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## An Integrative Approach to Mindfulness-Based Symptom Management for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

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Running Head: MINDFULNESS-BASED ME/CFS MANAGEMENT

An Integrative Approach to Mindfulness-Based Symptom Management for Myalgic  
Encephalomyelitis/Chronic Fatigue Syndrome

Lisa Barer

Submitted to the Mindfulness Studies Program  
in partial fulfilment of the requirements for the degree of  
Master of Arts  
Lesley University

Advisors: Nancy Waring and Melissa Jean

May 2019

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### Acknowledgments

There are several people I would like to thank for their support and guidance throughout this program and dissertation. My professors and advisors at Lesley University, particularly Alice Armstrong, Nancy Waring and Melissa Jean, provided important input at various critical junctures in the journey, and also encouragement throughout.

I have been exceptionally lucky to study under several very influential teachers and practitioners prior to this program. Each of them played crucial roles in my personal and professional growth: Kristin Buhr, Judith Hanson Lasater, Jon Kabat Zin, Saki Santorelli, Nicole Marcia, Melanie Phillips, Naseem Gulamhusein, and Jan McNeill. To them I owe the varied knowledge base that ultimately led me to this program of study. And without their wisdom, generosity, and encouragement, I would not be the teacher and person I am today.

Finally, I would like to thank my parents, Rachel and Morris Barer, and my husband Geoff Costeloe for their endless love and support. I struggle to put into words what you all mean to me. Thank you for always loving, encouraging, and believing in me.

## TABLE OF CONTENTS

ACKNOWLEDGMENTS .....	3
ABSTRACT.....	6
METHODS.....	8
MYALGIC ENCEPHALOMYELITIS/CHRONIC FATIGUE (ME/CFS) .....	10
MINDFULNESS .....	22
MINDFULNESS AND THE BRAIN.....	23
MINDFULNESS AND MINDFULNESS-BASED COGNITIVE THERAPY (MBCT) FOR MANAGING SEVERAL CENTRAL ME/CFS SYMPTOMS.....	26
MINDFULNESS FOR PAIN AND OTHER PHYSICAL ME/CFS-RELATED SYMPTOMS .....	26
MINDFULNESS FOR DEPRESSION: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS.....	30
MINDFULNESS FOR ANXIETY: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS.....	32
MINDFULNESS FOR WELL-BEING: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS.....	34
MINDFULNESS AND THE NERVOUS SYSTEM, ENDOCRINE SYSTEM, AND IMMUNE SYSTEM: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS.....	36
MINDFULNESS AND ME/CFS-SPECIFIC STUDIES.....	39
COGNITIVE BEHAVIOURAL THERAPY (CBT).....	41
TENETS OF THE THEORY.....	42
CBT CORE PRINCIPLES.....	43
ME/CFS AND THE CBT DEBATE .....	48

CBT FOR WORRY AND ANXIETY: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS..... 50

CBT FOR DEPRESSION: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS ..... 51

RELAXATION AND RESTORATIVE YOGA ..... 52

EVIDENCE BASE FOR EFFECTS OF RESTORATIVE YOGA: POTENTIAL IMPLICATIONS FOR ME/CFS PATIENTS ..... 54

SUMMARY OF RESEARCH EVIDENCE..... 56

SPECIFIC PROTOCOL RECOMMENDATIONS: MINDFULNESS, CBT, AND RESTORATIVE YOGA..... 57

    MINDFULNESS INTERVENTIONS..... 58

    CBT INTERVENTIONS ..... 60

    RESTORATIVE YOGA INTERVENTIONS..... 64

CONCLUSION..... 68

REFERENCES ..... 70

APPENDIX A..... 85

APPENDIX B ..... 86

### Abstract

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic health condition; its etiology is poorly understood, and treatment options are limited to management of symptoms. Current recommended treatment options are controversial, and evidence of effectiveness is limited. This paper proposes a novel model for symptom management of ME/CFS using mindfulness-based interventions, cognitive behavioural therapy (CBT), and relaxation techniques. A comprehensive review of available evidence is used to support this approach. The idea is that, working synergistically, these three approaches, grounded by mindfulness-based principles, can address many of the symptoms of the illness and help patients better cope and manage their day-to-day lives.

This work is particularly important in a field that is under-researched and under-funded. There is still little understanding of pathology, or viable treatments, for ME/CFS patients. Yet there are millions of individuals afflicted with ME/CFS who deserve current scientifically-validated treatment options. In the absence of curative options, treatment alternatives must recognize the gravity of, and how best to address, the unique symptomology of the condition.

The literature review suggests that the combined use of mindfulness, CBT and restorative yoga can be effective in individual symptom management for ME/CFS. However, the limitations are that this three-pronged model has not yet been empirically tested. This project leaves the door open for, and establishes the importance of, future research.

An Integrative Approach to Mindfulness-Based Symptom Management for Myalgic  
Encephalomyelitis/Chronic Fatigue Syndrome

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a serious medical condition that has a significant impact on an individual's body, emotions, and day-to-day life (Centers for Disease Control and Prevention, 2018). ME/CFS is little understood in terms of its pathology or treatment protocol (De Meirleir et al., 2003; Carruthers et al., 2011a). The disease and its treatment are currently under-researched, and the available recommendations tend to be, in some cases, somewhat outdated and not evidence-based (Doucleff, 2017). Aside from the clinically recommended use of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) in symptom management (Ferne, Murphy, Wells, Nikčević, & Spada, 2016; Mayo Clinic, 2018; Spencer, B., 2015), there appears to be a dearth of treatment protocols. Various studies have looked at the use of mindfulness or yoga in managing symptoms of ME/CFS (De Meirleir et al., 2003), and research has established these three approaches (CBT, mindfulness, and yoga) individually as successful in managing various symptoms of ME/CFS. Yet only one of the three is currently clinically recommended by doctors, and the three together have not been formally proposed as an effective treatment/management plan for the myriad physical and emotional symptoms of ME/CFS.

The thesis begins with a description of the methods used throughout. This is followed by a comprehensive summary of ME/CFS – what it is, its physiological and biological roots, and controversies related to its identification and treatment. I then examine each of the three protocols, both in their own right, and then in the context of treatment for ME/CFS symptoms (in adults only; pediatric diagnostics and treatment are not addressed). Ultimately, an integrative mindfulness-based protocol, using these three complementary approaches in tandem, is proposed and explored for effectively managing the physical and emotional symptoms of ME/CFS. I also

propose the acronym “MBSM-ME/CFS” to represent this mindfulness-based symptom management model (MBSM) for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

### **Methods**

The over-arching objective of this thesis, as noted at the outset, is to develop an evidence-informed, mindfulness-based model for symptom management of ME/CFS using mindfulness-based interventions, CBT, and relaxation techniques. The model is critically dependent on the evidence base. Thus, the methods for the thesis are grounded in the literature review. In particular, five separate (but at times overlapping) bodies of research were canvassed:

- i) Literature to gain an understanding of the illness, and specifically on the clinical nature and symptom manifestations of ME/CFS. This includes some considerable effort to disentangle the often-competing views of what the illness is, or is not (which turns out to be critical to the evidence on how to address it);
- ii) Literature on the effectiveness of mindfulness-based approaches alone and then specifically on symptom management in patients with ME/CFS;
- iii) Literature on the effectiveness of CBT approaches alone and then specifically on symptom management in patients with ME/CFS;
- iv) Literature on the effectiveness of relaxation therapies alone, with a specific focus on restorative yoga, and then specifically on symptom management in patients with ME/CFS;
- v) Literature on the effectiveness of combinations of these approaches, on symptom management in patients with ME/CFS.

For each of these bodies of literature, I used a database search strategy that was built around a small number of key words.

**Databases searched:** University of British Columbia library holdings; Lesley University library holdings.

**Search terms, phrases and key words used for each literature review:** Mindfulness, Mindfulness-Based Stress Reduction, Mindfulness-Based Interventions, MBIs, mindfulness and chronic illness, mindfulness and chronic fatigue syndrome, mindfulness and ME/CFS, Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, ME, CFS, ME/CFS Definition, ME/CFS systematic review, ME/CFS Symptom Management, ME/CFS treatment, ME/CFS pathology, restorative yoga, restorative yoga and ME/CFS, restorative yoga and chronic illness, relaxation and chronic illness, relaxation and ME/CFS

**Search engines used:** Google

**Restrictions:** Database searches were restricted to academic journals, peer reviewed journals, and e-books. Articles and books were not restricted by publication date. Searches were also restricted to English language.

The searches produced, as one would expect, varying numbers of results. The search related to mindfulness and mindfulness-based interventions surfaced the largest number of potential works of interest. The searches related to relaxation and restorative yoga yielded the least. Once a search was completed, I reviewed abstracts where possible to ensure that each identified article or book was, in fact, relevant to the topic. For articles, I eliminated any that had not appeared in peer-reviewed journals.

Each relevant and peer reviewed article obtained was read in detail before inclusion in the review. Because of the scarcity of the strongest type of empirical evidence (that based on randomized controlled trials) in these areas, articles with weaker methods were not eliminated, but specific limitations were noted for these within the review. The MBSM-ME/CFS model proposed in this thesis is a result of my own parsing of the literatures noted above.

In terms of positionality, my research has been influenced by my interest in mindfulness, yoga and CBT protocols, as well as my own personal struggle as a patient living with ME/CFS. I mitigate this throughout the review by noting any obvious weaknesses with particular studies or intervention models themselves. I also make no claims that this model is for treatment purposes, but rather is for symptom management only. As well, the three particular approaches to symptom management were, in part, chosen because I have found them useful in my own life.

### **Myalgic Encephalomyelitis/Chronic Fatigue (ME/CFS)**

There is considerable controversy over the current state of diagnosing and defining ME/CFS. Some of the most recent literature calls for a separation of ME and CFS as two distinct illnesses (Twisk, 2017, 2018). However, there is still a great deal of overlap between these conditions, and a great deal of confusion still surrounds proper diagnostic criteria. The U.S. Institute of Medicine (2015) published a rather concise summary of the evolution of the CFS, ME/CFS, ME, case definitions and diagnostics. But even this document acknowledges that “[w]hile all of the criteria make clear that they are describing and defining the same illness, some vary in the terminology used to refer to the illness or to specific symptoms” (p. 50). Because of this state of affairs, this thesis draws on all relevant literature, including works that define ME/CFS as one condition. As the criteria further crystallize in this seemingly ever-changing field, it will be important for those interested in this research to stay tuned and current. However, everything proposed in this paper is meant to be applied to the *symptom management* of (not medical treatment of) the condition. Therefore, whether it is viewed as one or as two distinct entities, the symptomology of ME and CFS is such that the proposed symptom management methods proposed here can still be applied to all individuals with symptoms characterizing ME, CFS, ME/CFS and whatever other new labels may be applied in the future.

Most people with ME/CFS can look perfectly well on the outside (and often have normal results from the usual battery of diagnostic tests), but feel, every day, like they are battling some version of the flu. ME/CFS is a spectrum disorder, meaning there can be a wide variety when it comes to the severity of symptoms (Brea et al., 2017). A once-active, full-time-employed, healthy person can be rendered completely bed-ridden by the illness, unable to speak, or feed themselves (at worst). At the other end of the spectrum, mild to moderate experiences of the illness might allow someone to remain employed while still having to spend all of their ‘down time’ resting and recovering in order to be able to go to work (Brea et al., 2017).

The Canadian Consensus Criteria (De Meirleir et al., 2003) (CCC), published in the *Journal of Chronic Fatigue Syndrome*, as well as the more recent International Consensus Criteria (ICC) (Carruthers et al., 2011a) (building on the Canadian consensus document (De Meirleir et al., 2003)) are two of the most comprehensive documents to be found on the state of the illness, and to offer appropriate protocols for the condition. They make clear that ME/CFS is a “severe systemic, acquired illness that can be debilitating” (De Meirleir et al., 2003, p. 8). The pathology of this chronic condition is still largely unknown, but the cause is often thought to be a viral infection that ultimately affects the neurologic, immune, and endocrine systems. Since its etiology is not clear, ME/CFS has remained largely misunderstood and mislabeled. Research has begun to “strongly point to widespread inflammation and multisystemic neuropathology” (Carruthers et al., 2011a, p. 327). ME/CFS can be defined as “a complex disease involving profound dysregulation of the central nervous system (CNS) and immune system, dysfunction of cellular energy metabolism and ion transport and cardiovascular abnormalities” (p. 328).

Several viruses have been associated with (though none conclusively linked as a cause of) ME/CFS; these include Epstein-Barr Virus, Human Herpesvirus-6 and 7, Enterovirus, Cytomegalovirus, Lentivirus, Chlamydia, and Mycoplasma (Carruthers et al., 2011a). Infection

types can range from “respiratory infections, bronchitis or sinusitis, or gastroenteritis, or an acute “flu-like” illness...Other prodromal events that may stress the neuroimmunoendocrine regulatory system include immunization, anesthetics, and exposure to environmental pollutants...heavy chemicals, and heavy metal” (De Meirleir et al., 2003, p. 9). Prior to infection, patients generally report being healthy and leading normal, active lives. Physical trauma, and other rarer precipitating events (e.g. blood transfusion) have also been linked to ME/CFS. ME/CFS is found across all racial and ethnic demographics, but appears to be particularly “prevalent in females” (p. 9).

It is worth summarizing the diagnostic criteria for ME/CFS from the CCC (De Meirleir et al., 2003) and from the more recent ICC update (Carruthers, 2011a) in order to see the similarities/differences and so the evolution of the illness criteria. The diagnostic criteria for ME/CFS from the CCC (De Meirleir et al., 2003) are as follows: a patient will present with fatigue, post-exertional malaise (PEM), sleep dysfunction, and pain (though a small percentage of patients will experience neither sleep dysfunction nor pain), and have at least two or more neurological/cognitive symptoms, and at least one autonomic, neuroendocrine or immune-related symptom.

