Understanding MCS

A Therapist's Guide to Multiple Chemical Sensitivity and Environmental Illness

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The Center for English Language Arts Publishing
Boston, Massachusetts

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Publisher website: http://celaonline.com
Discount available on bulk orders: publishing@celaonline.com

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ISBN 978-0-9910504-2-0

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All names of clients and identifying information have been changed to protect privacy.

This book is intended for informational purposes only and does not constitute medical advice. If you feel that you may have MCS, EI, or a mast cell related disorder, please contact your physician to receive medical help. The information presented here is in no way a substitute for receiving medical advice and treatment from your doctor.

The books, articles, and websites mentioned in this work, and their content, are provided solely as informational and educational resources.

The Center for English Language Arts Publishing
Boston, Massachusetts

Where would I be without love, family, and friends

for

Martha Angelo
Joan Arches

Mum

Maureen, Erick,
Sara, Eric, Lee

Absent friends

and always for Paul

Thank you!

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Introduction

There are several different names that are used when talking about the chronic illnesses some people experience after exposures to chemicals: Mast Cell Activation Syndrome, Multiple Chemical Sensitivity, Environmental Illness, Sick Building Syndrome, Idiopathic Environmental Intolerance, Gulf War Syndrome, Desert Storm Disease, Gulf War Veterans Illnesses, mastocytosis. All of these are names of environmental illnesses or Eis.

Environmental Illness (EI) is an overarching term that is used to describe the illnesses and diseases that some people have whose symptoms and reactions occur or worsen when they are exposed to chemicals and substances in the environment, on other people, and on themselves. In an EI, something in the environment is toxic and/or an irritant or incitant and can cause individuals to have mild to life-threatening reactions from their exposure to the chemical or substance.

Multiple Chemical Sensitivity (MCS) is a term used to name the experience of being chemically sensitive. People who have sensitivities to multiple chemicals are typically suffering from an Environmental Illness (EI).

The effects of MCS and Eis on an individual and on their life can be devastating. Internationally MCS has been gaining increasing recognition as being a physical condition not psychological. As more and more agencies in the United States acknowledge MCS and other EIs as the physiological disabilities they are, based on current and ongoing medical research, and follow in the footsteps of the CDC, Social Security Administration, the American Lung Association, U.S. Consumer Product Safety Commission, U.S. Department of Housing and Urban Development, and the U.S. Department of Education, who continue to act increasingly in support of individuals with chemical sensitivities, I trust the American

Medical Association and medical community at large will ultimately pay heed.

Current research has shown a direct correlation between chemical sensitivities, MCS, and mast cells and mast cell activation spectrum related disorders. I have included information about Mastocytosis and mast cell related disorders. (For research and further information, see Heuser, "The Role of the Brain and Mast Cells in MCS," and the research conducted by T.C. Theoharides, PhD, MD at mastcellmaster.com.) The presenting symptoms typical of MCS often mirror many of the symptoms presented by individuals with mast cell related illnesses, and the main treatment protocol for both MCS and mast cell related diseases is avoidance of triggers. Clinicians working with clients who have mast cell related disorders and clinicians working with clients who have MCS will need to address many of the same issues in their treatment planning, goal setting, and treatments.

I have written this book as a tool and guide primarily for therapists—social workers, mental health counselors, expressive therapists, psychologists—but it is my hope that it will be used to inform all clinicians and health care professionals, to raise their awareness, and to deepen their knowledge and understanding as they plan the care and services they will provide for clients suffering from these very serious and chronic diseases.

Understanding MCS

1
What are EIs?

A Brief Overview: MCS

Multiple Chemical Sensitivity (MCS) is a twentieth century disability. A child of the post World War II explosion of popular chemicals for the home, plastics, petroleum products, and pesticides, MCS is robbing an increasing percentage of the population of their jobs, their homes, their relation-ships, and sadly their lives. We live in an age of chemical warfare and chemical disasters. The shelves of our stores bulge with items for personal care, sheets for the dryer, softeners, detanglers, deodorizers, fresheners, perfumes, car trees, pesticides, and plastics. There is a human cost.

Environmental Illness (EI) is an overarching term that is used to describe the illnesses and diseases that some people have whose symptoms and reactions occur or worsen when they are exposed to chemicals in the environment, on other people, and on themselves. In an EI, something in the

environment is toxic and/or an irritant or incitant and can cause individuals to have mild to severe and life-threatening reactions from their exposure to the chemical or substance.

Multiple Chemical Sensitivity (MCS) is a term that is used to name the experience of being chemically sensitive. People who have sensitivities to multiple chemicals typically are suffering from an EI.

Chemical sensitivities, Multiple Chemical Sensitivity (MCS), mastocytosis, Mast Cell Activation Syndrome (MCAS), and mast cell activation spectrum related disorders come under the overarching heading of Environmental Illness (EI). Asthma, lung cancer from cigarette smoke, mesothelioma (a cancer often caused by exposure to asbestos) are all Eis.

The National Institute of Environmental Health Sciences includes in their 2007 publication, “Environmental Diseases from A to Z,” in addition to asthma and cancers, dermatitis, emphysema, goiters, fertility problems, lead poisoning, mercury poisoning, immune deficiency diseases, kidney disease, nervous system disorders (which includes the brain, spinal cord, and nerves,) pneumocociosis (or black lung disease) and vision problems.

Research by Meggs and the National Academy of bcScience in 1996 showed 16% of the population in New Mexico with chemical sensitivities but only 2% having been diagnosed with MCS, in California almost 16% of the population with chemical sensitivities and 6.3% diagnosed with MCS or chemical illness, and that "4% of the U.S. population is becoming ill every day from chemicals, this means that over 11 million people have moderate to severe MCS," (Meggs cited in Gibson, 2002, 7-9). MCS is not psychological. It is a real, physiological illness.

A consensus definition and criteria for MCS were established in 1999 and published in *Archives of Environmental Health* in June of the same year. The consensus was signed by thirty-four clinicians and medical researchers from the United States and Canada. In it they state, "(1) The

symptoms are reproducible with repeated [chemical] exposure; (2) The condition is chronic; (3) Low levels of exposure [lower than previously or commonly tolerated] result in manifestations of the syndrome; (4) The symptoms improve or resolve when the incitants are removed; (5) Responses occur to multiple chemically unrelated substances; and (6) Symptoms involve multiple organ systems," (https://www.ncbi.nlm.nih.gov/pubmed/10444033).

In 2004, Bernie Howard, Acting Deputy Director for the Office of Disabilities at the U.S. Department of Housing and Urban Development (HUD), made a statement referencing the Fair Housing Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act, stating, "HUD considers Multiple Chemical Sensitivity to be a disability under these laws," (www.chemcialsensitivity foundation.org).

The Center for Disease Control (CDC) implemented a policy in 2009 that addresses the issue of chemical sensitivity in the workplace. It is a thirteen-page document created to "protect and maintain safe indoor environmental quality (IEQ)...to all CDC workers...in all their locations," (CDC, 2009, 1).

Eis such as MCS wreak havoc in people's lives. People do not always realize or know that what they are experiencing has a name. What they do know is loss. Many people with MCS and Eis are unable to work due to the onslaught of chemicals in their work environment. Many people with Eis have lost their jobs, their homes, their friends, their community, identity, and sense of self. The numbers are increasing. Veterans of wars are returning home needing treatment for a disability the American Medical Association does not yet recognize other than in inappropriate terms.

The Question of Cause: MCS

Several theories have been presented by different doctors and researchers about possible causes of MCS. Some believe that chemical sensitivity is caused by a high-level exposure to chemicals, a series of low-level exposures to chemicals, or a combination of the two.

The Environmental Illness Resource, an online information resource community for individuals with many different types of chronic environmental and mast cell related illness such as fibromyalgia, Irritable Bowel Syndrome, Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, and Autism, presents on their website a list of theories for possible causes of MCS that includes:

- Hypersensitivity in the limbic system of the brain. The functions of the limbic system include emotion, behavior, long-term memory, one's sense of smell. Animal studies have shown both large acute exposures and low-level exposures to certain organic chemicals can result in hypersensitivity of the limbic system to subsequent minute exposures to the same and similar chemicals.

- A cycle of elevated nitric oxide levels that leads to chronic sensitivity. Dr. Martin Pall, Professor Emeritus of Biochemistry and Basic Medical Sciences at Washington State University believes the symptoms are the result of a trigger (mainly chemical exposure) that results in the body getting stuck in a cycle of elevated nitric oxide levels leading to chronic sensitivity of the brain and central nervous system.

- Carbon monoxide exposures

- Impaired detoxification/low glutathione paired detoxification of chemicals foreign to the body. (http://www.ei-resource.org/illness-information/environmental-illnesses/multiple-chemical-sensitivity-%28mcs%29/)

Pamela Reed Gibson, PhD, psychologist and professor at James Madison University, has conducted research into many aspects of MCS and its effects on individuals who experience chemical sensitivities. She includes as possible causes:

- Limbic kindling and neural sensitization where a nerve cell has been isolated and stimulated repeatedly with either chemicals or electricity at a level that does not cause it to fire. After these exposures, the nerve cell eventually fires at an exposure level to the chemical/electricity that is below the amount typically needed for the nerve cell to fire. Nerve cells can be kindled to react at lower levels of stimulation through repeated exposures.

- Neurogenic inflammation where cells in the airway become damaged from irritants and generate inflammation. Neurologic connections with other parts of the body develop reactions and causes inflammation at these other sites in the body, and MCS develops in much the same way as Reactive Airway Dysfunction.

- Depleted enzyme systems (Gibson, 2002, 5-7).

Environmental Medicine is an area of medicine that focuses on the illnesses people experience through their interaction with the environment and their exposures to the

chemicals or excitants found in the environment. One of the basic theories of Environmental Medicine is the concept of "total load." The website of The American Academy of Environmental Medicine (AAEM) shares the following information regarding total load:

"The total load concept postulates that multiple and chronic environmental exposures in a susceptible individual contribute to a breakdown of that person's homeostatic mechanisms...Multiple factors coexist, usually over a prolonged period of time, in bringing about the disease process. Individual susceptibility to environmental agents occurs for a variety of reasons including genetic predisposition, gender, nutritional status, level of exposures to offending substances, infectious processes, and emotional and physical stress," (www.aaemonline.org/introduction.html).

The concept of total load in chemical sensitivity and EIs means that a person's body can tolerate only so much exposure to chemicals before it becomes saturated and reaches its limit; before the person becomes sick.

Sherry Rogers, MD, a physician and specialist in Environmental Medicine, lists in her book *Chemical Sensitivity* (1995), three important principles of chemical sensitivity:

1. It can produce *any* symptom, in *any* person, at *any* time, but the brain is the most common target organ involved;

2. There is a vast range of individual susceptibility;

3. The spreading phenomenon – exposure to one chemical produce[s] susceptibility to other environmental components. (8-9).

She highlights body chemistry—a person's genetic and inherited predisposition and ability—as a key factor regarding

why everyone is not affected equally when exposed to chemicals, and why some people are better able to process these chemicals, to metabolize, break down, and get rid of them, than others, "How well we perform this enormously complicated job depends on our genetic or inherited ability and on the extent of the environmental burden [total load] of chemicals challenging us," (9).

A Brief Overview: Mast Cells & Mast Cell Disorders

Everyone has mast cells throughout their body in every organ system, including the brain. When a person comes in contact with a chemical or substance to which they react, their mast cells degranulate and give off histamine and other chemicals. The histamine and other chemicals pumped into their system by the degranulating mast cells cause the person to exhibit the symptoms we commonly associate with an allergic reaction including sneezing, itching, watery eyes, rashes, skin flushing, hives, difficult breathing, dizziness, mood changes, cognitive impairments, GI distress, and more.

In a mast cell/mast cell activation related disorder, something has gone wrong with the mast cells. There may be, for example, too many of them, they could be irregularly shaped, or they could be degranulating—as in mast cell spectrum activation disorders—and be over active for unknown reasons. A person with a mast cell/mast cell activation related disorder may experience severe and life-threatening reactions to even very small amounts of a chemical or substance. Individuals with a mast cell/mast cell activation related disorder need to avoid exposures to the chemicals and substances to which they react.

Mastocytosis (masto), Mast Cell Activation Syndrome (MCAS), and mast cell activation related disorders share many of the same symptoms typically associated with MCS. Current research (see T.C. Theoharides, MD, research at

mastcellmaster.com) has shown that the reactions to triggers that individuals with MCS experience have a basis in mast cell function and mast cell degranulation. Theoharides includes as diseases with a basis in mast cell activation and degranulation asthma, autism, Irritable Bowel Syndrome, Chronic Fatigue Syndrome, interstitial cystitis, migraines, and fibromyalgia, (see mastcellmaster.com).

Mastocytosis and mast cell activation spectrum disorders share many of the symptoms typically associated with MCS (see Meggs, "Mechanisms of allergy and chemical sensitivity.") I know of two clients who have been diagnosed with both MCS and a mast cell related disorder. One client has MCS and Mastocytosis. The other client has MCS and Mast Cell Activa-tion Syndrome (MCAS). Current research suggests a link between MCS and mast cells. Gunnar Heuser, MD, an expert researcher in the field of neurotoxicology, writes in his article "The Role of the Brain and Mast Cells in MCS," of the "overlapping syndromes of mastocytosis and MCS," stating, "At this time the diagnosis of MCS is considered justified only in the absence of diseases such as mastocytosis...This exclusion will require that all patients with MCS be tested for mast cell disorder...I believe that this indeed should be done...I postulate that chemical injury can trigger a mast cell disorder," (www.tldp.com/issue/210/roleoftheb.htm and also located at www.ei-resource/org/articles/multiple-chemical-sensitivity-articles/the-role-of-the-brain-and-mast-cells-in-mcs/).

The Mastocytosis Society Canada has an article posted on their website (www.mastocytosis.ca) that provides clear and detailed information about EIs, Mastocytosis and mast cell related disorders, and the lived experiences of many of the individuals who have these diagnoses. These insights can also be applied to many people with EIs regarding the disabling effects of their illness and its impact on their lives. I have included the article here in its entirety.

The Mastocytosis, MCAS & IA Patient Experience

Originally published January 2011
Updated April 2012

We are sharing information about the rare disorders Mastocytosis (Masto), Mast Cell Activation Syndrome (MCAS), and Idiopathic Anaphylaxis (IA), which we have derived from a number of sources in Canada and internationally. Our intention is to educate by sharing Mastocytosis patient experiences reported over 10 years. These experiences are often beyond what has been researched and published in medical journals. Masto, MCAS, and IA can be severe and equally disabling. This is intended for general information purposes only and of course does not constitute medical advice. PLEASE SEE YOUR PHYSICIAN for medical advice and treatment.

