drugs to keep up.⁷

As Bifo (2009b: 116) further notes, there is a proliferation of pathologies such as panic, dyslexia and ADHD that he claims are due to an 'overload' of information and stimuli.

'Well, I managed a day but only just. I passed out asleep almost as soon as I got home from work and have woken up exhausted and in pain. My legs are so weak and heavy I can barely move them, and simply putting on a cardigan was agonising. Needless to say I had to ring in sick again. [...] Even though I rested all day yesterday, I woke up at 3:30 this afternoon (after 14 hours sleep) completely wiped out'.

Michael, who has not been diagnosed with CFS, is trying to keep up being 'productive' despite the consequences this has for his health. He teaches pupils with severe learning difficulties and autism, work that involves a high level of subjective investment. At the time he posted this, he had been off work for four weeks (2 weeks holiday and 2 weeks sick leave) and was already feeling he was going 'stir crazy stuck at home'. To what Michael had been describing, his interlocutor Chloe commented that 'it's certainly the post-exertional fatigue'. Michael slept 14 hours but still did not feel rested, a common description of CFS. CFS individuals have their own lived temporalities. As already mentioned, they often describe their past identities as 'workaholics'. After experiencing the 'biographical disruption' of illness, some might form new relations with their 'selves', forced as they are to accept their new limits. At times, that opposes in contradictory ways the normalising discourses which value 'fitness to work'. Teachers, such as Michael, are extremely time disciplined. They have to be very energetic to survive in the profession, especially if they are dealing with pupils with special needs. Some teachers often describe their tiredness as 'tiredness in the head', but that does not in itself explain why they show higher sick leave rates (Widerberg, 2006). A possible explanation is that they have more scheduled breaks and a system with substitute workers that provides sick leave without increasing the workload for oneself or one's

colleagues, though Michael was worried that his colleagues would have to cover his workload. In today's globalised capitalist economy, a constant reorganisation of workplaces takes place in order for efficiency to be increased, which is supported by a discourse of autonomy and flexibility for both employees and employers. It is often not possible to work in that increased tempo for 8 hours. Furthermore, the possibility of not working when ill is something not equally available to all. At times, ill people can work from home with a PC (of course, if the nature of the work allows that). It is just normal to be tired, to have sleeping or other problems, problems that do not need to be talked about (Widerberg, 2006). This is very true for academics because their 'stimulating' jobs make them invest all their energy in their work.

Time for rest and recreation has become too expensive to be structurally possible within contemporary capitalism. Not only is the 'workplace nap' not seen as resistance, it is actually allowed or encouraged (Baxter and Kroll-Smith, 2005; Kroll-Smith, 2009). For instance, in the US, Nike and other multinationals encourage their employees to take a nap and have arranged special places with comfortable mattresses and sleep masks (and alarm clocks for those who 'overdo' it). Sleep used to be a moral evil because it wasted money and spoiled the flesh, and fatigue became the primary concern of 'scientific management'. Today 'it is safe to assume that drowsiness, defined as the absence of mental acuity, is the primary problem of working bodies', write Baxter and Kroll-Smith (2005: 39). Discourses around sleepiness proliferate as it is identified to be responsible for a variety of problems, from 'simple' work accidents to the explosion of the space shuttle Challenger. In a climate of generalised flexibility, the distinction between private and public time does not stand any more. In modernity, public time was the time for work and private time was dispensable time for rest and sleep. As we have mentioned, people can now work from home with the help of technology, but with ever increasing control placed upon them. By trusting employees and

making them to internalise surveillance, increase in productivity can be ensured. However, sometimes trust and self-surveillance are not enough and organisations have to survey whether the employees are actually making ‘good’ use of their time. This is the case, for example, with my informant Karen. Karen sometimes works from home, from her PC, for a company which surveys the rate of use of her PC. The blurring of the boundaries between public and private time also blur the distinction between holidays, rest days, weekends, and work days. If we can trust a recent US annual poll on ‘work-life balance’, 16 per cent of 2,500 workers ‘reported feeling guilty about missing work while on vacation and seven per cent actually feared their time off could lead to unemployment’.⁸

Sleepiness is now not ‘a prelude to sleep’ but, as often described, ‘a potential risk to self, others and the interests of business’ (Baxter and Kroll-Smith, 2005: 39). In the US, the National Commission of Sleep Disorders estimated that a huge amount of money is lost each year because sleep deprivation leads to higher stress and reduced productivity. Capital wants, on the one hand, unlimited expansion but, on the other hand, has to deal with reduced productivity as a result of sleepiness. The normalisation of the workplace nap becomes a necessity. The ‘tired mind’ needs rest (though the distinction Baxter and Kroll-Smith draw between the ‘tired body’ and ‘tired mind’ is somewhat problematic). The ‘drowsy’ person does not think very clearly and is prone to bad judgement. A key to managing the modern employee is to understand ‘what is the minimal sleep duration necessary to maintain an acceptable level of performance’ (Stampi, 1992: 13, quoted in Baxter and Kroll-Smith, 2005: 40). The proponents of napping suggest it is a normal part of the human sleep-wake cycle and provides many benefits especially for those who have prolonged, irregular work schedules. Companies are now being employed to advise on how to scientifically study sleep, circadian rhythms, alertness and performance, to improve or minimise safety issues. Rosekind *et al.* (2010) surveyed 4188 employees from four major US corporations to assess the ‘cost of poor

sleep'. Sleep disorders, they say, carry a multitude of personal and societal consequences. Although occupational medicine has demonstrated the importance of addressing a variety of health issues in the workplace (e.g. smoking or back problems), insomnia and sleep disturbances 'are rarely the focus of public health and workplace safety initiatives' (Rosekind *et al.*, 2010: 95). The competitive global economy, but also issues such as long commutes, has nonetheless increased the number of people working nonstandard shifts. Poor sleep is related to 'depression, suicide, anxiety, and disability, diabetes mellitus, obesity, and hypertension' (Rosekind, 2010: 91). It seems that deprivation of sleep or poor quality of sleep can be related to almost everything. Those who report excessive daytime sleepiness due to disturbed sleep are more vulnerable to accidents and injuries both on and off the job. People are categorised in different groups, i.e. 'insomnia', 'insufficient sleep syndrome' (ISS), 'at risk', and 'good sleep', and compared to each other in order to evaluate the overall productivity loss. A questionnaire called the Work Limitations Questionnaire (WLQ) is used to assess health-related limitations in ability to work and the associated productivity losses and costs.

Research is also being conducted to see whether CFS individuals are just 'tired' or also 'sleepy' (Neu *et al.*, 2008). To make the comparison, people with regular sleep-wake schedules (the 'control group') were employed and no shift working was allowed. Those people also had no significant somatic conditions and current or past mental disorders. Among other things required was, prior to sleep recording, a sleep diary to assess regular sleep-wake schedule. The control group was compared with the 'CFS group' and the 'SAHS group' (SAHS stands for 'sleep apnea-hypopnea syndrome'), with the overall research aim being to find out whether people diagnosed with CFS suffer not only from fatigue but from 'excessive daytime sleepiness' (EDS), to investigate the 'objective' and 'subjective'

sleepiness in a fatigue-associated condition such as CFS. The result supported the clinical distinction between fatigue and sleepiness, although they might overlap.

Callard and Magulies' (2011) genealogy of 'rest state' research, as it emerged in debates surrounding the cognitive neurosciences over the past decade, suggests that these studies are now reframing inner mental life. Callard and Magulies argue that these research studies have significant implications for advancing our theoretical understandings of self and subjectivity. They believe that through the reconfiguration of rest, the resting brain is conceptualised as a matrix that is constituted as perceptually productive, intrinsically creative, and future oriented. Creativity and the brain and creativity are joined in the current productivist dreams of capitalism. The brain is sometimes seen as the heart of productivity and creativity. Brain potentiality has been linked with constant adaptability and flexibility, as it leads to individual success. Security, predictability, as well as leisure, are not valuable here (Pitts-Taylor, 2010: 644). Popular neuroscience discourse links brain enhancement with a flexible subject demanded by neoliberal economies, something even truer for women with the extra societal pressures placed upon them. Furthermore, the imperative to 'take care of the brain' gives rise to an interesting paradox. As Brennikmeijer (2010: 108) notes, 'people work on their brains because they want to improve themselves; something that appears to require a distinction between the self and the brain, because the self tries to regulate its brain'. But neoliberalism is not a unified ideology, nor should we expect medical and other discourses to be unified. Discourses are always supported or opposed by other discourses. Let us now consider a story of one CFS blog user, Kate:

'I thought my CFS had become manageable to the point that I could go back into-part time work. I actually managed to get a job in the sector that I wanted to work in by complete accident. I had registered an interest in social careers and a retirement home boss called me out of the blue for an interview. I had a second interview, all the while thinking that I'd be about to work and train as a

care assistant at 20 hours a week – spread over 5 days, 8am-midday – all would be excellent. Sadly it's not panning out like I had hoped. I'm into my second week, I've already had a day off due to extreme fatigue and contracting a cold Turns out that my job description is not "care assistant"[,] it's "domestic/care assistant" which wasn't explained to me before I started working here. Now I find it hard to enough to keep a two bedroom flat in order and now I have to do four hours of vacuuming, polishing, window-cleaning, room-cleaning and bathroom cleaning five days a week. I'm in so much pain, I can barely manage to get out of bed in the morning, I dragged myself into work this morning, took one look at the vacuum cleaner and burst into tears and sat on the floor in the cleaning cupboard not knowing how the hell I'm going to manage to keep this job. [...] I can't clean 12 bedrooms and 16 bathrooms and all the common areas and maintain any energy. I slept badly, for 10 hours last night (after a 3 hour nap when I got it) and still felt like I'd been kicked half to death when I got up this morning. My painkillers aren't working and I need to keep this job. [...] [H]ow do I approach my boss and explain that I do actually like it there and wish to stay on but more as an assistance to the residents than a domestic cleaner. [...] Sorry for the moan, am at my wits' end with trying to be useful member of society and pretty much failing at it in my first fortnight'.

Kate gets caught in a vicious circle of fatigue (and possibly depression, as sufferers from CFS might feel depressed by the hardships they have to endure and their stigmatisation as 'workshy') and work as she tries to navigate through her obnoxious work conditions. Kate has to do a job that she did not ask for and cannot in any way handle, at least not without serious consequences for her health. Of the individuals diagnosed with CFS who can work, when they can, there are some who work in precarious conditions and often face financial problems and debt (e.g. house benefit problems). Although it would be an exaggeration to claim that these cases consist of the majority, they highlight the difficulties that people diagnosed with CFS might have to face. These should be put in the context of the attempts to

transfer the cost of reproducing labour-power down to labourers. Disabled and ill people increasingly face cuts in their benefits and attacks as being 'lazy' or as making fraudulent claims that burden 'law-abiding' tax payers. The recent suggestion of the NHS to not treat obese people with major health problems is paradigmatic of the neoliberalisation of health services and of the rationalities that support them. Besides the precarious working conditions of part of the CFS population, which is under-recognised in the CFS literature, when those people do work, even in regular jobs, they often face a variety of issues. Due to their concentration and memory problems, to mention only two, work can be very difficult, especially in today's 'attention economy'. Another problem people diagnosed with CFS might face, as do other people with 'invisible' illnesses (Vickers, 1997; see also Munir *et al.*, 2005), is the dilemma of whether or not to disclose their illness to their employers. People with CFS are encouraged to disclose their illness to their employers in order to be treated according to the often very formalistic anti-discrimination laws.