The clinical definitions used for each of these criteria are as follows: (1) fatigue is defined as having “a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level (De Meirleir et al., 2003, p.11); (2) PEM is defined as having “an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability” post exertion, that can be coupled with worsening of pain, and/or any other symptoms the patient already experiences, followed by a “pathologically slow recovery period—usually 24 hours or longer” (p. 11); (3) sleep dysfunction is defined as having an unrefreshing sleep or quality of sleep or sleep rhythm disturbance; (4) pain presents as

changeable and with a “significant degree of myalgia” (De Meirleir et al., 2003, p. 11) (muscle or joint pain) throughout the body, as well as headaches “of a new type, pattern or severity” (p. 11); (5) neurological/cognitive manifestations dictate that two or more symptoms be present: “confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances...[a]taxia, muscle weakness...There may also be overload phenomena: cognitive, sensory – e.g., photophobia and hypersensitivity to noise and/or emotional overload, which may lead to a “crash” period and/or anxiety” (p. 11); (6) patient must present with at least one symptom from two categories concerning autonomic, neuroendocrine or immune symptomology: (a) autonomic symptoms could be “orthostatic intolerance – neutrally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea (p. 11); (b) neuroendocrine symptoms might include: “loss of thermostatic stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change – anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress” (De Meirleir et al., 2003, p. 11); (c) immune indications include “tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals” (p. 11); (7) the individual must be ill for six months prior to diagnosis.

Physicians must be meticulous in ruling out all other possible disorders before making a clinical ME/CFS diagnoses. And ME/CFS can be comorbid with other chronic conditions such as “Fibromyalgia (FMS), Myofascial Pain Syndrome (MPS), Temporomandibular Joint

Syndrome (TMJ), Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud's Phenomenon, Prolapsed Mitral Valve, Depression, Migraine, Allergies, Multiple Chemical Sensitivities (MCS), Hashimoto's thyroiditis, Sicca Syndrome, etc.” (De Meirleir, 2003, p. 13). Conditions such as IBS, migraines, or depression may precede onset of ME/CFS, but then become associated with, or worsened by, it.

Updated criteria no longer require the six-month waiting period for a diagnosis (Carruthers et al., 2011a; Carruthers et al., 2011b). The ICC (Carruthers, 2011a) document, interestingly, does away with fatigue as its own distinct criterion for diagnosis, and instead appears to integrate it into updated criteria for PEM. While PEM is still often used to describe this symptom, the updated term for PEM is PENE (post exertional neuroimmune exhaustion (Carruthers, 2011a)). The term has evolved to reflect that “[m]alaise’ – a vague feeling of discomfort or fatigue...– is an inaccurate and inadequate word for the pathological low-threshold fatigability and postexertional symptom flare” (p. 331). As well, PENE is identified by the ICC as the “hallmark feature” (p. 333) of diagnosing ME (ME/CFS). PENE is described as having the following features:

1. Marked, rapid physical and/ or cognitive fatigability in response to exertion [as] minimal [as] daily living or simple mental tasks, can be debilitating and cause a relapse
2. Postexertional symptom exacerbation e.g. acute flu-like symptoms, pain and worsening of symptoms.
3. Postexertional exhaustion may occur immediately after activity or be delayed by hours or days.
4. Recovery period is prolonged...24 h or longer [and a] relapse can last days, weeks or longer.
5. Low threshold of physical and mental fatigability...(p. 329)

The next diagnostic criterion, according to the ICC (Carruthers, 2011a), directs attention to neurological impairments. A potential patient must experience at least one symptom from either (1) neurocognitive impairments such as processing issues or short-term memory loss; (2) pain e.g. headaches or generalized pain in muscles, joints, or throughout the body; (3) dysregulated sleep patterns such as reversed sleeping hours or awakening unrefreshed in the morning after a night's sleep; (4) “neurosensory, perceptual, and motor disturbances...e.g. inability to focus vision, sensitivity to light noise, vibration, odour, taste and touch...[and] muscle weakness, twitching, poor coordination, feeling unsteady..., ataxia” (Carruthers, 2011a, p. 330). There is still clear overlap here between the original CCC (De Meirleir et al., 2003) and the ICC (Carruthers, 2011a), but categories are presented a little differently, with sleep dysfunction and pain no longer listed as their own distinct categories and instead nested under the neurological impairment category.

The next two diagnostic sections in the ICC document replace the CCC's (De Meirleir et al., 2003) categories of autonomic, neuroendocrine and immune symptomology. The symptoms previously clustered in these three categories can now be found under the “immune, gastro-intestinal and genitourinary impairments” and the “[e]nergy production/transportation impairments” categories (Carruthers, 2011a, p. 330).

The diagnostic category of immune, gastro-intestinal and genitourinary deficiencies dictates that at least one symptom from each of the following categories must be presented: (1) flu-like symptoms that are chronic or recurring; (2) vulnerable to contracting viral infections with delayed recovery time; (3) gastro-intestinal disturbances such as nausea, pain, bloating, or irritable bowel syndrome; (4) urinary tract problems such as frequency, urgency, and frequent night-time waking to urinate; (5) “sensitivities to food, medications, odours, or chemicals” (Carruthers, 2011a, p. 330).

The “[e]nergy production/transportation impairments” category requires at least one symptom from each of the following sub-categories: (1) “[c]ardiovascular: e.g. inability to tolerate an upright position – orthostatic intolerance, neurally mediated hypotension, postural orthostatic tachycardia syndrome, palpitations with or without cardiac arrhythmias, light-headedness/dizziness” (p. 330); (2) difficulty with respiration; (3) abnormalities of body temperature (e.g. hot flashes, cold flashes, feeling feverish with or without presence of fever); (4) intolerant to extreme temperatures. (Carruthers, 2011a)

It is clear that both the CCC and ICC “focus on similar sets of symptoms, but they differ markedly in the number of symptoms required and how those symptoms are defined” (Institute of Medicine, 2015, p. 51). Most importantly, both sets of criteria list the primary symptoms of fatigue/PEM/PENE, pain, and sleep dysfunction as necessary for a diagnosis. And as noted earlier, the criteria set out in both documents require some combination of autonomic, neuroendocrine, and immune symptoms, even if those have been categorized differently.

It is important to note, at this juncture, that amongst the general population and many in the medical profession, ME/CFS is often still treated as a psychological condition. Though psychological symptoms can arise (e.g. depression and anxiety may occur, or if pre-existing, may worsen with ME/CFS), these consensus documents both make the biological basis for this condition clear and unequivocal. ME/CFS is *not* a result of depression *nor* is it synonymous with it. These kinds of beliefs and misperceptions, particularly within the medical community, have caused “confusion in the past, and inappropriate treatment” (De Meirleir, 2003, p. 27). As “patients live in a depressing situation with severe social and activity restrictions at work, play and in relationships, it is not surprising that situational depression occurs in a subset of patients in reaction to their illness” (p. 27). Not surprisingly, the quality of life (QOL) of ME/CFS patients displays a marked reduction when compared to those suffering from other chronic

illnesses (Komaroff et al., 1996; Schweitzer, Kelly, Foran, Terry & Whiting, 1995). Furthermore, there is no clear understanding of recovery trajectories from the disease, other than that patients studied over the course of nine years, who had the least severe manifestation of symptoms at the onset of the study, had a greater chance of recovery (Pheley, Melby, Schenck, Mandel, & Peterson, 1999). There were no other predictors (e.g. demographics) of recovery.

Treatment protocols for ME/CFS comprise five general considerations (De Meirleir et al., 2003): (1) support for patient and their well-being as top priority: because of the lack of understanding of the disease pathology, the patient is faced with a great deal of “confusion and uncertainty” (p. 36) about their illness. Reducing and managing uncertainty and the unknowns is of utmost importance; (2) patient education: this includes ensuring that the patient has a good understanding of their illness, its symptoms and impacts, and tools for adapting and coping with their circumstances; (3) individualized treatment protocols: each person will present symptoms for the disease along a spectrum of severity. Different interventions or habits will aggravate or help each person’s unique symptom cluster. Being able to offer a unique, individualized program, and to ensure that each patient is equipped to adapt coping strategies as they see fit, will help with overall therapeutic experience and outcomes; (4) patient involvement, empowerment and autonomy: the CCC (De Meirleir et al., 2003) states that “[t]he rules of healing differ from those of curing and must come from within” (p. 37). Acknowledging the patient’s own knowledge base, instincts, and experiences, “is an integral part of their healing process” (p. 37); (5) effectiveness of treatment: ME/CFS is under-researched, and therefore many treatment options have not been empirically validated. There are very few blinded, randomized controlled trials for ME/CFS treatment. Most treatment plans for ME/CFS are self-help-based. In terms of strength of evidence, these protocols fall under a category of “opinion of

expert committees or respected authorities” (De Meirleir et al., 2003, p.37). The goal of any treatment program in such circumstances should be to

empower the patient by encouraging them to trust their own experiences, to enhance the patients’ awareness of the activities and environments in which they can cope without exacerbating symptoms and pace themselves accordingly. The program should aim at optimizing the patient’s ability to maintain function in everyday activities, being as active as possible within their boundaries, and then gently extending those boundaries. (p. 37)

Treatment guidelines as outlined by the CCC (De Meirleir et al., 2003) are as follows: (a) the patient’s physician should be the one to assess the “patient’s ongoing condition, treatment and recovery” (p. 37); (b) therapeutic practitioners should be well versed on ME/CFS; (c) the treatment program must appreciate and reflect an understanding of the biological etiology of ME/CFS: the program must be considerate of “[t]he patient’s total illness burden...the patient’s symptoms and [fluctuating] activity boundaries...Information and sensory overload, unrealistic expectations, and inappropriate pacing [can] cause stress and anxiety and exacerbate the patient’s symptoms. [There must be an understanding that] [t]he limitations of the patients’ impairments/dysfunctions are a biological reality of their illness...Early warning signs of a pending ‘crash’ must be respected” (p. 38); (d) a suitable and flexible treatment plan for healing should be constructed in collaboration with the patient.

A treatment program should offer lifestyle skills and coping tools:

- (1) patient education should include: (a) resources on ME/CFS for the patient and loved ones; (b) fostering awareness of symptoms through “[m]indfulness exercises” (p. 39), in order to recognize and prevent energy crashes; (c) relaxation and stress reduction practices that include “breathing awareness...[and] various forms of meditative practices. These...should be kept quiet and simple to encourage calmness and avoid fatigue.

- [M]editative and relaxation practices are useful to punctuate physical and cognitive activities with rest periods and to withdraw from excessive sensory and motor stimulation” (De Meirleir et al., 2003, p. 40); (d) pragmatic techniques for energy preservation in day-to-day tasks (e.g. helpful kitchen tools, preparing food ahead of time, and personal care alterations); (e) household adjustments (e.g. furniture layout, lighting, temperature control, organizational tools, reminders and realistic task structuring); (f) prevention of exacerbating factors (e.g. avoiding exposure to known illnesses, alteration to sleep schedule, overcommitting, over-exercising, excess sensory stimulation, unnecessary stress, known food sensitivities);
- (2) self-improvement: (a) allocating time for self-care efforts (e.g. reflecting on “feelings, needs, values etc.” p. 41); (b) listening to inner guidance and feelings; (c) creating clear emotional and physical boundaries/knowing and accepting one’s limitations; (d) exploring the edge of emotional boundaries: fostering “coping skills and gradually re-expos[ing] oneself to situations that had previously given rise to anxiety and/or ‘crashing’ (p. 41); (e) exploring edge of cognitive boundaries: participating in pleasant mental activities regularly (e.g. puzzles, reading, etc.), within one’s limits, and gently exploring expansion of boundaries, within reason;
- (3) Regulating and encouraging sleep through a regular bedtime and other sleep hygiene practices;
- (4) A healthy diet eaten at regular times;
- (5) Suitable activity program: finding activities and activity levels that are appropriate.

Cognitive Behavior Therapy (CBT) and Graded Exercise Therapy (GET) are/were two recognized, additional treatment options surrounded by much controversy. These treatment recommendations came out of the PACE trials (Pacing, graded Activity, and Cognitive behavior

therapy randomised Evaluation) (see, e.g., White et al., 2011). One hypothesis for using CBT is that an ME/CFS patient's symptoms are "learned due to wrong thinking" (De Meirleir et al., 2003) p. 47). This hypothesis denies the pathophysiology that is known about ME/CFS to date and is ultimately detrimental to the patient. The research that favours the combination of CBT/GET therapy has largely been refuted by Goudsmit and Howes' recent study (2017), among others (Geraghty, 2017). Goudsmit and Howes' (2017), open by stating that "[t]hese interventions are based on a model which assumes that symptoms are perpetuated by factors such as misguided beliefs and a lack of activity...[a]nalysis indicates that the researchers have shown significant bias in their accounts of the literature and may also have overstated the effectiveness of the...treatments" (p. 1159). Further, the authors assert that the researchers promoting these treatments demonstrate "bias and lack of respect for alternative approaches...[that] has led to a misrepresentation of the illness, the minimisation of the reported adverse reactions to graded exercise therapy (GET) and a less sympathetic attitude towards patients" (p. 1160). One of the researchers involved in the combination treatment trial was reported to have claimed that patients develop fear around exertion; patients believe that exercise will exacerbate their illness and through cognitive behavioural therapy they can overcome these seemingly false beliefs, and gradually increase their activity levels (Goudsmit and Howes, 2017; Spencer, 2015). This view is largely inconsistent with a significant body of research evidence illustrating the biological abnormalities associated with the illness (Costa et al., 2005; Germain et al., 2018; Goudsmit et al., 2009; Goudsmit and Howes, 2017; Günther et al., 2018; Lane et al., 2003). It is also worth restating that the primary symptoms of the disease are fatigue and PEM, conveniently not addressed at all by this treatment option. Indeed, GET would appear to be quite obviously counter-productive for anyone suffering with PEM. Ultimately, GET is controversial because of

its rigid ideology around exercise for this population, its lack of a rigorous research basis, and the concern that exercises not catered specifically to the individual could aggravate symptoms.

