BREAKTHROUGH FOR CHRONIC FATIGUE SYNDROME, M.E. AND FIBROMYALGIA

HOW NEUROBIOLOGY AND EPIGENETICS POINT THE WAY TO RECOVERY

> VOLUME 1 CHRONIC NEUROSOMATIC ILLNESS



Judith Maizels, PhD., MBHMA

with Fiona Adamson M.Litt., Adv. Dip. Psych., MBACP

Wellwise Press • Hertfordshire • England

Preface to Volumes 1 and 2

Who the Book Is For

For the Person with CFS/ME and/or Fibromyalgia

I was ill with myalgic encephalomyelitis (ME) for twenty-five years, marked by periods of remission and relapse, and made a full recovery in 2004, since when I have enjoyed a completely symptom-free life. I am also an independent research scientist and, since 2009, have worked as a neurosomatic therapist for people who have been diagnosed with chronic neurosomatic disorders like chronic fatigue syndrome (CFS), M.E., and fibromyalgia. I have written this book (both Volumes 1 and 2) primarily for you, the person with CFS/ME and/or fibromyalgia. Two of the greatest problems for people with CFS/ME and fibromyalgia are the lack of a sound, scientifically based explanation for their illness and the absence of simple, effective, scientifically-based treatment. These failings mean that so many people living with these illnesses are treated with disdain or disbelief about their symptoms, accused of being lazy or mentally ill, and neglected or rejected by many in the medical establishment. I have been the victim of these insults. I know what it is like to be disbelieved, to have my symptoms trivialised, and to have my long years of ME dismissed as "yuppie flu". I know only too well the despair and helplessness of yet another relapse. I even lost my academic career for "not getting better quickly enough".

But I also know the relief, awe, and joy of making a complete recovery after twenty-five years of illness. It was my own full recovery – and my freedom from all symptoms – that inspired me to explore how recovery was even possible after so many years of illness. Once I started this journey, I found myself immersed in many exciting new discoveries that have been emerging from the realms of neuroscience and epigenetics in just the last decade or two. I gradually realised that these were the fields of research that could now offer the key to understanding the origin of my own illness and help to explain how, with appropriate interventions, I was able to dispel all the symptoms of my illness and build my new life as a well person.

And of course, I have been inspired by these enormously exciting and vitally important insights (still) emerging from these revolutions in neurobiology and epigenetics to write this book. I feel passionately about sharing these potentially life-transforming breakthroughs in our understanding not only of how these chronic illnesses develop, but perhaps more importantly, how individuals can make a full and permanent recovery. I hope that, in writing this book and sharing with you, the reader, the scientific breakthroughs that helped me to become well again, the ideas we share here will reveal to you – and to other people living with these awful illnesses – how and why you became ill and how you too can make a full and permanent recovery.

A Note for the Clinician, Carer, Therapist, and Practitioner

If you are a family member, carer, clinician, or therapist (or a well person wanting to remain well) caring for someone with CFS/ME or fibromyalgia, you are invited to explore this neurosomatic approach as a way of gaining insight into how we as therapists and practitioners can help people with CFS/ME, fibromyalgia, and other similar conditions to regain their full health. The approach described in this book (both volumes) can help everyone keep their own neurobiology functioning at optimal levels of resilience, offering avenues for us all to remain adaptable and well throughout life by developing healthy coping strategies to deal with the many stresses and challenges we may face.

I believe this book also rectifies some of the serious failings in the current narrowly focused research into CFS/ME and fibromyalgia, and in the often poor provision of care for people with these illnesses. The book is designed to help patients and clinicians alike to understand the complex origins of these illnesses and to show how people with these debilitating chronic disorders can recover their full health.

About the Author

My Illness History

I was diagnosed with ME in 1979, when I was thirty years old, following a bout of glandular fever (infectious mononucleosis). Having been born and brought up in London, I had only started my new job as a university lecturer in geography and earth sciences at a Scottish university just 9 months earlier. I battled with symptoms of chronic fatigue, "brain fog", cold fevers, muscle aches, and bouts of illness-related despair for much of the following twenty-five years. I struggled to continue with my teaching and research, and during "good" years was able to travel the world doing field research and publishing my findings. But after fifteen years of repeated six-month relapses I was "invited" to take early retirement on health grounds, which I reluctantly accepted at the age of forty-five. I remained ill for much of the next decade. Whilst bedridden, I started drawing (with my geologist's pen) and eventually became a full-time "intuitive artist". With fellow artists I set up and ran an arts charity and magazine for untrained artists on the margins of society. Latterly, as both my parents developed dementia I did my best to help care for them, whilst initially still struggling with chronic illness myself.

During those twenty-five years of chronic illness, I tried almost every treatment known at the time, and nothing helped to alleviate the symptoms more than temporarily or minimally. The treatments I tried included acupuncture; homeopathy; reflexology; herbal remedies; vitamin B12 injections; hypnotherapy; raw food diet (salads and vegetables); dietary exclusions of wheat, dairy food, and yeast; several periods of psychotherapy; Jungian psychoanalysis; autogenic relaxation training; Reiki; shiatsu; Shen massage; emotional release therapy; graded exercise; Eckhart Tolle teachings; spiritual healing; and breath meditation. After twenty-five years, I still found myself struggling to cope with debilitating symptoms and a disrupted life.

It was from this state of resigned despair and desperation that I finally persuaded myself to try a mind-body treatment known as Reverse Therapy, a method developed by British psychologist Dr John Eaton.¹ Much to my utter astonishment, and following a three-month programme of hard work and re-education of some of my old ways of thinking and behaving, **my symptoms literally seemed to switch off.** It felt like a miracle. I was finally a relatively fit, well, and active person again. Since becoming completely symptom-free I have enjoyed an exciting, varied, fulfilling, happy, yet still challenging life as an artist, scientist, carer, and neurosomatic therapist, supported by a loving partner and nourishing friendships. I am a lover of life and the natural world, an explorer of ideas, and a believer in the strength, courage, and compassion of the human spirit.