However, dis/ability' and 'in/dependence' are better conceived in an ontologically open way (we will say more on the debate over whether disabled people have to 'improve' themselves later on). It may be objected that disability is a medical category, that it is the social organisation of a person's impairment or difference, of the lived experience of disability, and that impairment is the word that disabled people prefer (Oliver, 1990; Shakespeare and Watson, 1997). Though that would be a pertinent objection, 'dis/ability' and 'in/dependence' cannot be treated as fixed things as they are 'event[s] of time-spaces that mediate their multiple realities of in/dependencies and dis/abilities instead' (Schillmeier, 2008: 217). Kate can partially do things because of her condition, which is fluctuating, but also because of the environments that she finds herself in; or rather, to be more precise, the fluctuating 'nature' of her condition is conditioned by her interaction with other forces. Kate lives in different temporalities with different capacities or in different 'time-spaces' with different levels of

‘dis/ability’. On her ‘good days’, Kate might have to use her expended energy to work in order to sustain herself. That can lead to a worsening of her health and abilities. In such a case, she might blame herself for her condition and for not being able to keep her job. What we saw in the previous chapter, the fact that people diagnosed with CFS might at times blame some ‘nasty’ virus for their condition, can be seen as a kind of ‘defence mechanism’ that alleviates the societal burdens placed upon them. A strategy of victimisation very frequently operates to make people blame themselves for their troubles and feel shame or guilt for trying to ask for help, claim benefits or better working conditions. In contrast to this, a small minority of women diagnosed with CFS seem to be aware that they are doing forms of labour that are not regarded as labour. Jane’s post to Adelle who was feeling guilty for not being able to work and to provide the most to her family in terms of domestic responsibilities exemplifies that: ‘You [are] working. You’re busting your ass [*sic*], the only difference is that you’re not getting any credit (or financial security) for it’.

Almost all of my informants were unable to work and in debt, especially those that were single and without a ‘support network’ of friends and relatives. My informant Thomas is now in his sixties and has been out of work for the last ten years. He has to take care of his old and ill mother and urged me to ‘report’ that he had to frequently borrow money from his neighbour. Lisa, also in her sixties, but who can occasionally work, mainly from home, as she was a business analyst and therefore quite familiar with computers, also has to take loans from her neighbour – some people diagnosed with CFS, as we have seen, are familiar with computers and are self-employed, working from home (on disability and self-employment in Europe, see Pagán, 2009). Although Lisa thinks that the ‘official support’ is quite good – she referred to the NHS’ provision of a social worker who takes care of her – still her living expenses are too high. Sali, who preferred not to be anonymous, suffers from several emotional traumas, panic attacks, and physical problems (e.g. being ‘overweight’ and having

coordination problems), is unable to work and in debt. As she told me, she could not even buy a wheelchair that she deemed necessary, a technology that, we can say, would mediate her body and expand her capacities. Sali has currently no relatives or friends who could provide any kind of support; she has two children, from one of her two marriages, who have completely abandoned her. Her last acquaintances were from her local church but they too have abandoned her because she is 'immoral'. Sali was previously a gardener for a few years but her National Insurance (NI) does not provide her with anything; all the money she derives comes from disability benefits. Sali told me 'I would love to work and be healthy' (Interview 4), but that seems almost impossible. In such a state, 'it is difficult to exist' (Interview 4), she said. Although she has her own coping mechanisms that give her some freedom to do a few things, still it is a constant battle with her body's abilities. According to her, you have to 'read the body signs every day' (Interview 4). When you wake up you instantly know how much energy you have. Sometimes she wakes up and feels a 'one ton weight', which means she has to stay in bed. Other days, when she wakes up she knows she has a limited 'amount' of energy to do things. On such days, Sali might try to do a 'little house-something' (Interview 4). For example, it usually takes her one week to clean the bath. In this way, Sali's bodily knowledge allows her to stay within her 'required' energy limits. When you have CFS 'you can't plan anything' (Interview 4), Sali told me, and again this is a common statement of people diagnosed with CFS. As with other individuals diagnosed with CFS (and depending on the chronicity of the condition), Sali lives in a constant present. She cannot plan more than a few hours ahead; she cannot, for instance, do more than a small walk. In a Spinozan understanding of the body, the body's boundaries and 'limits' are constantly reconfigured through its encounters with other bodies. It is through the interaction with the environment that a body's *conatus* may be increased or decreased. In contrast to liberalism, the expansion

of humans is not an individual issue. 'Limits' are just thresholds, not points of closure. As Braidotti (2006: 244) says:

'The utterance: "I can't take it anymore!" far from being an admission of defeat, marks the threshold and hence the condition of possibility for creative encounters and productive changes. [...] The ethical project is not the same as the implementation of ruling standards of morality. It rather concerns the norms and values ... that can be applied to the quest ... for newly negotiated limits'.

As for example with blind people (Schillmeier, 2008; see also Law, 2003: 7-9), limits are not ontological givens. Different temporalities and spatialities, actual and virtual (to follow Deleuze), relate and coexist with each other, without being fused into one, to produce 'blindness' (Schillmeier, 2008) or, in our case, fatigue. After all, drugs, wheelchairs, the presence (or absence) of other humans, and even viruses, are all constitutive of fatigue.

Braidotti's Spinozistic position has similarities with Canguilhem's and Foucault's conception of norms (Macherey, 1992; see also Juniper and Jose, 2008).⁹ Contrary to much poststructuralist theory, for Foucault life has a positivity of its own as it produces norms that exceed given medical classifications, setting at the same time the standards for new classifications. Normality is usually defined from limits derived from population data, which implies that pathology or disease is simply an excess or deficit of a particular variable. Canguilhem (1966/1991), however, regarded normality and health as being functional characteristics of the whole organism and defined health as the ability to adapt to challenges posed by the environment, the ability to create new norms for new settings (cf. Novas and Rose, 2000; Rose, 2001).⁹ Nietzsche said that 'there is no such thing as health in itself'; Canguilhem would agree. Properly speaking, there is nothing normal, everything is an exception (Ojakangas, 2005: 16). Greco (2004: 3) nicely summarises Canguilhem's idea of

health: '[H]ealth is to be thought of as a form of active and dynamic *normativity*, and not merely in terms of a correspondence to measures of *normality*'. Normativity is the opposite of being 'normed' since it is the capacity to invent norms. Foucault built his own research on Canguilhem's work and came to historicise not only social norms but organic ones too. In Foucault's work there are two notions of norm. On the one hand, there is a negative view of norms in which they operate primarily through juridical exclusion, and, on the other hand, there is a positive view where norms act through a biological process of inclusion and regulation. For Foucault, norms 'do not pre-exist their correlative interventions insofar as they produce both the field and the specific elements on which they act' (Juniper and Jose, 2008: 7). In other words, norms are completely immanent to life.

Now to turn back to labour, with Marx we know that with the wage the worker receives, s/he can reproduce his/her labour-power. In capitalism, health is seen as the individual's capacity (Varul, 2010: 78), as the optimal capacity for work (Donzelot, 1980/1991: 260), as a commodity (Turner, 1987: 172). Of course a static conception of health, as Marx's, is problematic. Following Canguilhem, Varul asserts that '[i]f health is understood as elasticity, as a resource that enables adaptation to and new absorption of new challenges', then 'an exhaustion of this reserve is the more disruptive the more fluid and flexible the world of work becomes' (Varul, 2010: 80). In addition, the new conceptions of health involve the probabilistic definitions of people 'at risk' (Armstrong, 1995). Fatigue is no different. Fatigued people are identified as 'being "at risk" of sickness absence or work disability' (Janseen *et al.*, 2003: 71). Health and other human capacities, such as the capacity to work and reproduce, are configured as forms of capital 'open to speculation not only for individuals and their families, but also for states and transnational investment' (Adams *et al.*, 2009: 259). Various, and often conflicting, discourses encourage individuals diagnosed with

CFS to either accept their ‘limitations’ or to overcome them. In both cases, fatigue requires some form of management. Their ‘energy’ is to be kept stable if it cannot be maximised.¹⁰

For people diagnosed with CFS, not being able to work or reach the socially accepted goals is deemed a personal tragedy. Consider the following medical statement concerning CFS:

‘There is also loss of future - the career and personal goals that structure most of our life journeys are lost in the blank horizon of ongoing illness. Many sufferers complain of their lack of ability to plan for the next day, let alone planning and building a future’.¹¹

How are we to understand this ‘loss’? Without denying the anguish CFS people might feel, we have to see how such medical discourses seem to equate life with career, to take future to be the idealisation of a ‘successful’ career which one has to anticipate and against which to judge his/her life. To live and to be creative, one’s becoming, can be reduced to capitalism’s productivist demands.

In the next section, we are going to examine some of the intersections between labour-power and disability and their relations to fatigue. We are going to focus on the ways various institutions try to ‘activate’ ill people like those in CFS, but first we have to say a bit more on the historical emergence of disability as a category that falls into the domains of medicine and labour. That requires a very brief historical detour on disability, though we have to acknowledge that it is beyond the scope of our research to deal with the issue of disability in all its complexity.

Labour-Power and Disability

In the medieval world, what we now call ‘disability’ was founded on the notion of being unfit for work and people who fell into that category were generally exonerated from the obligation to work and were provided a moral and, later on, legal right to assistance (Ville,

2009). In an era 'when work required all of one's capacities and physical energy, when it was synonymous with pain and effort, any weakness, whatever its origin, meant one was unfit for work' (Ville, 2009: 60), and those who exhibited such signs were therefore exonerated from the obligation to work. The association of infirmity with ineptitude was made at the end of the Middle Ages by the separation of poor people into those who were eligible for the first policies of assistance and those who were not. This distinction was ended when the high level of mobility of the poor was threatening the feudal system by forcing them to remain where they were, as the unavoidable condition of having no possessions. The distinction between the 'deserving poor' and the 'vagrants' was a response to that social unrest. On the one hand, there was an expansion and specialisation of social assistance (leper-houses and hospital-houses) and, on the other hand, a repression of begging and vagrancy as, in parallel to the performance of charity, the authorities asserted secular laws that linked idleness to evil. Through a long and complex process, the inevitable nature of ineptitude was challenged and disability came to be seen as a 'recoverable' situation compatible with certain forms of productivity (Ville, 2009: 61). The administrative categories 'able to work' and 'unable to work' were developed 'to identify those who because they did not or could not, participate in the central work system and were a threat to the social order' (Jolly, 2000: 796; also quoted in Galvin, 2006: 501). Work has been a major form of subjectification connected to the formation of the 'ideal citizen'. Over the past two centuries, disability has retained that integral connection with work. In particular, the medicalisation of disability has been embedded in a framework that aims to rehabilitate impaired people so that they can participate in the labour force and develop the qualities of self-sufficiency, health, wealth and consumerism. In the UK, since the early 1980s, income support systems have increasingly come under attack because, it is claimed, they produce a form of dependency and passivity which is self-perpetuating and highly damaging to the life chances of welfare recipients. They

are seen as ‘people whose self-responsibility and self-fulfilling aspirations have been deformed by the dependency culture’ (Rose, 1996a: 59) – we should acknowledge that while when talking about precarious workers welfare benefits can reinforce state paternalism, the case of disability rights may be more complex.

Whereas the term ‘handicapped’ marked individual bodies as insufficient, ‘disability’ re-orientates critique away from the individual malfunction and toward interactions of bodies with inadequately adapted environments (Mitchell and Snyder, 2010: 179). Disability moves away

‘from late eighteenth-century ideals of individual capacity (and, ultimately, social Darwinian “unfitness”) toward populations that experience socially produced exclusions based on sensory, cognitive, and/or bodily “typicality”. In other words, as a result of Disability Studies scholarship and modern day disability movements, disabled people have shifted from modernity’s exception (a lineage of defect to be isolated and eradicated) to postmodern exceptionality (failing bodies resuscitated by an increasingly medicalized state)’ (Mitchell and Snyder, 2010: 179).