It is unknown what causes or triggers Mastocytosis, MCAS, or IA. Prolonged stress, emotional or physical trauma, illness/ infections, surgery of any kind, and even childbirth have all been reported as contributing factors to the development or escalation of the disease. The basis of Mastocytosis and MCAS is a malfunctioning yet important immune system cell called a mast cell. Anything which triggers the immune system, including surgery, will trigger mast cell degranulation. The chemicals released through mast cell degranulation are the initiators of severe and prolonged symptoms of Mastocytosis, MCAS, and contributes to IA.

Mast cells are created in the bone marrow and are found in every part and system of the human body, including the brain. Everyone has mast cells. In healthy people, mast cells function correctly. In Mastocytosis and MCAS patients, the mast cells may be malformed, increased in number, and/or behaving abnormally. Mastocytosis is classified as a neoplastic disorder (like cancer) and recently, also as a stem cell disorder. MCAS patients will have various markers of Mastocytosis in their bone marrow but may not meet the entire [World Health Organization] WHO diagnostic criteria for Masto. It is theorized that MCAS may actually be the early stages of Systemic Mastocytosis but more research needs to be done in that area to know for sure. Due to the mast cell being part of the immune system, Masto and MCAS patients often experience

autoimmune-type responses but these responses are secondary to the mast cell disease.

Mastocytosis Society Canada strives to educate patients, caregivers, the general public, and physicians fully about these rare disorders. This is crucial to target helpful treatments to lessen suffering and hopefully slow down progression of the illness. Current treatment focuses on managing the ongoing symptoms of the disease but do very little, if anything, to slow its progression. There is presently no cure for Mastocytosis, MCAS or IA.

Most physicians do not recognize or understand Mastocytosis, MCAS, or IA as most doctors have not been trained to recognize these disorders. In fact, most mast cell disease patients go years before getting a proper diagnosis. Misdiagnosis is very common as a doctor cannot diagnose what he or she has never heard or witnessed. Additionally, the existing diagnostic tests have proven to be unreliable and inconsistent, evidenced by disparate results amongst the international Mastocytosis, MCAS, and IA patient base.

Internationally, there appears to be a consensus amongst Mastocytosis patient groups, mast cell researchers, and physicians experienced in treating Mastocytosis, MCAS, and IA, as to the following:

1. Existing Mastocytosis diagnostic tests need to be improved or completely new tests need to be developed. We estimate that approximately half the Mastocytosis patient base worldwide does not meet the current diagnostic parameters, however they do experience benefits from being treated for Mastocytosis. Many patients are being diagnosed clinically with MCAS and/or IA based solely on their symptoms, in an effort to help them find some relief. This approach is working resulting in saving patients' lives, and physicians acknowledging that medicine just does not know nearly enough about mastocytosis yet.

2. Patient experiences of symptoms and secondary conditions (arthritis, osteoporosis, pancreatic tumours, chronic fatigue, ehlers danlos, connective tissue diseases, POTS, fibromyalgia, raynauds, cancer, cerebral aneurysms), are

often beyond what has been medically outlined as within the Mastocytosis definition. However, many Mastocytosis patients suffer at least one of these complications. Some have/had more than one.

3. Medical research has barely scratched the surface in full defining, diagnosing, and treating Mastocytosis, MCAS, and IA. As a result, the stages or classifications of Mastocytosis, and the resulting effects or symptoms of each stage, are misleading or incomplete. MCAS and IA are often not addressed. Medicine does not know this disorder or mast cells nearly well enough to provide answers to all that patients endure and suffer. Physicians experienced in treating Mastocytosis, MCAS and IA patients are aware of this. Many Mastocytosis patients experience some or all of the symptoms in the same severity (*Reference: The Mastocytosis Research Institute in France,* http://www.ncbi.nim.nih.gov/pmc/articles/PM C2386235/).

   For example, Cutaneous (skin) forms and Indolent Systemic Mastocytosis present the same symptoms as Aggressive Systemic Mastocytosis, both in type and severity. Thus, many patients with Skin involvement, Indolent Systemic Mastocytosis, MCAS, and/or IA suffer continuously and live extremely restricted, largely isolated, quiet lives in order to best control their immediate environments. These are not benign or minor diagnoses. All forms of Mastocytosis, including MCAS and IA, are in many cases life-threatening and patients diagnosed with all forms typically experience continual escalation of current symptoms, and development of new symptoms over time.

4. Current treatments do not remove or prevent all the symptoms. Patients with Mastocytosis, MCAS, and IA suffer a wide range of life-threatening and/or disabling and permanently damaging symptoms. This prevents many patients from living a normal life and basically existing in a state of catering to their disease to try to lessen their suffering. The most basic daily life activities induce suffering and internal damage over time for Mastocytosis patients. For example, symptoms are triggered by simple

> activities such as daily bathing, inhaling airborne scents/chemical toxins, walking or any other exercise, eating, cognitive processing (concentration, learning and memory impairments,) being in extreme temperatures (hot or cold in weather or water,) talking for extended periods of time, engaging in social activities, stress or fatigue, and even for some, getting dressed every day. Friction and sensitivity to clothing, pressure, and coming in contact with man-made materials are enough to trigger symptoms for some patients. Foods and drinks often play an enormous role in triggering the symptoms, with the main troubles caused by foods and drinks which are naturally high in Histamine, Tyramine, Gluten, and/or Salicylates.

Mastocytosis, MCAS, and IA negatively impact working and personal lives. Many of these patients have a restricted diet of very few foods they can safely eat, constant fatigue, episodes of vertigo, and anaphylaxis as well as inability to exercise on a regular basis (includes walking) due to fatigue and weakness and all the other symptoms. On a daily basis, many patients experience difficulty with tasks requiring concentration, learning, retention, or anything relying on memory or information processing skills. Many people suffering with these rare disorders cannot commit to anything in terms of a schedule or regular routine because their symptoms vary in type and severity from day to day and often hour to hour. They are continuously symptomatic with disabling effects such as fatigue, sudden unexplained episodes of drops in blood pressure (very common,) anaphylaxis and anaphylactoid reactions, flushing, shaking and tremors, and poor concentration.

Most Mastocytosis, MCAS, and IA patients find that medications do not eradicate or prevent their symptoms. This disorder requires avoidance or minimization of exposure to triggers in addition to taking medications. Triggers can be anything which cause mast cells to degranulate. This includes hormonal activity, emotions (positive or negative), physical activities, positive/negative stress, foods and drinks, temperature, and exercise/exertion of any kind. It is only by controlling their exposure to triggers in addition to taking medications, that they can achieve some relief from the symptoms, but it is not total relief and this does not return them to functioning normally on a consistent and reliable basis. Their good days are

very few and far between, rarely even lasting a full day. Most of these patients share this same experience.

Typically, Mastocytosis, MCAS, and IA patients experience increasing limitations and greater suffering over their lifetime. If they push against their symptoms, believing that "trying harder" or pushing to complete tasks (laundry, grocery shopping, visiting a friend, cleaning,) the symptoms become more severe and prolonged and continue to ricochet setting off other symptoms for days, weeks, or months on end. There is no predictability to the array of symptoms. There is no way to make the symptoms behave consistently or to be able to garner better control over them. The medical research community has not yet fully figured out mast cell disorders. In the meantime, patients are driving the medical research via their physicians reporting the escalating symptoms and secondary and tertiary complications suffered by their patients. Everyone wants to have the answers, patients most of all.

Mastocytosis, MCAS, and IA patients often look normal or healthy to others, especially when they are enjoying one of their better days/moments when their symptoms are subdued or well controlled, as during these times they may be able to be more active. However, these stable periods do not endure and it is the fluctuating nature of the illness that causes much difficulty for the person with Mastocytosis. Many of these patients are not seen regularly by people outside their immediate family or caregiver except for those rare occasions when they are feeling well. As a result, people fail to understand Mastocytosis, Mast Cell Activation Syndrome, and Idiopathic Anaphylaxis, and the extent to which they prevent individuals from living normal and active lives.

Mastocytosis, Mast Cell Activation Syndrome, and Idiopathic Anaphylaxis are irreversible and life-threatening rare disorders, and in most cases the symptoms are extraordinarily difficult to manage.

by Mastocytosis Society Canada
www.mastocytosis.ca/masto.htm

The Question of Cause: Mast Cell Disease

According to the U.S. Department of Health & Human Services, National Institutes of Health (NIH) Genetic and Rare Disease Information Center (GARD), most cases of mast cell disorders that are systemic are caused by somatic mutation in the KIT gene. The KIT gene encodes a protein that helps to control many important cellular processes such as cell growth and division, survival, and movement (https://rarediseases.info.nih.gov/diseases/8616/systemic-mastocytosis).

This protein is also important for the development of certain types of cells including mast cells (immune cells that are important for the inflammatory response). Mutations in the KIT gene can lead to an overproduction of mast cells which accumulate in the internal organs and lead to the symptoms of mast cell illnesses (IBID).

Although there are cases of systemic mast cell disease reported in more than one family member, GARD reports these cases as being rare and that the majority of systemic mast cell illnesses occur in people with no family history of the condition (https://rarediseases.info.nih.gov/ diseases/8616/systemic-mastocytosis). However, when it does occur in more than one family member, it may be inherited in an autosomal dominant manner. This means that the mutations are located in the germ cells (egg and sperm). To be affected by an autosomal dominant condition, a person needs to have mutation in only one copy of the responsible gene in each cell. A person with this form of a systemic mast cell disease has a 50% chance with each pregnancy of passing the mutation to his or her child (IBID).

From the Mast Attack website: (https://www.mastattack.org/2015/05/mast-cell-disease-fact-sheet/)

Mast Cell Disease

- Mast cell disease includes all forms of disease in which your body makes too many mast cells or those mast cells do not function correctly.
- Mast cell disease is rare, affecting less than 200,000 people in the US.
- 90% of mast cell disease only affects the skin (edited to add: based upon estimates of mastocytosis population – counts of MCAS/MCAD not yet available).
- The remaining 10% is systemic disease.
- Multiple people in a family sometimes have mast cell disease, but the heritable gene has not been identified.
- Cutaneous and systemic mastocytosis, mast cell sarcoma and mast cell leukemia are proliferative, meaning your body makes too many mast cells.
- Mast cell activation syndrome/mast cell activation disorder are not proliferative, meaning there is a normal amount of mast cells behaving badly.
- Monoclonal mast cell activation syndrome is borderline for proliferation, meaning the body is thinking about making too many mast cells or is just starting to.
- The biggest risk for most mast cell patients is anaphylaxis, a severe, life-threatening allergic reaction that can be triggered by many things.
- There is no cure for mast cell disease, but children sometimes grow out of it for unknown reasons.

Types of mast cell disease

- Cutaneous mastocytosis (CM) is too many mast cells in the skin.

  - This causes rashes (sometimes permanent), hiving and blistering.
  - Urticaria pigmentosa (UP), telangiectasia macularis eruptive perstans (TMEP) and diffuse cutaneous mastocytosis (DCM) are the types of cutaneous mastocytosis. (Edited to include DCM.)
  - It is diagnosed by skin biopsy.
  - You can also have mast cell symptoms that aren't related to the skin, like nausea, vomiting, weakness, headache, palpitations, etc.
  - Solitary mastocytoma is a benign mast cell tumor usually found on the skin, but sometimes elsewhere. It is sometimes included in the cutaneous mastocytosis category.
  - Children sometimes outgrow cutaneous mastocytosis.
  - When adults develop cutaneous mastocytosis, they usually also have systemic mastocytosis.
- Systemic mastocytosis is too many mast cells in an organ that is not the skin.
  - The bone marrow is usually where too many mast cells are found, but it is sometimes found in other organs.
  - You can have systemic mastocytosis with or without cutaneous mastocytosis.
  - It is diagnosed by biopsy of an organ other than skin. Other testing like scans and organ tests may be necessary.
  - Indolent systemic mastocytosis (ISM) is stable with no organ damage. Life span is normal.
  - Smoldering systemic mastocytosis (SSM) is progressing towards a more damaging form with some signs that organ damage is beginning. Life span may be shortened if progression is not controlled.
  - Aggressive systemic mastocytosis (ASM) is a dangerous form with organ damage that

requires chemotherapy to control. Life span is shorter.
    - Mast cell leukemia (MCL) is a malignant form with organ damage that requires chemotherapy. Life span is significantly reduced.
    - Mast cell sarcoma(MCS) is a malignant form with organ damage that requires chemotherapy. Life span is significantly reduced.
- Mast cell activation syndrome (MCAS)/ Mast cell activation disorder (MCAD) is when a normal amount of mast cells behave badly. (Edited to change mast cell activation disease to mast cell activation disorder.)
    - It is clinically similar to indolent systemic mastocytosis. Life span is normal.
    - Biopsies are negative.
- Monoclonal mast cell activation syndrome (MMAS) is when a person meets some of the criteria for systemic mastocytosis but not all. It indicates the mast cells are starting to think about abnormal proliferation.
    - It is clinically similar to indolent systemic mastocytosis. Life span is normal.
    - Biopsies are positive for one or two minor criteria for systemic mastocytosis.

(from Lisa Klimas Mast Attack, https://www.mastattack.org/2015/05/mast-cell-disease-fact-sheet/)

Recognizing EIs

Individuals who have EIs or are suspected of having EIs, such as MCS and mast cell spectrum related disorders, present with myriad complaints involving multiple organ systems. They frequently feel unwell all the time. EIs are often misdiagnosed or not diagnosed by physicians. Many doctors are unwilling to consider or acknowledge a diagnosis of MCS or other EI. I know a client who had a physician laugh

in his face while telling him, "I don't condone or support your diagnosis. I don't even think it's real." Another client had a physician who, after reviewing medical notes from a specialist, forcefully stated, "What you need are intensive psychiatric interventions." This client has a systemic mast cell disease: Mast Cell Activation Syndrome (MCAS). The physician in question had access to the mast cell specialist's notes because the physician's primary care office was part of the same hospital as the mast cell specialist. The physician continued, telling the client, "I will put a stop to these needless and unnecessary referrals." The doctor was wanting to put a stop to the referrals to the mast cell specialist who was treating the client with anti-mast cell mediator medication that was showing positive results.