My Scientific Journey

I trained as a scientist, gaining a PhD in earth sciences, as well as teaching about the scientific method and undertaking research for over thirty years, although in some of those years I worked part time, and in others I was bedridden. I remain dismissive of anything that claims to be a miracle cure or reflects ignorance or so-called bad science. But becoming well, permanently, raised a huge number of questions in my own mind about how the mind-body approach could possibly work, and as a scientist, I wanted to investigate for myself how certain mind-body

treatments could possibly be so effective in eliminating the symptoms of CFS/ME and fibromyalgia. Here are some of the questions I explored:

• How could a mind-body approach possibly work?

• If the mind-body approach really works, does this mean that the traditional biomedical model for treatment of CFS/ME is invalid?

• What physiological, neurological, and other biological processes are really responsible for the symptoms of CFS/ME and fibromyalgia?

• Why are more people, including those in the medical profession, not taking mind-body treatment seriously or regarding it as a valid route to recovery?

• What does the mind-body approach tell us about the origin and meaning of this illness?

• What can we learn from the mind-body approach about ourselves as human beings and how we deal with the challenges of major changes in our lives?

As I explored and reflected on these important questions, I began to learn about the science of brain-mind-body connections and became engrossed in the remarkable discoveries from the world of neuroscience that are transforming our views of illness, the body, the mind, and, above all, the brain. I discovered that there is indeed a sound scientific basis both for the origin of the symptoms of CFS/ME and fibromyalgia and for the means of dispelling them. This book addresses these various questions through exploring these neurobiological and epigenetic breakthroughs in our understanding of these chronic disorders, showing the extent to which they underlie the development of CFS/ME and fibromyalgia.

Coming from a contrasting discipline associated with largely inert substances like rocks and ice rather than neurons, proteins, and hormones, I had to start almost from scratch as I began investigating neurobiological processes for the first time. I believe, however, that coming fresh to a new discipline has also offered me some advantages over established researchers in the various fields of human biology. It is worth remembering that, while I have applied the same scientific method to this new discipline as I had in my previous research field, my experience has taught me that many major shifts in understanding arise when scientists move from one discipline to another, bringing with them a new, more open perspective and a set of challenging new questions. I believe that my own shift in disciplines has helped me gain a wider, more integrative, multidisciplinary understanding of CFS/ME and fibromyalgia than has yet been advanced by many specialists in these illnesses. I hope I have brought to this analysis a fresh sense of wonder, a passion for understanding the processes of illness and recovery more deeply, and great optimism from witnessing how the valuable new insights emerging in the fields of neurobiology and epigenetics are already leading an increasing number of patients to make a full recovery.

My Training and Practice as a Neurosomatic Therapist

In 2005, I began training as a Reverse Therapist, and although I almost completed the training, I was thwarted by difficult family circumstances from completing it when I had planned. When I had the opportunity to repeat the training in 2007, I discovered that by then, my ideas had evolved so much that I no longer felt comfortable working within the specific protocols of Reverse Therapy. I preferred to work within a framework of greater scope and depth, and to be open to providing longer-term support of clients when needed. Having had personal experience of counselling, psychotherapy, and psychoanalysis (as a client) for more than forty years, I then undertook further training in counselling skills and wellness coaching, and in 2009 I began working with clients in private practice. I see myself as one of that growing band of professional "scientist-practitioners"² whose practice is informed by a broad scientific knowledge base, whilst at the same time offering clients a professional, empathic, creative, reflective, mindful, focused, and ethical approach to guiding and supporting them on their own path to recovery. I describe more fully in Volume 2 my journey from being a patient to becoming a neurosomatic therapist.

My Collaboration with Fiona Adamson

In many ways, this book (both Volumes 1 and 2) represents a collaboration between myself and my partner, Fiona Adamson, an experienced transpersonal and Gestalt psychotherapist, coach, and supervisor. Fiona had already worked with the transpersonal perspective, which sees symptoms as symbols or messages from the unconscious mind that are there to guide people living with chronic illnesses like CFS/ME and fibromyalgia to reflect on and change aspects of their lives. Our main areas of collaboration have therefore been within Fiona's particular fields of expertise, including interpersonal neurobiology, developmental psychology, and therapeutic approaches to recovery.

Together, we have discussed the most significant findings in these areas and combined these with our experience of working with clients to build an integrated model of illness from which we have designed an effective and clear step-by-step programme for full recovery from these debilitating illnesses.

Breakthrough: The New Neurosomatic Paradigm for Illness and Recovery

The Neurobiological Role of Emotions and Environmental Epigenetics

One of the most remarkable and unexpected findings I came across in the neurobiology research was that emotions are really forms of energy. As such, we experience our emotions in our body in the form of flows and surges in the levels of hormones and other neurochemicals as they move through our neural networks and are released into our bloodstream. I was amazed to learn that there really is a biological link between emotions held in the body – as neurochemicals – and their physical expression as symptoms. The research convincingly showed me that if our emotions are blocked, then so too is our energy; conversely, when we express our feelings freely, our emotional energy flows freely too, and we feel energised and well. Most excitingly for me, I realised that – for the first time in my life – I could indeed sense my energy physically surging through my own body whenever I gave voice to my true feelings.

A further remarkable finding I came across lies in the field of environmental epigenetics, which reveals that our life experiences – both past and present – can alter the behaviour of our genes. This area of science has developed only in the past decade or so and clearly offers us a second major revolution in our understanding of illnesses like CFS/ME and fibromyalgia.

However, there were also theories and insights that at first I found shocking. For example, I found it hard to come to terms with the realisation that my early life experiences should have had such profound and long-lasting effects not only on the neurobiology and neural development of my brain, but consequently on how I have dealt with life's stresses ever since – all without my conscious awareness. I was shocked to discover that the organisation of my own brain when I was a child had increased my vulnerability to developing ME in the first place.

As I delved into the neurobiology of these newest findings about brain-body connections, I became increasingly convinced that many of my old ideas about CFS/ME and fibromyalgia needed to be challenged – and that an exciting new radical paradigm for these illnesses was finally taking off. And the more I learnt about these ideas and what they meant, the more I realised how clearly they could explain my own personal experiences of illness, how I was able to recover, and how I have remained well.