With disability ‘incapacity’ is seen not as retrieving a ‘damaged’ nature but as something which has to be culturally rehabilitated. Disabled people are not seen as social pariahs anymore but as research opportunities. They are not simply a ‘burden’ on the state but much more potential objects of care and value, as capital, in its effort to renew itself, increasingly targets them. Capital now finds itself targeting imperfection, e.g. impotency, depression, hearing loss, and chronic fatigue (Mitchell and Snyders, 2010: 190). Whereas in the past disabled people were trained to recognise their disabled parts as inferior, late capitalism trains everyone to separate their good from bad parts.

Measuring Fatigue

Let us now see how various institutions try to deal with the ‘inactive’ population and the CFS

segment more specifically. The Public Health Research Consortium (PHRC), which works for NICE and is funded by the Department of Health Policy Research Programme, is a collaboration of 11 UK institutions that has as its main aim the tackling of socio-economic disparities in health. PHRC's report compared and synthesised evidence on policies and interventions that might help ill and disabled people to return to work from Canada, Denmark, Norway, Sweden, and the UK. 'In the UK, employment rates for people with a chronic illness and disability are low and show a social gradient, with less skilled manual workers suffering the most' (PHRC, 2009: 1). As the report makes clear, the employment situation in the UK for people with 'limiting' illness and 'low education' is 'problematic', the result of 'adverse macroeconomic conditions combined with a relatively low level of active market policies' (PHRC, 2009: 1); that should be dealt with by making employment more 'disability-friendly' by offering financial incentives to employers (as in the case of *Work Trial*) and educating the disabled while not at work to increase their 'employability'.¹² Various points can be made with regard to the PHRC report. For one, how the hidden stigma associated with some interventions has to be considered and, concomitantly, the need for qualitative studies (e.g. about why employers might be discouraged from employing certain disabled people). 'Individual-level interventions' that offer personal case management and job search assistance, that help to build supportive and trusting relations between claimants and case managers, to overcome concerns and build confidence have been implemented in the UK (i.e. the *New Deal for Disabled People* (NDDP) and the *Pathways to Work*).¹³ These interventions might be effective but they may not be as efficient as reducing welfare benefits. The NHS encourages CFS people to avoid ill-health retirement if they have not been 'appropriately' treated, for example with CBT, and bemoans that '[u]nfortunately, some sufferers may also relapse', when others improve enough to work, if not recover fully.¹⁴ The recognition of the 'problems' created by the UK having 'one of Europe's most de-regulated

labour markets' (PHRC, 2009: 2) is also important. 'There are opposing hypotheses about whether a flexible labour market is good or bad news for people in ill-health', the report claims (PHRC, 2009: 3). By that the authors of the report mean that 'low employment protection will leave the labour force more unprotected against macroeconomic forces, but, conversely, might at the same time make it easier for individuals with lower education and reduced work ability to get employment' (PHRC, 2009: 5). Those with the 'double burden', as they call it, of 'low education' and chronic illness, are exposed to the higher risk of 'post-industrialisation' which demands flexibility, skills, capacity and productivity, etc. The discursive framing of disability as recoverable, the confluence of health with labour-power and capacity, and the 'depoliticisation' of economic relations, leaves little choice to ill and disabled people but to try return to work. Adam posted the following:

'I have received a letter from my local Jobcentre telling me I have to attend a 'Pathways to work interview' on I am not in receipt of ESA [Employment and Support Allowance] (yet) & get IB/IS & DLA [Incapacity Benefit/Income Support and Disability Living Allowance]. After 48 hours of worry[,] I have just managed to telephone to get more information: have been told there is 'nothing to worry about, the meeting is just a general chat about benefits'. Am I worrying about nothing?'

In the UK, the Benefits Agency (BA), JobCentres, and lately JobCentre Plus (JCP) replaced what was once called the 'employment agency' (Cole, 2007; Wiggan, 2007). Employment agencies were developed and used for the governance of mass unemployment in the 1930s. They functioned as stigmatising, demoralising, predominantly masculine spaces. The unemployed were the societal junk (Cole, 2007). To be unemployed was to be 'meaningless', as Kracauer has observed (quoted in Cole, 2007: 133). Being in the 'non-work' zone was having no social worth and dignity, having a body deprived of vigour. JobCenters' progeny

were the Manpower Services Commission (MSC), set up by the Employment and Training Act (1973). These new entities specialised exclusively in the registering of individuals as unemployed and the advertising of job vacancies, losing the function of benefit administration. In 1987, JobCentres came under the ambit of the newly created Employment Service, the umbrella organisation that has been replaced by the JCP. From the beginning, JobCentres were represented as ameliorating the brute stigmatisation of the employment agencies. The JobCentres facilitated the continuation of the long tradition of dividing the ‘deserving’ from the ‘underserving’ poor that has been previously institutionalised by the separation between employment agencies and workhouses. JobCentres, which were part of the New Labour strategy to reconnect the socially excluded to the mainstream, targeted not only unemployed men but also the ‘economically inactive’ population such as single mothers and the disabled. Both the JCP and the DWP represent significant reorganisations of the administration of employment and social security policy. The impetus for the reorganisation of the UK Employment Service (ES) and BA was part of a specific redirection of social security to support labour market ‘activation’ of both traditional ‘jobseekers’ and non-traditional ‘economically inactive’ users of social security services. JobCentres and now JCP’s discourse of ‘jobseeking’ creates a more privatised and mobile experience of ‘being unemployed’ (Cole, 2007; see also Southwood, 2011: 43-62; Darmon and Perez, 2011). The unemployed has his/her ‘personal advisers’ and is bombarded by images of consumerism and happiness that s/he is losing and will achieve if s/he is ‘responsible’ and ‘active’ and follows JCP’s advice. As Southwood (2011: 54-55) puts it, the new unemployment policies are ‘likely to result in a ratcheting up of the help-/blame-yourself rhetoric’.

The British government has been much criticised by disability groups for the sweeping cuts in Employment and Support Allowance (ESA), ‘the chief benefit for Britain’s 2.5 million sick and disabled people’, as *The Guardian* wrote (Wintour, 2011). The changes involve

changes in the work capacity assessment (WCA), a test, introduced in 2008, which sick and disabled people have to take before being eligible for the benefit (we will say more on this shortly). On the other hand, in July 2011, the Social Security Advisory Committee (SSAC), which provides advice to the UK government on social security proposals, and to which the government has to respond, were asked to report on the mandatory work programme which will see some benefit claimants forced to carry out 30 hours a week of unpaid work for four weeks or face losing benefits.¹⁵ As some benefits claimants' organisations and activists said, that would be a 'great gift' for corporations and charities. Moreover they have also been worried about ill people having to travel up to three hours a day to placements, on top of the 30 hours a week unpaid work. Benefits claimants organisations and activists said that the most worrying aspect of SSAC's report was that mandatory work activity, or 'workfare', will be made by JCP advisors largely on a whim: 'Claimants can be fully engaged with the (benefit) conditionality requirements but in effect a claimant can still be mandated to do more'.¹⁶ Of course, as they went on to add, the consequences of this can be devastating for thousands of people with health problems. People with cancer, MS, and other medical problems have been already forced onto Job Seeker's Allowance (JSA). People diagnosed with CFS could not and do not constitute an exception to that, especially given the 'invisible' nature of their illness. The DWP is currently only planning to 'recruit' 10,000 people onto workfare per year, while there are around 1 million people who have been claiming JSA over a year, and this might be due to the expenses (e.g. insurance and management) that such an action will require, the activists claim. The DWP has, in parallel with these changes, launched what is called Work Capacity Assessment (WCA), an assessment of the 'ability to work' that should be our focus now.

As a part of the large-scale Maastrich cohort study (MCS) on fatigue at work, and funded by the Netherlands Organization for Scientific Research (NOW), Janseen *et al.* (2003: 71)

used the Checklist Individual Strength (CIS) to predict absence from work. The CIS has been developed for clinical populations, ‘in particular for people suffering from chronic fatigue syndrome but was also validated in the working population’ (Janseen *et al.*, 2003: 71). It contains 20 items that are scored on a 7-point Likert scale. It is a multidimensional self-report questionnaire that covers the following subscales: ‘[S]ubjective fatigue (eight items on somatic symptoms and general feelings of fatigue), reduction in motivation (four items), reduction in concentration (five items) and reduction in activity (three items)’ (Janseen *et al.*, 2003: 71). Items do not refer to the ‘work situation’ but are stated in general terms, and the reference period of the scale is the last two weeks. Studies which deal with the discrepancies between ‘perceived energy’ and ‘expended energy’ in individuals diagnosed with CFS (Jason *et al.*, 2009a), remind us of Mosso’s own attempts to distinguish ‘subjective’ from ‘objective’ fatigue. Being very subjective, fatigue needs to be ‘objectively’ studied if it is to be managed.

Now, separately from the surveillance of the working population and the identification of its strength and energy, there is another process of surveillance, this time directly applied in order to distinguish between those who are able to work and those who are not. The ESA was introduced in 2008 to replace the existing incapacity benefit (IB) for new claimants. It aimed to give more ‘help’ to those who might, with support, be able to work. The testing of the ability to work has been outsourced to Atos Healthcare, a French company. Atos’ ‘expertise’ is in consulting, technology and health care, and is proud of its ‘world-class’ offering and continual innovations in those fields. As one reads on its website:

‘Atos Healthcare provides independent medical advice to the Department for Work and Pensions (DWP). We conduct disability assessments for people claiming a range of disability benefits including Employment Support Allowance, Incapacity Benefit, Disability Living Allowance and Industrial Injuries Disablement Benefit. Each year Atos Healthcare process over 1.2 million

referrals for medical advice completing over 800,000 face-to-face medical assessments within our nationwide network of over 140 medical examination centres'.¹⁷

As Atos states, through the introduction of the new ESA, it works closely with the DWP to support its agenda of 'Work for those who can and support for those who cannot'. The test decides whether or not one remains in ESA. If one does not pass the test, because one is not considered to have a limited capability for work, one has to consider appealing this decision or claiming Jobseekers Allowance instead. The test assesses a person on his or her ability to carry out a number of physical and mental health activities and points are awarded on the basis of limitations with respect to each activity. These points are totalled up and if the total reaches the threshold of 15, one is deemed to have limited capability for work and thus stay on ESA.

The physical functions in the limited capability for work test are grouped into 11 different types of activity: Walking; Standing and sitting; Bending and kneeling; Reaching; Picking up and moving things; Manual dexterity; Speech; Hearing; Vision; Continence; and Remaining conscious. Within each type of activity there is a list of descriptors with associated scores ranging from 0 to 15. The descriptors describe related tasks of varying degrees of difficulty. One scores when s/he is not able to perform the activity described. Though more than one descriptor may be applied to someone, s/he can only pick up one score from each type of activity; in each case whichever scores the highest. If one scores 15 in any one activity, one automatically passes the test. If one scores less than 15, it can be added to the scores one picks up from any of the other types of activity, in both the physical and the mental parts of the test. If the total reaches 15, one passes the test. On the other hand, the 'mental, cognitive and intellectual' functions are grouped into sets of activities under the following ten headings: Learning and comprehension in the completion of tasks; Awareness of hazard;

Memory and concentration; Execution of tasks; Initiating and sustaining personal action; Coping with change; Getting about; Coping with social situations; Propriety of behaviour with other people; and Dealing with other people. As with the physical descriptors, there is a list of descriptors under each activity heading. The scoring follows a similar pattern.