The individual with MCS or another EI who comes for counseling and psychotherapeutic support may feel trapped into explaining their very real physiological illness in psychiatric terms. Although individuals with EIs may present as having psychological symptoms, it is vital to recognize that not all psychological reactions have a psychological cause. A very good example of this is anaphylaxis.

Anaphylactic and anaphylactoid are two types of life-threatening allergic reactions that happen in your body in two different ways. Anaphylactic reactions occur in people who have been previously exposed to a substance at least once and have become sensitized, through the exposure, to the substance. Anaphylactoid reactions, however, do not require prior exposure and sensitization. Anaphylactoid reactions can occur following a first-time, single exposure to a substance. Anaphylactic and anaphylactoid reactions produce the same clinical signs and symptoms in the person and, medically, they are both treated in the exact same way. The term 'anaphylaxis' is used for both types of reaction (http://www.emsworld.com/article/10324669/anaphylactic-and-anaphylactoid-reactions).

Epipen injectors are prescribed for people who are at risk for anaphylaxis, as anaphylaxis can be life-threatening. An Epipen contains a single dose of epinephrine that a person injects into their outer thigh when they are experiencing the symptoms of anaphylaxis. The Epipen website, http://www.epipen.com, notes: "Symptoms of anaphylaxis may include trouble breathing; wheezing; hoarseness (changes in the way your voice sounds); hives (raised reddened rash that may itch); severe itching; swelling of your face, lips, mouth, or tongue; skin rash, redness, or swelling; fast heartbeat; weak pulse; feeling very anxious; confusion; stomach pain; losing control of urine or bowel movements (incontinence); dizziness, fainting, or 'passing out' (unconsciousness)." Another common symptom is a feeling of impending doom.

The Environmental Illness Resource lists several of the most common symptoms a person with MCS may experience when reacting to an exposure. These include "fatigue, headaches, disorientation, dizziness and faintness, nausea, flu-like symptoms, irregular or rapid heartbeat, muscle and joint pain, gastrointestinal problems, mood disturbances such as depression/anxiety/irritability, short-term memory problems, asthma and breathing problems, rashes," (http://www.ei-resource.org/illness-information/environmental-illnesses/multiple-chemical-sensitivity-(mcs)/).

Unless informed otherwise, a doctor, clinician, or other healthcare professional may mistake symptoms of anaphylaxis (e.g., anxiety, confusion, stomach pain, feelings of impending doom,) as psychological symptoms stemming from a psychological cause rather than, more accurately, as psychological symptoms stemming from a physical cause. The same is true with many EIs such as MCS and mast cell activation related disorders. Unless informed otherwise, a doctor, clinician, or other healthcare professional may mistake symptoms of an EI such as MCS (e.g., anxiety, confusion, disorientation, stomach pain, irregular or rapid heartbeat, mood disturbances,) as psychological symptoms

stemming from a psychological cause rather than, more accurately, as psychological symptoms stemming from a physical cause.

The behaviors of a person who has MCS or an EI can often be confused with the symptoms of mental illness, for example, Obsessive Compulsive Disorder or a delusional disorder. A person with MCS may seem hyper-vigilant and compulsive to an untrained observer who is not informed regarding their medical need for avoidance and what that entails. Instead, what is seen is someone asking a lot of detailed questions about the physical environment, about what laundry soap you wash your clothes with, what brand of deodorant you wear, what shampoo you use, what the carpets in your office are cleaned with and how often, what you use to wash the surfaces and windows in your office, what type of heating system is in use in the building, are there air fresheners, when was the last time you had your office treated by an exterminator and exactly what pesticide was used, while appearing to be fixated on invisible fumes—and the harm these fumes are causing them—that no one else seems able to perceive.

Triggers and Reactivity

Individuals with MCS and Eis can experience mild to severe reactions from exposures to often very minute amounts of chemicals. The chemicals to which a person with MCS can react vary from person to person, as do the specific reactions. One person with MCS or an EI may experience dizziness, agitation, and cognitive impairments when exposed to car exhaust fumes. A second person with MCS or EI may experience severe abdominal and stomach cramping, diarrhea, and nausea when exposed to car exhaust fumes. A third person with MCS or EI may not react to car exhaust fumes at all. However, each and every person with MCS or an

EI will have consistent reactions to their specific triggers. The person with an EI who becomes dizzy, agitated, confused, and disoriented when exposed to Brand X laundry detergent will become dizzy, agitated, confused, and disoriented every time they are exposed to Brand X laundry detergent.

The Environmental Illness Resource notes on their website regarding triggers: "Reactions in MCS are triggered by a vast array of everyday chemicals from perfume to diesel exhaust...Typically a sufferer will notice a sensitivity to one or two things to start with, perfume and cigarette smoke for example, and then will rapidly become sensitized to more and more chemical sources over a relatively short period of time,"(http://www.ei-resource.org/illness-information/environmental-illnesses/multiple-chemical-sensitivity-(mcs)/).

A partial list of chemicals and situations/environments to which persons who have or are suspected of having MCS or an EI may react (on themselves, on others, and in their environment) includes:

- Pesticides
- Plastics
- Exhaust fumes (car, truck, machinery e.g. mowers, blowers)
- Paint, finishes, solvents, shellac
- Inks and dyes
- Detergents
- Cleaning products at work (industrial strength)
- Household cleaning products
- Laundry detergents
- Fabric softeners
- Dryer sheets
- Disinfectants and germicides
- Hand sanitizers
- Air fresheners, room deodorizers, car trees
- Petroleum products
- Carpet refreshers

- Carpets (especially new carpets)
- Adhesives/solvents
- Cooking spices
- Shampoos and conditioners
- Hair sprays/gels/mousse
- Soaps, lotions, bath gels
- Personal care products
- Makeup/cosmetics
- Cigarette smoke
- Air conditioners
- Heating/air conditioning systems that recycle and re-circulate the air
- Gas heating systems
- Renovation work (interior and exterior)
- Particle board (and many, many other building materials)
- Dry cleaning chemicals and anything that has been dry cleaned
- Copy machine chemicals
- New clothing
- Stress
- Intense emotions (positive or negative)
- Extreme temperatures (cold or hot)
- Physical activity, exercise
- Preservatives in food and medications
- Additives in food and medications
- Flame retardant chemicals found on clothing, mattresses, bedding, furniture, carpeting

Some people with MCS or an EI may react to electrical and magnetic fields when exposed to power lines, cell phones, electric generators, electrical appliances and machinery. Electric and magnetic fields (EMF) invisible lines of force that surround any electrical device that is plugged in and turned on. EMFs are made up of waves of electric and

magnetic energy moving together (radiating) through space. Electrical fields are produced by electric charges and magnetic fields are produced by the flow of current through wires or electrical devices, (https://www.safespace protect ion.com/emf-health-risks/what-is-emf). The evidence of studies and research continues to mount throughout medical communities about the harmful effects to our health from exposures to EMFs, (https://www.safespaceprotection.com/ emf-health-risks/emf- health-effects/).

The California Department of Health Services found, in 1998, that electrical sensitivities affected 3.3% of the 2,072 adults surveyed in their California Adult Tobacco Survey. 3.3% extrapolates to approximately eight million Americans with electrical sensitivities (Gibson, 2002, 8-9).

A partial list of common reactions individuals may experience includes:

- Nausea, vomiting, diarrhea
- Increased need to urinate
- Stomach and abdominal pain/cramping
- Exhaustion, extreme lethargy
- Dizziness
- Confusion, disorientation, forgetting
- Difficulty concentrating
- Problems with breathing
- Tongue swelling, airway swelling
- Irregular heart beat, tachycardia
- Elevated blood pressure
- Low or sudden drops in blood pressure
- Elevated pulse rate
- Anxiety
- Panic
- Agitation, irritability
- Anger
- Weeping

- Suicidal ideation
- Numbness and tingling to skin and extremities
- Tinnitus
- Nasal congestion, runny nose
- Chest pressure and pain
- Joint/muscle/bone pain
- Rashes, hives, skin eruptions
- Headaches, migraines
- Fever, flu-like symptoms
- Blurred vision, double vision
- Swelling of feet, hands, arms legs, fingers, toes
- Swelling of lips, tongue, roof of mouth, face
- Uterine cramping, bleeding

Reactions do not always occur immediately. Reactions can occur four hours, eight hours, sixteen hours, two or three days after an exposure. Reactions can last for weeks or longer leaving the person exhausted, dizzy, in pain, with varying degrees of cognitive impairment, unable to work, and often with lingering GI distress. The most basic daily life activities can become difficult if not impossible to perform.

Current Medical Treatment Protocols

Picture your human body as a clear drinking glass. You wake in the morning, the glass is relatively empty. You go to work, school, drive the car, walk, eat, go shopping, spend time with friends, go to a restaurant. As you move through your day, the glass fills with the chemicals you encounter through breathing, through foods, through touching and handling items, in the air, chemicals you absorb through your skin, eyes, and hair. A healthy person's body is able to process these chemicals more efficiently. A person with MCS is not so able. The glass fills, and fills, and fills until it over-flows. The way for the glass to empty is to avoid exposures to

the chemicals that fill it. It is the job of every person with MCS to keep their "glass" as empty as possible.

Chemical sensitivity does not follow the rules of drug-oriented medicine. Drugs and surgery are currently the first line approaches in conventional western medicine in the treatment of most diseases. Give a drug, a foreign chemical, to a person with MCS who already has a compromised system and you will make that person worse (Rogers, 1995, 11).

There is no cure for MCS. There is no cure for mast cell related disorders. Individuals with MCS and mast cell related diseases must avoid exposures to the chemicals to which they react. Repeated exposures cause more and more damage and harm. The person becomes more and more sensi-tized to the chemicals with every exposure. Their reactions become increasingly severe while being exposed to smaller and smaller amounts of chemicals. A client with MCS and MCAS explained it to me this way:

> *I had to see the doctor. The doctor's office is in a hospital and this one particular hospital has horrible, horrible fumes. Worse than in any other hospital I've been in. Every time I go to see this doctor in this hospital, I run the risk of never ever again being as healthy as I was just prior to the visit. It's happened. The hospital that my MCS specialist is in has the most fumes of any other hospital I've been in. Before I saw my MCS specialist for the first time, I needed only half a Benadryl for a reaction—tongue swelling, airway closing, difficulty breathing—once or twice in a day, and not every day. I could wear my earrings. I could eat organic avocados and organic tomatoes. I reacted so badly from that first visit that ever since I've had to take Benadryl in order to eat anything at all—a whole tablet, not a half like before. I*

became so much more sensitized to things that I was able to tolerate before the visit. That first visit was a year ago. I still take four, five, six doses of Benadryl or more every day, whole pills, or else I can't eat, can't breathe. Plus hydroxyzine [for respiratory distress]*. I used to be able to eat twelve things. Ever since that first visit I can only eat six things. Now I react to things I didn't used to react to before. I'm not able to tolerate things that didn't bother me so much before. My hands and feet never used to swell up before. It's awful, scary. Less and less makes me react worse and worse. And it lasts for longer and longer. Weeks. Months.*

There are different protocols and combinations of protocols that may be used by doctors who treat individuals with MCS. Chelation therapy is used by some physicians to remove heavy metals from the body; vitamin and nutrient supplements such as folic acid, B12, increased daily doses of vitamin C, may be prescribed; treatments with nebulizers may also be recommended. Issues regarding diet may be focused on and may include monitoring not only the foods ingested but the chemicals associated with the foods and their packaging, as well. Many doctors recommend eating organic foods. Regardless of the associated treatments that individuals with MCS may or may not utilize, everyone with MCS absolutely must avoid exposures to the chemicals to which they react on themselves, on others, and in their environment.

The protocols used by doctors who treat patients with mast cell related disorders such as Mast Cell Activation Syndrome (MCAS) can be very individualized, focusing on relieving that person's symptoms, and may include antihistamines (e.g., Benadryl, hydroxyzine, Claritin, Allegra, Zantac, doxepin), anti-mast cell mediator medications (e.g., Gastrocrom,

cromolyn sodium), and steroids (e.g., Prednisone) to stabilize mast cells. (www.mastocytosis.ca/treatment.htm).

The Mastocytosis Society, Inc., (USA) provides on their website an “Emergency Care for Mast Cell Disease Patients” brochure detailing precautions for these patients including:

- Mast cell activation symptoms can quickly disintegrate into anaphylaxis, and simple symptoms should never be overlooked nor should treatment be delayed

- Additional doses of H1 and H2 antihistamines may be needed to control itching, abdominal pain, nausea, diarrhea and bloating even after acute anaphylaxis has responded to treatment

- Control the patient’s environmental temperature and stress to avoid setting off a mast cell reaction again (http://tmsforacure.org/documents/TMSERBrochure.pdf)

There are many psychotropic medications prescribed in the treatment of anxiety and other psychological disorders, as well as in the treatment of insomnia, motion sickness, and vertigo, (e.g., Elavil, Xanax, Trazodone, benzodiazepines such as diazepam/Valium, clonazepam, lorazepam/Ativan, meclizine,) that also are antihistamines, have antihistamine properties, and/or can inhibit mast cell activity through various mechanisms of action (see Yousefi, et al, 2013, "The 1, 4-benzodiazepine Ro5-4864 (4-chlorodiazepam) suppresses multiple pro-inflammatory mast cell effector functions"; Hoffman, et al, 2013, "Inhibitory effects of benzodiazepines of the adenosine A(2B) receptor mediated secretion of interleukin-8 in human mast cells.")

When mast cells become active—degranulate—they release histamine and other chemicals into the body. It is the release of histamine that causes the reactions we commonly

associate with allergic responses. Research suggests a connection between MCS and mast cells (see Heuser, 2013).

What this means is that a client with an EI such as MCS or a mast cell related disorder when prescribed, for example, certain anti-anxiety medications may show positive effects and de-creased symptoms but the positive effect and decrease in symptoms are not due to a psychotropic medication acting on and improving a psychological condition. The positive effect and decrease in symptoms are due to the client taking a medication that is an antihistamine, has antihistamine and/or has antihistamine-like properties, and/or is a mast cell activity inhibitor.