These latest findings from neurobiology remind us that much of the evidence we seek in order to understand these illnesses is already "out there". My endeavour has been to gather together all these vital new pieces of the puzzle to create an informed, radical, integrative, and practical new scientific paradigm. More importantly, I realised that at last this latest research evidence provided the basis for a new, comprehensive model of both illness and recovery for people living with CFS/ME and fibromyalgia – a model which could be used as the basis of a recovery programme that, as numerous individual case studies show (examples are given in Volume 2), can be highly effective in dispelling all the symptoms of illness, permanently.

The Neurosomatic Approach

The book (both Volumes 1 and 2) proposes a new, sound, integrated explanation of CFS/ME and fibromyalgia based on extensive neurobiological evidence. According to our new model, CFS/ME and fibromyalgia are the direct result of a genuine epigenetically-acquired neurosomatic condition. We use the term 'neurosomatic' to describe chronic disorders like CFS/ME and fibromyalgia which arise through dysregulation of neurobiological systems. Dysregulation in neurosomatic illness primarily affects those elements that are involved in the chronic stress response in individuals whose neural networks were subject to early life "programming". The fundamental premises of this book are that

• these disorders result from changes in gene behaviour, rather than directly from our genetic inheritance, i.e. they are epigenetic in origin, and are the result of early life "programming" of our neural networks, and

• the brain remains plastic and malleable throughout our lives.

These findings mean that we can change for ourselves both the behaviour of our own genes and the neurobiology of our own brain-body system in ways that allow us to overcome our illness, even after many decades of debility, to make a full and permanent recovery.

Developing the Neurosomatic Recovery Programme (NSRP)

Using this new neurobiological understanding of CFS/ME and fibromyalgia, Volume 2 of the book introduces our Neurosomatic Recovery Programme (NSRP), carefully designed to help individuals dispel all the symptoms of these debilitating illnesses, permanently. While the NSRP is also based on my own experience of recovery from CFS/ME, our **specifically proactive form of neurosomatic therapy** draws on some of the basic principles both of John Eaton's Reverse Therapy approach³ and of the Mind-Body Prescription approach for treating chronic pain as developed by John Sarno, professor of rehabilitation medicine at New York University School of Medicine.⁴ Once Fiona and I began working with clients in private practice, we gradually honed the recovery programme yet further, helping to guide and support people living with CFS/ME and fibromyalgia to make a full recovery.

The NSRP is founded on our new concept of Neurosomatic Intelligence (NSI), which offers a coherent, scientifically based route to rebuilding more healthy and resilient neural networks that act to "switch off" the symptoms – once and for all. The NSRP uses a proactive, step-by-step process to guide and empower people living with these illnesses to

• discover why they became ill, as reflected in stress response patterns generated by neural networks established early in life,

• discover what authentic action they need to take to regain their health, and

• create healthy new neural networks and more resilient stress response patterns by taking the most authentic action for them that dispels their symptoms.

Our proactive neurosomatic approach acknowledges the genuine severity of the symptoms but uses no drugs, special diets, or specific exercise, relaxation, or massage programmes. Nevertheless, we do acknowledge that certain dietary, mineral and vitamin supplements, and exercise that actively contributes to resolution of the neurosomatic stress response (as explained later), can support the recovery process and enhance wellbeing.

All clients who have completed the programme have made a full recovery; while some clients have dropped out for financial or other reasons, it is the case that the high recovery rate may at least partly reflect the self-selected and motivated nature of the clients who have embarked on the programme. Clients who have made a full recovery have included a woman who had had CFS/ME for almost 30 years, and another who had had fibromyalgia for 50 years; clients who fully recovered have included those whose illness started suddenly, apparently following an infection or being in a stressful situation, as well as those whose illness crept up on them gradually. The consistently high recovery rate amongst those completing the NSRP, as illustrated in the case studies referred to in the book (especially Volume 2), do provide powerful case-study support for the model and the approach we have proposed.

Nevertheless, any recovery programme such as ours contains scope for further refinement and development, so we encourage clinicians to establish randomised control trials (RCTs) in the future as a means of providing a more thorough test both of our model and of the recovery programme. We further acknowledge that the NSRP is not appropriate for people with CFS/ME and fibromyalgia who may require specialist psychiatric intervention.

If our approach appeals to you as someone living with CFS/ME and/or fibromyalgia, we encourage you to test the efficacy of the recovery programme for yourself.

Writing This Book

Many of the ideas in this book (both Volumes 1 and 2) are therefore based on my own personal experience of illness and recovery, and on extensive research of the literature; I have also drawn on my own experience of working with clients who have participated on the recovery programme. Despite my best efforts, I have only been able to read a tiny proportion of the 8.2 million articles, books, and reports of research findings and ideas that have been published about CFS/ME (and 16.4 million about fibromyalgia) over the past few decades, as cited on Google Search. This vast database is testament to the prodigious global research effort – by thousands of passionate researchers in a multitude of disciplines – that has been directed towards furthering our understanding of these disorders. Unfortunately, most research studies are highly reductionist, disparate, and disconnected from one another, focusing only on a tiny part of the puzzle, and oblivious to the whole picture. In completing this book, I have therefore tried to read as widely as possible, and to bring together the numerous interconnections between the many different areas of study that together span the world of CFS/ME and fibromyalgia.

In reviewing the research described in this book, there are of course many references that I have missed and many whose detailed scientific significance I may not fully have grasped. Another constraint on my reading is that I have excluded, as far as possible, all reference to studies that are based on animal experiments, as I find it distressing to read about their suffering. Because of my own experience of CFS/ME and a (self-imposed) time limit in writing the book, I do acknowledge that the primary emphasis in this book is CFS/ME, rather than fibromyalgia; while I may have devoted less attention to fibromyalgia, the evidence we present supports the view that fibromyalgia is a closely related but distinct condition, such that our neurosomatic model fully represents both illnesses.

Completing the book has proved to be one of the most difficult tasks I have ever undertaken, as my typically perfectionist and driven personality, fearful of getting it "wrong" or of omitting some crucial evidence, has been both a blessing and a huge obstacle to admitting to myself that the book is finished. In my own mind, the book is never finished, as fascinating new ideas and clinical findings seem to be emerging every day.