This entire controversy has taken on a life of its own, with accusations being hurled back and forth. In 2018, 94 ME experts signed an open letter to the medical journal, *The Lancet*, asking that the PACE trial data be independently re-evaluated; this was the latest iteration of three letters (the original having been sent in 2015) that have been met with a lack of response from *The Lancet*. For those interested in the raging debate around GET and the PACE trials, the ME-pedia.org webpage entitled “PACE Trial” (2019) affords an entry point.

While there appears to be a growing understanding that CBT/GET is not a desirable approach to helping patients suffering with ME/CFS, there is a case to be made for CBT alone, based on the notion that it can assist in “fine-tuning...the patient’s understanding and coping behavior...[and] may achieve some improvement in his or her quality of life” (De Meirleir et al., 2003, p. 47).

At this time, there is no clearly established, widely recognized and accepted, cure or set treatment protocol for ME/CFS. The most prevalent and evidence-based view is that patients and physicians must work together to create a treatment program that works based on the individual’s needs stemming from their symptom cluster and severity. This approach is generally helpful in managing and coping with ME/CFS symptomology. While many of the recommended treatment options are not yet empirically validated, “there is some scientific basis and/or recommendations of experts in the field with clinical experience that justifies their inclusion” (De Meirleir et al., 2003, p. 50). Any number of the recommendations are worth exploring under the care of a physician, and with an understanding that side effects are possible, and that modifications should always be made when necessary.

With this in mind, the next section explores the use of mindfulness in symptom management. First mindfulness is defined and the latest brain research on mindfulness explored. This is followed by a review of the possible use of mindfulness in managing various ME/CFS symptoms. Finally, some specific literature on the use of mindfulness in ME/CFS, and on notable effects that mindfulness can have on various systems of the body, are reviewed.

### **Mindfulness**

The study of mindfulness is still relatively new to the psychology and neuroscience fields. However, over the past decade there has been increased interest in this field. In particular, a number of studies have emerged that examine the positive impact of mindfulness on the brain. Mindfulness can be described as a particular way of paying attention to each moment (Kabat-Zinn, 1990). A formal mindfulness practice is composed of various kinds of meditation that have their roots in Buddhist traditions. These meditation practices can include intentionally focusing one's attention on breath, sounds, sensations, or consciously observing one's thoughts and emotions as they arise (Kabat-Zinn, 1990). One paper (Bishop et al., 2004) proposed a "two-component model of mindfulness" (p. 232) in an attempt at an operational definition. The first component describes self-regulation of attention on the immediate experience, and the second outlines the quality of attention brought to each moment. Mindfulness fosters the ability to bring curiosity, acceptance, and a quality of non-judgment to one's thoughts, emotions, or sensations in the body. This is in stark contrast to the automaticity, or habitual reactions, of individuals' usual mode of relating to themselves and the world around them. Instead, mindfulness can help offer perspective on one's thoughts and feelings, allowing for greater acceptance of them, an understanding of their impermanent nature, and recognition that they are not synonymous with who we are. By bringing this certain quality of attention to one's thoughts, emotions, and/or sensations, an observational space is created between oneself and the immediate experience; this

allows for greater thoughtfulness, reflection, reduced reactivity, and the capacity for objective observation of one's thoughts or feelings.

In what follows, the effects of mindfulness on the structure and function of the brain are explored. This provides the foundation for an examination of mindfulness as a specific intervention for managing several central ME/CFS symptoms.

### **Mindfulness and the Brain**

Several studies over the past decade have examined the structural brain changes that take place in meditators. A longitudinal study (Hölzel et al., 2009) examined the effects of an 8-week Mindfulness-Based Stress Reduction (MBSR) program on stress using MRI scans to track changes in amygdala gray matter density (the amygdala plays a key role in stress responses). After the intervention, participants reported lower perceived levels of stress that correlated with decreased gray matter density. Another controlled study showed that meditators had better executive control and emotional acceptance than non-meditators (Teper & Inzlicht, 2013, p. 85). A controlled longitudinal study, also conducted by Hölzel et al. (2011), examined novice meditators participating in an 8-week MBSR program. Neuroimages taken before and after the program showed increased gray matter density in the hippocampus, temporo-parietal junction (TPJ), posterior cingulate cortex (PCC), and cerebellum. These regions of the brain are responsible for “learning and memory processes, emotion regulation, self-referential processing, and perspective taking” (Hölzel et al., 2011, p. 36). The changes in the hippocampus may account for “improved function in regulating emotional responding” (p. 40). The TPJ is involved in the process of understanding others' emotions and “there is evidence of greater activation of this region during feelings of compassion in meditators” (p. 41). The PCC is involved in “assessing the relevance or significance of a stimulus for oneself...particularly important for the integration of self-referential stimuli in the emotional and autobiographical context of one's own

person” (p. 41). The cerebellum is mostly known for its role in speech and motor functions, but it also plays a “crucial role in the regulation of emotion and cognition...[regulating] the speed, capacity, consistency, and appropriateness of cognitive and emotional processes” (Hölzel et al., 2011, p. 41) in a manner similar to regulation of motor control.

Somewhat earlier, Lazar and colleagues (2005) had examined brain changes as a result of meditation practice. They found that meditation affected cortical thickening in areas such as the prefrontal cortex (responsible for executive control, affect regulation, memory and more). Other research has found differences between the left and right hemispheres of the frontal and prefrontal cortices of meditators and non-meditators (Davidson et al., 2003; Davidson & Lutz, 2008; Kabat-Zinn 2005). Kabat-Zinn (2005) explains that “brain asymmetry between the left and right hemispheres occurs regarding emotional expression” (p. 370). The left hemisphere of the brain is often associated with “positive emotions such as happiness, joy, high energy, and alertness” (Kabat-Zinn, 2005, p. 370), as well as being the logic and language center; the left hemisphere can be thought of as the list-maker, the labeler, or the *ideas man* (Siegel, 2011). The right hemisphere is linked to the subcortical areas (such as the brain stem and limbic system) (Siegel, 2011) of the brain associated with more “difficult and disturbing emotions, such as fear and sadness” (Kabat-Zinn, 2005, p. 370), and is more directly linked to bodily sensations and survival responses (Siegel, 2011). The stark contrast in affect of individuals who have suffered a hemispheric stroke is a helpful example for understanding these hemispheres’ functions. For example, a left hemisphere stroke (causing left side impairment) can leave a person feeling “like the world just ended...they are incredibly depressed...” In contrast, a “...right side stroke is called the *laissez-fair* response” (Arden, 2011, 1:03:00), indicated by the individual’s extremely care-free and upbeat disposition. In these cases, the communication between, or functions of, the left or right hemispheres has been lost, and the individuals are left with an imbalance of right or

left dominance.

Just as these hemispheres' functions can be damaged, so too can they be strengthened. Two studies conducted by Davidson and colleagues (2003; 2008; Kabat-Zinn 2005) found significant differences in left and right-sided activation in meditators. One study looked at novice meditators (Davidson et al., 2003) while the other looked at the brains of experienced monks (Davidson & Lutz, 2008; Kabat-Zinn 2005). In both cases the meditators were shown to have greater left-than right-sided activation. This is good news for those looking to begin a mindfulness practice with no previous experience. It is also good news for the chronically ill; if taking on a mindfulness practice can potentially have the effect of bolstering the brain's "feel good" abilities, this could be helpful for dealing with emotional and physical repercussions of living with a complex chronic illness such as ME/CFS.

More recently, Gotink, Meijboom, Vernooij, Smits, & Hunink (2016) set out to determine whether the brain changes seen in long-term meditators (Lazar et al., 2005; Tang, Hölzel, & Posner, 2015) would be evident in novice meditators after an 8-week MBSR course. In fact, "[t]he prefrontal cortex, the cingulate cortex, the insula and the hippocampus showed increased activity, connectivity and volume...[a]dditionally, the amygdala showed decreased functional activity, improved functional connectivity with the prefrontal cortex, and earlier deactivation after exposure to emotional stimuli" (Gotink, Meijboom, Vernooij, Smits, & Hunink, 2016, p. 32) – the effects did, indeed, mirror those found in long-term meditators. All of these areas are linked to emotion, attention and response regulation, as well as self-referential processes, interoception, interpersonal mechanisms, and perspective taking (Gotink, Meijboom, Vernooij, Smits, & Hunink, 2016).

A recent systematic review (Young et al., 2018) looking at the effects of mindfulness on brain activity, offers much stricter inclusion criteria than previous attempts. The review included

just seven out of 39 studies, with inclusion criteria specifying for longitudinal studies and only within-subjects changes that assessed “functional activity using fMRI...before and after interventions...This approach provides confidence that observed changes were associated with the intervention itself...This is an important distinction between the current systematic review and previous reviews including studies using both within-subjects and between subject designs (e.g. Gotink et al., 2016)” (p. 431). In the results of this review, the authors note that in “manualised mindfulness-based interventions across longitudinal fMRI studies...[the insula is a] central [player in] self-awareness and interoception” (p. 432). This supports the notion of mindfulness being key in bringing about greater “‘present-moment’ awareness” (p. 432). Additionally, the review found support for the roles of the anterior cingulate cortex and midline prefrontal cortex in “acceptance and meta-awareness” (p. 432).

This growing body of evidence suggests strongly that mindfulness can affect the brain in ways that are central to mental health and physical sensation management. This is especially important when thinking about ME/CFS symptom management.

### **Mindfulness and Mindfulness-Based Cognitive Therapy (MBCT) for Managing Several Central ME/CFS Symptoms**

Noted earlier in the literature were some key symptoms of ME/CFS (De Meirleir et al., 2003). Some of the most prominent and common symptoms of the illness are pain, fatigue, depression, and anxiety. These make life very challenging for a person living with ME/CFS and can affect one’s general sense of well-being. The following sections address the use of mindfulness as a mediating factor for these symptoms.

#### **Mindfulness for Pain and other Physical ME/CFS-Related Symptoms**

Brain mechanisms responsible for sensations such as pain, are shown to be modulated by mindfulness (Gard et al., 2012; Zeidan et al., 2015). Mindfulness has the ability to increase

“cognitive control and decreases[e] sensory processing” (Gard et al., 2012, p. 2692), thereby modulating clinical pain (Kabat-Zinn, Lipworth, and Burney, 1985). Through the attention and non-judgemental principles of mindfulness, one is able to re-evaluate, or reappraise pain as less frightening or significant (Wiech et al., 2006). Further, a neuroimaging study (Grant, Courtemanche, and Rainville, 2011) illustrated how mindfulness “practitioners have different neuronal responses to painful stimuli than controls, involving greater activation in the insula (anterior to posterior) and thalamus and decreased activation in [prefrontal cortex] PFC” (p. 2693). What these studies show is that it is possible to alter (through both brain structure and function) how one views and experiences pain through the proverbial lens of mindfulness.

Jon Kabat-Zinn spent years of his career working with patients in his pain clinic in Boston. In his book *Full Catastrophe Living* (1990), he details how mindfulness is/was effective for those struggling with difficult sensations and pain. Mindfulness, he explains, can help sufferers detach from identifying with the pain as “mine.” By creating observational space, one can view pain as something that is simply occurring and ever-changing (even if it is chronic in nature). He notes that because treatments for some chronic pain conditions are not always successful, having another tool for pain management is essential when a patient is told they must “learn to live with it...[T]oo often, they are not taught *how*. *Being told that you have to learn to live with pain should not be the end of the road—it should be the beginning*” (p. 286). Kabat-Zinn is also careful to note that using a tool of the mind is not meant to imply that the pain that exists, exists only in the mind (a large misconception of ME/CFS symptoms, as noted earlier). He goes on to explain how pain is not just something occurring in the body, or the mind, but is a multi-system issue. The brain registers various electric signals as ‘pain’, and there are “many well-known pathways within the brain and the central nervous system by which higher cognitive and emotional functions can modify the perception of pain. The systems perspective on pain

opens the door for many different possible ways to use your mind intentionally to influence your experiences of pain” (Kabat-Zinn, 1990, p. 288). ‘Moving toward’ the sensations experienced – observing them rather than resisting or distracting from them – offers “insight and understanding” (Kabat-Zinn, 1990, p. 291) into the body and the ever-changing levels of pain/shifting nature of sensation. The idea is that mindfulness meditation allows for an alteration in the way one views or is in relationship with hardship/pain. Mindfulness can bring new vantage points from which to view pain, including the ability to notice and appreciate the absence of pain, and the joys and pleasures still accessible to someone facing chronic pain. When pain is particularly difficult, Kabat-Zinn offers a technique used with his clinic patients called “putting out the welcome mat” (p. 295)

Since [pain] is already present...we do what we can to be receptive and accepting of it...[relating] to it in as neutral a way as possible, observing it non-judgementally, feeling what it actually feels like in detail...opening up to the raw sensations...breath[ing] with them and dwell[ing] with them from moment to moment. (p. 295)

Mindfulness, then, is not about getting rid of pain, or fighting against the sensations, but rather about creating compassionate space within oneself to notice and accept it, as it is, in each moment that arises. Some moments will be worse than others, but it is the experience of being fully present to each of those moments, even asking questions about the pain in any given moment (e.g. in this moment, how bad is it? Is it tolerable?), that allows for the opportunity to say, ‘I can manage this sensation, in this moment.’

There is also an important distinction that can be made, through mindfulness, between pain and suffering. This lesson comes directly from Buddhist teachings, found in the Pāli Canon, and made particularly clear in the Buddha’s ‘two-dart’ analogy. The Buddha explains to his disciples that everyone feels physical pain. However,

[w]hen an untaught worldling is touched by a painful (bodily) feeling, he worries and grieves, he laments, beats his breast, weeps and is distraught. He thus experiences two kinds of feelings, a bodily and a mental feeling. It is as if a man were pierced by a dart and, following the first piercing, he is hit by a second dart. So that person will experience feelings caused by two darts. (Samyutta Nikaya, 36.6)

The physical pain is the feeling that one experiences and observes in the moment; the rising and falling of physical sensation. However, suffering comes about as a mental process, an inner narrative or dialogue that takes place *about* the pain we experience. Comments, reactions, judgments, etc., about the pain *are not pain itself*. And often, for the average individual who has not practiced and developed the keen observational skills fostered through mindfulness, these thoughts about sensations are conflated into what one would assume to be the painful feeling itself. These thoughts are not pain, nor are they necessarily correct in any way; rather, they are “reactions of your own mind when it is not ready to accept the pain and wants things to be different from the way they are, in other words, pain-free” (Kabat-Zinn, 1990, p. 296). Practicing mindfulness of sensation in each moment, builds a greater sensitivity to what is pure sensation (pain) and what is unhelpful narrative (suffering). In this way, mindfulness can help modify one’s perspective on the experience of pain.