Although the individual may appear to be responding to an anti-anxiety medication, what is more likely is that the person is responding to taking an antihistamine and/or mast cell activity inhibitor, and the resulting stabilization of the mast cells and/or blocking of histamine is what is causing the reduction in symptoms. Symptoms decrease because mast cell degranulation decreases as mast cells are stabilized and also because of the antihistamine and/or antihistamine-like properties blocking histamine receptors and decreasing reactions. It is a case of a person being prescribed a right-acting medication for a wrong reason (see Hain, 2013; Hoffman K., et al, 2013; Stahl, 2008; Yousefi, et al, 2013).

2
DSM-5 and EIs

Coding and EIs: ICD Codes

The *International Classification of Diseases* (ICD) is a system of codes used to classify and diagnose diseases. It is owned and published by the World Health Organization (WHO) and is used by clinicians, practitioners, hospitals, insurance companies, and other agencies throughout the world. The United States is required to use the ICD to classify injuries and diseases through an agreement they have with WHO. WHO periodically revises and updates the ICD. In the United States in 2014, at the time the first edition of this book was originally written, we were using the ninth revision of the ICD, or the ICD-9. However, the rest of the world had been using the ICD-10 since 1993. It became mandatory that the United States shift from the ICD-9 to the ICD-10 starting October 1, 2014. WHO released the ICD-11 on June 18, 2018 which is available on the WHO website at www.who.int/classifications/icd/en/.

There are many ICD codes for EIs that apply to MCS and EIs in general, medical terms, for example, 989.8 Toxic Effect of Other Substances Chiefly Nonmedicinal as to Source, and 989.9 Toxic Effect of Unspecified Substance Chiefly Nonmedicinal as to Source, as well as specific medical conditions that occur due to a person's exposure to a chemical and the specific reaction, for example, 506 Respiratory Conditions Due to Chemical Fumes and Vapors, 310.8 Cognitive Disorder Due to Neurotoxin Exposures, 506.4 Chronic Respiratory Conditions Due to Fumes and Vapors, E980.7 Poisoning by Agricultural and Horticultural Chemical and Pharmaceutical Preparations, E997.2 Injury Due to War Operations by Gases, Fumes, and Chemicals. New ICD codes were implemented in 2017 specific to mastocytosis, Mast Cell Activation Syndrome (MCAS), and other mast cell activation spectrum related disorders. Visit The Mastocytosis Society website at https://tmsforacure.org for specific information.

It is important to keep at the forefront when diagnosing, coding, and planning for a client with an EI or suspected of having an EI, MCS, masto, or a mast cell activation related disorder that many of the issues they present with are secondary or due to the physical illness, and that these symptoms are then compounded by the normal emotional reactions one experiences to having and living with a chronic illness. However, there can also be clients with MCS or an EI who have an actual history of mental illness. It is not always an easy task to tease apart what symptoms are physiological and chemical reaction based from symptoms that are indeed psychologically based. A history of mental illness by itself does not negate a diagnosis of an EI or MCS but should incur further examination and observation regarding symptom manifestation history and severity as presented by the client, and a possible referral to a physician who specializes in Environmental Medicine.

ICD codes for the client with MCS or suspected of having MCS include 989.9 Chemical Sensitivity, 293.83 Mood

Disorder with Depressive Features Due to Toxic Exposures, 310.8 Cognitive Disorder Due to Neurotoxin Exposures. ICD-10 codes for the client with MCS or suspected of having MCS include F06.4 Anxiety Disorder Due to Another Medical Condition, F06.31 Depressive Disorder Due to Another Medical Condition With Depressive Features, F06.32 Depressive Disorder Due to Another Medical Condition With Major Depressive-like Episode, F06.34 Depressive Disorder Due to Another Medical Condition With Mixed Features.

DSM-5 Z codes for an EI or MCS might include: Z75.3 Unavailability or Inaccessibility of Health Care Facilities, Z75.4 Unavailability or Inaccessibility of other Helping Agencies, Z59.7 Insufficient Social Insurance or Welfare Support. The DSM-5 includes Z codes in their list of ICD-10 codes.

The Diagnosing Format

The DSM-5 ushers in a changed format for diagnosing. No longer multiaxial, the DSM-5 recommends an approach that is domains or systems oriented, similar to that used in hospital documentation. Axis V, Global Assessment of Functioning (GAF), has been dropped. Axes I, II, and III information is to be combined into one section. The psychosocial and environmental information previously written on Axis IV is now to be replaced with ICD-9-CM V codes and the new ICD-10 Z codes. (Lists of these codes are included in their own section at the back of the DSM-5.)

The DSM-5 instead adopts the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0). The WHODAS 2.0 is based on the *International Classification of Functioning, Disability and Health* (ICF) and is to be applied across all areas of healthcare and medicine (DSM-5, 2012, 16).

WHODAS 2.0 and MCS

The WHO *Disability Assessment Schedule 2.0* (WHODAS 2.0) is an assessment measure based on the ICF. It comes in three different versions and is available online as a free pdf download through the American Psychiatric Association website at https://www.psychiatry.org/home/search-results?k=whodas%202.0:

- 36-item version – gives most detail, allows to compute overall and six domain-specific functioning scores, available as interviewer-, self-, and proxy-administered forms, average interview time is twenty minutes

- 12 item version—useful for brief assessments and 12+ 24 item version. It is reliable, valid, and has a cross-cultural application study spanning nineteen countries around the world

- 12 + 24-item version – uses twelve items to screen for problematic domains of functioning, based on positive responses to the initial twelve items, respondents may be given up to twenty-four additional questions, can be administered by interview or computer-adaptive testing

The WHODAS 2.0, (test and scoring information pdf can be downloaded from the WHO website,) is made up of thirty-six questions and assesses in six domains: understanding and communicating; getting around; self-care; getting along with people; life activities (household/ work/school); participating in society. The questionnaire asks about the difficulties a person has had in the six domain areas

of their lives due to health or mental health conditions during the past thirty days. Questions are presented in a "In the past 30 days, how much difficulty did you have in…" format and the person completing the questionnaire is asked to circle one response. The possible responses are: none (1), mild (2), moderate (3), severe (4), extreme or cannot do (5).

The "Understanding and Communicating" domain section includes questions that address concentration, memory, problem-solving, new learning, understanding what others are saying, and being able to start and maintain a conversation.

The "Getting Around" domain section includes questions that address ability to stand for lengths of time, getting out of your home, walking long distances. The "Self-care" domain section includes questions that address ability to bathe, dress, eat, be alone. The "Getting Along with People" domain section includes questions that address dealing with strangers, friend-ships, getting along with people who are close to you, making new friends, sexual activities. The "Life Activities" domain section includes questions that address household responsibilities, time management, completing tasks, priority setting.

The "Participation in Society" domain section includes questions that address joining in community social activities, barriers to socialization, living with dignity, experienced social prejudice, time demands of health condition, emotional and financial impact of health condition, as well as familial impact of health condition.

The WHODAS 2.0 can be scored in two different ways. The first way is called the "Simple" scoring. It is a quick, hand scoring approach. The number values assigned to each item are added up by domain. There is no weighting. It is a simple adding up of the scores. The second way is the "Complex" method and uses a computer. The computer program is available from the WHO website.

It is imperative for the clinician who is assessing a person with an EI, MCS, masto, mast cell activation spectrum related disorder. or is suspected of having one, and is using the WHODAS 2.0 to keep in mind that this is an individual who will have some degree—minimal to profound—of difficulty concentrating, remembering, analyzing, problem solving, learning new tasks, understanding what is being said to them, starting and maintaining conversations, etc., when they are experiencing a reaction after an exposure to chemicals. At the times when they are not experiencing a reaction to a chemical exposure, they usually do not experience the cognitive impairments.

Although the questions on the WHODAS 2.0 begin with, "In the past 30 days, how much difficulty did you have in," this is not an easy question for the person with as EI to answer. Every person with an EI is at risk for chemical exposures in any and all environments, especially those that depend on the behaviors of others. A person with an EI who lives in an apartment building does not have control over renovation work in the building, exterior work on the property, chemicals used by other tenants, chemicals used in the common areas. A person with an EI has no control over roadwork, construction, blasting, the neighbor painting next door, mulch. All of these are factors that impact the EI sufferer across all six domains of the WHODAS 2.0.

The "Getting Along with People" section of the WHODAS 2.0 has a question that asks how much difficulty you have had in the past thirty days "Dealing with people you do not know," (DSM-5, 2013, 747). Individuals with an EI avoid people they do not know. Strangers are a minefield of chemicals and unknown, potentially harmful substances. A person with an EI (MCS, mast cell spectrum related disorders) could answer "severe" or "extreme/cannot do" to this question, a response easily misunderstood if one is unfamiliar

with the illness, leading to potentially damaging and erroneous conclusions.

The WHODAS 2.0 will, however, provide clear in-sights into how an individual with MCS is managing their illness, is maintaining avoidance and minimizing exposures, and the effectiveness of their coping skills. Every WHODAS 2.0 question is an area of need for most people with an EI; each question the start of an important conversation.

Level 1 Cross-Cutting Symptom Measure and EIs

The *Level 1 Cross-Cutting Symptom Measure*, adult version, is a 23-item measure that assesses an individual over thirteen psychiatric domains: depression, anger, mania, anxiety, somatic symptoms, suicidal ideation, psychosis, sleep problems, memory, repetitive thoughts and behaviors, dissociation, personality functioning, and substance use. Each item asks the person (or the informant if it is being completed by a third party,) how frequently or how much they have been bothered by a specific problem over the past two weeks. The specific problems include little interest or pleasure doing things; feeling down, depressed, or hope-less; avoiding situations that make you anxious; feeling that your illness is not being taken seriously enough; problems with memory; not feeling close to other people or enjoying your relationships with them. The person is asked to circle the number that corresponds with their answer. Answers are rated on a scale of 0 – 4 with 0=none at all, 1=slight (rare, less than 1-2 days), 2=mild (several days), 3=moderate (more than half the days), 4=severe (nearly every day), (www.dsm5.org/Pages/Default.aspx).

As with the WHODAS 2.0, it is essential that the clinician scoring the *Level 1 Cross-Cutting Symptom Measure* results for a person with an EI understand that this is a client who will have some degree of discomfort or inability in the

majority if not all of the thirteen domains due to their chronic illness. Eis affect mood, cognitive ability, sleep patterns, and personal relationships. Many individuals who are living with a chronic disease experience depression, anger, anxiety, sleep disturbances, and some degree of impaired capacity. The client with an EI such as MCS and other mast cell activation spectrum related disorders also experience these symptoms when they are having a reaction to a chemical exposure—psychological symptoms that are due to a physical and not psychological cause.

Cultural Formulation Interview and EIs

The DSM-5 defines culture as referring to, "systems of knowledge, concepts, rules, and practices that are learned and transmitted across generations. Culture includes language, religion, spirituality, family structures, life-cycle stages, ceremonial rituals, and customs, as well as moral and legal systems," (DSM-5, 2013, 749). Chronic illness, like any disability, has its own culture. It is important to be familiar with the culture of MCS or other EI, as well as with those of chronic illness and disability, when conducting the DSM-5 recommended *Cultural Formulation Interview* with a client who has an EI such as MCS or other mast cell related disease.

The sixteen-question interview as presented in the DSM-5 can be modified, and the clinician's understanding and interpretation of the questions and client responses adapted, to accommodate the culture of EIs. Through the questions regarding, for example, cultural perceptions relating to cause, context, and support, the clinician can elicit insights regarding how a client with an EI has internalized their having a chronic illness, noting especially their understanding of societal and cultural expectations of wellness and their new level of wellness and functioning as impacted by the symptoms of the illness and the disease process.

The *Cultural Formulation Interview* questions cover such areas as stressors and supports, spirituality, and self-coping. Responses in all of these areas can be tremendously insightful for the clinician as to the client's internalized reality of experience of both their illness and the systems with which they interact. There is no aspect of a client's life that is not impacted by their having an EI. The answer a client with an EI provides in response to a question about, for example, their relationship with another person must always been understood as reflecting not only the cultural identity of the client as it pertains to his or her ethnic and racial cultural groups, but also his or her conceptualization of disability, function, resilience, and self-worth within the cultural context of environmental illnesses and chronic illness.

3
Clinical Considerations

Chronic Illness

Any individual living with a chronic illness experiences loss, changes in lifestyle, changes in body concept and sense of self, sadness, varying degrees of isolation. A person living with a chronic illness can experience changes in mood as well as feelings of decreased worth, helplessness, hopeless-ness.

An individual living with the chronic environmental illness of MCS or another mast cell related disorder may be hit doubly hard, experiencing what are the normal psychological responses to having a chronic illness coupled and overlapped with the physiologically based symptoms of their reactions that affect these same body systems.

When having a reaction to a chemical exposure, a person with an EI can become agitated, emotional, irritable, tearful, exhausted, anxious, depressed, angry, have suicidal thoughts. They can have panic attacks. A chemical exposure can cause cognitive impairments for the person with an EI leaving them confused, unable to remember, not knowing

where they are. Reactions to chemical exposures can affect the person's hearing, sight, ability to understand what is being said to them, and their ability to understand what they read.

The person who has at EI should be encouraged to pay attention to and learn to identify the ways they react and to which specific chemicals, in order for them to not only better understand and manage their behaviors when experiencing a reaction to an exposure to chemicals, but even more importantly so that they can understand the cause of an emotion or feeling they may be experiencing. It can be enormously helpful for someone with an EI, when having a reaction, to be able to tell themselves, "Okay. I recognize this. This is a reaction to exhaust fumes from the cars on the road," and in this way better manage the anxiety, or agitation, or panic, or restlessness, or cognitive impairment, or whatever their reaction may be to the trigger. It is very easy for the person with an EI, as well as the clinician, to confuse the symptoms of an EI with those of a psychological condition. Keep in mind that the person with an EI can react hours or even days later following an exposure to chemicals, and their reactions can last for weeks.

The approaches and methods currently used when treating individuals with chronic illness tend to focus, to a greater or lesser extent, on what are looked at as maladaptive behaviors of the client. Support accompanying these approaches typically includes: (1) client education when noncompliance with treatment is attributed to a knowledge deficit on the part of the client where the doctor, nurse, or other healthcare professional provides education and training for the client with the goal of improving the client's ability to self-manage their care; (2) the client is given a simple and straightforward directive regarding how to change their maladaptive behavior, for example, for them to quit smoking, or to eat less sugars and carbohydrates, or to exercise regularly; (3) the client is referred for psychotherapy.

In situations where medical professionals feel that the client's noncompliance with treatment issues are severe, there will be a referral for psychotherapy. In these instances, the therapy tends to be health-focused, looking at personality dynamics and family dynamics. The goal is not to change the client's maladaptive behaviors but "to modify [the client's] core personality dynamics—maladaptive schemas," (Sperry, 2006, 18).