The ideas in this book are my own and reflect my own thoughts, and those of Fiona, on the latest research findings to date. Of course, we do not purport to provide all the answers to these debilitating illnesses, nor do our ideas necessarily provide a route to recovery for everyone who has these conditions. Despite these potential limitations, I am confident that the ideas presented in this book have a sound, integrated grounding in scientific theory, supported by clinical studies, my personal experience of my own illness and recovery, and my own practice working with people with CFS/ME and fibromyalgia. The proposed model of illness and recovery is based on the fact that the neurobiological and epigenetics evidence has allowed us to challenge many of the current myths and misconceptions about the origin and treatment of CFS/ME and fibromyalgia. In particular, our breakthrough approach challenges the views that CFS/ME and fibromyalgia are conditions that are "all in the mind" or cannot be remedied. Quite the opposite: these illnesses are genuine, epigenetically-acquired chronic neurosomatic disorders – and, most importantly, they can be reversed.

While this book is largely theoretical and evidence-based, we do introduce the principles of the Neurosomatic Recovery Programme. For those seeking a more practical guide for recovery, we refer you to our forthcoming recovery handbook (provisionally titled *CFS/ME and Fibromyalgia: A Handbook for Recovery from Chronic Neurosomatic Illness)*, which guides people living with these chronic illnesses through the step-by-step programme using simple explanations, case studies, discussion of potential obstacles to recovery, and practical exercises.

In addition, length restrictions for Volume 1 mean that the full reference list is published only at the end of Volume 2, although it is also freely available from our web site at www.proactive-neurosomatic-therapy.com. A short on-line e-book is also available from this web site.

Neurosomatic Models Provide a Vital Multidisciplinary Perspective

Throughout the book we have introduced a series of models, many of which are presented as flow charts, and many of which may at first appear to be hugely complex. These models provide a new and vital interdisciplinary perspective that is largely absent from the vast number of reductionist studies that tend to characterise research into CFS/ME and fibromyalgia. Each of the many models presented throughout the book represents particular components or perspectives – or sub-models – of the overall complex neurosomatic model of both illness and recovery, and so we have distinguished each of these separately by name.

For me, with my background in earth sciences and spatial information, the flow charts in particular represent valuable route maps. They can help us track the multidisciplinary pathways by which complex neurobiological processes generate the symptoms of chronic neurosomatic illness and allow recovery to take place. I hope that, rather than being put off by complicated-looking flow charts, readers will be open to the insights that they provide into how the various neurobiological factors are interconnected, enhancing our understanding of how change can occur within complex chains of biological phenomena. Of course, neurobiological processes are hugely complex, often non-deterministic, non-linear, and unpredictable, so that the models can only act as simplified representations of selected elements of complex organic systems.

The Neurosomatic Paradigm and the Breakthrough for Recovery

Now that I have experienced recovery for myself after twenty-five years of illness, sustained my full recovery since 2004, and realised the value of the neurosomatic brain-mindbody approach to treatment, I feel committed to and passionate about bringing this approach to people with CFS/ME and fibromyalgia. This commitment and passion to help others become well, together with my new-found knowledge and understanding about how we become ill and how we can recover, spurred me to write this book. I also feel it is important to dispel the huge number of damaging myths about the origin and treatment of these illnesses, myths and beliefs based on outdated and narrowly focused research that hinders people's recovery and may trap them for years in unnecessary suffering. The message of this book for many people with CFS/ME and fibromyalgia is therefore that **you do not need to remain ill any more**. owners

Introduction

What is Chronic Neurosomatic Illness? A New Paradigm for the Neuroscience Age

Welcome to the Neuroscience Age

We are living in one of the most exciting times in medical history, a time when we have convincing new scientific explanations for the origin of a wide range of chronic illnesses like chronic fatigue syndrome (CFS), myalgic encephalomyelitis (ME), and fibromyalgia. The findings of neuroscience show us not only how and why we develop symptoms but also how new proactive neurosomatic treatment programmes can help dispel these symptoms.

This research means that we now need to transform how we regard these illnesses. We now know that people with CFS/ME, and the closely related condition of fibromyalgia, and other similar neurosomatic conditions, no longer need to be ill.

Since the mid-1990s, and especially since the early 2000s, we have seen a revolution in our understanding of how a number of illnesses may develop and how people can recover their health. This revolution is the outcome of an explosion in the volume of research into the neurological workings of the brain and its neurobiological links with the body and the symptoms of chronic illnesses.

The latest neurobiological research, which is reviewed in both Volumes 1 and 2 of the book, confirms what all sufferers of these chronic conditions already know: namely, that **these illnesses produce genuine and severely debilitating symptoms**. The research shows us that these symptoms are triggered by overactivity of the autonomic and neuroendocrine systems (i.e. behaviour of the nervous and glandular systems), and in particular, the sympathetic nervous system (SNS), and the pathway linking the hypothalamus (H), the pituitary (P), and the adrenal glands (A), which together form the HPA axis. We also know now how deeply implicated are the brain's neural networks, largely inherited from our genes and altered by early childhood experiences, in controlling how we deal with life's challenges. We can now see how and why, for many individuals, these challenges may initially stimulate the sympathetic nervous system and the HPA axis to move into a "hyperaroused" state that in turn can eventually "crash", resulting in a "hypoaroused" state or "metabolic collapse". Physiological shutdown of this kind can cause dysfunctions of the nervous and immune systems, producing a wide range of other painful and debilitating symptoms associated with dysregulation of these bodywide neurobiological systems.

What is Chronic Neurosomatic Illness (CNI)?

Brain Behaviour as the Key Factor for Understanding the Origins of Illness and Recovery

Recent research in the neurosciences is beginning to reveal to us how the behaviour of the brain helps explain both the **origins** of chronic illness and how **recovery** from such illness is possible. Research into brain neuroscience has been growing at an exponential rate since 1992, with the advent of the first magnetic resonance imaging (MRI) and functional MRI (fMRI) scans, in which brain activity can be observed while an individual is engaged in mental tasks.¹ The fMRI scan measures changes in the levels of oxygen consumption by different regions of the brain during an individual's performance, changes that are used as indicators of the levels and

patterns of brain activity. Hence, it is only within the past decade or two that technological advances in brain imaging – now including many other forms of X-ray, positron emission tomography (PET), and magnetic imaging² – have revealed some of the crucial processes affecting the onset and development of disease, and the processes that allow symptoms to be dispelled.