Kabat-Zinn (1990) also, importantly, notes how “you can work with [other life problems, or sensations, or challenges] in the same way you will face and work with pain” (p. 292). For example, one can “work with” the extreme discomfort (that some patients may even categorize as pain) of ME/CFS symptoms such as extreme fatigue, PEM/PENE, nausea, neurological/cognitive, autonomic, neuroendocrine or immune symptoms, that are central to ME/CFS. ‘Crashes’ or “overload phenomena” (de Meirleir et al., 2003, p. 18) resulting from hypersensitivity to stimuli such as light or sound are also common. A patient can be affected by

cognitive, emotional, and motor overload. These “overload phenomena may precipitate to a ‘crash’ where the patient experiences a temporary period of immobilizing physical and/or mental fatigue” (p. 18). Further, the CCC notes that teaching mindfulness to ME/CFS patients is important for managing or recognizing

early warning signs [in order to] prevent crashes: Mindfulness exercises encourage patients to be mindful of the impact of activities and environments on their physical, cognitive and emotional states within the ongoing flux of experience. This encourages recognition of the early warning signals of excessive fatigue and/or sensory stimulation, information overload [and] excessive stress... (De Meirleir et al., 2003, p. 39)

In this way mindfulness helps patients bring awareness to early signs of potential crashes, and can help with better overall management of symptoms and energy conservation.

### **Mindfulness for Depression: Potential Implications for ME/CFS Patients**

The DSM-5 defines major depressive disorder (MDD), categorized as a unipolar depression, as “a period of two or more weeks marked by at least five symptoms of depression, including sad mood and/or loss of pleasure. If a unipolar depression persists, it is described as a “persistent depression”, or dysthymia. This is identified when someone feels depressed for most of the day, more often than not, consistently for at least two years. Whether someone with ME/CFS has a pre-existing diagnosis of depression or has become depressed from the difficult life circumstances that accompany ME/CFS, there is evidence to show that mindfulness-based interventions, also known as MBIs, can be helpful in managing its symptoms (Franca and Milbourn, 2015).

Brain imaging studies (Brockmann et al., 2011) have begun to piece together the brain circuits that work together in unipolar depression. It is posited that the prefrontal cortex, hippocampus, amygdala, and Brodman Area 25 (part of the cingulate cortex) are all involved in

the integrative processes of depression. Recall that all of these brain areas are known to be affected by mindfulness practice.

An MBI intervention known as Mindfulness-Based Cognitive Therapy (MBCT) shows promise. MBCT is a therapeutic intervention that synthesizes traditional Cognitive Behavioral Therapy (CBT) protocols (more on CBT later in this review) with mindfulness. Because much of depression is characterized by negative thinking and emotion, mindfulness can help an individual start to see thoughts and emotions as just thoughts and emotions; it allows a person to view these as objects of experience that come and go, rather than as fundamental identifying features of who they are. Furthermore, mindfulness' particular way of paying focused attention is "supported by the anterior cingulate cortex and the lateral prefrontal cortex (PFC)...these PFC changes promote an alternative to conventional attempts to cognitively reappraise negative emotion" (Farb, Anderson, & Segal, 2012, p. 1). The limbic system is also involved in the process of moment-to-moment "sensory awareness" (p. 1). When an individual can focus on each moment, and treat each thought or feeling/sensation as a fleeting event, this way of paying attention provides "an alternative to cognitive efforts to control negative emotion" (p. 1).

This way of relating to depressive thoughts and emotions via MBCT training has also been shown to be very effective against depressive relapses. Interestingly, the results from a 60-week study (Teasdale et al., 2000) showed that "[f]or patients with 3 or more previous episodes of depression...MBCT significantly reduces risk of relapse/recurrence. [But] [f]or patients with only 2 previous episodes, MBCT did not reduce relapse/recurrence" (p. 615). A follow up study (Ma & Teasdale 2004) uncovered that this discrepancy in success was not related to the number of depressive episodes (two versus three), but rather was due to the different types and severity of depression. The relapses that occurred for patients with three or more previous episodes (where MBCT was successful in preventing future relapse) were usually from "the occurrence of

old habits of dysfunctional patterns of thinking...[and were more] autonomous...out of the blue” (Segal, Williams, & Teasdale, 2013, pp. 400- 401). This type of unipolar depression can also be referred to as an endogenous depression, characterized by “a response to internal factors” (Comer, 2014, p. 228). In contrast, relapses in patients with only two previous episodes of depression were more commonly related to “the occurrence of major life events, such as unemployment, deaths, or serious illness in the family, or breakdowns in relationships” (Segal, Williams, & Teasdale, 2013, p. 400). This type of depression is referred to as a reactive, or exogenous, depression, following “clear-cut stressful events” (Comer, 2014, p. 228). This study makes it evident that while MBCT/MBI can be an effective treatment for depression, it is not a one-size-fits-all protocol and is likely to be more effective in some circumstances than in others.

It is also important to note, from Edmondson and MacLeod’s (2015) study on psychological well-being and its relationship to depression, that those experiencing depression are low on the domain of self-acceptance. Their study highlighted the necessity for depression protocols that emphasize and foster well-being, rather than having a singular focus on relieving psychopathology. The relationship between mindfulness and well-being is considered in more detail below.

### **Mindfulness for Anxiety: Potential Implications for ME/CFS Patients**

Worry is a normal and adaptive part of being human, but some types of worry are not constructive, and turn into longer-term conditions of anxiety. Living with an illness like ME/CFS, with no clear explanation of pathology, treatment, or amelioration, can lead to runaway mental patterns of worry and anxiety about the unknown and managing one’s life.

Research on mindfulness practice and its effects on anxiety offers some interesting and hopeful outcomes. Mindfulness practice can “encourage [individuals] to *accept* the present rather than worry about what *might be* (Nezu, Nezu & Lombardo, 2004, p. 121). Mindfulness

intervention offers a proverbial wide-angle lens with which to view one's life and symptoms. One mindfulness intervention for anxiety – Acceptance and Commitment Therapy (ACT) – is structured around the constructs of compassion for oneself, acceptance, and perspective taking (Yadavaia, Hayes, & Vilardaga, 2014). The latter two constructs are all about seeing thoughts and emotions as simply thoughts and emotions; in other words, worries are simply objects of experience, or “mere events of the mind” (Comer, 2014, p. 122). A recent randomized controlled trial (Yadavaia, Hayes, & Vilardaga, 2014) showed that “ACT was significantly superior to the control condition in self-compassion, general psychological distress, and anxiety” (p. 248). Self-compassion and acceptance of thoughts and emotions are counterpoints to the struggle and avoidance experienced in unbridled worry, so commonly found in patterns of anxiety.

An earlier study (Kabat-Zinn et al., 1992) examined the efficacy of an 8-week MBSR intervention in 22 patients being treated for anxiety. The results showed “significant reductions in anxiety and depression scores after treatment [and] [t]he number of subjects experiencing panic symptoms was also substantially reduced” (p. 936). A three-year follow-up study (Miller, Fletcher, & Kabat-Zinn, 1998) on 18 of the 22 original patients looked at any long-term effects. The majority of participants kept up their meditation practice, and results showed ongoing benefits in the patients, measured on both anxiety scales and panic scores.

Another study examined the impact of mindfulness on anxiety by looking at autonomic (brainstem) markers of “flexible emotion regulation, such as heart rate variability (HRV)...[as] [g]eneralized anxiety disorder (GAD) has been associated with both low levels of mindfulness and HRV” (Mankus, Aldao, Kerns, Wright Mayville, & Mennin, 2013, p. 386). The results showed a positive correlation between GAD symptoms and HRV, suggesting that for those with high GAD, mindfulness could improve autonomic nervous system (specifically, parasympathetic) effects on heart rate. This kind of preliminary work (and its uncommon look at

an autonomic marker (HRV) of emotion regulation) supports the inclusion of mindfulness in treatment options for those who suffer with anxiety. And anxiety so often occurs in those with complex chronic illnesses such as ME/CFS.

### **Mindfulness for Well-being: Potential Implications for ME/CFS Patients**

Mindfulness meditation should not be classified simply as a relaxation technique. In fact, it requires a great deal of diligence and focused attention. But mindfulness can often *indirectly* lead to feelings of calm and equanimity. For example, when attention is paid to the breath, and breathing is intentionally or unintentionally slowed, this can often result in feelings of calm or relaxation due to the activation of the parasympathetic nervous system. Further, the awareness fostered by mindfulness practice creates mental and emotional space between one's thoughts and reactions. This way of paying attention is the heart of how mindfulness bolsters one's sense of well-being and equanimity; greater perspective taking, or awareness of thoughts, emotions, and bodily sensations naturally shifts how one relates to oneself. For example, feelings such as anger/resentment, pity, or frustration with oneself can be viewed as simply fleeting emotional states, rather than a familiar personal narrative that one might normally believe and perpetuate. In this way, mindfulness instead fosters feelings of kindness, patience, compassion for oneself, and even gratefulness, thus enabling a state of well-being. And unlike traditional CBT, mindfulness allows for "a focus beyond the removal of symptoms...[and instead] help[s] people foster various aspects of well-being (e.g. a positive self attitude and meaning in life), by accepting their difficulties and connecting with what they value" (Jackson & MacLeod, 2017). In this way, a practice of mindfulness complements, and may even help bolster, the traditional practice of CBT (Jackson & MacLeod, 2017).

The mental shift towards feelings of greater well-being that can take place from practicing mindfulness, can also be seen at the structural level of the brain. A study that used an 8-week

MBSR program (Singleton et al., 2014) included both MRI and a psychological well-being inventory to determine changes in participants' well-being. Before and after results compared the brain images from specific brain regions with the self-reports. Results showed positive changes in well-being that "positively correlated with gray matter increases" (Singleton et al., 2014, p.1) in related areas of the brain. Siegel (2007) also found that particular areas of the brain are associated with feelings of well-being, and that these areas undergo changes during meditation.

A meta-analysis of "neuroimaging in meditation practitioners" (Fox et al., 2014, p. 48) shows "eight brain regions consistently altered in meditators, including areas key to meta-awareness...[and] self and emotion regulation" (p.48). Some more specific results found for self-regulation were "down-regulating and reappraising..., better ability to regulate negative emotion..., adaptive behavioral responses...self-control, [and] behavioral flexibility" (p. 63).

While a causal link between meditation and these brain changes cannot necessarily be claimed, strong correlational evidence has accumulated, and this has motivated rapid growth in related research. Studies such as the ones outlined here reinforce the amazing potential of the brain to "rewire itself" (Goleman & Davidson, 2017, p. 52) through mindfulness practices. With this potential, it does not take a great leap of faith to imagine how meditators may find themselves feeling more compassionate and experiencing sensations of greater emotional well-being in their day-to-day lives.

Some of the mechanisms that underlie a sense of well-being are self-compassion and positive mental states. Mindfulness-Based-Interventions (MBIs) applied over a three-week period were in fact found to promote these underlying mechanisms of self-compassion and positive feelings towards oneself, thus promoting an overall state of psychological well-being (Rodríguez-Carvajal, García-Rubio, Paniagua, García-Diex, & de Rivas, 2016).

Another study looked at self-compassion (offering kindness and understanding to oneself) as a construct of mindfulness interventions, and its role in mental well-being. This research showed that “self-compassion is a robust predictor of...quality of life” (Van Dam, Sheppard, Forsyth & Earleywine, 2011, p. 123), and a key factor in MBIs for mental health and well-being.

It is exciting to see the emergence of consistent evidence (albeit at this point it is largely correlational) that supports the notion of mindfulness creating changes at the functional and structural level of the brain. Feelings of well-being and improved QOL are also likely happening due to these brain changes. Knowing that ME/CFS patients experience very low QOL compared to those suffering from other illnesses (Komaroff et al., 1996; Schweitzer, Kelly, Foran, Terry, Whiting, 1995), there would appear to be great potential benefit to practicing mindfulness as a moderator for QOL in ME/CFS.

### **Mindfulness and the Nervous System, Endocrine System, and Immune System: Potential Implications for ME/CFS Patients**

Mindfulness has also been shown to have an impact on the nervous system, endocrine system, and immune functions. Because these three systems are notably implicated in ME/CFS, it is worth examining the possible effects mindfulness interventions could have.

Evidence suggests that mindfulness has an impact on various nervous system functions. One such effect is on blood pressure. A literature review published recently at Case Western Reserve University (Solano López, 2018) on the topic looked at five studies that noted a “reduction in systolic and diastolic blood pressure between the intervention and control groups” (p. 1005). But the authors also note the small number of studies and limitations associated with research methods used.

Research (Braeken, Jones, Otte, Nyklíček, & Van den Bergh, 2017)

that looked at pregnant women and the effect of mindfulness on their autonomic nervous system, showed that more mindful mothers had a decrease in parasympathetic activity. Furthermore, mindfulness practices that involve the body, such as yoga or tai-chi, have been shown to have positive effects on stress reduction and heart rate variability (Zou et al., 2018). In another study (Shearer, Hunt, Chowdhury & Nicol, 2016) that examined a mindfulness intervention and its effect on college students' stress and heart rate variability (HRV), it was pointed out that many mindfulness studies often rely on inactive control groups. Instead, this one utilized both an inactive and an active control group where students were assigned to interact with a dog. At post-treatment assessment, using electrocardiogram data, both the mindfulness group and the active control group showed positive results; but HRV, "a measure of the body's ability to modulate psychological stress" (Shearer, Hunt, Chowdhury & Nicol, 2016, p. 232) was "significantly higher...during the cognitive challenge than those in the other 2 groups, signifying a more adaptive response to stress" (p. 232). In addition, a study (May et al., 2016) that examined the physiological effect of brief mindfulness practice (15 minutes) on heart performance, using female undergraduate students, recognized "a link between mindfulness and cardiovascular functioning via correlational and experimental methodologies...The intervention had a strong positive effect on cardiovascular modulation by decreasing cardiac sympathovagal tone, vasomotor tone, vascular resistance and ventricular workload" (p. 168). In other words, the findings suggest that brief mindfulness practice "may contribute to positive effects on central cardiovascular hemodynamics and cardiovascular autonomic modulation" (p. 171).