Although these can be excellent approaches when working with individuals who have more familiar chronic illnesses such as diabetes, obesity, nicotine addiction, or hypertension, none of these approaches are entirely suitable for working with a client who has the chronic illness of MCS or a mast cell activation related disorder. These clients will experience symptoms when exposed to the chemicals to which they react. Unfortunately, they do not have complete control over their exposures because they can't control the behaviors of others.

In order for a person with an EI to receive any kind of medical care, they have to be actively noncompliant with their treatment. The number one treatment protocol for individuals who have an EI is avoidance. They must avoid exposing themselves to the chemicals and environments that cause their reactions. Going to the doctor, to the hospital, to the clinic necessitates exposure to chemicals that have the potential to cause irreversible damage.

Intake and Presenting Symptoms

Most agencies have their own intake forms to use during the initial information gathering sessions with a client. These forms ask questions about the reasons for the client's visit that day, medical history, family history, substance use history, mental health history, hospitalizations, medications,

allergies. They also ask demographic questions such as the client's age, marital status, race, ethnicity.

The client with MCS may or may not already have the medical diagnosis of MCS, EI, or a mast cell related disease before seeking counseling support. As with the WHODAS 2.0, the *Level 1 Cross-Cutting Symptom Measure*, and the *Cultural Formulation Interview*, the responses a client with MCS provides to the intake questions and questionnaires need to be understood within the context of their environmental illness and its symptoms.

A person who has an EI, with or without the formal medical diagnosis of the disease, often presents with symptoms that typically fall under the category of psychological and as such are presumed to have a psychological cause. The symptoms may have been worsening over time. It is very possible that the client may have been to multiple physicians who say there is nothing physically wrong with the person. The client may have had allergy testing done that shows he or she does not have allergies. They may have had additional testing with results all within normal ranges. Meanwhile, the person continues to experience their symptoms and can become increasingly disabled due to the constant re-exposures to chemicals at home and at work.

There are questions that need to be added to the intake questionnaire and information gathering process that address the symptoms and issues a client with an EI, or a client suspected to have an EI, experiences in order to better assess the client's needs and the best direction in which to proceed regarding treatment planning, treatment, and referrals. These questions should address:

- The client's specific symptoms, (type, frequency, severity, and date of initial onset)

- The client's exposures to chemicals (e.g. pesticides, paints, solvents, cleaners and detergents, mulch and other yard and garden products,) at work and at home

- The frequency of exposures, initial exposure dates, and duration of reactions

- Military experiences, if the client is a veteran, and possible exposures to chemicals while serving

- Information about their diet, their reactions in relation to meals and meal preparation

- Information about their dental and surgical history including materials used. Many individuals have started having symptoms after a root canal, surgery, or anesthesia (Rogers, 1995, 32)

- The impact the symptoms have had on the client's ability to work and the client's quality of life

Look for consistencies in client responses that show, for example, every time the client gets in the car they become ill, or every time the client is in a particular physical environment they become ill, or every time they handle a certain substance or go into a certain room they experience a reaction, and that the reactions stop when they are no longer in the presence of the car, or the room, or the person, or the substance.

Therapists assessing and evaluating a client who may have MCS, EI, or a mast cell related disorder should be looking for information from the client that clarifies the client's meaning of "feeling sick" while listening for patterns in how the client details their experience of their symptoms

both physically and within specific environments. What situations does the client avoid? What materials, items, substances is the client unable to touch or handle? Does the client report being "allergic" to anything?

Many individuals are not able to maintain a great deal of objectivity while in the throes of a reaction. They can miss the connections between exposures to certain chemicals and the specific reactions that result. Clients may also become overwhelmed by the severity and frequency of their reactions and be unable to differentiate separate triggers and their correlating symptom responses.

A client who has an EI like MCS or a mast cell activation related disorder, or who is suspected of having one, presents with issues that may include but are not limited to:

- Headaches, migraines
- Feelings of pressure around the face and head
- Feeling spacey, problems concentrating, problems remembering
- Feeling tense and anxious, panic attacks
- Irritability, crying spells, spells of rage
- Loss of interest in things
- Suicidal ideation
- Rashes, hives, itching
- Irregular heartbeat, tachycardia, chest pressure, chest pain
- Burning and watery eyes, blurred vision
- Tinnitus, muffled hearing
- Problems breathing including problems with their tongue swelling, coughing, increased phlegm and mucus, asthma-like symptoms
- Nausea, vomiting, diarrhea, abdominal pain
- Muscle/joint/bone pain
- Fever, flu-like symptoms
- Exhaustion—often extreme exhaustion

The questions a clinician asks need to elicit essential information in order for them to assess and determine if indeed there is a relationship between the client's presenting symptoms and issues—which may or may not be mimicking symptoms of a psychological condition—and possible exposures to chemicals.

Claudia S. Miller, MD, has developed a screening instrument for chemical intolerance, the QEESI (Quick Environmental Exposure and Sensitivity Inventory). The QEESI is a questionnaire for clients to complete either online or using a paper and pen version. The online questionnaire is available at www.qeesi.org. The pdf download is available on Dr. Miller's website at www.drclaudiamiller.com. The QEESI is a validated questionnaire that helps researchers, doctors, and their patients identify individuals with multiple chemical intolerances (www.qeesi.org). Both versions are available free of charge.

Grace Ziem, MD, physician and MCS specialist, has created a two-page "Quick Environmental Health Questionnaire" that can be downloaded from her website http://www.chemicalinjury.net (click "Medical Care" at the top right to get a list of her forms, then click the first one called "Summary Health and Environmental History Form," to download.) It is a questionnaire in a user-friendly format for the client to complete.

Barriers to Accessing Healthcare

If a client's EI symptoms interfere significantly with their ability to breathe, work, attend school, do housework, the Americans with Disabilities Act (ADA) considers the person to be disabled. To aid individuals who are disabled in accessing services, the ADA requires the removal of barriers in public accommodations when it is "readily achievable," a phrase they define on their website as meaning, "easily

accomplished and able to be carried out without much difficulty or expense," (www.ada.gov). The client with an EI faces many barriers and potential barriers to accessing healthcare.

Transportation is frequently difficult for a person with an EI to manage. Public transportation is often impossible because of the concentration of chemicals in the confined space of a bus, subway train, or taxi. Elevators can also be prohibitive for the same reason. Many people with an EI have extreme difficulty with cars due to the exhaust fumes, plastics, and chemicals in the upholstery and carpeting. They are either unable to get to medical and other appointments or do so only with great difficulty—and then can be quite ill from the exacerbation of their symptoms due to the exposure to chemicals, sometimes for many weeks afterwards.

Public areas, offices, and hospitals are full of chemicals that can harm a person who has an EI. Medical offices can be especially potent due to the use of stronger disinfectants and germicides. It is important to keep in mind that, for the person with an EI, most environments are layered with chemicals to which they may react.

Picture a therapist's office. There is usually a desk, several chairs, one or two (or three) tables, a clock, pictures on the wall, bookshelves, books on the shelves, knick-knacks on tabletops, papers on the desk, pens, paperclips, stapler, a box of tissues, perhaps some toys if you work with children, carpeting, area rugs, a cushion or two, a computer. There is a heating system and an air conditioning system. There is paint on the walls and on the ceiling. All of these items give off chemical fumes we can't see but to which the person who has an EI will probably react.

Most fabrics are treated when they are made with chemicals to keep the colors from fading too quickly. Carpets are treated with chemicals for similar reasons and to repel dirt. Furniture upholstery is often treated with anti-staining chemicals such as *Scotch Guard*. Formaldehyde is a common

chemical with which furniture and car upholstery are treated. Many people with an EI react to dry cleaning chemicals and to clothing and other items that have been dry cleaned. Has there been any recent renovation work to the office? Individuals with an EI can react to the chemicals given off from particle board, wood, and many other construction materials and processes.

People with an EI can react to plastics, petroleum products, metals, foam (used to stuff many types of cushions, pillows, seats, sofas, etc.) They may react to inks and dyes, to chemicals that make up carbon-free forms. Consider all this as one layer.

Another layer is the cleaning products used in the office to wipe, wash, disinfect. These are the general purpose cleaners as well as stronger chemicals, depending on where the office is located, a hospital versus a private practice setting. This layer of chemicals also includes pesticide treatments of waiting rooms, foyers, session rooms, hallways, air fresheners, carpet fresheners or refreshers, room deodorizers

Still another layer of chemicals the person with an EI has to contend with is the chemicals on other people. This includes perfumes, laundry soaps, fabric softeners, dryer sheets, shampoos, conditioners, bath soaps and gels, cosmetics, lotions, antiperspirants and deodorants, other personal care products, jewelry, hand sanitizers. People also carry on them the fumes from being in a car, if they have driven, plus the fumes from all the other cars on the road with them while they drove, and the fumes from all the places they've been in the course of the day prior to their arrival to your office. Everyone leaves their residual chemical fumes on the furniture and in the rooms and areas they pass through everywhere they go.

Think about your own laundry soap, dryer sheets, shampoo, bath soap, personal care products, driving. Think about the office cleaning chemicals and pesticides. Think about the number of clients you see in a day, in a week, in a

month, plus all the other people who come and go in your office—and everyone leaves some of their residual chemicals on the furniture, the floors, the items in the room. Now enters the client with an EI who reacts to all the chemicals in the environment and needs to avoid exposures.

Reasonable accommodations need to be discussed in advance in order to provide the client who has an EI with as safe an environment as possible

Reasonable Accommodations

The fact of an environmental illness cannot be removed from any equation involving a client who has or is suspected of having an EI, as it impacts everything they do. A client I know related to me a situation where she contacted her insurance company in writing to request their approval of an out-of-network psychologist who had experience working with clients with MCS. Initially, her request was denied by the insurance company and, in a letter, they provided her with a list of approximately twelve therapists and agencies who were part of their network of providers and instructed her to select someone from the list. The client contacted the suggested providers. Some were counselors who specialized in pediatric and/or adolescent psychology. Others had specialty areas of geriatric psychiatry, addictions, anxiety disorders, psychopharmacology, bipolar, schizoaffective disorder. Several of the agencies were straightforward about their inability to meet the medical needs of a client with MCS. The client shared with me the response of one of the Intake Coordinators in particular with whom she spoke over the telephone: [names have been changed]

Mr. Blank, the Intake Coordinator, said that he has serious concerns about the possibility of my receiving treatment at their facility due to my physical disability. Their facility, Mr.

Blank explained, occupies a first floor and two sub-levels on a very busy street. He said that car, bus, and truck exhaust fumes are an issue. He also said mold is an issue on the lower levels of the building, and that they have a very large practice—40+ clinicians and each with a large caseload. Mr. Blank said he understands about having MCS and the need to avoid exposures to chemicals, and said that there is no way to control the building chemicals (cleaners, carpets, building renovations) and staff and client chemicals sufficiently to not pose a threat to my health.

The reasonable accommodations a person with an EI might request when visiting a therapist's or other healthcare office include: having access to a bathroom that does not use any kind of air freshener or deodorizer; shortened wait times in order to minimize exposures to chemicals in waiting areas; the clinician and staff to not wear scented products, to not wear clothing that has been dry cleaned, and to not use dryer sheets and/or fabric softeners when laundering their clothing; pest control methods that are non-toxic; clinician and staff to use alternatives to alcohol hand sanitizers such as plain, unscented glycerin soap, (www.chemicalinjury.net). These are general accommodations. Triggers and symptoms can vary from person to person. Ask your client for his or her specific triggers and sensitivities to best accommodate their needs.

Creating a Safer Environment

Creating a safer environment for a client with an EI begins with addressing and implementing specific reasonable accommodations to make the physical environment more tolerable. A safer environment for a client with an EI also involves learning how to best support the individual when he or she is having a reaction, especially a severe reaction:

clients should carry emergency medical identification cards and wear emergency medical identification bracelets or pendants at all times.

H.E.A.L. of southern Arizona, an online chemical sensitivity support organization, provides on their website a letter template for First Responders (www.healsoaz.org/hospital_access.htm). The letter is intended to be copied onto each person's doctor's letterhead and to be signed by the client's physician. It briefly explains the EI and lists basic steps to follow to ensure the patient's safety during treatment. The letter can be modified to fit the individual medical needs of any person with an EI and should be carried with them at all times. It is for use during emergencies, for EMTs, and in the ER, but can also be shared with other medical and healthcare professionals to provide important treatment information.

Have ready the client's emergency contact information including their hospital of choice.

Be trained in how to administer an Epipen in cases of severe reactions and anaphylaxis. There are two types of Epipens now available, the traditional injectable in the clear plastic tube/case with the yellow top and the new digital injectable which, when activated, will talk you through the steps to administer.

Write anything down that you want the person with an EI to remember. EI reactions can affect the person's memory.

Don't make decisions based on your own sense of smell. People with an EI can react to even the smallest amounts of chemicals in their environment.

Remember: a person with an EI who is experiencing a reaction to an exposure to chemicals isn't able to "remain

calm" and requests to do so—with the best of intentions—often worsen the reaction.

Remove the person who is having a reaction from the environment and the chemical exposure to the outdoors (reactions resolve when triggers/incitants are removed).

Offering telephone and online session options is a way of creating a safer environment for clients with an EI who are physically unable to come every week or every-other week to an office due to their illness.

4
Building the Treatment Plan

Treatment planning for the person with an EI, such as MCS, needs to begin with the knowledge and understanding that many—if not most or all—of the client's presenting symptoms occur as reactions with a physical cause. However, these individuals also experience the normal emotions and psychological responses typical of any person coping and living with a chronic illness. Both of these realities need to be addressed equally in the diagnostic summary, problem list, goals, and objectives of treatment planning.