Unfortunately, within the world of modern orthodox medicine, integrating the dramatic findings of recent neuroscience research, and their implications for our understanding of illness and for helping patients to recover from chronic illness, requires a radical paradigm shift, a process that may take many decades. In particular, the most powerful finding from neuroscience research into chronic illness is that many medical disorders are the outcome of the complex interaction of biological processes within the brain and the body that involve not just physiology. As we show later in the book, neuroscience now demonstrates that the symptoms of illness represent the outcome of continuous flows of neurobiological information, in the form of neurochemicals, electrical, electromagnetic, and other signals, between two main regions of the brain: the outer white matter, known as the **cortex**, and the inner, deeper region, known as the limbic system. The cortex is where many of our cognitive processes are concentrated, that is, our thoughts, beliefs, decisions, and expectations. The limbic system is composed of a group of structures that govern our emotional world: our memories and the emotions attached to them, our instinctive responses to fear and anger, and our emotional responses to every moment and event in our lives. However, many brain images may be difficult to interpret, brain scans do not really indicate how the **mind** works – scans based on experimental trials, for example, only allow us to infer the processes operating within our mind.

Defining Chronic Neurosomatic Illness (CNI)

Since the late 1940s, the view has been advanced that impaired connections between and within the cortical and limbic systems might lie at the root of many illnesses – particularly those which psychologists traditionally call 'psychosomatic'.³ It is only with the advances in brain imaging and neurobiological research over the last twenty years that neuroscientists have found evidence to support this early view – but in ways that demonstrate that the processes involved are highly complex and multi-faceted, and range in spatial scale from the molecular to the social, and on time scales ranging from a single moment to a full life-span. While this new and expanding field of science is more accurately described as brain-mind-body medicine, we use the term 'neurosomatic' to describe illnesses derived from disrupted cortico-limbic neural connectivity. Our approach explores the developmental and neurobiological origins of these forms of disrupted neural systems and how they contribute to the development of these neurosomatic illnesses.

The term neurosomatic more precisely indicates that the physical symptoms of illness are generated by dysregulation of neurobiological systems, especially those involved in the chronic stress response. This understanding of the origins of CFS/ME and fibromyalgia as neurosomatic is supported by substantial clinical evidence not only of widespread dysregulation of the autonomic, neuroendocrine, and immune systems in these disorders, but also of the origin of these dysfunctions in early life programming of brain neurochemistry, neural networks, brain plasticity, and the stress response system in ways that can generate symptoms of chronic neurosomatic illness (CNI) later in life.

In addition to CFS/ME and fibromyalgia, many other conditions can be at least partially be classified as CNIs. These include a wide range of 'medically unexplained' somatoform disorders (or somatisation disorders), many of which exhibit symptoms that overlap with those of CFS/ME and/or fibromyalgia, and include idiopathic chronic fatigue and pain⁴. Other CNIs appear to include irritable bowel syndrome and certain other gastrointestinal disorders; a variety of pain syndromes such as rheumatoid arthritis; skin disorders, like psoriasis; some forms of cancer; some allergies, hypersensitivities, and recurrent infections; some sinus and respiratory infections; some genito-urinary disorders; and some cardiovascular, cardiopulmonary and autoimmune disorders, possibly including elements of motor neurone disease and multiple sclerosis.

Although we independently applied the term "neurosomatic" to CFS/ME, fibromyalgia, and other similar illnesses several years ago, it was first used by US physician and neuropharmacologist Jay Goldstein in 1996 to describe CFS and fibromyalgia syndrome.⁵ He regarded CFS and fibromyalgia to be just two of a large number (well over a hundred) of related brain disorders associated with impaired central neural processing in the brain. His recognition of the main factors contributing to the development of neurosomatic illnesses – including genetic susceptibility, child developmental issues, and an increased susceptibility to environmental stressors resulting from a reduction in neural plasticity – also play a significant role in our own model. However, while Goldstein's approach to treatment is largely based on pharmacological interventions, our own approach explores more fully and more widely the multifarious roots of these illnesses as the basis for our own proactive recovery programme.

Our new neurobiological model also attempts to integrate the many different elements that lie at the root of neurosomatic illness within a single, over-arching theory that helps explain why some people are particularly vulnerable to developing chronic neurosomatic disorders like CFS/ME and fibromyalgia, and – perhaps more importantly for those who have been diagnosed with these conditions – how they can reverse both the neurosomatic and epigenetic constraints that have contributed to their illness, thereby permanently dispelling their symptoms.

The Origins of Illness and Recovery

A. Genetics and Environmental Epigenetics

Underpinning all these neurobiological processes are the crucial roles played in the development of CNIs first by our genetic make-up, which affects our **genetic predisposition**, and second, by the **influence of our early life experiences** on the behaviour of our genes. Epigenetics research has only recently revealed that while the genes (and their various mutations) that we inherit from our parents appear to be fixed and immutable, the **behaviour** of many of our genes is altered by our life experience. This means that genes are switched on or off in response to a wide range of environmental conditions, a process known as **environmental epigenetics**. Early life experiences in particular have been shown to control brain development, potentially acting to increase our vulnerability to a variety of illnesses in later life. This vulnerability can therefore be acquired in childhood, and a huge amount of research evidence now points to the "epigenetically acquired" origin of illnesses like CFS/ME and fibromyalgia.

So our genetic inheritance does not control us to the extent to which scientists once believed. And, even more importantly, gene behaviour has been found to remain open to modification throughout our adult lives. So while some may regard our genetic inheritance as making us more vulnerable to illnesses like CFS/ME and fibromyalgia, an appropriately designed recovery programme can actually help restore aberrant gene behaviour to normal functioning and reverse the neurobiological dysfunctions that have sustained the illness.

The role of genes in the development of illness is explored later in Part 1, while in Volume 2, we explore how environmental epigenetic processes can lead to illness and how gene expression can subsequently be transformed by our own actions in ways that lead to recovery.