Mindfulness has also been shown to have an influence on the endocrine and immune systems. First, it is important to note that a recent systematic review (O'Leary, O'Neill & Dockray, 2016) found the effects of mindfulness interventions on cortisol levels to be inconclusive and called for more rigorous testing. While mindfulness may have an impact on

cortisol (within group studies yielded significant changes, while randomised controlled trials did not), the differences found between study types does not support a conclusive positive correlation. However, a randomized controlled trial (Hoge et al., 2017) that examined the relationship between mindfulness interventions, stress hormones and an immunological response in a group of 70 adults with generalized anxiety disorder (GAD), showed promising results. Adrenocorticotrophic hormone (ACTH) and pro-inflammatory cytokines were sampled and the MBSR group experienced reductions in both compared to the control.

An older study (Robinson, Mathews & Witek-Janusek, 2003) looked at the effects of MBSR on individuals infected with Human Immunodeficiency Virus (HIV). The results showed a marked increase of natural killer cell activity and number in the MBSR group when compared to the comparison group. No significant results were found for measures pertaining to the endocrine system; the dehydroepiandrosterone sulfate (DHEAS - a male sex hormone) levels, however, were “substantially lower than in previously reported samples” (p. 690), and cortisol levels in the MBSR group were similar to those in the other HIV group. However, it was noted that due to the dysregulation of adrenal hormones found in this population, “it is possible that the effects of the interventions, if any, would have been masked as a result of the disease process itself” (Robinson, Mathews & Witek-Janusek, 2003, p. 690).

A 2017 study (Reich et al.) looked at the effects of MBSR on levels of inflammatory biomarkers in breast cancer survivors (BCS). The MBSR group was compared to a usual care group, and blood levels of pro-inflammatory cytokines were measured. MBSR was found to help in normalizing blood levels of pro-inflammatory cytokines “where some cytokine levels increase[d] while others decrease[d]”, marking immune restoration. A study done in 2013 (Rosenkranz et al.) examined psychological stress, meditation, and the body’s inflammatory response. The study matched an MBSR group with an active control group using the Health

Enhancement Program (HEP) as a means of reducing induced stress and inflammation; “[t]he Trier Social Stress Test (TSST) was used to induce psychological stress and inflammation was produced using topical application of capsaicin cream to forearm skin” (p. 174). The groups demonstrated comparable cortisol levels and self-reported reduction in stress, but the MBSR group’s inflammatory response was much smaller than the HEP group. These results are hopeful for the use of meditation as a mediator for inflammatory conditions.

### **Mindfulness and ME/CFS-Specific Studies**

Studies looking at mindfulness in the context of ME/CFS specifically are very limited. A recent small, uncontrolled, pilot study (Katinka, Eva Therese, Ida, & Jens, 2017) consisted of 10 ME/CFS patients (eight women and two men) undertaking an eight-week mindfulness training program. Measures of anxiety, fatigue, rumination, and depression were measured before and after the training; the results showed moderate to large effect sizes in the expected direction (e.g. reductions in all parameters). Patients also reported that mindfulness practice felt like a “different kind of rest”...providing “more energy” than if they were sleeping or just lying down during the day” (p. 246). The researchers noted that mindfulness training may have garnered “a more accurate perception of physical symptoms...[which] may have facilitated energy conservation” (p. 246). Patients reported “increased quality of life and more adaptive coping” (p. 240). This can be seen in the patients’ reduction in rumination from pre-test to post-test, which was maintained at follow-up. Dispositional mindfulness was also measured, and while there was no effect at post-test, a follow-up effect was present. Patients also noted that “they “are not improved, but feel better”, which indicates improved quality of life and changed attitudes towards their conditions even if the symptoms [like] fatigue still might prevail” (p. 246). This last point is particularly important — though symptoms of the illness are not necessarily ameliorated by mindfulness, the ability to cope, and have a greater quality of life as a result, is

bolstered. The researchers noted that their results were consistent with a few earlier studies (Fjorback et al., 2013; Rimes and Wingrove, 2013; Surawy, Roberts and Silver, 2005).

A controlled study (Sampalli, Berlasso, Fox & Petter, 2009) looked at the effects of MBSR on women with multiple chemical sensitivity (MCS), chronic fatigue syndrome (CFS), and fibromyalgia. The participants engaged in a 10-week MBSR program. Pre- and post-tests were used. Post-tests were implemented immediately at the conclusion of the study, as well as at a three-month follow-up. Waitlisted women were used as the control group. There were 50 participants in the intervention category and 26 in the control group. The MBSR group showed statistically significant improvement at both post-test and three-month follow-up. The control group results were unchanged. The study illustrated the “importance of complementary interventions such as MBSR techniques in the reduction of psychological distress in women with chronic conditions” (Sampalli, Berlasso, Fox & Petter, 2009, p. 53). The researchers also noted that “most importantly” (p. 58) an intervention of this nature provides individuals with a way to accept the present moment. In this way one’s “locus of control” (p. 58) is reoriented from external measures (“success, approval” (p. 58)) to internal measures of control.

A very recent, uncontrolled, study (Stubhaug, Lier, Abmus, Rongve, & Kvale, 2018) used a shorter MBSR intervention on ME/CFS patients. The intervention was a four-day program consisting of cognitive and mindfulness-based therapeutic methods as well as some physical activity and writing (framed within a CBT/mindfulness/acceptance and commitment model). A total of 305 subjects participated in the study over an open enrolment period of one year. Evaluations were done via self-report one week prior to the start of the intervention, and then again at one week after the intervention. Additional data collection occurred at three-months post and one-year post. The results illustrated statistically significant changes in 80% of the participants after the intervention. Results were maintained at the one-year follow-up. The

researchers acknowledge the possibility of selection bias, with this group of participants potentially favoring this particular treatment approach — many ME/CFS patients are wary of “biopsychosocial interventions, and possibly because...these [types of] patients did not accept referral to the [intervention], [this would have] contribut[ed] to the possible selection bias” (p. 8) and low dropout. Despite this concern, the researchers believe the success of the intervention was due to the content, where the focus was on

restoring sleep, emphasizing...the acceptance of the present status, and challenging more actively the illness perceptions of CFS/ME. Possibly, such a concentrated format allowing for extensive education and challenge of cognitive illness perceptions and behavioral patterns of avoidance, as well as offering an existential frame of acceptance of the present situation could be a key effectiveness factor. (Stubhaug, Lier, Aßmus, Rongve, & Kvale, 2018, p. 8)

The results reported by these authors was also noted to be in line with other similarly condensed interventions. It is fresh studies like these, with a focus on CBT methods and mindfulness, that sets the stage for future biopsychosocial interventions for symptom management, and other complementary and integrative approaches such as the one proposed in this thesis.

### **Cognitive Behavioural Therapy (CBT)**

As noted earlier, MBCT is a hybrid of cognitive behavioural therapy and mindfulness. CBT in its pure form, with its specific tools for understanding and reframing cognitive distortions, is also an important psychological method for managing emotional and physical struggles. The tenets of the theory and some main cognitive behavioural principles are reviewed before an examination of CBT in the specific context of ME/CFS.

CBT harnesses a combination of principles from Cognitive Therapy (CT) (developed by Aaron T. Beck in the 1960's) and Behavioural Therapy (BT) (developed in the 1950's by

multiple contributors) (Westbrook, Kennerley, & Kirk, 2007). The marriage of the two spawned the core CBT principle: emotions and behaviours are influenced by cognitions. CBT ultimately works to shift one's perspective and behaviours to more realistic, adaptive, coping approaches.

### **Tenets of the Theory**

Westbrook, Kennerley and Kirk (2007, pp. 3-8) identify six fundamental principles of CBT: cognitive, behavioural, 'continuum', 'here and now', 'interacting systems', and empirical. The cognitive principle is the basic belief "that different cognitions give rise to different emotions" (Westbrook, Kennerley, & Kirk, 2007, p.5). For example, a positive appraisal of a compliment will likely result in a positive emotional response (e.g. an elevated mood). But this principle also acknowledges that different people will appraise and respond differently to comparable experiences. How they are interpreted will have a direct effect on the emotional response in the intended recipient. In this way "cognitive appraisals of events can affect the response to those events and [so there can be] clinical value in modifying the content of these appraisals" (Dobson, 2001, p. 5).

From the cognitive perspective, emotion and "behavior change may be effected through cognitive change" (Dobson, 2001, p. 5). In contrast, according to the behavioural principle it is our behaviour that affects our cognitions and emotions, "that changing what you do is often a powerful way of changing thoughts and emotions" (Westbrook, Kennerley, & Kirk, 2007, p.5).

The 'continuum' principle looks at "mental health problems as arising from exaggerated or extreme versions of normal processes" (Westbrook, Kennerley, & Kirk, 2007, p.5) as opposed to being something abnormal; problems are distributed along a continuum, with mental wellness at one end and severe pathology at the other.

CBT's therapeutic model focuses on the present, as the 'here and now' principle outlines (Westbrook, Kennerley, & Kirk, 2007, p.6). Unlike the psychodynamic models that view

understanding the past as essential to successful treatment, CBT's emphasis is on current cognitive and behavioural issues – how one reacts to triggers and stimuli – rather than their origins (Schuyler, 2003, p. 43).

The 'interacting systems' principle suggests that cognition, affect/emotion, behaviour, physiology, and the environment operate through feedback loops, whereby one system is affected by a stimulus of some kind, which then informs another system, and so on (Westbrook, Kennerley, & Kirk, 2007, p.6). For example, if someone is faced with a stressful life event (becoming chronically ill and unable to work full time), the cognition ("What will I do for income? How will I pay the bills?") may lead to an emotion (anger, frustration, worry, sadness) which induces a physiological response (tightness in the chest, shortness of breath, crying), which might then lead to a behaviour (taking anger out on a loved one).

The empirical principle is important in identifying CBT as an evidence-based theory (Westbrook, Kennerley, & Kirk, 2007, p. 7). A meta-analysis documented CBT's success in dealing with a number of mental health issues including depression, anxiety, chronic pain, and post-traumatic stress disorder, to name but a few (Butler, Chapman, Forman, & Beck, 2006).

### **CBT Core Principles**

I propose a three-tiered pyramid visualization to represent CBT's "levels of cognitions," (p. 10). or types of negative thinking. Negative automatic thoughts (NATs) live at the top. These are central to CBT (Westbrook, Kennerley, & Kirk, 2007). They are the "stream of thoughts that almost all of us can notice if we try to pay attention to them" (p. 8). They are maladaptive/misinterpreted appraisals of reality. NATs happen "automatically and without effort (although it may take effort to pay attention to them and notice them)" (p. 9) and can directly affect one's mood. Dysfunctional assumptions sit at the second layer of the pyramid. They are "the 'soil' from which NATs sprout" (p. 10). They are more general than NATs and are often

conditional statements of ‘if this... then that’, or ‘shoulds’ and ‘musts’. At the bottom layer of the pyramid lives schemas, or core beliefs. These are how one views oneself, other people, and the world. They are one’s “absolute statements...seen by the person as fundamental truths that apply in all situations” (p. 10). These usually take the form of “I am...” statements (e.g. I am bad, I am worthless...) but are not always consciously accessible. However, they shape much of one’s thinking about themselves and the world and filter up into dysfunctional assumptions and NATs. It turns out that the “[m]ost successful CBT research to date targets NATs” (Westbrook, Kennerley, & Kirk, 2007, p. 10). This makes sense, as these default, negative thoughts are the most easily accessible, or easy to ‘catch’. Common examples of negative automatic thinking are referred to in CBT as cognitive distortions, or “cognitive biases” (p. 172). Cognitive distortions are like a labelling system for one’s automatic thoughts. For example, if a thought says “I’ll *never* be able to enjoy life like I did before my illness”, this NAT would be categorized under the cognitive distortion label of “overgeneralization” (Burns, 1980, p. 40; Westbrook, Kennerley, & Kirk, 2007, p. 172). A therapist would educate an individual about NATs and cognitive distortions and help in the identification and questioning of “unhelpful cognitions [and] biases” (Westbrook, Kennerley, & Kirk, 2007, p. 178). Therapists work with clients to then test, challenge, and modify thought patterns (Westbrook, Kennerley, & Kirk, 2007). With time, clients begin to develop their skills and come up with more rational responses to their negative thinking (e.g. “I do still enjoy being in my garden the same as I always have”, or “I love watching movies”, or “I enjoy being with my family or closest friends like I always have; we just adjust to doing things at home more often than not”, etc.). The end goal of CBT is to enable individuals to do this work on their own.