The needs and issues of the client with an EI can be many and varied. EI-specific areas of clinical consideration should include:

- **Avoidance**—how successful is the client in avoiding triggers and minimizing exposures to the chemicals and substances to which he or she reacts

- **Ongoing chemical exposures**—at what levels of chemical exposures the client may experience on a regular basis at home and at work

- **Reactivity of the client**—the severity of the client's reactions and the degree of impact they have on the client's ability to function at home and at work

- **Safe haven**—what measures has the client put into place at home to create as chemically-free an environment as possible

- **Reasonable accommodations**—have any reasonable accommodations been requested and put into place at work, when receiving medical care, and in other public situations

- **Client education regarding EIs**—understanding their illness, reactions, and triggers; recognizing they are having a reaction while they are experiencing it; the importance of avoidance

- **Support systems**—what support systems does the client have and do these supports understand the client's illness

- **Impact of illness on life-style**—includes work, housing, recreation, ability to drive and get places, nutrition, income and ability to earn, health insurance

- **Impact of illness on relationships**

- **Impact of illness on client's self-concept**, self-worth and self-esteem, body image, future plans, dreams, goals

The psychological impact of having a serious, chronic illness on a person's life needs to be addressed. Potential areas for clinical consideration should include:

- Loss
- Grief/Mourning
- Anger
- Isolation
- Depression
- Denial
- Anxiety
- Shame
- Low self-esteem
- Low self-worth
- Confusion
- Pain
- Trauma
- Fear
- Frustration

Goals and Objectives

Goals and objectives need to be realistic and they also need to be understood within the context of the chronic illness of an EI. Typical goals and objectives in treatment plans for individuals with chronic illness tend to come from the cognitive behavioral perspective of changing a client's maladaptive behavior, (such as noncompliance with medications, or non-compliance with a food plan,) or addressing a client's knowledge deficit. We are more familiar with the disease processes and the needs of clients suffering from chronic illnesses such as diabetes, hypertension, cancer, epilepsy, Chronic Fatigue Syndrome, and Lupus than we are with MCS and mast cell activation related disorders. It is an essential component of the work we do when supporting a client with a chronic illness to know about that chronic illness,

the disease process, how it impacts personality and social interchanges, how the illness is experienced by the individual, and how all of these in turn impact the disease process. (Sperry, 2006, 63).

When setting goals and objectives for the person with MCS or a mast cell related disorder, issues of wellness should be addressed. Wellness is defined as, "an integrated method of functioning which is oriented toward maximizing the potential of which the individual is capable," (Sperry, 206, 11). Wellness can also be understood as "a process of making choices for a successful existence...or as a way of life oriented toward an optimal state of health and well-being," (Sperry, 2006, 11).

Phases of Chronic Illness

An individual diagnosed with a chronic illness may experience many different emotions as well as changing mental, physical, philosophical, and spiritual states as they try to work through and cope with their symptoms, with having a chronic illness, and with the many changes in life and lifestyle these realities may incur. Patricia Fennell in her book, *The Chronic Illness Workbook* (2001), presents a four-phase model that is a highly insightful approach to understanding and working with clients who have been diagnosed with a chronic illness:

Phase One is called the *Crisis* phase. In this phase, the individual has experienced a worsening of symptoms to the extent that they may feel it is now an emergency—a crisis. People at this phase may seek out medical treatment in the hopes of a diagnosis in order to relieve their suffering. Some may seek out spiritual support. Others may try to self-medicate through alcohol or drugs. Friends, co-workers, significant others may not believe, can reject the individual. In Phase One, the individual is coping with and trying to handle the

immediate traumas, hurts, pains, and symptoms of their illness and of having the diagnosis of a chronic illness (33).

Phase Two is called the *Stabilization* phase. In this phase, symptoms may appear to plateau. The individual is becoming more familiar with their chronic illness and may think they're getting a little better. Things, however, can still be quite chaotic. The individual may try to continue with life activities in the way they did before they became ill, but is unable to do so and thus experiences relapses. The individual may internalize their periods of relapse as failures while continuing to try to find ways to cope and somehow return to their pre-illness life. In Phase Two, the individual begins the work of stabilization and the restructuring of their life, lifestyles, and understandings (33).

Phase Three is called the *Resolution* phase. In Phase Three, the individual has learned their illness patterns and has learned how others respond to their illness. In this phase, individuals begin to accept that they won't be returning to their old lives and that the old "self" is gone. This can be a devastating phase in many ways, but it is also a phase that brings with it the task of developing a new self and a new philosophy for living (33).

Phase Four is called the *Integration* phase. Here the individual may experience plateaus of their symptoms and relapses, but is able to integrate elements of the old, pre-illness "self" with their new concept of self. In Phase Four, individuals move toward expanding their understanding of self and self-worth to include their illness and to integrate this under-standing into their philosophy for living and their sense of spirituality; to experiencing a "complete life in which illness is only one part," (33).

Interventions

The experience of living life with a chronic illness can be, for many people, a changeable journey moving back and forth through all four phases as they adjust and readjust their concept of self, their understanding of wellness, and their ideas of what makes for a meaningful life. Not every person who has a chronic illness experiences all four phases. Many individuals with chronic illness get caught in a reoccurring loop, cycling between phases, some never reaching Phase Four (Fennell, 2001, 50).

Phase One Interventions:

The goal of Phase One support—*Crisis*—is to contain the crisis and keep the person safe, (51). Individuals who have an EI, are suspected of having an EI or a mast cell related disorder, when reacting to a trigger, may experience profound exhaustion and other disabling symptoms that can last for days or weeks after an exposure. These reactions can leave the person unable to complete essential tasks and activities of daily living. The individual may become unable to buy food, prepare meals, do laundry. They may experience cognitive impairments and not remember if they have eaten or if they have taken medications. A person can become agitated and unable to sleep, can experience emotional outbursts and fits of weeping after an exposure to chemicals. Avoidance is essential, however, the individual may become so compromised by the severity of their reactions that they are unable to maintain themselves and their environment in as chemical-free a condition as needed without help.

Phase One interventions should involve assessing for trauma as trauma often accompanies illness, and identifying supports for the client: who is available to assist with going to the grocery story, pharmacy, banking; who is available to assist with laundry and other cleaning and household tasks

(while adhering to specific protocols to keep the individual's environment as chemical-free as possible); who should be included on an emergency contact list.

It is important to remember that people cannot come and go freely into the home environment of a person with MCS. Anyone going into the home of a person with an EI, suspected of having an EI, or a mast cell related disorder will need to be as chemical-free as possible. This includes the laundry soaps they use, their bath soaps and personal care products, the materials their clothing is made out of (for example, fleece is made from plastic and many clients with an EI react to plastics and petroleum products,) and the places they have been prior to arriving at the home of the client with an EI. Often the best meaning friend can make a person with an EI such as MCS and other mast cell activation spectrum related disorders experience a worsening of symptoms simply by being there.

Activities such as tracking daily symptoms are only as effective as the client's ability to avoid triggers. In order to successfully decrease their symptoms, the individual must avoid exposures to the chemicals to which they react.

Phase Two Interventions:

The goals of Phase Two support—*Stabiliztion*—involve building the foundation for a "new" life based not only on observing and understanding the limitations and boundaries imposed by chronic illness but also realizing that life still has meaning and purpose (Fennell, 2001, 97). Support here involves regrouping, understanding the effects of trauma, understanding the reactions of others.

Phase Two interventions include: learning to recognize triggers; learning to recognize reactions; matching reactions to triggers; learning to recognize and associate specific activities with a worsening of symptoms; adjusting work hours or even stopping work; developing support systems.

Phase Three Interventions:

The goal of Phase Three support—*Resolution*—involves a deepening of the process of accepting life with a chronic illness while learning and valuing that we are more than our illness, (Fennell, 2001, 128). The person with an EI experiences enormous loss: of identity, self, home, partners, friends, and dreams. These losses need to be respected and grieved. It is no easy task to become the phoenix rising from the ashes.

Phase Three interventions embrace the existential while supporting the client's growth process: journal keeping, reauthoring life narratives; expression through the visual arts, music, dramatic arts, dance and movement; body-mind-spirit practices. Interventions here support the individual's sense of truth, authenticity, and their lived experience of illness and pain as it translates into new personal goals and a new sense of purpose.

Phase Four Interventions:

The goal of Phase Four support—*Integration*—is to merge the chronic illness within a new spiritual and philosophical framework while achieving the highest level of wellness possible, (Sperry, 2006, 8).

Phase Four interventions are a continuing of support as the individual lives with their chronic illness yet experiences a full life in spite of limitations and includes: ongoing expression through the creative arts; body-mind-spirit practices; journal keeping; socializing as much as able; maintaining relationships with family and friends; developing new associations and friendships.

Suggested Reading:

Psychological Treatment of Chronic Illness, by Len Sperry, MD, PhD **|** M*anaging Chronic Illness Using the Four-Phase Treatment Approach*, by Patricia A. Fennell **|** *The Chronic Illness Workbook*, by Patricia A. Fennell, MSW, LCSW-R

5
Disability, Social Security, and the Functional Assessment

It is not uncommon for many individuals suffering with an EI such as MCS and other mast cell related disorders to become so incapacitated by the severity of their reactions and symptoms, and their duration, that they are unable to work. The process of applying for financial assistance and disability support through the various agencies can be daunting. Applications are often lengthy. The format in which many of these forms are written, both online and hard copy versions, are not always appropriate when detailing the needs, limitations, and the specific medical and related information agencies require for the person with MCS. In this area especially, the significance of having medical and healthcare practitioners and professionals who understand MCS and mast cell related disorders is crucial.

The Americans with Disabilities Act (ADA) requires a person to meet certain criteria—one out of the following three—in order to be considered disabled:

- Having a physical or mental impairment that substantially limits one or more of the major life activities;

- A record of such an impairment;

- Being regarded as having such an impairment, (ADA, 1990, Sec. 3).

Major life activities according to the ADA include but are not limited to caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. The ADA also includes among major life activities the operation of a major bodily function including but not limited to functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive function (https://www.ada.gov). The reactions a person with an EI experiences when exposed to chemicals typically affect multiple body systems and can impair all major life activities.

The definition of disability that the Social Security Administration (SSA) uses is: "the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months," (www.ssa.gov).

The individual with an EI needs to convince examiners who may know nothing at all about Eis, MCS and other mast cell activation related disorders that they are not able to work

anywhere doing anything and demonstrate or explain that they: "(a) become debilitated by exposures to common chemicals and (b) have no control over these exposures that depend upon other people's behavior," (Gibson, 2002, 28). The burden of proving functional limitation falls to the person with the EI and their treating health professionals.

Private Disability Insurance

Employers sometimes offer private disability benefit options in addition to health insurance to their employees. However, as Pamela Reed Gibson, PhD, notes in her book, *MCS: A Survival Guide* (2006), although many employers may offer disability insurance (for a fee), these policies often contain exclusions for conditions that resemble MCS and many companies are getting wavers from states that exclude them from having to pay disability benefits for more than two years for "self-reported symptoms." If these agencies classify the employee's EI as "self-reported," they will only pay benefits for two years and then another diagnosis will need to be used (263).

There are doctors who do not recognize MCS, as well as other EIs including mast cell and mast cell activation related illnesses, as being physiological, as well as doctors who do not recognize MCS and EIs at all, while others see MCS and EIs at best as being controversial, and all may be unwilling to make the diagnosis. I know a client who received a diagnosis of MCS from an allergist at a well-known city hospital. The MD wrote in the patient record that this patient has the diagnosis of multiple chemical sensitivities. Two months later, this same MD wrote in the client's medical record that the patient was self-diagnosed, which was completely untrue. When this person—in the middle of the disability application process and collecting the required supporting documentation—contacted the doctor's office

asking about the incorrect second entry, the nurse practitioner initially quickly said that the doctor probably wrote that because the person had come to the doctor saying he or she thought they had MCS. The client let the nurse know this was not the case, that they had been referred by their primary care physician to the allergist to find out exactly what was wrong, and that they had never heard of MCS before the doctor's diagnosis. The client was able to tell the nurse the exact page and line in the medical record for both the entry where the MD gives the diagnosis of MCS and the later erroneous entry while she checked and verified the information in the hospital computer. The nurse located the discrepancy, put the person on hold to speak with the doctor, then came back on the line saying, "The doctor says he is not going to change anything he wrote." My client continued saying, "But what he's written down is not true." The nurse simply repeated her statement, "The doctor says he is not going to change anything he's written." At the time, my client was not aware of the HIPAA regulations and how, by law, this situation of a doctor's refusal to correct or update medical records can and should be handled. Regardless, the doctor's inclusion of "self-reported," albeit erroneously, posed a threat to my client receiving needed disability insurance benefits.

Welfare

Welfare programs are state regulated. Each state determines their eligibility criterion for individuals who qualify as low-income under the minimum accepted state levels for means. These programs tend to offer cash assistance, food assistance/food stamps, help with child care, medical help, and vocational rehabilitation assistance. Typically applications for state assistance can be found online with the option of requesting a hard copy application through

the mail and have specific sections to be completed and signed by the person's primary care physician and/or disability specialist(s).

State agencies may have and use their own disability determination services to review applications and assist with the decision-making process as to whether or not a person is disabled according to state criteria and to approve or deny an applicant benefits based on these findings. If an individual is found to be disabled and is approved for disability benefits through a state agency, the state agency may have that person sign paperwork agreeing to reimburse the state agency for all or part of the monies they will receive in state Welfare benefit payments should the individual be approved for disability assistance through Social Security, (SSI or SSDI). The state reimbursement money will be taken out of any lump sum disability payment the individual may receive from Social Security Administration. Many state agencies require that individuals apply for SSI through the Social Security Administration.

SSI

Supplemental Security Income (SSI) is a need based program that is available for individuals with low-income who qualify. The SSI program is managed by the Social Security Administration (SSA) but the money used to pay SSI benefits does not come out of Social Security taxes. SSI is paid for by U.S. Treasury general funds not the Social Security trust funds, (see SSA Publication No. 05-11000 ICN 480200, February/August 2012). SSI provides monthly cash payments to qualifying persons who are elderly, disabled, or blind. Applying for SSI benefits is a process, forms are lengthy. Information is required from physicians and specialists with forms they will need to complete and sign. An adult with a disability cannot apply online for SSI and must contact their

local SSA office in person or by telephone. Applications are reviewed by Disability Determination Services (DDS). DDS reviews all of the applications sent in to the Social Security Administration for disability benefits. They also review appeals.

Qualifying for SSI depends on a person's income and assets and those of their spouse. The individual needs to live in the United States or the Northern Mariana Islands and be a U.S. citizen or national (but in some cases noncitizen residents can qualify.) Some of the documentation required includes the person's Social Security card, birth certificate, copy of lease or mortgage, payroll slips, bank books, bank statements, insurance policies, names and contact information for doctors, hospitals, and clinics that have provided care and medical services for the person, (see SSA Publication No. 05-11000 ICN 480200, February/August 2012).