When the WCA was brought up in the conversation I had with Sali, with her characteristic honesty, she told me ‘they are going to force people to work’ (Interview 4). The description of the experience CFS sufferer Jayne Austin had with Atos, which we have to quote at length, is equally, if not more, telling:

‘I naively thought my GP’s sick notes (now fit “notes”) would be evidence enough to ensure benefit support throughout my recovery. Having paid my NI contributions consistently, I suppose I considered it my right. I was diagnosed at Bristol’s NHS ME service, and had further medical evidence outlining biological reasons for my symptoms thanks to private tests unavailable on the NHS. I was wrong. Not only is this country failing its 250,000 ME patients in terms of research and treatment, it also offers little chance of welfare support due to the way the new work capability assessment (WCA) is carefully constructed, Orwellian-style to cut out illnesses such as mine. I underwent the Atos work capability assessment in July 2009, which I subsequently failed as I didn’t meet the test’s points threshold. The physical examination comprises basic functionality tasks, such as raising one arm. The patient is asked to perform each task only once, and therein lies the flaw. The ability to perform a task once doesn’t prove that you can repeatedly perform various tasks day in day out, let alone work. This is especially true in the case of ME, where repeated and strained activity causes knock-on fatigue, pain and debility. The WCA doesn’t measure this. I had also submitted a thorough “limited capability for work” questionnaire, ticking many “it varies” boxes – ME is a fluctuating chronic illness. Little did I know that this would translate as scoring zero points for each of the test’s descriptors. I only became aware of the points system after consulting Action for ME, which gave me a list of the descriptors (they weren’t provided with the questionnaire). The wording and language used simply didn’t allow for fluctuating “hidden”

illness. [...] As it stands, I can manage a few hours of work per week, which often leaves me debilitated. I was on ESA and “permitted work” before my appeal failed. Without the treatments I pay for (unavailable on the NHS) I doubt I would maintain even that level of work. My own doctor’s letter states that working over 10 hours may risk a relapse. But to qualify for return-to-work credit – an incentive that encourages sickness benefit claimants back to work – I must work at least 16 hours per week. So where does this leave me? I don’t need an “incentive” to work; I find the idea quite insulting’.¹⁸

As we have seen, many people diagnosed with CFS feel that they are being misdiagnosed with CFS as they take CFS to be, in contrast to ME, an invalid and harmful category, a category that refers them to diagnostic assessments such as Atos. A similar case is that of Mary, another CFS blog user, who believed she was diagnosed with CFS by an ‘incompetent’ neurologist while she was facing mental problems, problems that Atos ignored. As she put it,

‘for the moment this CFS label is drowning me with ATOS, DWP and HB. [...] [T]he medical is a farce[,] as soon as they see CFS they just treat you like a malingerer who is wasting everyone[’]s time and [is] after benefits for no REAL medical problem [A]pparently the nurse [who examined me at ATOS] knows better than my GP, Neurologist, several Psychiatrists and Therapists as well as my physiotherapist and Orthopaedic consultant’.

Having reviewed her file and having read her GP’s letter, an Atos official assured Mary that she would be awarded anywhere between 18 and 24 points and recommended that she was put in the support group, making it obvious that she was not fit for work and that she should be reexamined after at least one year, something that did not happen. As Mary claimed, she has no money or support from anyone apart from her parents and her young daughter and has been receiving calls from the HB ‘debt chasing department’ because she has been unable to

pay her rent. Mary's is one more case of a person who by being unable to work, by not having a medical diagnosis that would automatically register her as a legitimate benefits claimant, and, finally, by being examined by a possibly inflexible assessment by Atos, faces the risk of being evicted from her house. It seems that in a period where the welfare state is significantly reduced or attacked, as long as CFS does not have an objective diagnosis and legitimacy as an organic illness, such tests that separate those who can work from those who cannot (according to the current criteria of the 'fit' and 'employable' body), actually significantly increase the percentage of people classified as 'able' to work, as the overall structure of the test seems to be constructed in such a way, i.e. with very simple and non-repeatable tasks, as to include the maximum amount of people. This does not contradict the fact that disability is not ontologically given. In this case, to be more precise, disability is a product of the interaction between the fluctuating body capacities of CFS individuals and Atos' test. These tests function in a particular zone of objectivity, a zone which has its own criteria and standards of objectivity. Thus, what we have is a constellation of forms of objectivity and objectification of CFS and of other patients but with some forms of objectivity standing out and having more prevalence when it comes to issues of disability benefits and medical insurance (whether state or private). In both the UK and in the US, medical insurance is extremely difficult to obtain for illnesses, no matter how disabling they might be, which are considered psychogenic. The MEA, for example, reports there are some cases where the insurance company is no longer willing to cover people diagnosed with CFS, and is only willing if the payments are loaded. The MEA encourages people diagnosed with CFS who have been provided with a life insurance policy to help them produce a list of companies who are still willing to cover people diagnosed with CFS and whether this acceptance then requires a loaded premium. Notwithstanding the heterogeneity of the CFS population, in terms of economic, work, medical and psychological needs, as well as beliefs,

values, etc., CFS organisations and activists will, in all probability, continue to criticise and fight both JCPs and the WCA, demanding more lenient and 'fairer' treatments and tests.

Chapter Seven

Conclusion

For western societies, CFS constitutes a scientific object that needs to be studied and regulated as well as a biopolitical problem that needs to be governed. As discussed in chapter 1, biopower, through assemblages of authorities, knowledges and techniques, makes CFS subjects and tries to shape their conduct in order to increase their supposed autonomy, wellbeing and health. CFS identities are, however, made not only by government, scientific and medical authorities but also by the patients themselves. CFS advocacy groups contribute to the making of CFS with their mobilisation of funds, spokespersons and biomedical facts about CFS. The study of CFS, which requires exploring not only the evolution of fatigue and of CFS but the various medical and social categories, institutions, concepts and discourses that are relevant to the ways the body is conceived and regulated in different historical periods, can be achieved through the following crucial series of research questions. How did fatigue and CFS emerge as medical categories and what were their truth effects? What scientific disciplines have the authority to tell the truth about the CFS population? Parallel to that, what needs to be examined are the ways scientists studying fatigue and CFS construct different models of fatigue and CFS, the types of intervention into the population that get legitimised and the ways that these are accomplished, as well as how these interact with broader historical, national, and economic processes? Another area that was examined is whether CFS subjects resist the biomedicalisation of their experience of fatigue and/or whether they adopt biomedicine for their own purposes? Finally, and in relation to the aforementioned questions, the work regulation of CFS demands attention.

The Emergence of Fatigue

Rabinbach (1992) shows the historical production of the fatigued subject and traces the shift-

ng connections between the body, medicine and work. His rich study demonstrates how fatigue emerged as a scientific object and social problem in the late nineteenth century. It demonstrates how developments in physics, biology, medicine, and psychology deployed the metaphor of the working body as a human motor, how late nineteenth and early twentieth century became obsessed with energy and fatigue and how that informed utopian ideas across the whole ideological spectrum. My research tried to complement that analysis, first, by looking at the epistemological changes in medicine that led to that development and, second, by looking at fatigue's evolution after the 1930s, where Rabinbach situates the historical demise of that obsession. In other words, while Rabinbach's analysis is confined to a very specific period of time, I expand the time span of the evolution of 'fatigue'. Fatigue and CFS are not invariable essences but categories that change over time. Biopolitics itself should be studied genealogically. In that sense, it may, for example, be argued that because of the indistinction between the biological and the cultural, the distinction between the 'normal and the 'pathological' no longer holds (Rose, 1998; 2001; 2007c) and is being displaced by that between the 'functional' and the 'dysfunctional' (Katz and Marshall, 2004), as it can be observed in the fields of aging and sexuality. This study of fatigue can be regarded as a part of a series of genealogical studies of medical notions such as 'depression' (Rousseau, 2000), 'chronic illness' (Galvin, 2002), and the 'disabled identity' (Galvin, 2006). Fatigue once meant the 'extra duties of a soldier' and was confined to a very limited part of the population. Up until the advent of modernity, and more precisely until the 1870s, fatigue or weariness was considered a natural state that someone could inhabit which did not constitute a social problem. It was the concurrent changes in medicine and in socio-economic conditions that made 'fatigue' an object of power-knowledge. When visibility became dominant in the identification of diseases and when the humoral theories that supported western medicine for nearly two millennia begun to crumble, fatigue was articulated as a nervous condition. In

a period where major changes in the discourse of medicine occurred, such as William Harvey's 'discovery' of the circulation of blood, disease was articulated as a mere collection of visible symptoms. The body came to be viewed as a set of tissues, organs and functions to be analysed, defined, trained, and restored. The examination and control of the body was supported by the increasing demands of capitalist states for a healthy working class. Biopower replaced the ascetism of the body.

The advent of modernity made the scientific study of fatigue both possible and necessary. From being viewed as moral weakness and sin, fatigue became considered as both a physical and moral disorder. The need of the nascent European nation-states for a productive and with minimal illnesses population helped to expand of medicine and the improvement of working-class peoples' health. With capitalism, health came to be seen as the optimal capacity for work (e.g. Donzelot, 1980/1991; Turner, 1987; Foucault, 2003). European states' need for a robust working population was equalled by the respective needs of the US in the nineteenth century, when the psychiatrist George Beard first introduced the term neurasthenia in medicine. Having a similar medical system and being equally concerned with optimising work, the US had jumped on the bandwagon of the heavy industrialisation of production and of life. In Europe, where fatigue was born, it came to be viewed as something that could not only be objectively described but analysed and controlled, as Angelo Mosso claimed. That gave rise to utopian beliefs of unlimited productivity and social harmony. The belief that bodily fatigue was eliminable was challenged, however, as fatigue came to be viewed as a natural barrier to the efficient use of the body (Rabinbach, 1992: 133). The limits placed upon labour time were not so much the response to the demands for social justice but were rather the response to the demands for a more productive and not over-exhausted workforce. Neurasthenia, an illness with no organic symptoms, was partly responsible for that. As shown in chapter 3, modernity's relation to fatigue was ambiguous because it was both a social

threat and simultaneously it represented the access to the sweet pleasure of boredom (van Zuylen, 2009). ‘Da Costa’s syndrome’, a syndrome originally identified in men in wartime, was one of the many fatigue-related illnesses of the time, an illness that some of today’s scientists take it to be the same as CFS. The same is true for neurasthenia. In both cases, medicine was not willing to legitimate illnesses with no known organic aetiology. With some notable exceptions, medicine treats such illnesses as psychogenic or ‘medically unexplained’, or as malingering. That has been the case for many illnesses such as multiple sclerosis (MS) and HIV/AIDS that were once considered psychogenic. It is not very surprising that according to popular discourse CFS patients are deemed ‘malingerers’ who fabricate or exaggerate their symptoms and exploit the welfare system.

From Fatigue to CFS

Rabinbach (1992) argues that by the 1920s, as the nature of industrial work depended less and less on physical effort, the disabilities of work shifted away from fatigue to psychological ones, above all to stress; a process that, as my research findings suggest, has continued up until today with the rise of illnesses like burn-out. Rabinbach’s argument seems to be accurate because despite the fact that after the First World War, but also after the Second World War, extensive long-term fatigue studies were carried out both in the UK and the US, fatigue did not have the importance it once had. The notion of stress substituted fatigue as an illness with equally disruptive effects in work and social life. During the interwar years, researchers from both physiologic and social science disciplines were concerned with finding stability in a greatly unstable world (Viner, 1999). Stress could not have emerged without the developments in microbiology and immunology. As argued in chapter 2, the emergence of CFS would have been equally impossible without them (Luthra and Wessely, 2004: 2364). The immune system has become one of the sources of bodily energy and vitality. Medicine’s

growing ability to localise illness in the body's interior (Nettleton, 2004) replaced humours and vapours by nerves and, in turn, nerves by cells as the source of the body's energy.