The following is a list of cognitive distortions summarized from both Burns (1980) and Westbrook, Kennerley and Kirk (2007). Most of the examples in each category have been oriented towards plausible cognitive distortions found amongst those living with ME/CFS:

1. All-or-nothing thinking: seeing things as “black [or] white” (Burns, 1980, p. 40) without middle ground. In other words, viewing things in extremes e.g. *I will never feel better; I can't do anything right; things always go badly for me*
2. Unrealistic expectations/high standards/should statements: having high or unrealistic expectations of self or others using ‘should’ and synonymous (i.e. must, ought to) statements (Westbrook, Kennerley and Kirk, 2007). When these statements are aimed at oneself the “emotional consequence is guilt”. When [directed] towards others, [the result is] anger, frustration, and resentment” (Burns, 1980, p. 40).
3. Catastrophizing: assuming the worst without just reasoning (Westbrook, Kennerley, & Kirk, 2007) e.g. *I'm going to be late and my reputation at work will be ruined; what if I lose my job...my home* (Westbrook, Kennerley, & Kirk, 2007); *I had to cancel again-- everyone is going to think I am a complete flake.*
4. Over-generalization: Using one example of a negative outcome to paint all outcomes in a negative light (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007) e.g. *I've messed up interviews before, so I'm sure it will just keep happening* (Westbrook, Kennerley, & Kirk, 2007); *I had a panic attack in public once, so I just know it's going to happen next time I'm out; I felt so horrible today, so I bet tomorrow will be the same; I'll never be able to enjoy life like I did before my illness.*
5. Mental filter: a mental orientation to the negative, where one focuses on the negative and negates the positives (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007). In other words, “[f]orgetting achievements and compliments but dwelling on a single

- criticism” or bad event (Westbrook, Kennerley and Kirk, 2007, p. 173) *e.g. I made one mistake during my lecture—I’m obviously not cut out to teach at all; the last time I tried to go see a movie my symptoms flared up and I had to leave the theatre—I clearly can’t go out to movies anymore.*
6. Disqualifying the positive: rejecting or dismissing positive experiences as if they “don’t count” (Burns, 1980, p. 40) *e.g. I was able to go for a walk today which I haven’t really been up for in the last couple weeks, but I was still so tired and nauseated; My pain wasn’t as severe today...but I don’t think I’m really getting any better; I got an A on my last paper...but I bet everyone did just as well as me—the professor is probably just an easy grader.*
7. Magnification or minimization: Exaggerating your shortcomings, while magnifying others’ achievements/qualities, or minimizing your own good qualities or achievements, and others’ undesirable qualities (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007). *E.g. Compared to \_\_\_ I’ve barely achieved anything in my life; I know I should be grateful for having what I have-- a loving husband, parents, and friends, somewhere to live --, but I can’t do things or work the way I used to. And with being sick, I’m not sure if I’ll be able to have a family of my own. Meanwhile, everyone around me is moving forward with their family lives and careers.*
8. Jumping to conclusions: coming to a certain conclusion without enough facts to support it. There are two types (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007):
- i. mind-reading: interpreting things as if you have factual insight into what another person is thinking about you, *e.g. I know they must think I am making up my illness.*

- ii. Fortune-telling: imagining things will go badly (Burns, 1980), *e.g. this new doctor's appointment is going to be a waste of time and effort—he won't be any different than the others I've seen.*
9. Emotional reasoning: believing the validity of feelings and thoughts, and drawing false conclusions (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007) *e.g. I feel like I can't continue to manage everything that's going on, so why bother getting out of bed?; I feel crappy either way, so why bother sticking to this special diet; I feel like I am letting people down all the time, so I must be.*
10. Taking things personally: taking responsibility for something (perceived as being bad) that happens that is outside of your control (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007), *e.g. that dinner went poorly.-- I'm sure it's because I was talking too much about my illness; I haven't heard from \_\_\_ in a while...I probably did something to make them upset.*
11. Self-blame/self-criticism/mislabelling or negative self-labelling: blaming oneself for something bad, without having just reason (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007), *e.g. "I feel ill...I must have brought it on myself"* (Westbrook, Kennerley and Kirk, 2007, p. 173); *If I'm not dealing with physical symptoms, I'm dealing with emotional symptoms...I feel like a one-woman circus...I'm just a broken person.*
12. Name-calling: Using self-deprecating language to refer to oneself (Burns, 1980; Westbrook, Kennerley, & Kirk, 2007), *e.g. I am a waste of space; I'm an idiot.*

Being able to appraise these automatic cognitions is key to having success with the CBT model.

Decentering was a term used by Beck that referred to the ability to perceive “cognitions as mental events rather than as expressions of reality” (Westbrook, Kennerley and Kirk, 2007, p.

174). Decentering allows an individual to “stand back and observe...recognising that a thought is

an opinion, not necessarily a fact” (p. 174). Decentering may sound similar to mindfulness; bringing awareness to thoughts, emotions, and sensations. This is where the intersection between mindfulness and CBT is of such value and has ultimately spawned the birth of MBCT.

Daniel Siegel (2011) explains very simply how this kind of attention to, as well as labelling of, our thoughts and attendant emotions can short-circuit cognitive distortions at the level of the brain. He calls this phenomenon “name it to tame it” (p. 116): “We can use the left language centers to calm the excessively firing right emotional areas” (p. 116) by naming “the emotions we are experiencing, rather than being overwhelmed by them” (p. xii). To further understand this process, imagine the right side of the brain, flooded with emotion, as if it were a grease fire. Let us use anxiety as the example of overwhelming emotion brought on by the distorted cognitions of “I’ll *never* be able to enjoy life like I did before my illness; I’ll never really feel better”. If left unchecked, the blaze will just continue to get worse, leaving the individual consumed by the ‘flames’. However, if this person has the capacity to be mindful, or practice decentering (also known as meta-cognitive awareness) (Westbrook, Kennerley and Kirk, 2007, p. 175), then the left hemisphere can be brought online through accurately naming the thought or emotion being experienced, e.g. “What am I feeling/thinking/experiencing? I am ‘overgeneralizing’ the situation...and that’s also definitely ‘all-or-nothing thinking’. It’s causing me to feel really anxious about my health and the future”. This engagement of the logical labelling ability of the left hemisphere can have the effect of smothering the proverbial fire. By “putting feelings into words (affect labelling)” (Lieberman et al., 2007, p. 421), the emotion (dominated by the right hemisphere, and subcortical regions) quiets as the language and logic centers are activated (in the left hemisphere). In this way, the language/labelling skills for one’s various cognitive distortions that CBT offers is invaluable to taking runaway emotions in hand.

### **ME/CFS and the CBT Debate**

It is clear, as noted earlier, that there are two still-competing views on the relationship between CBT and ME/CFS (Goudsmit and Howes, 2017; Spencer, 2015; White, Goldsmith, Johnson, Chalder, & Sharpe, 2013). One of the reasons for the difference in views may be related to the fact that one body of research always links CBT and GET together; “underpinning the protocols for CBT and GET...[is what is known as the] fear-avoidance model” (Goudsmit and Howes, 2017, p. 1160). This linkage of the two therapies may undermine the ability to focus on the possible positive effects of CBT taken alone on ME/CFS (or even in combination with the complimentary practice of mindfulness meditation). Some recent reviews of the two hypotheses (Goudsmit and Howes, 2017; Kindlon, 2017) suggest that there are other fundamental problems with the body of work that has studied CBT and GET; issues highlighted by Goudsmit and Howes (2017) range from researcher bias and limited rigor of trials, to denial of possible risks of the therapies, to “a clear reluctance to acknowledge findings which undermine their theory, notably reports of abnormalities in brain, muscle, and immune function [found in ME/CFS]” (p. 1160) (Costa, Tannock & Brostoff 2005; Goudsmit, Shepherd, Dancey & Howes, 2009; Lane, Soteriou, Zhang & Archard, 2003; Shepherd and Chaudhuri, 2016). In any case, resolving this difference of view is well beyond the scope of this thesis.

Building on the CCC (De Meirleir et al., 2003), the ICC (Carruthers et al., 2011a) serve to suggest that there is a sound scientific basis for expecting positive CBT effects on ME/CFS, especially when approached as an adaptive coping strategy, rather than a strategy to address a ‘fear-avoidance model’. There is also evidence, as already noted earlier, showing the positive effects that third-wave cognitive behavioural therapies, such as MBCT and ACT, have for depression and anxiety (Teasdale et al., 2000; Yadavaia, Hayes, & Vilardaga, 2014). Those criteria, and this evidence, then, serve as reasonable jumping off points for examining evidence

for use of CBT on the individual symptoms of anxiety and depression, often reported by those diagnosed with ME/CFS (De Meirleir et al., 2003).

### **CBT for Worry and Anxiety: Potential Implications for ME/CFS Patients**

Worry and anxiety can be experienced by everyone from time to time. But for those living with a chronic condition, they are a constant companion (De Meirleir et al., 2003). CBT offers practical tools to help shift maladaptive patterns of thought and/or behaviour (found in either anxiety or depression). Areas of behavioural analysis include: “behavioral deficits, uncontrolled behaviors, overcontrolled behaviors, overgeneralized behaviors, [and] difficult-to-extinguish behaviors” (Newman, 2013, p. 20). As we know, cognitive distortions or negative thinking are characterized by automatic thoughts, conditioned assumptions, and maladaptive schemas (Newman, 2013).

CBT recognizes anxiety by the theme of perceived danger, or “a bias towards the over estimation of threat” (Westbrook, Kennerley & Kirk, 2007, p, 12). Fears come from imagined, detrimental possibilities. The maintaining cycle of anxiety looks like this: “Trigger→ 1. Perceived threat→ 2. Problem response: cognitive and/or behavioural and/or psychological→ 3. Fear is unchallenged → 4. Fear remains intact: belief is unchanged” (p. 281). When CBT tools are applied, the anxiety cycle is broken: “Trigger→ 1. Accurately perceived threat→ 2. Alternative response: behavioural experiment→ 3. Fear is challenged: experience of coping→[Cycle is disrupted]→ 4. Old belief changes to a realistic belief (Westbrook, Kennerley & Kirk, 2007).

Myriad meta analyses (Butler, Chapman, Forman, & Beck, 2006; Deacon, & Abramowitz, 2004; Norton, & Price, 2007; Smits, Berry, Tart, & Powers, 2008; Stewart & Chambless, 2009) support the use of CBT as the ‘gold standard’ treatment for anxiety and worry. In an illness such as ME/CFS, anxiety and worry may occur on a regular basis. These may include worries

pertaining to daily symptoms (e.g. discomfort, unpredictability), the unknown (e.g. not knowing how long the overall illness state will last, or how long a short-term flare-up of symptoms will last; being unable to make long or short-term plans; being unable/unsure of how to take care of oneself physically, financially, etc.). All of these concerns boil down to a base fear of uncertainty — a key issue that CBT is designed to address (Robichaud & Buhr, 2018).

### **CBT for Depression: Potential Implications for ME/CFS Patients**

The classic CBT-based model of depression characterizes it as a “cognitive triad” (Westbrook, Kennerley & Kirk, 2007, p. 251) of negative views pertaining to the self, the world, and the future. This can have deleterious effects on one’s mental and physical health. Typical depressive thought maintenance cycles may look like the following:

[A] vicious circle linking depressed mood with negative biases and negative interpretations of symptoms, which leads to a negative view of the self, thus maintaining the depressed mood...[T]hose negative biases and symptoms of depression may lead to reductions of activity...which maintains the low mood because activities that previously gave pleasure or a sense of achievement are lost. Finally, the depressive biases and symptoms may lead to reduced attempts to cope and deal with problems, which leads to increased hopelessness and thus reinforces the depression (p. 252).

CBT’s effectiveness in the management of depression is well known (Beltman, Voshaar, & Speckens, 2010; Cristea, Huibers, David, Hollon, Andersson, & Cuijpers, 2015; Honyashiki, et al., 2014; Ljotsson, Hedman, Mattsson, & Andersson, 2017; Rubin & Yu., 2017). It is understandable how a “situational depression” (De Meirleir et al., 2003) may occur in someone living with ME/CFS. Feelings of depression or hopelessness may stem from the physically debilitating, painful or frustrating symptoms; a sense of loss around identity and how they functioned prior to the illness (socially, professionally, or any other identifying social/emotional

roles); social isolation; (often extremely) reduced activity levels and relegation to a primarily indoor /at-home lifestyle. Various CBT tools can help with managing depression symptoms. CBT for depression aims to: 1. “counteract any negative cognitive biases and develop a more balanced view of himself, the world and the future” (Westbrook, Kennerley & Kirk, 2007, p. 253); 2. Re-establish or create new doable activities, “especially activities that bring a sense of pleasure or achievement” (p. 253); 3. Increase “active engagement and problem-solving” (p. 253). These three targets for managing depression with CBT tools would be eminently applicable in depression brought on from ME/CFS. CBT for anxiety and depression in ME/CFS is explored in further detail, with some specific exercises offered, below in the “protocol recommendations” section.

### **Relaxation and Restorative Yoga**

Restorative yoga was developed by B.K.S Iyengar in Pune, India. Iyengar, one of the world authorities on yoga, is known for the creation and inclusion of props in yoga, as a means to avoid injury. Throughout his career, he also experimented with supported poses in service of illness and injury recovery (Lasater, 2011). And thus, a restorative form of yoga was born. Judith Hanson Lasater is another world-renowned yoga teacher and student of Iyengar, who explains how restorative yoga poses are actually a form of ““active relaxation”. By supporting the body with props, we alternately stimulate and relax the body to move toward balance” (2011, p. 6). This tandem effect, to both energize and soothe the body and mind, can be very beneficial for those experiencing comorbid symptoms such as anxiety, depression, fatigue, and pain. Lasater explains how “[i]n general, restorative poses are for those times when you feel weak, fatigued, or stressed...[and] you can practice the poses when ill or recovering from illness or injury” (p. 6). Importantly, she notes Herbert Benson’s (1992) term, the “relaxation response,” as a key aspect of restorative practice. This term describes the unique “physiological and mental responses that

occur when one consciously relaxes” (Lasater, 2011, p. 5). During a time of true relaxation, the body enters a “state characterized by a slower heart rate, metabolism, rate of breathing, lower blood pressure, and slower brain wave patterns” (Benson & Stuart, 1992, pp. 92 – 93). Further, she explains the importance of this active form of relaxation versus other forms of rest:

To relax is to rest deeply. This rest is different from sleep. Deep states of sleep include periods of dreaming, which increase muscular tension, as well as other physiological signs of tension. Relaxation is a state in which there is no movement, no effort, and the brain is quiet. (Lasater, 2011, p. 5)

In this way, true relaxation is also different from simply being reclined and watching television, reading, or using an electronic device. It is also quite different from resting without focused attention. Killingsworth and Gilbert’s (2010) research suggests that “a wandering mind is an unhappy mind” (p. 932). They found that if people’s minds were wandering, they were unhappy, whether or not they were thinking about pleasant or unpleasant matters. The focused, mindful attention produced through a restorative yoga practice counteracts mind-wandering.