SSDI

Social Security Disability Insurance (SSDI) can be applied for online for persons who are 18 years or older, not currently receiving benefits on their own Social Security record, unable to work because of a medical condition that is expected to last at least 12 months or result in death, and has not been denied disability benefits in the last 60 days (www.socialsecurity.gov/applyfordisability/#a0=0).

The SSDI application is lengthy and detailed requiring specific information regarding the disability, its onset, the person's physical and mental health medical history, their medications, hospital/clinic/physician visits, the symptoms the person experiences, the extent to which these symptoms limit the person's ability to function mentally, physically, and in the work place, as well as all the supporting documentation for everything. There are sections of the application that the

individual's primary care physician, specialist(s), and any and all treating physicians and clinicians need to complete and sign. SSA will accept for review functional assessment reports completed by adult third-parties (Form SSA-3380-BK). Third-party sources include, for example, previous employers, family members, staff members (http://www.socialsecurity .gov/OP_Home/ rulings/di/01/SSR85-16-di-01.html).

The wait for review on an SSDI appeal can take up to two or more years before receiving a court date for when the case is to be presented before a judge for review and a determination. The individual applying for disability benefits through SSA can retain a lawyer or other legal representation to assist them with the process. The fee that attorneys or agencies can charge is set by the federal government at 25% of the person's lump sum award with a federally set not-to-exceed maximum amount. The attorney is paid from the lump sum the individuals receives once their application for disability benefits has been approved.

An individual who has been approved to receive disability benefits through SSA will receive a lump sum payment as well as the ensuing monthly payments. The lump sum payment is the amount of money SSA owes to the individual that covers the period of time the person waited for their determination starting in the sixth month after either the date they filed their application with SSA or the date of their last day of work, decided by SSA or a judge depending where in the process an application is approved. Lawyer fees and the reimbursement of any state Welfare monies owed are paid directly to the attorney and the state agency before the individual receives the balance as a lump sum payment. The lump sum payment is typically not one single direct deposit but a series of direct deposits of smaller amounts over several months.

SSA considers a person disabled "only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, con-

sidering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy," (http://www.socialsecurity.gov/OPHome/ hallex/ II-04/II-4-1-5.html).

SSA is concerned with the person's ability to perform work—***any kind of work***—regardless of whether or not the work is in the person's pre-disability area of skill and training. A former president of a college with a PhD in astrophysics, for example, who has become disabled may conceivably be found by SSA's DDS to, yes, be experiencing limitations to the extent that he or she is no longer able to perform their previous job duties, but they are perfectly capable of stringing beads or putting groceries into bags at the local supermarket, and may have their application for disability benefits denied with the finding that although the individual is not able to perform work in their regular profession, they are able to be gainfully employed in these other capacities.

Example of the Process

Names and identifying information have been changed to protect privacy.

January 4, 3015. Ms. X is diagnosed with MCS.

January 28, 3015. Ms. X has become so disabled she can no longer work. Her last day of employment is January 28, 3015.

February 3015. Ms. X completes and submits an online application for SSDI benefits and a telephone application for SSI with SSA. Ms. X also applies for state Welfare assistance, completing and submitting an online application with her local state agency. These are all separate applications. All the applications require supporting documentation, including multiple page forms, for doctors to complete, sign, and submit.

Supporting documentation SSA requires includes but is not limited to copies of letters from doctors and specialists, medical records verifying all visits, emergency room records, clinic records, forms for doctors to complete and sign attesting to the disability, length of its duration, whether or not it is total and permanent, physical and mental residual functional capacity forms completed by doctors/specialists, bank statements, proof of income or proof of zero income, lease or mortgage.

SSA can request Ms. X be examined by a physician, psychologist, and/or psychiatrist of their choosing. This may not necessarily be a doctor who is informed or knowledgeable about MCS or EIs, or believes MCS and EIs are real. If Ms. X does not agree to the examination, should they request one, her application can be denied.

Supporting documentation the state agency may require can include: bank statements, letters from doctors, completion of state agency forms by doctors requiring their signature, pay stubs, proof of receiving or not receiving unemployment benefits, proof of out-of-pocket medical expenses, copies of medical records and hospital/clinic records, birth certificate, social security card, copy of driver's license, lease/mortgage, statement from landlord verifying tenancy and monthly rent amount.

Ms. X is initially approved for state emergency benefits and services available for the elderly, disabled, and children who qualify. Paperwork and agreements are signed. The state agency decides, based on the information submitted, that Ms. X can receive $300.00 per month in emergency cash benefits, $200.00 per month in food stamps, assistance with health insurance, reduced co-pays on doctor visits, and lower prescription medication co-pays through Medicaid. The cash benefit that Ms. X receives is divided into two equal amounts

with the first direct deposit (of $150.00) occurring at the beginning of each month and the second direct deposit (of $150.00) occurring towards the end of each month.

April 3015. Ms. X receives the first direct deposit of state Welfare benefits. This initial deposit amount is greater than what the ongoing payments will be because benefits are paid retroactive to the date the application for benefits was first submitted.

May 3015. Ms. X receives notification from SSA that her applications for both SSI and SSDI disability benefits have been denied. Ms. X follows the SSA instructions and applies for an appeal, called a Reconsideration. The SSA notification letter includes a list of documents their DDS reviewed in order to make their determination. Ms. X noticed that one of the hospitals/agencies listed by SSA was the breast clinic at his local hospital. Ms. X telephoned SSA and learned that SSA had on file in their computer system not the contact information for medical records for the hospital itself (where Ms. X had received repeated emergency room treatments for her severe reactions) but instead they had contact information for the hospital's breast clinic only where there was no record of her ER visits and the treatments she received.

May 3015. Ms. X receives notification in the mail that her primary care physician, who has been extremely supportive and very willing to complete forms and write letters, will be leaving the practice at the end of June 3015. The doctor's new practice will be in the center of the city's downtown area on the eighth floor of a high-rise. Ms. X is unable to follow her doctor due to the inner-city location, the exhaust fumes, the chemicals. She decides to try one of the doctors remaining at the practice as her primary care physician.

June 3015. Ms. X receives written notification in the mail that her state Welfare benefits will stop as of August 3015. The state agency has determined that she is not disabled according to their definitions and standards. The form letter continues, explaining their appeal process which involves completing, signing, and submitting the request for an appeal form printed on the back of the same letter. During the appeal process and while waiting for a determination, the person will continue receiving their full benefits. Should the appeal be denied, the person will then have to pay back all the cash benefits he or she received after the initial stopping of benefits date (in this example, August 3015.)

Ms. X contacts her state agency case manager to verify the information and procedures. The case manager, understanding the need for avoidance, tells her to write all over the appeal form that she needs to have a telephone hearing due to her disability.

July 3015. Ms. X files the Reconsideration, including all supporting documentation she gathered, with SSA.

Ms. X now retains a disability lawyer. The disability lawyer informs her that: (1) in almost all cases the Reconsideration is denied; (2) there is nothing for the lawyer to do until the Reconsideration has been denied; (3) once the Reconsideration has been denied and the lawyer is notified, his law office will then submit the next batch of forms and supporting documentation and request a review by an administrative law judge; (4) it usually takes a minimum of fourteen months from the date of submission of these forms to hear from SSA who will assign the case to a judge and schedule the hearing date.

Once again, SSA can request Ms. X be examined by a physician, psychiatrist, and/or psychologist of their choosing.

This may not necessarily be a doctor who is informed or knowledgeable about MCS or EIs, or believes MCS and EIs are real. If Ms. X does not agree to the examination, should they request one, her application can be denied.

August 3015. The new primary care physician appears reluctant to write prescriptions for the medications Ms. X takes, especially the Prednisone, and unwilling to write letters stating Ms. X has MCS. The doctor will, however, write letters saying Ms. X is suffering from a mental illness.

September 3015. Ms. X is examined by an MCS specialist. This specialist refers her to an allergy/immunology specialist feeling there may be some mast cell issue as the symptoms Ms. X presents with are not typical of MCS alone.

October 3015. Ms. X's Reconsideration is denied by SSA.

October 3015. Ms. X telephones a physician who had been her primary care physician many years before. This doctor is currently not accepting new patients. Ms. X asks if he will take her back as a patient. He agrees while telling her, "I have never had a patient with this before."

November 3015. Ms. X is examined by the immunologist who schedules her for testing for mastocytosis and prescribes Gastrocrom, a mast cell stabilizer. The doctor tells her that it is his hope that the medication will "bring down your reactions enough so that it won't be so dangerous for you to just be out."

It is a slow process of gradual increases in dose over many months. It takes a year to get to the maximum dosage.

Ms. X's primary care physician writes letters for various agencies including the housing authority as Ms. X now has a

Section 8 voucher to subsidize her rent. The doctor also writes letters requesting reasonable accommodations due to disability for Ms. X to not be physically present at meetings. The doctor, however, is reluctant to complete the SSA functional assessments or her lawyer's disability assessment form saying he doesn't know enough about the illness to say outright that Ms. X is totally and permanently disabled. He suggests the specialist complete these forms.

February 3016. The immunology specialist officially gives Ms. X the diagnosis of Mast Cell Activation Syndrome (MCAS) but declines completing the forms suggesting they be completed by the MCS specialist. The MCS specialist said the primary care physician should complete the forms.

February 3016. Ms. X has a telephone hearing with the state Welfare agency. Prior to the telephone hearing, Ms. X was able to submit copies of the immunology specialist's notes, his diagnosis of MCAS, and copies of the MCS specialist's notes from the medical records at both of these hospitals. The state determines that she is disabled and her application for state emergency benefits is accepted.

April 3016. Ms. X receives notification in the mail that her primary care physician is leaving the practice July 1st.

July 3016. Ms. X receives notice in the mail that her case has been assigned to an administrative law judge and that she is scheduled for a hearing in two months time.

Ms. X's attorney wants to submit paperwork requesting the judge make a determination based on the medical record and medical documentation as Ms. X is not able to be physically present at a hearing due to her disability, her need for avoidance, and the severity of her symptoms. Appropriate forms and supporting documentation are submitted. The

attorney needs a doctor to complete the functional assessments and disability forms.

Ms. X searches for a doctor. In desperation, she contacts an MCS specialist after reviewing the doctor's website. Although in the same state, the doctor is not geographically close enough for her to schedule a visit. She telephones and asks if perhaps they could recommend a primary care physician whose office is closer to where she lives and who knows about MCS and EIs. The next day the doctor telephoned her and gave her the name of an integrative care medical center. She was able to schedule an appointment at the end of July. This doctor was very knowledgeable about EIs, MCS, mast cell issues, and avoidance. She completed all the SSA functional assessment forms as well as the lawyer's disability forms.

September 3016. Ms. X is referred by her primary care physician to a dermatologist regarding strange-looking rashes Ms. X has on her legs and arms. The dermatologist immediately upon examination said, "Yes, that's mastocytosis. That's mast cells."

September 3016. Ms. X is determined to be totally and permanently disabled by the administrative law judge and is approved for disability benefits based on the medical records and medical documentation.

It was a long two years. Ms. X struggled every day to survive with incapacitating symptoms, unable to work, relationships dissolving, battling a system not set up to accommodate the needs of individuals with EIs. Ms. X shared with me, "I really think that I was approved for disability in the end because I was able to have an additional diagnosis—the mast cell stuff—that is more medically recognized and accepted, if not well understood," she laughs and shakes her head, "I told my first doctor, in the beginning, that I didn't

care if he wrote down I was crazy as a coot as long as I could get some financial help. How else was I supposed to buy food? I can't work. I needed that emergency money so badly. It was horrible."

Pamela Reed Gibson, PhD, has conducted life impact studies on people who have MCS. In her publication, *Accommodating People with MCS* (2002), she notes:

- Three-quarters of the people studied had lost their jobs or had to stop working due to MCS, and only 7% were working in conditions they considered safe for their health (26-27).

- Because of financial desperation, some people reluctantly allowed the use of psychiatric diagnoses in order to receive benefits necessary for them to survive (31).

- SSA's listing of impairments includes over 150 categories presumed to meet the severity test for acquiring benefits. MCS is not on it and, being unlisted, must be the "medical equivalent" of one of the [other] listings (29).

- MCS falls into the category of impairment that is difficult to document by medical fact, and therefore the person MUST prove functional limitation (29).

Functional Assessment

The role of health professionals in the SSA disability determination process is crucial, especially the treating health professionals who provide medical evidence on behalf of their clients. SSA defines “treating” health professionals, or

the "treating source," as the person's own physician, psychologist, or other acceptable medical source that has provided the client with medical treatment or evaluation and has or has had an ongoing treatment relationship with the client. SSA acknowledges that the treating health professionals are usually the best source of medical evidence about the nature and severity of the client's impairment(s), (www.ssa.gov/professionals/greenbook/ce-general.htm).

There are three basic functional assessments that SSA requires: (1) The adult applicant completes a multiple page functional self-assessment form about their medical condition, symptoms, and limitations they experience in their ability to engage in any substantial gainful activity due to the medical condition and symptoms; (2) The applicant's treating health professionals complete a physical residual functional assessment; (3) The applicant's treating health professionals complete a mental residual functional assessment.

There is an SSA Mental Residual Functional Capacity Assessment form that can be completed, however its rating scale format does not adequately or accurately represent the array of multiple organ system reactions the person with an EI such as MCS and other mast cell activation related disorders may experience nor the profound impact of these reactions on their ability to function in any arena. The forms ask, for example, that the health professional rate the person's sustained concentration and persistence (in areas such as ability to carry out very short and simple instructions and ability to maintain attention and concentration for extended periods) on a rating scale of 1 to 5 where 1 is Not Significantly Limited, 2 is Moderately Limited, 3 is Markedly Limited, 4 is No Evidence of Limitation in this Category, and 5 is Not Ratable on Available Evidence, (Form SSA-4734-F4-SUP, 10-2004).

EIs and their symptoms are dependent upon exposure to triggers. As long as the individual with an EI is successful in avoiding the chemicals to which they react on themselves, on

others, and in the environment, their reactivity can be quite low and they may not in those moments experience the functional limitations and impairments to the same degree as when they have been exposed to chemicals and are reacting. The SSA Mental Residual Functional Capacity Assessment form seems more appropriate for other disabilities whose symptom presentation is more black-and-white and can with greater accuracy translate to a rating scale.