Significantly, while by the 1930s, most contagious diseases had either been eliminated or controlled cases of severe and inexplicable outbreaks of fatigue illness have taken place over the years. Terms like post-viral fatigue syndrome (PVFS) and chronic fatigue immune dysfunction syndrome (CFIDS), and finally that of CFS, have been given to those inexplicable outbreaks of fatigue illness. The epidemiological shift away from infectious diseases towards chronic, sometimes manageable but rarely curable, illnesses like diabetes (Wasserman and Hinote, 2011) makes it somewhat difficult to claim that CFS is a post-infectious illness. Furthermore, the management of chronic disease is no longer restricted in the clinic, though the clinic still plays a significant role (Bharadwaj, 2006; Latimer *et al.*, 2006; Featherstone *et al.*, 2005), but is instead diffused across the numerous patterns of individual behaviour. While these patterns are constrained by social structures, the epidemiological model is individualistic, emphasising notions such as 'lifestyle' (Nettleton, 1996). It has been suggested that many CFS subjects were exhausted by their previously over-demanding work lives (Ware, 1992; Clarke, 2003). It is also not very surprising that CFS subjects are described as having a 'maladaptive perfectionist personality style' (Courjaret *et al.*, 2009: 14), a 'malady of the will' (see Galvin, 2002). Throughout the thesis, I tried to make the argument that CFS constitutes primarily a welfare problem to be urgently addressed (Ross *et al.*, 2004; Jason *et al.*, 2008; Jason *et al.*, 2009a). Congruent with the thesis developed in chapter 1 that biopolitics is now a concern of multiple actors mobilising around the promises of science and medicine, CFS organisations are utilising that discourse in order to draw attention to their illness' seriousness and demand more funding for biomedical research. CFS patients' energy has to be 'modulated', as argued in chapter 5, but how this is to be done for an illness described as an 'enigma' (Pearce, 2006) is debatable. As

long as CFS remains stubbornly elusive, the efficiency of each available treatment is contestable. The epistemic uncertainty of CFS creates an unremitting cycle of surveillance and intervention through which it can be, as far as possible, managed.

CFS as a Scientific Mystery

CFS is not just a ‘medical mystery’ (Ross *et al.*, 2004: 1104); it is also an economic and moral problem and, possibly, an infectious disease. The majority of people diagnosed with CFS are unable to work and ‘function’ according to dominant social norms. In line with the general tendency of the responsibilisation of individuals (Rose, 1999b), CFS subjects are discursively positioned as ‘autonomous’ and ‘active’ citizens. In chapter 2, I showed that along with viral infections, various explanations have been suggested for CFS including of the maladaptation immunological system and dysfunctions of the nervous system. However, CFS still lacks what Lakoff (2008: 744) describes by the term ‘disease specificity’, i.e. some specific causal mechanisms that are located within the sufferer’s body. CFS lacks a ‘biomarker’. Biomarkers have become an integral part of modern medicine and psychiatry, signifying the diminishing importance of patients’ narrations of their experiences and of the clinician’s interpretation of observable clinical symptoms (Metzler, 2010). CFS is variously described; for example, it is perceived as being a contemporary form of hysteria (Showalter, 1997) or as an illness in which biology and culture are equally important (Zavestoski *et al.*, 2004: 168). The gendered nature of CFS is clear as women have much higher prevalence than men. In terms of social class, current epidemiological data suggest that it equally affects all social classes. Additionally, CFS has been considered as an ‘emerging functional syndrome’ like premenstrual syndrome (PMS) or as a ‘new socio-medico disorder’ (Dumit, 2000; 2006), i.e. a disorder that borders between the mental and the biological and is contestable. Similarly, Rose (2006) speaks of ‘disorders without borders’, i.e. disorders whose symptoms

can be variously coded by physicians, psychiatrists, medical market research agencies, and patients. Finally, CFS has been described as a multisystem illness (e.g. Ortega-Hernandez, 2009). While it is well known that medicine is characterised by uncertainty, what fundamentally underlines all these descriptions is the notion of 'biosociality'. Biosociality refers to the new types of sociality assembled around the proliferating categories of somatic suffering that create new forms of contestation around recognition and expertise (e.g. Epstein, 1995; Rabinow, 1999; Callon and Rabearisoa, 2004). As already mentioned CFS organisations collaborate with scientists and educate themselves about the intricacies of biomedicine, thus being an active force in the production of scientific facts about CFS.

Scientific objectivity is the temporary and localised stabilisation of epistemic closures, a matter of intervention and not of epistemological certainty. That non-epistemological understanding of science is illustrated in Mol's (2002) ethnography of atheroscleroses. Mol shows how atherosclerosis is enacted as an object in a range of interrelated and overlapping practices. Now, while biomedicine's critique is well established, the objectification of patients and the standardisation of procedures are not necessarily harmful (Timmermans and Almeling, 2009). Furthermore, not only does diagnosis provide an explanation for the suffering of a patient but, much more, it defines reality. Different forms of objectification of CFS lead to different types of social effects for patients. Drawing on the relevant literature and the findings of my research (in particular chapters 4 and 6), my study suggests that the diagnosis of CFS is a field of contestation not only in the clinical setting (Cooper, 1997; Horton-Salway, 2002) but on a broader level as well as CFS patients seemingly make 'excessive' welfare claims.

CFS is heterogeneously classified, diagnosed, treated, and researched. There is considerable ambiguity over the definitions of ME and CFS. While the WHO classifies ME as a debilitating neurological illness, it classifies CFS as a condition with abnormal symptoms and

chronic fatigue as a somatoform disorder (exactly as CFS is regarded by the American Psychiatric Association). The ambiguity over the classification of ME and CFS is heightened as other classificatory systems classify them differently. My study shows that as with other illnesses CFS is characterised by a conflict between classification systems, something very common in contemporary biomedicine (Bowker and Star, 2000). Also, ME is much more legitimate as a category in the UK than in the US. According to psychiatric discourse exemplified by one of the leading researchers in CFS for many years, the professor of epidemiological and liaison psychiatry at the Institute of Psychiatry at King's College London, Simon Wessely, CFS is a psychosomatic illness. Wessely has repeatedly argued that CFS lacks any 'objective' pathological evidence and that it is similar to neurasthenia (David and Wessely, 1993). On the other hand, biomedical researchers (e.g. Komaroff, 2006) and CFS organisations claim that CFS wrongly lacks recognition as organic. According to Emeritus Professor of Medicinal Chemistry at the University of Sunderland, Malcolm Hooper and his collaborative work with the ME Association UK (Hooper, 2008; 2010), the psychiatrists who support Wessely's opinions believe CFS is 'medically unexplained'. That is why it is perpetuated by 'inappropriate illness beliefs', 'pervasive inactivity' and by 'being in receipt of disability benefits'. According to Hooper, there is a deliberate misinterpretation of all biomedical evidence and lack of provision of special facilities (other than psychiatric clinics) and state benefits for CFS patients. As described in chapter 4, my own findings suggest that these beliefs are true for the majority of CFS patients.

The CFS community is in search of a biomarker that will legitimise its suffering. That may be the single most important goal of CFS organisations which operate through independent local support groups and provide support to CFS patients and their families and friends. As with other patient advocacy groups (Rabeharisoa, 2008a), there is lately a considerable expansion of CFS organisations on a European level. CFS organisations are acquainted with

the processes of biomedicine and demand funding for ‘scientific’ investigation into the causes, consequences and treatment of CFS. For instance, in 2011 and 2008 respectively, MEA provided in its website a summary of studies related to the XMRV virus and of the distribution of unfunded biomedical research by the Medical Research Council (MRC). Similar to Epstein’s (1995; 1997) study of HIV/AIDS advocacy groups, my research suggests that CFS organisations are to some extent ragmented and in conflict with each other, with some being considered more aligned to the government and others as being ‘grass-roots activist’ organisations. Furthermore, as Dumit (2000) has suggested, different patient advocacy groups have to compete with each other over limited funds, making the funding opportunities for less recognised illnesses, such as CFS, more difficult.

Standardising CFS, Optimising Energy

CFS’s objectivity is partial as CFS exists among fractional and competing classifications. The attempts to standardise its definition, diagnosis, and treatment remain partial and on-going. As shown in chapters 4 and 5, CFS’s objectivity is always in the making, a product of the conflicts and collaborations of the actors that constitute the world of CFS. While the standardisation of diagnostic categories and biomarkers are an increasing demand for biomedicine, CFS is difficult to standardise, one of the reasons being its incomplete existence as a biomedical illness. Biomedicine’s growing demand for standardisation is illustrated by the fact that biomedical researchers need clear diagnostic tests to justify applications to funding agencies that increasingly demand comparable and reproducible results, and that pharmaceutical corporations require standardised diagnosis if they are to develop and sell their products (Knaapern and Weisz, 2008: 127). The various standardisations and classifications of CFS order the social lives of scientists, institutions, and patients. For instance, while the standardisation of clinical trials determines the most efficient treatment

for CFS patients, the ‘discovery’ of a new virus, originally identified as the causative agent for CFS, gave rise to a new ‘political economy of hope’ (Novas, 2006) and changed the dynamics between pharmaceuticals, patients, and institutions in the CFS world. In a different way, insurers require valid tests by which the separation of CFS patients who can work from those who cannot can be achieved. The identification of the XMRV virus as the causative agent for CFS and its eventual disproval was marked by various instances of contestation, illustrating the complexity and ambiguity that a scientific controversy entails. CFS sufferers demand a biomedical explanation that will destigmatise their condition and potentially improve (or even cure) it. CFS subjects search for energy to work, to devote care to themselves, to their families and friends. The reason as to why people diagnosed with CFS lack energy is precisely the issue. Is it a post-infectious condition and, if so, what is its causative agent? Is it genetically transmissible to children? Is it an illness that equally affects the immune system and the brain? Lastly, is it an illness that is organic but which at the same time has social and psychological dimensions? My study shows that such types of questions constitute the primary concerns for people diagnosed with CFS.

The management of CFS subjects’ symptoms is, as everything with CFS, heterogeneous. Through a variety of clinics, methods and treatments, CFS subjects try to find the best possible way for the optimisation or stabilisation of their energy. Of course, this does not mean that all CFS subjects accept the current social norms of the ‘fit’ body and struggle to improve their health. The plethora of CFS identities cannot be homogenised. In the UK, access to clinical care can be achieved through the National ME Centre (NMEC), through the CFS service at King’s College and the Maudsley Hospital in London, through NHS’s Clinical Network Coordinating Centres (CNCCs) across the UK, or through other clinics, specialised or not. The provision of CNCCs were announced in 2004 as a matter of urgency, further illustrating how the CFS community is a very significant actor in the making and

management of CFS. The majority of facilities offered to CFS patients specialise in fields such as neuropsychiatry and psychology, thus, other areas such as those of immunology and infectious diseases are undermined. Now, while there are many, mainly non-pharmacological, treatments or ‘rehabilitation strategies’, only two have demonstrated reproducible evidence for their efficacy in non-severely affected CFS patients: cognitive behaviour therapy (CBT) and graded exercise therapy (GET). That is in line with the premises of evidence-based medicine (EBM) which demands that specific treatments for symptom-based diagnoses be recommended. While EBM raises significant problems for the provision of health care and has been severely criticised, as already mentioned, the standardisation of health care provision is not necessarily harmful nor should it be demonised (Timmermans and Almeling, 2009; see also Timmermans and Mauck, 2005). Doctors and other practitioners have always the capacity to adapt protocols to their needs (Bowker and Star, 2000). A determinist, top-down application of such a discourse should not be expected.