Of course, there is still much that we do not know and on which future research needs to be focused. But there is now sufficient evidence to demonstrate that, for most people living with CFS, ME, and fibromyalgia, their illness is indeed a reversible epigenetic neurosomatic disorder.

B. Three Core Areas of Neuroscience

Our new neurosomatic model of CFS/ME and fibromyalgia offers a scientifically-based explanation of both illness **and** recovery, and forms the basis of our Neurosomatic Recovery

Programme (NSRP). The model draws on three core areas of recent neuroscience research, integrating the main findings that are of particular significance for people with CFS/ME and fibromyalgia. These three key areas of neuroscience are illustrated in Figure 1. These three core areas all lie within the overriding context of a fourth factor, namely, our genetic inheritance and the impact of life experience on changes to our epigenetic profile. The diagram indicates the parts of the book in which we discuss each of these areas of research.

These core areas of recent research throw light on the origins of illness and on how environmental (nurture) and genetic (nature) factors – and their interactions – contribute to an individual's vulnerability to developing chronic neurosomatic illness. This book shows how these factors can predispose an individual to coping with life's challenges in ways that can sustain the chronic stress response rather than resolving it, and it explores the evidence that living with a chronically unresolved stress response can trigger and sustain the dysfunctions of the autonomic and neuroendocrine systems that generate the symptoms of CFS/ME and fibromyalgia.



Figure I.1 The Theoretical Disciplines underpinning the Model of Chronic Neurosomatic Illness and Recovery as applied to CFS/ME and Fibromyalgia

(1) The Autonomic, Neuroendocrinal, and Immune System Responses to Perceived Stress

There is now substantial evidence that perceived stress can trigger dramatic changes in activity of the autonomic nervous system (ANS) and HPA axis, leading to the development of chronic symptoms of hyper- or hypoarousal. While these dysfunctions generate the symptoms of illness, they are not the root cause of illness. Instead, the processes working within the ANS and the HPA axis are the **outcome** of a chain of complex neurobiological processes which are largely governed by the two other crucial areas of very recent research, namely: **the development of neural networks and the neurobiology of emotions.**

Although the physiological response to chronic stress is now widely recognised as playing a crucial role in the development of the symptoms of CFS/ME and fibromyalgia, what has not been recognised until now are the processes that govern **how and why certain individuals may be particularly vulnerable** to this kind of stress response. Only through understanding the neurobiological processes that give rise to the chronic stress response can we explain how and why the body's stress response system becomes activated and sustained, in turn giving rise to the chronic symptoms of these disorders. Similarly, only because of our improved understanding of the neurobiological processes that trigger the ANS and HPA axis dysfunctions and produce these symptoms, has it been possible to devise an appropriate and effective recovery programme. Parts 1 and 2 of this volume devote particular attention to the autonomic and neuroendocrinal processes leading to development of CFS/ME and fibromyalgia.

(2) The Development of Neural Networks

Neuroscience research has shown that an individual's health and vulnerability to illnesses throughout life are largely affected by the degree of integration of neural networks across different regions of the brain, both between the left and right brain, and between the outer cortical regions (often regarded as more cognitive areas) and the deeper subcortical structures (often regarded as more emotional areas) of the brain. The brain's neural networks are almost completely developed before we are three years old, but the detailed form of these structures is dependent on epigenetic processes, that is, on biochemical processes that switch genes on or off in response to our early life experiences. When these networks are not fully integrated, we are more likely to deal with life's challenges in old "unhealthy" ways, using survival strategies that developed very early in life. One of the features of these early neural networks and associated survival strategies is that they often encourage people to hold on to their emotions, blocking their emotional energy by directing their energy inwards rather than outwards in ways that prevent stress responses from being fully resolved. These neural networks therefore play a crucial role in the development of illness later in life and affect how individuals can recover.

But we now know that **these networks can be modified and new neural pathways created throughout life**, thereby allowing individuals to learn new, symptom-free ways of dealing with stressful life situations. The book explores how to build the new "healthy" neural networks necessary for recovery.

Part 3 focuses on the development of neural networks and the many complex factors that can impair neural development and integration in childhood in ways that increase an individual's vulnerability to chronic illnesses like CFS/ME and fibromyalgia later in life.

(3) The Neurobiology of Emotions

We know that virtually every region of the brain is involved in processing emotions, activating extensive neural networks that link all the main brain areas. As human beings, we are utterly dependent on our emotions in order to perform even our most basic cognitive functions, but much of society seems to discourage people from expressing their feelings and often teaches us to keep our emotions to ourselves. This book shows how emotions are created by the

movement of certain neurochemicals around the brain and the body, in turn generating or blocking the release of energy. When we do not express our emotions freely, the brain can release harmful amounts of stress-related neurochemicals and the flow of neurochemicals can become blocked. These processes can impede the flow of healthy neurochemicals – sometimes for many decades or even for a lifetime. Blockage can in turn disrupt the physiological stress response resulting in long-lasting and harmful dysregulation of the body's hormone balance, as well as dysfunctions of cell behaviour, immune function, and energy levels.

In Parts 4, 5 and 6, we explore the significance of the neurobiology of emotions, and the contrasting effects of blocking or expressing our emotions – and our emotional energy – on the development of chronic neurosomatic illness.

Medicine for the Neuroscience Age

The Neurosomatic Recovery Programme, like many other brain-mind-body approaches, focuses on the **root causes of an illness** by exploring the interactions between the brain, the mind, and the body, and the links between emotions and physiology, and the impact of these interactions on the endocrine (glandular), nervous, and immune systems. Brain-mind-body treatment therefore refers to interventions that address the neurobiological interconnectedness between one's feelings, thoughts, experiences, memories, and actions on the one hand, and the body's physiological responses, in the form of symptoms, on the other.

Consultant child and family psychiatrist Barry Wright from the multi-disciplinary child and adolescent mental health team within York NHS Trust, who has written specifically about CFS/ME treatments available for young people, for example, reminds us that all serious physical illnesses like CFS/ME have numerous physiological, emotional, and social consequences – **and vice versa.**⁶ By only focusing on one avenue of investigation and dismissing any others, we as a society miss the possibilities offered by more integrated, multidisciplinary, holistic treatment options, jeopardising the recovery options for so many people struggling to live with these conditions.