Restorative yoga offers a kind of marriage between meditation and relaxation, in that it both quiets the mind and body, and offers a space to observe mindfully and to reflect on points of attention, as one would during meditation. It also uniquely offers reclined positions in which to practice mindfulness for those who have symptoms that make it difficult to sit upright or find a comfortable position. Restorative yoga allows and encourages one to find optimal postures for comfort and rest. It can be practiced on the floor using a yoga mat or blanket, or even in bed or from a chair. The restorative practice also offers various planes, or objects of attention, for one’s mindfulness practice; just as one might use the breath, sound, or sensation as a point of focus for mindfulness practice, in restorative yoga the body is placed in specific positions, so one may immediately gravitate to a mindfulness practice with focused attention on the body and

sensation. Because the body is being placed in a particular way, there are ample objects of attention to work with, such as the feeling of the body in its particular restorative position/in space, the tactile sensation of the parts of the body in contact with the ground or bed underneath them, the weight of blankets or support of props, general body sensation, breathing, etc.

### **Evidence Base for Effects of Restorative Yoga: Potential Implications for ME/CFS Patients**

There are no studies, to the best of my knowledge, on restorative yoga as an intervention for ME/CFS. In fact, there is very little empirical research on relaxation of any type and its effects on ME/CFS. According to Meeus et al.'s (2015) systematic review, only three studies (as of that date) had examined the effects of relaxation on ME/CFS. These studies have used a variety of relaxation protocols rather than one consistent method. The authors of the review note that this could be responsible for the “[i]nconsistencies in some of the finding[s]” (p. 231). Two of those studies (Deale, Chalder, Marks & Wessely, 1997; Deale, Husain, Chalder & Wessely, 2001) that looked at CBT versus Relaxation, found (via self-report) that CBT was more effective in improving patients’ functional status. However, Meeus et al. (2015) point out that these results of “general improvement” may be influenced by patients’ perceptions. It could be that patients’ expectancies are higher regarding comprehensive treatment approaches compared to relaxation therapy alone” (p. 230). This is a form of confirmation bias where individuals are biased towards their preconceptions.

While there is a larger body of research on the active yoga practice of hatha yoga and its effects, there are only a modest number of studies that have examined the possible effects of restorative yoga in the context of various other health concerns and conditions. Danhauer et al. (2009) used restorative yoga as an intervention for women with breast cancer and found promising results. Though the sample for this pilot study was small, the results suggest that restorative yoga could be beneficial for “emotional outcomes and fatigue” (p. 360). Participants

“with higher negative affect and lower emotional well-being at baseline derived greater benefit from the yoga intervention compared to those with similar values at baseline in the control group” (Danhauer et al., 2009, p. 360). Further, the restorative yoga group saw a substantial within-group amelioration in fatigue. This study also showed that restorative yoga was a realistic undertaking for women with breast cancer. Symptoms like fatigue that are common to breast cancer patients and ME/CFS patients, allow one to surmise that 1. restorative yoga has potential utility and 2. it could generalize to other populations such as patients with ME/CFS.

A recent study (Pandey & Huq, 2017) that looked at the effects of restorative yoga on hemodynamics also yielded significant results. The study involved 45 participants randomized into three groups: stretching, quiet relaxation, and restorative yoga. Compared to the quiet relaxation group, the restorative yoga group had reduced blood pressure (BP) and heart rate (HR). And while the stretching group also saw reduced BP and HR, the restorative yoga group’s reductions were significantly larger. Further, the reductions lasted for at least 24 hours in the restorative yoga group but not in the quiet relaxation group.

Hetherington (2016) studied a group of hospital workers, notably in a high stress profession and susceptible to “compassion fatigue” (p. 5). The study took place over a six-week period, with 16 participants. Participants were taught various restorative yoga poses, with an emphasis on focused breathing and fostering relaxation. The restorative yoga was found to be beneficial for lowering the stress response in this population.

As a hopeful note for things to come, one recent study proposal (Macnamara et. al., 2018) intends to examine the effects of relaxation on sleep and functioning in patients with ME/CFS and depression. It will be the first of its kind to conduct a randomized controlled trial using a “personalized intervention based on the participant’s maximal autonomic relaxation response” (p. 7). The hypothesis being tested in this study is that the ME/CFS patients will experience

improvement in “sleep quality, reduced daytime fatigue and other symptoms, and enhanced functional status” (p. 7).

The handful of studies noted here show the potential utility of restorative yoga interventions. However, there is at this point in time also an obvious gap in the research on restorative yoga in general, and as a specific intervention for ME/CFS patients’ symptoms.

### **Summary of Research Evidence**

The research discussed in this review suggests strongly that the combination of mindfulness, CBT, and restorative yoga could be effective as a combination intervention for ME/CFS patients’ symptom management. No such intervention currently exists, and there is enough (suggestive) evidence for each of these domains/methods to support an integrative, mindfulness-based protocol built around these three interventions. I suggest that given their individual (actual or suggested) effects on ME/CFS, and given the differences in approach and focus, they are likely to work synergistically in patients suffering from ME/CFS, again not as a cure but as a set of management tools aimed at improving coping capacity and quality of life. It also must be reiterated that though two of the three approaches suggested are cognitive in nature, this does not, nor should it, lead to the false conclusion that ME/CFS is a psychological condition; this condition, as should be evident from the literature reviewed above, is biologically based, affecting multiple systems of the human body.

The protocol itself could take on any number of different structures. As one example, one could practice mindfulness meditation in the morning and/or evening. As the foundation of the triad, mindfulness is arguably the most important practice. The CBT and restorative yoga prongs of the protocol should be grounded by mindful awareness, thus making it a mindfulness-based overall approach. One can then utilize MBCT and CBT tools throughout the day’s challenges, reframing negative thought patterns and better managing undesirable physical sensations. A

mindful restorative yoga practice could also be undertaken at any time of the day as a way of intentional rest, or before bed to help manage dysfunctional sleep patterns. Taken together in this way, throughout the day as needed, this trio seems likely to serve the practitioner well as a powerful ME/CFS symptom management package.

Further, mindfulness meditation and restorative yoga are cost-effective, home-based practices. There are a number of good quality, and relatively inexpensive, digital mindfulness applications or audio tracks available for download. Free, high quality mindfulness meditations and talks are also available from dharmaseed.org. And many reputable meditation teachers also offer meditation CDs. Restorative yoga can be learned from books and videos and is one of the most adaptable practices; as noted earlier, various poses can be practiced in bed or in a chair, and yoga props can be made out of one's existing pillows, blankets and chairs. While enlisting the services of a CBT therapist is not inexpensive, there is a great deal of literature on CBT and MBCT to be utilized as at-home learning tools if seeing a CBT therapist is beyond one's financial means. However, the hope is that this protocol can be developed into a more detailed ME/CFS-specific symptom management workbook with audio recording and/or discounted access to a reputable digital meditation application. The objective of the workbook and accompaniments will be to obviate the need for the ME/CFS patient to find the necessary tools piece-meal; all content will be oriented to the management of this chronic illness.

### **Specific Protocol Recommendations: Mindfulness, CBT, and Restorative Yoga**

This section explores some specific intervention techniques from each of the three symptom management categories assessed in this review. A technique/exercise is proposed under each section, followed by a rationale. Mindfulness practices are explored first, followed by CBT, and the section concludes with specific restorative yoga suggestions. Together, these

interventions make up the proposed integrative mindfulness-based symptom management for ME/CFS (MBSM-ME/CFS) approach.

### **Mindfulness Interventions**

Mindfulness, as evidenced in this review, can be helpful with cognitive and physical symptom management. Below is a list of mindfulness practices that could be useful in ME/CFS symptom management, with illness-specific relevant modifications noted. The suggested interventions are drawn from traditional mindfulness practices, MBSR protocol, and mindfulness-based interventions used in chronically ill patients living with cancer (McCown, Reibel, & Micozzi, 2016):

1. **Body Scan:** in this mindfulness practice, one brings attention to the body. This helps one learn that “[e]very state of mind is reflected in a state of body, and...every emotion or thought has repercussions in the body” (Carlson & Speca, 2010, p. 46). In bringing conscious attention to the body, greater awareness is fostered; this becomes helpful in identifying emotion states such as anxiety, fear, feelings of depression, etc., and what they feel like, or where they live, in one’s body.

The practice often begins with attention at the feet, and slowly, part by part, one’s attention is directed upwards through the body. In addition to experiencing intense emotional states, someone living with a chronic illness like ME/CFS may, at any given time, be experiencing pain, nausea, aches, temperature control issues, heart palpitations and more. The “[i]llness itself can increase [one’s] sense of alienation from [the] body...The body scan is a way of reacquainting [oneself] with the body in a loving and gentle way” (p. 46). This is especially important in chronic illness when one may feel “betrayed [by, or] angry [with]” (p. 46) their body. The body scan is an opportunity to explore the body, “embracing it, flaws and all” (p. 46). But when the body is in an illness

state, exploring it can be a very sensitive, even upsetting, experience. It is important to guide ME/CFS patients through the process at a comfortable pace (which will vary with each individual), only exploring those parts of the body about which there is a sufficient comfort level, and slowly building from that foundational place. A body scan may not even include the whole body the first several times, or ever. Sometimes simply exploring neutral ground (that might be a hand, or a foot) is the place to begin building bodily awareness (McCown, Reibel, & Micozzi, 2016, p. 387). With this practice, and all meditation practices, the practitioner can choose whether they are more comfortable with their eyes closed or left softly open.

2. Mindfulness of Breath: Using the breath as a point of focus for meditation is convenient and simple. The breath is always accessible as long as one is alive, and simply requires that direct attention be paid to it; as opposed to *thinking* about breathing, one pays focused attention to the flow of the inhale and exhale breath. (Kabat-Zinn, 1990; Carlson & Speca, 2010). This attention might focus on sensation, sound, or noting/counting the breaths. One may also “discover that it is possible to direct [one’s] breath with great precision to various parts of [the] body in such a way that it will penetrate and soothe regions that are injured or in pain, [and] at the same time...calms and stabilizes the mind” (Kabat-Zinn, 1990, p. 56). However, the breath is not always a neutral point of focus for all individuals. It can be a source of “strong emotion[s] or physical reaction[s]” (McCown, Reibel, & Micozzi, 2016, p. 387). Exploring the breath carefully, for short periods of time, or using a different point of focus altogether (e.g. sensations in the foot or hand, sensation of one’s pulse, sounds, etc.) are all valid options.
3. Seated Meditation and Adaptations: Most instructions for mindfulness meditation encourage an upright, dignified seated position, whether it be on the floor/on a cushion,

or seated in a chair, and if one is seated in a chair it is recommend that one avoid reclining as much as possible (Kabat-Zinn, 1990; Carlson & Speca, 2010). Working with discomfort is also encouraged, as one's discomfort can become a part of the practice itself as points of "observation and inquiry" (Kabat-Zinn, 1990, p. 65). Also, "[r]elaxing into discomfort sometimes reduces pain intensity" (p. 66). However, an acknowledgement of the potential for debilitating pain, fatigue and orthostatic intolerance must be factored in to a mindfulness practice intended for ME/CFS. At times, for example, sitting upright is not an option, and therefore the practice must be adapted. It is reasonable to assert that an individual with ME/CFS is better advised to practice comfortably lying in a supine position in bed than not to practice at all. Further, one may feel that being propped up in bed with pillows, or even seated upright in bed with blankets and pillows as supports, are other reasonable options. There is a greater risk of sleepiness or losing track of one's attention in a reclined position, but it certainly should not become a barrier to practice, nor something that makes patients with ME/CFS feel singled out in instances where they are unable to practice the way one is traditionally "supposed to."

### **CBT Interventions**

The main goal for using CBT in ME/CFS symptom management would be to address and modify negative automatic thoughts and the resulting cognitive distortions and safety behaviours often associated with worry, anxiety and depression. The following is a short list of CBT interventions that could be useful in ME/CFS symptom management. The CBT tools included are not exhaustive, but have been selected specifically for their ease of use and relevance in managing ME/CFS symptoms. Further, these tools can be readily accessed on the internet or

from books, and can be practiced with or without the aid of a qualified cognitive behavioural therapist:

1. Decentering: the practice of ‘stepping back’ and viewing cognitions as opinions rather than facts. This practice crosses over with the awareness fostered by mindfulness and is helpful in each CBT intervention. (Westbrook, Kennerley, & Kirk, 2007)
2. Thought recording/dysfunctional thought record (Murdock, 2013): a thought record journal is a place to practice noticing and recording one’s cognitive distortions and offering more adaptive, rational thoughts in their place (see Appendix A for examples).
3. Utility and validity of cognitions: negative thought patterns, such as worry, can often seem (and sometimes truly feel) “protective” (Westbrook, Kennerley, & Kirk, 2007, p. 177). By anticipating possible scenarios, one feels as though they are better able to control an outcome or not feel caught off guard, e.g., “If I anticipate having a panic attack [nausea, stomach pain, exhaustion etc.], it won’t take me by surprise”. This is why it is important to challenge negative cognitions when they come up. While any of these suggested scenarios are a possibility for someone with ME/CFS, worrying excessively in advance of them is not necessarily adaptive or helpful; there needs to be an understanding of where appropriate planning ends (e.g. having one’s necessary medications on hand when one leaves the house; appropriately scheduling oneself so as not to over exert and trigger PEM/PENE) and excessive worry or safety behaviour begins. For example, “If I expect that I won’t be able to do “X” I won’t be disappointed” or “if I expect the worst thing then I won’t be as scared when the symptoms happen”, or not making *any* plans for fear of having to cancel (Westbrook, Kennerley, & Kirk, 2007). Examining the pros and cons of worry-based cognitions will help in making more adaptive choices and fostering greater flexibility of mind.