The efficiency of interventions to improve the health of people diagnosed with CFS is, if not equated, clearly associated, with CFS’s subjects’ ‘ability to work’ (e.g. Ross *et al.*, 2004). CBT is the most common form of intervention for CFS. According to the cognitive-behavioural model of illness, dominant in psychiatry, the patient’s interpretation of symptoms plays an important role in perpetuating the illness (Wessely *et al.*, 1989; Sharpe, 1991). CBT purportedly helps patients change the negative beliefs that they have and, if not to fully recover, at least return to a more ‘normal’ level of social functioning. On the other hand, GET is a type of physical activity that starts very slowly and gradually increases over time in order to avoid the extremes of over exercising during remittance or not exercising at all due to concern of relapse. CBT and GET are not the only forms of treatment recommended for the management of CFS subjects’ energy. Pacing is the third most common method for CFS’s energy modulation after CBT and GET. This technique also encourages behavioural change,

but unlike CBT, acknowledges the typical patient fluctuations in symptom severity and delayed exercise recovery. CFS patients are advised to set ‘manageable’ daily activity goals, ‘balance’ their activity, and, like GET, to rest in order to avoid possible over-exertion which may worsen their symptoms. That technique’s ultimate goal is, again like GET, to increase over time the level of ‘routine functioning’ of the individual. Finally, a technique that is sometimes recommended for the management of the CFS patients’ health is the lightening process (LP). LP is a non-medical treatment based on the interaction of the body and the mind. Its purpose is to help ‘clients’ determine and achieve personal goals. That is achieved through a combination of neuro-linguistic programming (NLP), ‘life coaching’ and osteopathy. Training programmes like NLP are provided by authorities such as HRM specialists, coaches and mentors and are part of the neoliberal discourses and practices that try to inculcate self-management. NLP is a form of psychotherapy that is sometimes used by and for employees in order to make them more productive. Once again, while all these treatments are criticised by CFS patients and their organisations, some find them, to varying degrees, successful. Different surveys report varying degrees of success for each of the major CFS treatments, i.e. CBT, GET, and pacing.

Drugs are another, though not the most common, option for people diagnosed with CFS. Some are self-medicated and experiment with various combinations of drugs that could potentially boost their energy levels. Some of those drugs are antiviral drugs or drugs that calm ‘overactive’ brains. Experimental drugs have to be tested in clinical trials and be approved by the relevant regulatory bodies such as the US Food and Drug Administration (FDA). Clinical trials evaluate the adverse effects of health-related interventions such as drugs, behavioural treatments, and preventive care. Clinical researchers, biostatisticians, pharmaceutical companies, physicians, and patient advocacy groups form a network of actors that engage in methodological and jurisdictional disputes over the interpretation of data

produced by clinical trials and fight over the ways (i.e. procedures, tests, etc.) in which clinical trials should be conducted (Epstein, 1995; 1997; Richards, 1988). The efficacy of CFS experimental drugs like Ampligen has been tested by a number of trials and has had mixed findings. The consistent replication of results, an imperative for modern biomedicine, has been impossible as many of those trials were based on a small number of patients. In chapter 5, I showed that while CFS patients and organisations demand more clinical trials, and in particular clinical trials that test the efficacy of experimental drugs and treatments, most CFS clinical trials test efficacy and safety of cognitive-behavioural or exercise interventions or treatments.

In the UK, a relatively large-scale government funded trial, the so-called ‘PACE trial’, was conducted between 2006 and 2011. The trial’s results showed that CBT and GET were the best and most cost-effective treatments for CFS while CFS advocacy groups argued that the PACE trial was over-simplified, that it used a flawed psychosocial illness model that ignored biological evidence, that it tested a non-representative version of pacing, and that the results seriously conflicted with their member surveys which showed that pacing is effective. Furthermore, they criticised the scientific integrity of the panel of the trial, which consisted mostly of members of the so-called ‘Wessely School’, and doubted the legitimacy and ability of statisticians, as well as the trial’s overall aim. CFS organisations’ demand for more clinical trials that are suited to the needs of people diagnosed with CFS, has been strengthened since the ‘discovery’ of the XMRV virus in 2006, the third known human retrovirus after HTLV and HIV, which was initially identified as the cause of CFS (Lombardi *et al.*, 2009; Lo *et al.*, 2010) but finally disproven (Erlewin, 2010; van Kuppelweld, 2010; Groom, 2010) to the detriment of both CFS patients who were hoping for a cure and of pharmaceutical companies who wished to develop and sell new anti-viral drugs. This shows the importance of CFS activism in the making of what CFS is. For instance, on 1st November 2010, CFS activists

protested at the UK Department of Health in London in order to raise awareness of the seriousness of the illness, condemn the National Institute for Health and Clinical Excellence Guideline (NICE) CG53 Guideline, and demand parity with other serious diseases such as HIV/AIDS. Also, since XMRV's 'discovery', there is an increase of activism by CFS patients in the UK including the bombardment of researchers with freedom of information requests and accusations that individual scientists are in the pay of drug and insurance companies. After being threatened, Wessely has stopped his research on CFS and seems to hold a 'milder' opinion, arguing that the neurosciences are the field where new insights into the nature of CFS are most likely to emerge.

Besides the viral aetiological account for CFS, the brain stands out as a very possible explanation. My research shows that the brain has become an integral part of the identities of people diagnosed with CFS and confirms Rose's thesis about 'neurochemical subjects' (Rose, 2007b). While the brain was never convincing as an explanation for CFS, it was not completely dismissed and seems to be gaining much currency as the possible aetiological locus for CFS (e.g. Schwartz *et al.*, 1994; Lange *et al.*, 1999; Schmaling *et al.*, 2003; DeLuca, 2005). Though neurodeterminism is an exaggerated position, the brain is increasingly considered the locus of our ability to plan and control ourselves and the explanation of all manner of human activities and experiences (Abi-Rached and Rose, 2010: 32). That is the result of the growing interest and sophistication of brain-imaging techniques which localise the features of the personality in particular regions of the brain. The case of post-traumatic stress disorder (PTSD) which was once considered a psychogenic illness (Drummond, 2010; Storrs, 2010) is a good example of that. Moreover, there are practical reasons for the popular endorsement of equating mental diseases with brain diseases as the insurance systems in both the US and the UK do not easily remunerate medically unexplained diseases. On the other hand, the proposed changes of DSM-V (scheduled to be published in 2013) and of ICD-11

(which will be published in 2014) will possibly combine several existing somatic categories into one larger category, that of ‘complex somatic symptom disorder’ (CSSD); this shows how far CFS is from being recognised as an organic illness by such authoritative classificatory systems and that the struggle for its standardisation is far from settled.

As shown in chapter 5, the emergence of the XMRV virus and the continuous struggle of CFS advocacy groups for the recognition and legitimacy of their illness as neurological have brought considerable results. While CFS escapes standardisation and is still considered both in medical and popular discourse as psychogenic, there are various and significant attempts to standardise CFS as a biomedical illness. As with other illnesses, CFS’s objectivity as a biomedical illness is based on the systematic recourse to collective production of evidence by inter-laboratory studies, multi-centre clinical trials and research consortia (Cambrosio *et al.*, 2006; 2009). Conferences and multidisciplinary approaches on researching CFS have escalated since the XMRV virus was found in some CFS patients’ blood. Invest in ME (IiME) published these findings in their 2010 conference, considering them a major breakthrough in the understanding and treatment of CFS. IiME claimed that, for 2011, the way forward was to focus on translational biomedical research into CFS with the initiation of clinical trials using ‘homogeneous patient cohorts’ and ‘correct clinical guidelines’ which were accomplished by the *International ME/CFS Conference 2011*. Another attempt to standardise both CFS’s biomarkers and treatment was the NIH’s ‘State of Science’ meetings on CFS of the same year. As the scientific director of CFIDS Association of America, Dr Suzanne Vernon, argued, different terminology and case definitions blur the lines between research and clinical medicine and create problems in comparing study results. Moreover, she argued, information standardisation and aggregation should help identify and prioritise studies, including biomarker ‘discovery’, biomarker replication and validation, preclinical and clinical studies and leveraging existing infrastructure and resources.

CFS as a Welfare Problem

The control of the working body, the optimisation of body movements, has (with some exceptions) been replaced by companies' management of the psychological well-being of workers. The notions of energy, fatigue, and health and their interrelations have changed. Individuals are responsibilised and held accountable for situations that may be far outside their control, such as keeping their jobs. Individuals often take recourse to antidepressants and other drugs to endure the increasing, and often overwhelming, work pressures and competition (Bifo, 2009a).

Although people diagnosed with CFS constitute a small part of the labour force both in the UK and the US, still, CFS is identified as a significant welfare problem. Similar to depression, a variety of mechanisms and programmes render CFS visible and manageable. Numbers suggest that over half of the people diagnosed with CFS are unable to work and nearly two-thirds are 'limited' in their work. More than half of people diagnosed with CFS are on disability benefits or temporary sick leave and less than a fifth work full-time (Ross *et al.*, 2004). When it comes to work, CFS is again heterogeneous. Nevertheless, CFS is identified as both the cause of diminishing productivity (Raynolds *et al.*, 2004) and as a burden to the welfare state (Jason *et al.*, 2008; 2009). While CFS is a factor that influences national productivity, late capitalism has moved beyond its Keynesian phase. Life-long, stable jobs have been replaced by temporary, insecure and low-paying jobs and welfare provision has been significantly restricted. That generalised instability in work and life is sometimes referred to as 'precarity' (see Standing, 2011). Welfare recipients, such as people diagnosed with CFS, are seen as 'people whose self-responsibility and self-fulfilling aspirations have been deformed by the dependency culture' (Rose, 1996a: 59). The increasing attack on the welfare state makes psychogenic illnesses more difficult to remunerate.

Therefore, having ‘objective’ criteria to distinguish invalid from valid claims is a necessity for insurers (Coetzer *et al.*, 2001: 170).

In late capitalism, physical energy and fatigue are not as important as objects of study and control because the nature of work and concomitantly the demands placed upon workers have changed. Fatigue now seems to be more ‘cognitive’ (Bifo, 2009b). What teachers often describe as ‘tiredness in the head’, a product of their extreme time discipline, may be a good example of that (Widerberg, 2006). Indeed, drowsiness, the absence of mental acuity, is the primary problem of working bodies today (Baxter and Kroll-Smith, 2005: 39). Nevertheless, fatigue studies (including studies of muscular fatigue) are still quite common. The study of fatigue and CFS and their rearrangement go hand in hand with the study and rearrangement of sleep (Rosekind *et al.*, 2010). Sleep disorders create various personal and societal problems. With the scientific study of fatigue and sleep, there is an emergence of new syndromes such as the so-called ‘insufficient sleep syndrome’ (ISS) and workers are identified as ‘being “at risk” of sickness absence or work disability’ (Janseen *et al.*, 2003: 71).

The energy levels of people diagnosed with CFS should be either optimised or, when that is not possible, kept stable. That is the demand of many CFS subjects themselves, though for different reasons (e.g. for getting to work). Although some openly blame their previous or current jobs (e.g. as too demanding or stressful) for their condition (and in that sense, like neurasthenia, it may be argued that CFS is a rejection of today’s productivism), not everyone has the same capacity to abstain from work, even part-time work. The fact that some people diagnosed with CFS might hold their work environment or some virus responsible for their illness alleviates the societal burdens placed upon them. When they are ‘able’ to work, CFS individuals often face a variety of issues including the dilemma of whether or not to disclose their illness to their employers (see Munir *et al.*, 2005) and the difficulty in performing due to

their physical and mental problems. Furthermore, and as there are no previous studies available, my findings (see chapter 6) cautiously reveal that some people diagnosed with CFS may be forced to undertake precarious works, putting their health or chances for recovery at risk.

That health should be better seen in terms of the organism's capacity to establish new norms (Varul, 2010) and that disability is better conceived in an ontologically open way (Law, 2003; Schillmeier, 2008) is a position that seems to be very much accepted in today's western societies. Disability is now considered recoverable (Mitchell, 2010; Ville, 2010). The modification and optimisation of bodily capacities is now almost mandatory. And while a body unaffected by technology and culture is not defensible, its 'optimisation' through technology should be problematised (Lupton and Seymour, 2000). CFS's fluctuating symptoms are an example of that. When, for diverse reasons, the mobility of people diagnosed with CFS is limited, some may, for instance, need the assistance of a wheelchair. CFS exemplifies the various and complex ways in which technology is used by people and how these problematise our notions of illness, disability and 'normality'.