Although brain-mind-body treatments have been common amongst complementary therapists for many decades, much of the recent evidence from neuroscience and epigenetics research that we describe in this book reveals that we cannot separate brain, mind, and body, a model followed by the orthodox, reductionist medical world. As Canadian physician and writer Gabor Maté argues, we now know that "there is no such separation; there is no body that is not mind, no mind that is not body."⁷

Some may regard the **psychological component** in this book as a cruel betrayal of their long-held beliefs that the mind plays no part at all in their illness. We hope to show that the latest discoveries in neuroscience and epigenetics offer an exciting new route to recovery founded on the increasingly convincing neurobiological evidence that **the psychological is neurobiological** – **and vice versa**. Thoughts, feelings, sensations, perceptions, symptoms, reactions, thoughts, and actions are all reflected in and generated by variations in epigenetic behaviour, affecting the production and transmission of neurochemicals, electrical and other sensory signals throughout the nervous system. So, while psychological processes are neurobiological in origin, neurobiology encompasses all our psychological processes. This paradigm shift encourages people to be ready to explore these ideas and test them out for themselves – for here at long last is a route that guides individuals to transform their own neurobiology sufficiently to get rid of their symptoms, once and for all.

Although the brain-mind-body approach *per se* is not new, the ideas and the recovery programme presented in this book contribute to what is the early stage of what we believe is indeed a revolutionary paradigm shift in the treatment of illness in the Western world. We believe that the kind of neuroscience-based brain-mind-body treatment we advocate for CFS/ME and fibromyalgia (and all CNIs) will become more universal during the course of the twenty-first

century. Of course, there is always the danger that brain-mind-body medicine will be hijacked by interventions that avoid self-reflection and mind-body links, such as deep brain stimulation or neuropharmacology. But already thousands of former sufferers of CFS/ME and fibromyalgia have made a full and sustained return to good health using one of a number of similar brain-mind-body approaches to recovery adopted by clinicians and practitioners across the globe. As we show in this book, however, the significance of our own approach is that it is directly linked to addressing the emotional roots of chronic illness and the neurobiological and epigenetic factors that increase an individual's vulnerability to developing these illnesses. The brain-mind-body approach that we advocate in this book demonstrates that the roots CFS/ME and fibromyalgia lie in our acquired neurobiological and epigenetic profiles, and that by transforming these profiles for ourselves, all the organic dysfunctions that generate the symptoms of these debilitating chronic illnesses can be permanently restored to healthy functioning.

Dilemmas

Who to Believe?

One of the great dilemmas facing people living with CFS/ME and fibromyalgia is **who to believe** when they are offered treatment or hear of various treatments being offered round the country by a variety of both conventional and complementary therapists, each propounding a different approach to diagnosing, managing, and/or alleviating their symptoms. The first port of call is normally the GP, many of whom, sadly, are unaware of the existence of relatively successful forms of treatment like the integrated brain-mind-body approach. From that point onwards, patients can find themselves at the centre of a large network of individuals, groups, and organisations who, for one reason or another, have some vested interest not only in their diagnosis and in their preferred modes of treatment, but even in acknowledging or denying the existence of these disorders.

Facing Hostility, Disbelief, and Stigmatisation

People living with these chronic conditions may find themselves being buffeted from one treatment to another, ranging from dismissive views of many psychiatrists to sympathetic but helpless doctors, to other sufferers themselves who are hostile to one particular treatment rather than another. Some of these negative points of view continue to hold powerful sway amongst many in the medical profession, despite being erroneous and damaging. Unfortunately, many of these professionals are so wedded to their own particular views that they become blind to effective treatments that do not fit their own theories. Certainly within the medical profession itself we see a huge range of opinions, ranging from psychiatrists who are convinced that CFS/ME and fibromyalgia are neurotic mental conditions to insightful GPs who refer patients to effective neurosomatics-aware therapists who work on a patient-centred basis to find the optimal recovery programme for them.⁸

Patients often find themselves trapped in a battleground between conflicting views, in which their own experience of debilitating illness, their own beliefs about its origins, and the role of the mind in their illness are often challenged and dismissed. Many patients are met with scepticism and disbelief – not only from their physicians, but also from the media and the public. According to one recent review of media content in the UK, 89 per cent of ME patient organizations considered CFS/ME to be physical, compared with 58 per cent of newspaper articles, and only 24 per cent of medical authorities (evaluated from medical websites and textbooks), with 63 per cent of the latter regarding CFS/ME to be both physical and psychological.⁹ Many patients with medically unexplained symptoms, especially women patients, have described how they felt rejected, ignored, belittled, blamed for their condition, and assigned

a psychological explanation for their illness by their doctor.¹⁰ Patients are left struggling not only with myriad confusing and debilitating symptoms, but also with medical uncertainty, scepticism, and disparagement, and often feel they are dismissed as "attention-seeking" or "difficult".¹¹

For many patients with CFS/ME and/or fibromyalgia, their doctor's consulting room can become an arena for a political contest based on mistrust, creating a damaging impasse between them.¹² Such a conflict regarding both the aetiology and treatment of their illness is hardly the conducive setting in which patients can be offered compassionate and constructive help in finding a route to recovery.¹³ Indeed, research has demonstrated that among the primary sources of stress and distress among patients with CFS/ME and/or fibromyalgia is that their illness is viewed with suspicion and they are accused of malingering.¹⁴ As Patricia Fennell, an internationally recognized specialist in the treatment of chronic illnesses, so aptly writes, "CFS has been trivialised, stigmatised, and minimised by the media, the medical community, society, and the public."15 Indeed, Fennell identifies six cultural factors that adversely influence the behaviour of people in the health-care system, including the intolerance of society and medical professionals in the face of suffering, illness ambiguity, and chronic illness.¹⁶ How many patients with these illnesses feel that their doctor or consultant has ever really listened – and heard – their account of the history of their illness, of their experience of illness, and of its place in their lives? When doctors are faced with chronic symptoms that vary from day to day, that they do not understand, and for which they cannot provide relief, instead of really listening to their patients' story and trying to meet their care needs, some doctors may resort to blaming or dismissing the patient for their own illness, or refusing to believe that they are ill at all.