4. Examining the worst-case scenario: Sometimes the best question to ask oneself is “what is the worst thing that could happen here?” By asking this question, an individual is faced with “nam[ing] the fear...[and the actual] problem that needs to be resolved. [And] [t]he corollary question “...and how would you cope?” then kicks off the process of problem-solving” (p. 177). In facing this ultimate problem (e.g. “I am scared of being nauseated in public”. Worst case scenario: “I am worried about throwing up or having diarrhea and not getting to a bathroom in time”. Or, “I am scared of having an episode of crippling abdominal pain”. Worst case scenario: “I feel like I might pass out because the pain is so severe”), the so-called ‘power’ of the imagined catastrophe is lessened when confronted and examined. Sometimes the worst-case scenario is also not a ‘catastrophe’ at all. Rather, most “uncertain situations will probably turn out fine and we’re generally able to cope with them” (Robichaud & Buhr, 2018, p. 73). This is not to downplay the very real struggles and hardships of living with a chronic illness. Sometimes the catastrophes are in fact real. The key here is in recognizing when they are not, or not likely to manifest into that. With practice one can become skilled at recognizing when the ‘worst-case scenarios’ are imagined. This also leads to greater recognition of familiar, ‘been here before’, symptoms, and the ability to acknowledge that you did in fact cope and survive (e.g. crippling pain or nausea that eventually passed).
5. Behavioural Experiments in tolerating uncertainty: Someone living with a chronic illness of any kind will likely begin to understand their illness, its symptoms and its triggers very well. There is enough first-hand evidence available to a chronically ill person in support of the notion that bad things will happen, or continue to happen, when it comes to their symptoms. However, one cannot know for certain what the future holds. It is important to remember that even in a chronic illness state, everything is changeable. Similar

symptoms are not *the same*. Each day is different, each sensation is different, no matter how similar it may all feel (noticing fluctuations in sensation in this way is actually a mindfulness practice). There is a great deal of short and long-term uncertainty experienced in all chronic illness, ME/CFS being no different. Tolerating uncertainty or practicing radical acceptance of whatever comes up is not easy. But there are small steps, known in CBT as behavioural experiments, to be tried in day-to-day scenarios, that help build up a proverbial muscle of tolerance. For example:

Uncertain situation: making a social plan with a friend—not sure if you will be able to keep the plans because of unpredictable health/symptoms. Safety behavior: Avoiding making plans altogether. Tolerating uncertainty: Make the plans but make them reasonable for you. Outcome 1: Felt anxious leading up to it but was able to keep the plans. Had a nice time and rested the next day. Outcome 2: Felt anxious and then had a PEM/PENE crash so had to cancel plans. Friend understood. We rescheduled. (Robichaud & Buhr, 2018)

Behaviour experiments such as these train the brain to tolerate small examples of uncertainty, which can actually help in tolerating larger, longer-term examples of uncertainty (e.g. finding job security/options while ill, making long-term plans/commitments, not knowing from one month to the next how you might feel and what you will be able to tackle, etc.) (Robichaud & Buhr, 2018).

6. Coping card: a coping card is a handy tool that serves as a reminder of the specific coping/management skills one has learned (Wright, Basco, & Thase, 2006, pp. 118 - 121). It is meant to serve as a convenient one-stop collective document; it is a reminder document, sort of like a menu, of all the coping tools one has in one's 'tool-kit'. The coping card is usually a cue card, or piece of paper to keep posted somewhere at home

like on the fridge or a home-office tack board, and an additional version can be carried on the person. New-age coping cards could be written up in an application on one's cell phone for easy access, or to be able to set reminders. A coping card for managing various ME/CFS symptoms would list specific intervention strategies (e.g. write in thought record), phrases ("you are not your thoughts", "you are not your illness", etc.), or any other exercises (breathing, mindfulness, yoga) that address general anxiety, depression, and any physical symptoms one may experience. See Appendix B for a suggested coping card example.

### **Restorative Yoga Interventions**

Restorative yoga, as noted, has a very small body of empirical research behind it at this time. However, the studies mentioned earlier help to give some indication as to its effective use in symptom management. According to several notable authors and renowned yoga teachers (many of whom hold Ph.D.'s or medical degrees), restorative yoga postures can be helpful in managing symptoms of fatigue, insomnia, pain, depression, anxiety, and even immune function (Farhi, 2000; Forbes, 2011; Iyengar, 2008; Lasater, 2017, 2011; McCall, 2012; McGonigal, 2009). However, it is important to note that restorative yoga, unlike the latter two mind-based interventions, may fall outside the scope of ability for some patients who are severely physically disabled by their condition. This protocol option is aimed at those who fall under the mild to moderate spectrum of illness and are still able to move around on their own. Those with physical impairments should always consult a physician before taking on any new physical activity (no matter how gentle). If, together with their doctor, they feel that restorative yoga poses are appropriate to undertake, then they may have a caregiver help them with setting up in one or two simple postures in bed. The one postural exception to the latter, is the basic relaxation

pose/*savasana* (in Sanskrit) which is taken simply lying on one's back, with arms and legs extended. Anyone lying in bed can take on this posture.

The following list details several restorative yoga postures that (generally speaking, mild to moderate) ME/CFS patients may find beneficial in their symptom management. With all of these poses, however, it is important for practitioners to be methodical and mindful as they transition into and out of poses to avoid any strain. The poses should be practiced with caution and care, and one can refer to any of the books/authors listed here for detailed instruction. A dedicated manual/workbook that details these poses specifically for patients with ME/CFS does not yet exist but would be ideal. Further, the postures listed below are listed in a specific order that is thought to work best in not jarring the nervous system (i.e. not moving from a supine pose directly to a prone pose (Forbes, 2011)). Poses should also not be held for too long, especially for beginners (a general rule of starting with 1-2 minutes in a pose would be recommended before increasing the time). (Please again refer to the books and authors listed for detailed instruction). All poses can be done either in bed, or on the floor with a yoga mat or blanket(s) for comfort. Props and prop alternatives are: yoga bolsters, firm blanket(s), yoga blocks (blankets, pillows, and towels can be substituted in place of traditional yoga props). In all poses, just as in meditation, there is the option to have eyes open or closed. Finally, the use of breath in all poses is important. Focusing on a slow and steady breath while being in a pose helps to further the relaxation response (Lasater, 2011). Using a 1:1 time ratio of slow and smooth breathing generally works well (Forbes, 2011), but in the event of a very active or anxious mind, one can switch to a 1:2 ratio of inhale to exhale (e.g. 4:8 seconds, etc.) The longer exhale breath can slow the heart rate and nervous system activity (Forbes, 2011).

1. Legs on a chair or up the wall: This posture is an inversion, with the legs elevated on a wall or bent and resting on a chair (for detailed instruction please refer to Judith

Lasater's books (2017, 2011). The pose can help regulate blood pressure (Iyengar, 2008) but if one has particularly low blood pressure from ME/CFS, it is important for the practitioner to monitor how they feel in the pose. If dizziness occurs, one should opt out of this posture and lay flat instead. This pose can also be helpful in reducing water retention and lactic acid buildup in the legs (Farhi, 2000), in reducing fatigue, stress, anxiety, depression (Forbes, 2011), and insomnia (Lasater, 2011).

Approximate timing: 1-7 mins.

2. Simple chest opener/backbend: This posture is a gentle variation on a back bend. It requires only a folded blanket as a prop placed under the back (a standard sized blanket folded in half three times (Lasater, 2017)). If the pose causes pain or discomfort in the lower back, options are to lower the height of the blanket by reducing the folds, or avoid the pose altogether (Lasater, 2017). If head support is needed (if one's chin is pointing upwards) a simple folded blanket should suffice. This pose has been found to ease back pain from constant sitting, calm the mind (Lasater, 2017), and ease depression (Forbes, 2011). Approximate timing: 1-2 minutes.
3. Bound angle pose: In this posture the practitioner lies supine, with the legs in a 'butterfly' or bound angle position where soles of the feet touch and knees fall away. This posture requires support for the head and legs, and additional supports for arms if available. A variation executed with the chest elevated is also an option (Iyengar, 2008). A pillow or two could be used in place of a yoga bolster for supporting the legs in the bound angle position. The head can be supported by a pillow or yoga blocks so that it feels level; the chin should not be tilting up towards the ceiling. Pillows, or a bolster, could be used if one desires to elevate the chest and head. This

pose is helpful for stress, depression (Forbes, 2011), regulating blood pressure and enhancing the immune response (Iyengar, 2008), in reducing fatigue and headaches, muscle tension (Farhi, 2000), and helping with insomnia (Lasater, 2011).

Approximate timing: 1 – 10 minutes.

4. Basic relaxation (*savasana*) pose: In this posture the practitioner lies flat (in bed, or cushioned on the floor with a yoga mat or blanket) with legs extended and arms by their side, either with or without props. If using props, pillows or a folded blanket can be used to support the head, and pillows or a bolster can be used to support the legs (extended straight). This basic relaxation pose helps to reduce fatigue, insomnia (Lasater, 2011), ease anxiety and depression (Forbes, 2011), and enhance the immune response (Iyengar, 2008). In the absence of practicing any other poses, this pose (practiced in bed) is often a viable option even for those with the most limited physical abilities. Lying still, one can bring attention to the body, to the breath, to sound, or physical sensation. Relative to some of the other postures, this pose can be held safely for longer periods of time (assessed by the individual). Approximate timing: 1 – 30 minutes (or longer if desired).
5. Side lying relaxation pose: This pose is done resting on one's side, in a fetal position. The head is supported in a neutral position, arms can rest under and over a pillow or bolster, and folded blankets or pillows can be used as support between bent knees. This pose is good for reducing anxiety (Forbes, 2011), exhaustion, as well as offering all the other benefits of regular *savasana*/basic relaxation pose (Lasater, 2017). Like the basic *savasana* pose, this pose can be held safely for a longer period of time (assessed by the individual). Approximate timing: 1 – 25 minutes.

6. Downward facing relaxation (*savasana*) pose: This pose is done in prone position, resting the body over a bolster. If a bolster is not available, a couch cushion is an excellent substitute prop for this pose, or several stacked pillows. If there is too much pressure on one's chest, a folded blanket or towel can be placed on the bolster to give support under the belly. The forehead can be supported either by resting on the backs of one's hands or on a small folded towel or blanket. Additionally, a rolled towel or blanket can be used to support the ankles. Resting on the front of the body activates the parasympathetic nervous system (Farhi, 2000), shifting the body into a restful state, and helping reduce anxiety (Forbes, 2011). Approximate timing: 1 – 3 minutes.

The hope is that these three interventions can be used together for MBSM-ME/CFS. As noted throughout, the appeal of these interventions is they are all relatively inexpensive and readily accessible; even the most health-challenged patients can potentially practice from bed. All materials can be found at present on the internet or in books. Each intervention type can be adapted to the individual, by the individual, or if resources and accessibility allow, by a qualified teacher or therapist in each of the three fields.

### **Conclusion**

This review paves the way for those interested in pursuing future research in the field of symptom management for ME/CFS. There is clearly room for additional research, particularly on the effects of the three covered interventions, on ME/CFS patients in particular. But the evidence base is at least strongly suggestive, and in significant parts already relatively clear, on the potential of each of these approaches in helping ME/CFS patients manage symptoms.

The proposed integrative mindfulness-based symptoms management for ME/CFS (MBSM-ME/CFS) package outlined above, though not yet empirically studied as a suite, shows promise as a cost-effective, accessible symptom management approach for those who are suffering from

this illness. This review also provides the foundational pieces for the development of a mindfulness-based symptom management (MBSM) manual; that is the next step in my personal journey, which will illustrate in far more detail how to use each of these interventions for patients with ME/CFS.

Because this population is so underserved when it comes to treatment, and there is still so little understood about the pathology of the disease, management and coping strategies are of utmost importance. At present, there is a virtual vacuum when it comes to specific treatment or management protocols. This can leave patients feeling neglected, confused and at risk of trying interventions that are unsafe or outdated for their illness. And finally, while the protocol proposed here might be helpful to some, it is also important to note that even symptom management tools are not a one-size-fits-all. One should always first discuss any new treatment or management approach with their primary care doctor as well as rely on their own personal discretion and understanding of their symptoms and needs. Each person is unique, and no one understands your body and mind better than you.

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Appendix A

Dysfunctional Thought Record

Situation I am in	Automatic thoughts	Cognitive Distortions	Alternative response
(example)  I am sick with ME/CFS and worried about day-to day-life and sustaining a job	(example)  “I should be able to do this; what if I can’t work again? I’ll never reach my goals. I feel broken and like I am a failure”	(example)  All or nothing thinking Catastrophizing Should statement Negative self labeling	(example)  “I have to remember that I am sick and be kind to myself. Being able to work and make money is a real-life concern, but there are manageable things I can still tackle. I also have family support and am looking into disability benefits. I am still able to write and can do some work from home. I am not broken or a failure; in fact, I am very strong for persevering everyday with all of these added challenges. I have a lot to be proud of”
I feel nauseated and am having terrible pain.	I felt so much better yesterday, but it never lasts. I am never going to get well. I can’t cope with this.	All or nothing thinking Catastrophizing Over-generalization Disqualifying the positive	I feel really crappy today, but I have been having some better days lately too. Compared to X months ago, that’s a real improvement. This nausea is unbearable, but I am bearing it, and I will get through it like I always do.

(adapted from Murdock, 2013, p. 339)

## Appendix B

<b>Mock-up of a Coping Card</b>
1. Write down automatic thoughts and cognitive distortions. What's a more adaptive response?
2. Give yourself credit for what you do: large and small e.g. I managed to shower today. I went for a walk today. I practiced restorative yoga in bed today. I was kind to myself today etc.
3. I am strong
4. I am learning to tolerate uncertainty when it comes to my health and my day-to-day life
5. It is normal to feel overwhelmed sometimes.
6. When I feel _____ in my body I am experiencing panic/anxiety/depression etc.
7. Practice mindfulness and restorative yoga
8. I don't have to believe what I think.
9. Do something enjoyable that feels manageable e.g. watch a favourite tv show, read a book for a short time if energy permits, take a bath, talk to a friend, go for a walk if energy permits or sit outside etc.