Disability's recoverability and the dismantling of the welfare state are very much connected. In the UK, in 2008, the Employment and Support Allowance (ESA) replaced the existing incapacity benefit (IB) for new claimants. It aimed to give more 'help' to those who might, with support, be able to work. Even if employment might sometimes be elusive for ill and disabled people (the 'inactive' population), a series of policy changes is trying to make employment more 'disability-friendly' by offering financial incentives to employers and to educate the disabled while not at work to increase their 'employability'. Moreover, the introduction of a new 'fatigue test' by Atos Healthcare (a French company to which the testing of whether an ill or disabled individual is able to work or not has been outsourced) makes their position more difficult. There are cases where the provision of Housing Benefits

(HB's) for ill and disabled people is no longer possible or restricted. UK disability groups, including CFS ones, have of course heavily criticised both the sweeping cuts in ESA and Atos' oversimplified and unfair test, showing, once again, the entanglement of science with activism.

While many fatigue-related illnesses have emerged and perished, CFS has persisted. CFS is a medical category that changes over time. The discursive apparatus that defines CFS changes over time. In times where the autonomous and self-managed individual is glorified, bodies diagnosed with CFS defy that glorification by remaining 'idle'. CFS remains elusive, trapped between medicine and psychology. My study shows that the history of CFS is characterised by periods where biological explanations take the lead and others where psychological explanations dominate (see also Ortega and Zorzanelli, 2010). The current period seems to embrace more biological explanations, though the road to be travelled until CFS is finally accepted as biological seems long. Although the XMRV virus was not proven to be the causative agent of CFS, it was significant in augmenting biomedical research on CFS. CFS is a heterogeneous world: it is a viral condition, a functional somatic disorder, a complex disorder combining many parts of the body, to name just a few of the circulating definitions of CFS. The uncertainty over whether ME and CFS are one and the same illness illustrates the uncertainty and complexity that marks the evolution of illnesses. But as my study shows, the heterogeneity of the CFS world is more clearly illustrated in the variety of CFS subjectivities and, concurrently, the variety of beliefs, values, and strategies of CFS subjects. Their concerns and demands vary greatly from demanding more biomedical research to dealing with benefits providers, improving their health, to finding a job or maintaining their current ones. The lack of discursive unity over CFS creates a constant uncertainty for, and quarrel between, members of the medical establishment and the CFS organisations, between the CFS activists and the institutions that manage it. As long as CFS

is broadly considered a psychogenic illness with no known organic aetiology, as an illness that exhibits medically unexplained symptoms, there is little space for the provision of disability benefits. CFS is caught up between different forms of objectivity but the legitimacy of a test like Atos' stands out as the ultimate judge of the (in)ability of people diagnosed with CFS to work. The increasing tendency to get ill and disabled people off of welfare dependence and to (if possible) get them back to work is clearly exhibited in the demands for better treatments for CFS, even if there is no agreed-upon explanation for the illness. CFS remains in an on-going battle between all the different actors that want to define it for their own interests.

Appendix

Table of Themes

1. Objectivity

- Diagnosis
- Nosology/Classification
- Donating their bodies
- Subjective accounts
- Clinical trials
- Funding
- Journals
- Comparing themselves with the HIV/AIDS movement
- Contesting and collaborating with doctors

2. Biosociality

- New collective identity
- Loneliness
- Activism
- Fears of transmitting the disease to others

3. Treatment

- Need for more CFS clinics
- Experimentation

4. Work

- Work Capacity Test
- Critique of
- JobCentre
- Self-employment
- Disclosure of illness
- Survival

5. Identity

- Social Stigma
- Need of explanation
- Biomedical

6. Biomedicine

- Objectivity
- Objectification
- Pharmaceuticals
- Hope for cure
- VS psychiatry

7. Time/Temporalities

- Time spent
- Time management
- Time for themselves
- Energy

Notes

Introduction

1. See <http://www.investinme.org/Article-050%20Sophia%20Wilson%2001.htm> (last accessed July 23, 2012); and <http://news.bbc.co.uk/1/hi/uk/5112050.stm> (last accessed July 23, 2012)
2. Wilson, C. (n.d.) 'The Story of Sophia and M.E.'. At: <http://www.investinme.org/Article-050%20Sophia%20Wilson%2001.htm> (last accessed July 23, 2012). It should be noted that the psychiatrist's gender is not known and hence I use the personal pronoun 'he' only for clarity's sake.
3. Wilson, C. (n.d.) 'The Story of Sophia and M.E.'. At: <http://www.investinme.org/Article-050%20Sophia%20Wilson%2001.htm> (last accessed July 23, 2012)
4. Wilson, C. (n.d.) 'The Story of Sophia and M.E.'. At: <http://www.investinme.org/Article-050%20Sophia%20Wilson%2001.htm> (last accessed July 23, 2012)
5. See <http://www.investinme.org/Article-050%20Sophia%20Wilson%2001-RIP.htm> (last accessed July 23, 2012)
6. Lacerda, E., Nacul, L., Pheby, D., Sphepherd, C., Spencer, P. (2010) 'Exploring the feasibility of establishing a disease-specific post-mortem tissue bank in the UK: a case study in ME/CFS', *Journal of Clinical Pathology*, 63: 1032-1034.
7. See <http://www.newscientist.com/article/dn9342-first-official-uk-death-from-chronic-fatigue-syndrome.html>; and <http://www.newscientist.com/article/mg19125620.600-not-sadly-the-first.html> (last accessed July 23, 2012)
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9. Robotham J. (2007) 'Victims give clues to the answers, in *The Sydney Morning Herald*. Sydney'. At: <http://www.smh.com.au/news/science/victims-give-clues-to-theanswers/2007/04/11/1175971183260.html#>. (last accessed July 23, 2012)
10. See http://webcache.googleusercontent.com/search?q=cache:_adaHG3qzBkJ:meagenda.wordpress.com/2010/09/03/mea-statements-review-of-nice-guideline-cg53-and-pace-trial-results/+NICE+Guideline+CG53&cd=5&hl=en&ct=clnk&gl=uk (last accessed July 23, 2012)
11. See <http://www.youtube.com/watch?v=hqwg5ZkmURk> (last accessed July 23, 2012)
12. Here and elsewhere, I put the word discovery in brackets because as van Loon (2002: 122) put it: 'When using words such as 'discovery' in relation to a narrative of a history of a science, one always runs the risk of re-inventing an unfolding of events through actions of heroes who – against all odds – provided new 'truths' despite the obstacles of 'tradition' and 'ignorance', often associated with vested interests'.
13. McKie, R. (21 August of 2011) 'Chronic fatigue syndrome researchers face death threat from militants', *The Guardian*. At: <http://www.guardian.co.uk/society/2011/aug/21/chronic-fatigue-syndrome-myalgic-encephalomyelitis>

Chapter One: The Biopolitics of Chronic Fatigue Syndrome

1. While I often refer to the category of modernity, it has to be clear that it is not in any way unified or unproblematic (see, e.g., Venn, 2009; Mezzandra, 2011).
2. On the complexity of the very notion of 'life' in biology, see Anidjar (2011) and Helmreich (2011).
3. I have the term 'race' under brackets to emphasise its problematic nature; see Hartigan (2008)
4. 'Life', too, has (re-)emerged as a theoretical-philosophical problem (Olma and Koukouzelis, 2007). This might raise questions such as: Is 'life' some force that always exceeds control or is this some

kind of naive vitalism? Can philosophical problems about life be translated into political ones and if yes how?

5. Nguyen's (2005) concept of 'therapeutic citizenship' is similar.
6. There is a rich tradition in political theory, originating in Carl Schmitt and Martin Heidegger and culminating in Jean-Luc Nancy and Chantal Mouffe, that differentiates 'politics' (*la politique*) from 'the political' (*le politique*). Mapped onto what Heidegger (1927/2004) called the 'ontological difference', a political difference between 'politics' (i.e. 'polity') and 'the political' (i.e. the 'essence' of politics) is drawn and a supposed 'oblivion' of the essence of 'the political' in modern times is often implied. Rancière loosely follows this distinction and gives it an entirely new meaning.
7. Although Rancière has on occasions clearly distinguished his work from Foucault's, in an interview he claimed: 'If, among the thinkers of my generation, there was one I was quite close to at one point, it was Foucault' (Rancière, 2003: 208-209).
8. On Rancière's ontology, see Deranty (2003) and Ieven (2009); and for a critical appraisal of his theory of politics, see Dean (2009).
9. Deleuze's philosophy is at times seen as anti-essentialist vitalism or 'biophilosophy'. I tend to agree with Marrati (2011) that for Deleuze there is no politics of life (i.e. 'biopolitics') and that life is not a concept.

Chapter Three: Towards a Genealogy of Fatigue and CFS

1. See <http://www.earlymoderntexts.com/pdfbits/desel2.pdf> (last accessed July 23, 2012)
2. The term neurasthenia was coined independently in 1868 by the psychiatrist Van Deussen (Stubhaug, 2008: 20). Before Beard's use of the term, it referred to a mechanical weakness of the actual nerves.
3. Engels's (1845/1887: n.p.) description of child labour in Manchester is revealing: 'They knew nothing of a different kind of life than that in which they toil from morning until they are allowed to stop at night, and did not even understand the question never heard before, whether they were tired'.
4. On the problematics of the relation between a physical account of energy and a physiological account of energy, and their connection to vitalism, see Caygill (2007).
5. Roldán (2010) suggests that at the beginning of the last century the European science of work was 'exported' in Argentina where it was hybridised with its deep Catholicism. However, Catholicism's distaste for idleness was not at all incompatible with the rationalisation of work. It was suggested that 'the optimum way of achieving a balance between nutrition, sleep and work consisted of constant efforts, the duration of which did not exceed eight hours. In addition, it was essential to have adequate conditions for restoring energy (energy for work) in the time devoted to rest' (Roldán, 2010: n.p.). Also, it should be noted that in Europe the division of time in 8 hours of work, sleep, and rest was probably first formulated by Robert Owen in 1817.
6. The quest for boosting bodily energy often led to inventions like the Heidelberg 'electric belt'. That belt could purportedly cure almost everything. As the *Sears 1900 catalogue* advertised it: 'For weakness in men and women, personal exhaustion, over brain work, vital, impotency, rheumatism, sciatica, lame back, railroad back, insomnia, melancholia, kidney disorder, Bright's disease, dyspepsia, disorders of the liver, female weakness, poor circulation, weak heart action and almost every known disease and weakness'. See <http://www.museumofquackery.com/ephemera/heidelberg.htm> (last accessed July 23, 2012)
7. However, as van Zuylen (2008: n.p.) suggests, 'post-Enlightenment culture entertains a curious love-hate relationship with fatigue. Its eradication would usher in an age of absolute energy and accomplishments, while its cultivation could lead to radical self-knowledge'.
8. DSM (*Diagnostic and Statistical Manual of Mental Disorders*) omitted neurasthenia in 1980.
9. Today, due to the developments in technology, soldiers can carry very heavy weights with no effort, with the use of artificial *exoskeleton* which is placed on the body and simulate its skeleton.
10. Factitious disorder entered the diagnostic canon in the DSM-III in 1980.

11. Martin (1990) saw a strong parallel between the discourse of immunology and Harvey's (1989) description of capitalism as 'flexible accumulation'. Annandale (2003: 93) would add that capitalism 'shapes biology in its own image'.