Hostility towards Brain-Mind-Body Medicine

When we looked at the responses to a 2007 BBC Radio 4 series on ME, we saw that a considerable number of people struggling to live with CFS/ME were adamant that their condition was entirely a physical matter, and they refused to contemplate any link between their minds and bodies. Given the hostile and dismissive reactions of many in the medical profession and the media to patients with CFS/ME and fibromyalgia, this angry reaction reflects a fully understandable fear that patients have of being blamed and stigmatised for their illness, a reaction that of course contributes to their conviction that any cure must be a purely biomedical one. However, as we show in the book, while utterly understandable, this antagonism towards brainmind-body medicine is now misplaced, based as it is on an outdated, Descartian paradigm of the mind-body split. Ideas based on twenty-first century research into the neurobiological and epigenetic processes causing these illnesses are now replacing those old ways of thinking not only about CFS/ME and fibromyalgia, but also many other chronic neurosomatic disorders.

Become an Independent-Minded Former Sufferer

The kind of medical attention that people living with CFS/ME or fibromyalgia receive largely seems to depend on which points of view their doctors have been exposed to, covering the whole gamut of confusing and powerful voices that claim these conditions as their own speciality. The various specialist groups within the medical profession are currently vying for the "rightful" claim to the diagnosis, desperate to be the group that comes up with the cure, whilst the patient is left confused and ill, a victim on this medical battleground. The approach we seek for our own recovery will partly depend upon who we believe can help us and what kind of treatment we can believe in and work with. What seems important now, however, is that whatever the current medical paradigm and whatever our own beliefs, there is now solid neurobiological evidence that CFS/ME and fibromyalgia are chronic epigenetically acquired neurosomatic disorders.

If you are someone living with CFS/ME or fibromyalgia, and you are willing to explore how brain, mind, and body are inextricably linked, this book shows you that there are now new ways available to restore your neurobiological and epigenetic profile to a healthy state and dispel your symptoms. One of the greatest sources of anguish for many people with these illnesses is that their illness and symptoms seem inexplicable, and that no one can offer any real answers to the questions of how and why they became ill – and how they can recover.¹⁷ Hopefully, as you read the book and judge the evidence for yourself, many of your uncertainties and doubts will be dispelled.

The Structure of the Book

The two volumes of this book explore the **neurobiological and epigenetic findings** that link the symptoms of CFS/ME and fibromyalgia with the causes of those symptoms, demonstrating how and why the symptoms can be dispelled.

Specifically, the book follows what can also be viewed as a chronological path representing the approximate sequence of discoveries of neurobiological evidence and the development of ideas in the fields of CFS/ME and fibromyalgia research.

Volume 1: Chronic Neurosomatic Illness

Parts 1 and 2:

Definitions, Theories of Illness Origin, and Biological Explanations for Symptoms

• Part 1 focuses on the more traditional findings and models relating to the biological origin of illness and symptoms.

• **Part 2** explores more fully the dysfunctions of the neuroendocrine and immune systems that give rise to the symptoms of CFS/ME and fibromyalgia.

Parts 3 to 6:

Neurobiological Basis of the Neurosomatic Model of Chronic Illness

• **Part 3** explores the **ten most significant discoveries in neurobiology** that have had the most profound impact on how we now regard chronic illnesses like CFS/ME and fibromyalgia. Early life stresses in particular are shown to impair brain development, in turn damaging one's life-long responses to stress, in many cases resulting in blocking of emotions and emotional energy.

• **Part 4** investigates the neurobiology of emotions, since emotions are shown to be flows of neurochemicals and energy through the body, with almost every brain region being involved in emotional processing. Poor neural connections between different brain regions can impair emotional processing and affect how well we deal with life stresses, potentially increasing our vulnerability to chronic illness.

• Part 5 shows how neural networks established in childhood can govern the coping strategies we adopt throughout our lives when faced with stress, in many cases leading us to direct our emotional energy inwards as a form of "freezing" behaviour, rather than outwards in the form of higher energy "fight-or-flight" responses or resolving stresses through social engagement. These different patterns of response to stress are considered within the framework of an inner, subcortical (i.e. unconscious) emotional conflict between what we have defined as our authentic "True Self", that desires self-expression, and our socially conditioned "Survival Mind", that blocks expression, a conflict that alters neurochemistry, neural connectivity, and brain activity.

We show how the symptoms of chronic illness arise where this inner emotional conflict remains unacknowledged and unresolved, and the voice of the True Self has become lost.

• Parts 6A and 6B explore more closely the neurobiological processes, the neural networks, and neurochemical pathways by which the Survival Mind blocks expression of the True Self, and investigates the neurosomatic and symptomatic consequences of this blocking process in CFS/ME and fibromyalgia.

Conclusion: The Neurosomatic Model of Illness

• The Conclusion summarises the developmental cascade model of chronic neurosomatic illness, and reviews the main predisposing, precipitating, and perpetuating factors for CFS/ME, fibromyalgia and other CNIs. The conclusion also highlights the major breakthroughs of this model for our understanding of the aetiology and risk factors for these chronic disorders, and how we can apply this new understanding to promote full recovery.

Volume 2: Recovery from Chronic Neurosomatic Illness

Volume 2 focuses on the neurosomatic and epigenetic model of recovery from CFS/ME, fibromyalgia and other CNIs; introduces the principles of Neurosomatic Intelligence (NSI) and our Neurosomatic Recovery Programme (NSRP); and shows how the new model helps to explain many of the epidemiological features of these disorders and why it is time to challenge the current medical paradigm for CFS/ME and fibromyalgia.

Summaries and References

Since much of the material presented in the book is complex and detailed, we present at the end of most chapters a summary of the major findings and their implications for CFS/ME, fibromyalgia, and other CNIs.

Owing to the length of this volume, we have only been able to provide a numbered list of notes and condensed references for each chapter, while the full alphabetical reference list for both volumes is presented at the end of Volume 2. A short select bibliography is also presented at the end of each volume. The full reference list is also freely available on-line from www.proactive-neurosomatic-therapy.com.