Chapter Four: Making of CFS Objectivity

1. See <http://news.bbc.co.uk/1/hi/health/3014341.stm> (last accessed July 23, 2012)
2. See http://www.theoneclickgroup.co.uk/documents/MECFS_docs/CHILD%20ABUSE%20SPECIALIST%20RUNS%20CENTRE.doc (last accessed July 23, 2012)
3. See Tutton (2008: n.p.).
4. See <http://www.cfidsselfhelp.org/library//will-i-get-better-tilting-odds-your-favour> (last accessed July 23, 2012)
5. See <http://www.sciencedaily.com/releases/2009/01/090105175025.htm> (last accessed July 23, 2012)
6. See also the 2007 ICD10. At: <http://apps.who.int/classifications/apps/icd/icd10online/?gg90.htm+g933> (last accessed July 23, 2012)
7. See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4064840 (last accessed July 23, 2012)
8. See <http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx>
<http://www.theoneclickgroup.co.uk/documents/PACE/THE%20PACE%20TRIAL%20IDENTIFIER%20.pdf> (last accessed July 23, 2012)
9. See <http://www.pacetrial.org/> (last accessed July 23, 2012)
10. PTSD is often considered an offspring of Da Costa's syndrome.
11. The XMRV virus, a newly 'discovered' virus, was initially believed to be the causative agent for CFS (more on this on chapter 5).
12. See <http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx> (last accessed July 23, 2012)
13. See http://www.show.scot.nhs.uk/App_Shared/docs/MainDoc.pdf (last accessed July 23, 2012)
14. See http://www.theoneclickgroup.co.uk/documents/ME-CFS_docs/CHILD%20ABUSE%20SPECIALIST%20RUNS%20CENTRE.doc (last accessed July 23, 2012)
15. See <http://www.chronicfatiguetreatments.com/forums/chronic-fatigue-syndrome-f1/topic707.html> (last accessed July 23, 2012)
16. See http://www.meactionuk.org.uk/Quotable_Quotes_Updated.pdf (last accessed July 23, 2012)
17. See <http://www.cfs-news.org/faq.htm> (last accessed July 23, 2012)
16. See <http://www.mererearch.org.uk/research/studies/2010/childrenqol.html> (last accessed July 23, 2012)
17. See <http://www.coalition4mecfs.org/about.html> (last accessed July 23, 2012)
18. See <http://www.chronic-fatigue-community.com/chronic-fatigue-syndrome-activist.html> (last accessed July 23, 2012)

Chapter Five: Standardising Through Intervening

1. This may be overstated but works like Martin's (1990) testify the degree to which capitalist metaphors 'colonise' peoples' experiences. I was given a DVD copy of the recorded event of an immunologist's talk in a local self-help group that one of my informants leads, whom I would like to thank. It is noteworthy that his talk was full of military metaphors and tropes such as 'troups', 'weaponry', 'enemy', 'battle', and 'tactical retreat'. Other 'themes', as he called them, that were used were 'balanced portfolio', 'batteries', and 'dialogue with your body'.
2. See <http://www.nmec.org.uk/mecentre.html> (last accessed July 23, 2012)
3. See <http://www.meactionuk.org.uk/CMO%27s%20Report.pdf> (last accessed July 23, 2012)

4. See <http://www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/get-informed/ME%202008%20%20What%20progress.pdf> (last accessed July 23, 2012)
5. See http://www.25megroup.org/campaignaware_severely_affected_presentation.html (last accessed July 23, 2012)
6. See http://www.25megroup.org/campaignaware_severely_affected_presentation.html (last accessed July 23, 2012)
7. See <http://www.nice.org.uk/media/0F3/49/CFSMEJRJudgementStatement130309.pdf> (last accessed July 23, 2012)
8. See <http://www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/get-informed/ME%202008%20%20What%20progress.pdf> (last accessed July 23, 2012)
9. See <http://www.globalconsultancyservices.com/coaching.html> (last accessed July 23, 2012)
10. See <http://www.nlpacademyscotland.co.uk/whatisnlp.html> (last accessed July 23, 2012)
11. See <http://www.dailymail.co.uk/health/article-427537/Could-ME-caused-adrenaline.html> (last accessed July 23, 2012)
12. See http://www.meassociation.org.uk/?page_id=1341 (last accessed July 23, 2012)
13. See <http://www.meassociation.org.uk/?p=3719> (last accessed July 23, 2012)
14. See <http://www.dailymail.co.uk/health/article-79042/ME-woman-cure-works-her.html> (last accessed July 23, 2012)
15. See Scott's (1998) account of homeopathy as a feminist form of medicine.
16. See http://www.cfs-info.com/joomla/index2.php?option=com_content&do_pdf=1&id=1398 (last accessed July 23, 2012)
17. See <http://www.hemispherx.net/content/investor/default.asp?goto=738>
18. APT is a combination of pacing and graded activity.
19. See http://www.sciencemediacentre.org/pages/press_releases/11-02-17_cfsme_trial.htm (last accessed July 23, 2012)
20. See <http://www.cfstheresistance.com/the-wessely-school-and-the-medical-research-council.php> (last accessed July 23, 2012)
21. Some members of the CFS blog believed that (clonazepam) Klonopin calms the brain by reducing the 'set point' at which its neurons are activated. Klonopin is a benzodiazepamine that is sometimes used by CFS individuals to help them with sleep. That is achieved by the increase in the production of GABA, a chemical that reduces neuronal activity.
22. See <http://edition.cnn.com/2010/HEALTH/08/23/chronic.fatigue.virus/index.html> (last accessed July 22, 2012)
23. See <http://www.examiner.com/article/breakthrough-for-chronic-fatigue-syndrome> (last accessed July 23, 2012)
24. See http://www.wpinstitute.org/about/about_mission.html (last accessed July 23, 2012)
25. See http://www.wpinstitute.org/news/docs/RGJ-medical_breakthrough.pdf (last accessed July 23, 2012)
26. See <http://www.plosone.org/annotation/listThread.action;jsessionid=CA8A144D535CB340555FCA9B7EEEA090?root=18075> (last accessed July 23, 2012)
27. See http://www.patentmaps.com/inventor/Mikovits_Judy_A_1.html (last accessed July 23, 2012) and <http://www.ei-resource.org/functional-laboratory-tests/gastrointestinal/neurotoxic-metabolite-test-%28nmt%29> (last accessed July 23, 2012)
28. See <http://www.vitaltherapeutics.com/about.htm> (last accessed July 23, 2012)
29. See <http://www.cerus.com/Investors/Press-Releases/Press-Release-Details/2010/Whittemore-Peterson-Institute-and-Cerus-Confirm-Inactivation-of-XMRV-by-the-INTERCEPT-Blood-System1122064/default.aspx> (last accessed July 23, 2012)
30. See http://www.americasblood.org/download/File/newsletter_sample.pdf (last accessed July 23, 2012)
31. See <http://www.investinme.org/IIME%20Conference%202011/IIME%202011%20International%20ME%20Conference.htm> (last accessed July 23, 2012)

32. See <http://www.research1st.com/2011/06/28/meeting-summary-mecfs-state-of-the-knowledge-workshop/> (last accessed July 23, 2012)
33. See <http://www.research1st.com/2011/06/28/meeting-summary-mecfs-state-of-the-knowledge-workshop/> (last accessed July 23, 2012)
34. See <http://www.cfids.org/profresources/grants-guidelines.asp> (last accessed July 23, 2012)
35. See <http://www.pandoranet.info/documents/LetterAPA-DSMCONCERNS2010.pdf> (last accessed July 23, 2012)

Chapter Six: The Work Regulation of CFS

1. Stewart *et al.* (2003: 3135) note that the ‘management and treatment of depression has changed substantially since the 1980s; use of pharmaceutical care and, more generally, access to care have increased and may have influenced disability status and how work time is lost’. Also, although we cannot analyse here how the selection criteria were determined, we can note how a 7-factor solution was deemed optimal among respondents with depression. Each factor included different items and degrees of covariance. To give an example, the three first of those factors included: (1) pain, weakness, or fatigue; (2) gastrointestinal complaints; and (3) panic or anxiety (Stewart *et al.*, 2003: 3137). As Stewart *et al.* (2003: 3138) note: ‘Only gastrointestinal complaints and panic or anxiety were common to individuals with and without depression. A dichotomous variable defined the presence of a factor-based symptom cluster. For each factor, the cut-point was defined at the 10th percentile of respondents without depression’.
2. Osborne (2003: 510) interestingly notes that ‘as a combination of doctrine and morality, the creativity explosion is unquestionably variegated and double-edged; it can be captured by business gurus and management writers, Californian lifestyle sects, new age groups, post-identitarian philosophers, literary critics turned cultural theorists, intellectuals, postmodern geographers, anti-globalization protestors, whoever’.
3. Here they follow Castel’s (1995/2003) distinction between positive individualism and negative individualism (disaffiliation); see also Castel, 2000.
4. See <http://news.bbc.co.uk/1/hi/health/3014341.stm> (last accessed July 23, 2012)
5. See also Robinson’s (2011) very useful summary of the various theories around precarity, from which I have benefited a lot.
6. We have to note the conservatism of Ehrenberg’s thesis that fatigue is caused by democracy’s abnegation of authority, i.e. church, family, and government, and that everyday life decision is up to us.
7. Medafinil (Provigil) is another example of a drug often consumed to boost performance. It is mainly used for excessive sleepiness (ES).
8. See <http://www.management-issues.com/2006/8/24/research/workers-struggle-to-escape-work-while-on-holiday.asp>. (last accessed July 23, 2012)
9. While some of Canguilhem’s ideas cannot stand any more, at least not without conceptual readjustment, his influence is still significant. See Greco (1998; 2005); Mol (1998); Rabinow (1998); Rose (1998); and cf. Latour (1991/1993: 91-94); Rabinow and Caduff (2006).
10. Hatherley has written in his blog post ‘Work and Non-Work’: ‘Work on the workshy. Work more to earn more. Work trials for the disabled, Cognitive Behavioural Therapy for those who don’t want to work’ (quoted in Vishmidt, 2010: n.p.). The famous dictum *Arbeit Macht Frei* was used by the disabled activists in the UK in the protests mentioned in the beginning of the thesis.
11. See http://www.nhsplus.nhs.uk/providers/images/library/files/guidelines/cfs_guideline.pdf (last accessed July 23, 2012)
12. A work trial can be defined as ‘a voluntary short agreement aimed at helping injured workers maintain or regain employment as part of a worker’s return to work strategy’. See <http://www.workcover.nsw.gov.au/injuriesclaims/injurymanagement/Returntowork/Vocationalrehabilitationprograms/Pages/Worktrials.aspx> (last accessed July 23, 2012)

13. New Deal for Disabled People (NDDP) was Labour's main employment programme for individuals in receipt of a disability or incapacity-related benefit. Pathways to Work is a programme that, through work trials, 'helps' people to find a job if they have a disability.
14. See <http://www.kcl.ac.uk/projects/cfs/health/> (last accessed July 23, 2012)
15. See http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/-DH_4139436 (last accessed July 23, 2012)
16. See <http://benefitclaimantsfightback.wordpress.com/> (last accessed July 23, 2012); see also <http://disabilitymessageboard.blogspot.gr/2010/09/disabled-people-protest-against-cuts.html> (last accessed July 23, 2012) ME/CFS organisations, as Anglia ME Action, have criticised benefit cuts on similar grounds. As they say, although people diagnosed with ME/CFS would like to work 'as indicated by the large number that attempt to do a little voluntary work when able) but are simply incapable of SUSTAINING regular full-time or even part-time work over the medium or long term without health deterioration'; see angliameaction.org.uk/docs/corporate-drift-net.pdf. (last accessed July 23, 2012). The Citizens Advice Bureau (CAB) has also expressed concerns at the number of people unexpectedly being found fit for work. CAB is endorsed by, among other organisations, Action for ME (AfE), Action for blind people, Carers UK, and Multiple Sclerosis (MS); see www.citizensadvice.org.uk/not_workin-g_march_2010_final.pdf. (last accessed July 23, 2012)
17. See http://www.atoshealthcare.com/services/disability_assessment (last accessed July 23, 2012)
18. See <http://www.guardian.co.uk/commentisfree/2010/aug/27/me-benefits-work-capability-assessment> (last accessed July 23, 2012)

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