The more complete format which allows for the specifics of the illness that is MCS or another mast cell related disorder, as well as each client's triggers, reactivity and symptoms, is the SSA Adult Consultative Examination Report for Mental Disorders. This format is a narrative presentation within which health professionals are asked to address the individual's prior and current medical history, primary symptoms, alleged reasons for not working, history of onset, progress of their disorder, individual's statement of current symptoms, type and effect of any treatments, past and current participation and success or failure in rehab, group homes, halfway houses, inpatient or outpatient treatment, current medications, social and family history, general appearance, behavior, general observations, general motor behavior, and a mental status examination. (http://ssa.gov/disability/professionals/greenbook/ce-adult.htm#Mental)

Although the DSM-5 has moved diagnosing away from the axial format, SSA requires a full multiaxial classification as set forth in the DSM-IV-TR including the prognosis and any recommendations to be included in the Adult Consultative Examination Report. SSA also requires the health professional to include in the report: an assessment of the person's abilities and limitations based on medical history and observations; their opinion regarding the person's ability to understand, carry out, and remember simple and complex instructions, sustain concentration and persist in work related activities; their ability to maintain effective social interactions on a consistent and independent basis with others at work; if

any hazards should be avoided and to specify which ones and why, (http://ssa.gov/disability/professionals/greenbook/ce-adult.htm# Mental).

Sample Consultative Examination Functional Assessment

Date: 09/00/3015
Client Name: Ms Smith *(imaginary client)*
DOB: 00/00/0000

The following functional assessment is an evaluation of the above named individual's psychological issues and their impact on her capacity to sustain activity over a normal workday and workweek on an on-going basis. Detailed information provided for each of the degree of limitation categories as per SSA-4734-F4-SUP and SSA History of Impairment forms.

General Observations and History of Present Illness
Ms Smith was referred for therapy by her Primary Care Physician in July 3015. We have been meeting weekly since that time. Ms Smith reported contacting an environmental medicine agency for the name of a therapist who specializes in working with clients who have chemical sensitivities and she was given my name.

Ms Smith is a pleasant and agreeable 43 year old American woman who came for examination in a car driven by a friend. She arrived for her initial appointment wearing a face mask with a filter which she explained helped her to breathe when in environments that have chemicals to which she reacts. She was able to remove the mask for part of the session after having the windows opened for fresh air to circulate.

Ms Smith reported a medical history that includes Multiple Chemical Sensitivity (MCS) diagnosed 00/00/3014, hypothyroid diagnosed 00/00/3007, and migraines since adolescence. She stated she was seeking support with dealing with the MCS, its symptoms, and the impact it is having on her life. Ms Smith described her reactions to chemicals as involving many different body systems including cognitive impairments and severe anxiety.

During these times, she reported becoming extremely agitated, anxious, confused, disoriented, "I can't remember anything," and "my friend says I'm like a different person," and inability to function. She denies feelings of depression and suicidal ideation. Ms Smith stated she has no history mental illness and has never been treated for mental illness. Ms Smith stated she has no history of substance use, does not smoke, does not drink alcohol.

The chemicals to which Ms Smith reacts, she reported, include: plastics, metals, glass, exhaust fumes, personal products (laundry soap, hand and body soaps and lotions, creams, perfumes,) room fresheners, cleaners and detergents, and that exposures to these and many other products cause anaphylactoid reactions, anxiety, panic, cognitive impairments. Ms Smith has stated that her current treatment protocol is avoidance.

Ms Smith is currently being treated for her disability by Dr. _____ at _____ Hospital, a specialist who works with patients with chemical sensitivities and pulmonary problems, and by her Primary Care Physician. Ms Smith was examined by an allergist and otolaryngologist at _____ Hospital who diagnosed her with MCS.

Current Medications

Ms Smith reported taking Synthroid, Benadryl, and hydroxyzine daily for her reactions and Prednisone PRN. She carries Epipens with her at all times as her reactions are anaphylactoid and life-threatening in their severity.

Activities of Daily Living

Ms Smith reported highly limited activities of daily living, stated that her disability and subsequent medical treatment made socializing next to impossible. She stated many people have stopped calling and that, "People don't understand about this disability." Ms Smith stated that she needs to avoid groups of people, even small groups, as well as public places including other people's homes and they are not able to visit her in her home. She reported spending time washing—

herself, her clothing, her dishes—due to her reacting to residual chemicals on things, on herself, and on others. She reported feeling exhausted much of the time, "In between reacting and being out of my mind with anxiety, completely unable to sit in a chair," she stated, "then I'm just exhausted and I lie there for days and weeks until I feel a little better from the fumes." She stated she can only use the telephone and the computer in very short spurts, "a couple of minutes tops," because she reacts to the plastic.

Most of the tasks she had performed independently prior to her illness, Ms Smith reported, she now requires varying degrees of support with from someone giving her a ride to the store, to the pharmacy, or to the doctor as she is no longer able to drive, to someone having to conduct her business for her as she experiences reactions from handling, for example, newspapers, money, pens, paper, pushing or holding a shopping cart.

Ms Smith stated she cannot eat most foods, has issues taking medications, cannot ride in an ambulance. She reports that she reacts to the chemicals and experiences severe and almost paralyzing anxiety along with the other physical symptoms of anaphylactiod reactions including but not limited to swelling of the tongue and airway, inability to breathe, closing airway, diarrhea, nausea, heart palpitations, disorientation, confusion, blurred vision, hearing loss, tinnitus, inability to understand what others say to her and what she reads. Ms Smith stated she prepares her own meals daily, does not use her oven—stovetop only—but that this use is minimal due to her limited diet. She reports that most foods "burn" her tongue and throat when she tries to eat them or that she gets "nauseous immediately, my tongue starts to swell up, I starting getting short of breath and unable to breathe and have stomach pain, so I spit it out." She reports reacting to tap water, as well.

Ms Smith reported she is unable to perform most household chores herself, needs assistance, and her friend does these things for her. Ms Smith can only use baking soda and vinegar to clean,

wash dishes, wash clothing. She can only use all natural glycerin soap to bathe and wash her hair, and is no longer able to use an antiperspirant or deodorant.

Work History

Ms Smith is an RN and teacher with a Master's Degree. She described her work history as "full" and "I love working with kids," and "I worked all the time." She stated she had been looking forward to further advancement at her job, "But then I got so sick and everything screeched to a halt. I can't do anything anymore." She reported never having been fired from a job.

Ms Smith stated she had "allergies to little things growing up like wool and pollen in the spring." She reported being exposed to pesticides at work, "They sprayed while I was inside," which she feels "was the straw that broke the camel's back," and that the otolaryngologist who diagnosed her with MCS had her find out what exact pesticide was used. When she informed him over the telephone that it was pyrethrin, she reported his response as being, "Yup, that did it. It's a neurotoxin."

Ms Smith reported having to miss partial and full days of work more and more frequently after the pesticide exposure due to reactions of increasing severity and her need for longer periods of time to recover from these reactions. She reported having to leave work in the middle of a shift because she was having a reaction and needed to be taken to an emergency room. She has since been unable to work due to the severity of her symptoms when reacting to chemicals. Ms Smith described herself at these times as being "unable to function."

Multiaxial Evaluation

Axis I:

293.84	Anxiety Disorder due to Another Medical Condition (ICD)

Axis II:

N/A

Axis III:

989.89	Chemical Sensitivity (ICD)
T78.4	Multiple Chemical Sensitivity/Allergy NOS (ICD)

Axis IV:

Problems with primary support group:

Receiving support from family and close friends is difficult for Ms Smith. Her current medical treatment is avoidance. Ms. Smith must avoid chemical exposures. This includes public places, groups of people, going to the homes of family and friends, others coming to her home. Her ability to use the telephone and computer is very limited due to the severity of her reactions. Ms Smith is very isolated.

Problems related to the social environment:

Ms Smith lives alone. Her main medical treatment protocol is avoidance. It is very difficult to maintain friendships or to have adequate social support when you must avoid being with people and being in most environments. Ms Smith is also very aware that when exposed to chemicals and experiencing a reaction, she can become severely anxious, agitated, and emotional and that these reactions can cause people to move away from her through their not understanding her disability.

Occupational problems:

Ms Smith is currently unable to work due to her reactions to chemicals, a situation that creates enormous stress and impacts all areas of her life. Ms Smith is physically unable to carry out most if not all work related tasks due to the severity of her reactions. The reactions she experiences when exposed to chemicals are not limited to the physical body systems but involve cognitive and mood impairments as well including extreme anxiety, agitation, panic, disorientation, confusion, not remembering, not being able to understand verbal and/or written communication, inability to speak clearly. She is rendered unable to function when exposed to chemicals and experiencing a reaction. Her reactions can be immediate and without warning. Ms Smith is at risk for chemical exposures and severe, life-threatening anaphylactoid reactions in

any and all environments, especially those that depend on the behavior of others.

Housing problems:
Ms Smith lives in an apartment building. Her symptoms are exacerbated through building renovations, paint fumes, adhesive fumes, and many, many other chemicals involved in the interior and exterior maintenance of an apartment building as well as through the chemicals and fumes from other tenants in the building. Ms Smith experiences repeated unexpected exposures to chemicals in her home environment that she is unable to control. This creates a great deal of anxiety, leaving Ms Smith feeling that she must always be on guard for potential threats to her health and exacerbation of her reactions.

Economic problems:
Inadequate finances, insufficient public welfare support.

Problems with access to health care services:
Ms Smith requires significant reasonable accommodations in order to minimize her risk of exposure while obtaining the healthcare services she needs. Ms Smith has difficulty with transportation and cannot use public transportation, taxi services, or ride in most cars. To do so would mean exposures to many chemicals including exhaust/petrochemical fumes and possible pesticides, putting Ms Smith at risk.

Other psychosocial and environmental problems:
Loss of relationships, physical and mental isolation, inability to control physical appearance, lack of choice about public behaviors, fear of chemical exposures and living a life that requires constant vigilance for threats in the environment, fear of an uncertain future lived at odds with our mainstream culture, ongoing management of a chronic illness.

Axis V:
Determining an accurate GAF for Ms Smith is challenging as her ability to function relates directly to the presence or absence, and degree of, chemical exposure-induced reactivity at any given time

coupled with a lack of advance warning of the presence of any number of chemicals to which she reacts, and the severity of her reactions.

Functional Capacity Assessment

Ms Smith is an alert and oriented x 3 woman who has been diagnosed with Multiple Chemical Sensitivity. She experiences considerable anxiety accompanied by panic when having a reaction to a chemical exposure. Her reactions are severe and life-threatening, and render her unable to think clearly, follow instructions, complete tasks. Her reactions significantly impair her ability to concentrate, her vision, her hearing. Because she does not have any advance warning when in the presence of chemicals to which she reacts, she is unable to prepare for her reactions. Her reactions can be immediate with swift escalation. Ms Smith is at risk for chemical exposure and severe, life-threatening anaphylaxis in any and all environments, especially those that depend on the behavior of others.

When experiencing a reaction, Ms Smith becomes highly agitated with often severe anxiety. At these times she does not interact well with others, becomes forgetful, disoriented, is unable to concentrate, and her judgment is poor. When reacting she has difficulty making decisions, frequently does not understand what people are saying to her, and is not able to follow written or verbal instructions. She experiences blurred vision and impaired hearing (muffled and tinnitus). Her anxiety can be so severe that, during a reaction, she may be unable to sit down. These reactions can occur at any time, without warning, and make it impossible for her to sustain an ordinary work routine. Ms Smith can also experience when reacting joint/muscle/bone pain, swelling of tongue, throat, and air way, inability to breathe, nausea, diarrhea, severe stomach and abdominal pain, blinding headaches, numbing of skin and extremities, weakness. Her ability to complete a normal workday and work week without interruption from symptoms is markedly limited. In addition, she requires extended periods of rest due to exhaustion from the chemical exposures.

Ms Smith is unable to physically touch or handle almost all plastics, most metals, and many glass and ceramic items. She experiences reactions to the chemicals that comprise such items as pens, pencils, paper, ink, copy machine, toner, computers, keyboards, mouse, chairs, tables, other furniture, carpets, glue, tape, paperclips, staples, tape and adhesives, cardboard, clothing materials, drying cleaning chemicals and anything that has been dry cleaned, dyes, cleaners, disinfectants, hand sanitizers, air fresheners, room deodorizers, re-circulated air in heating, ventilating, and air conditioning systems. Ms Smith reacts to chemicals in the environment and to chemicals/perfumes/personal care products/pet dander, etc., on other people. The mask with the filter Ms Smith uses does not eliminate the chemical threat and danger presented. It reduces it only. Reactions still occur. Ms Smith, even when wearing a mask, is still exposed to the chemicals through her respiratory system and absorption through her eyes and skin. Her ability to work in coordination or in proximity to others is markedly limited.

Ms Smith must avoid the chemicals to which she reacts. Adaptability is not an option for her. She does not always know when she is in the presence of a chemical to which she reacts until she finds herself gripped in the reaction, at which time her anxiety, agitation, and other symptoms escalate rapidly and to such a degree that she is effectively not able to function. Even the possibility of working at home is not an option for Ms Smith as she is not able to use the telephone or the computer, to handle books, pens, paper, ink, items made out of plastic and metal without experiencing a reaction.

MCS is a chronic illness and a chronic environmental illness whose prognosis is uncertain. Ms Smith's anxiety is considerable simply venturing out the door. This compounded with the escalated anxiety and panic she experiences, the cognitive impairments, as well as her other symptoms when exposed to chemicals and having a reaction render her markedly limited in all functional areas associated with and required in the workplace.

Signature: _____License #_____

6
Expanding the Lens

The emotional and psychosocial needs of a person who has MCS are intimately entwined with their physical disability, perhaps more so than with any other chronic illness. Traditional avenues for healthcare are often inaccessible for these clients due to the symptoms of their physical illness, the severity of the symptoms, and their need for avoidance. In order to provide support and services, we need to be able to reach outside the therapy "box" for alternatives.

Integrative Medicine

People who have an EI such as MCS and other mast cell activation related diseases may have grown to feel that conventional medicine does not address or understand their medical needs. It is common for individuals who have an EI, or who are suspected of having an EI or a mast cell related disease, to have negative experiences of health care from providers. EIs are not well understood in the conventional

medical community. The person with an EI may feel angry, hurt, betrayed, or abandoned by doctors, as well as frightened and alone.

Integrative Medicine is an approach to healthcare that offers individuals the treatments and interventions of western medicine and the treatments and interventions of non-western medicine. Commonly referred to as CAM—Complimentary & Alternative Medicine—"complimentary" and "alternative" medicines do not mean the same thing. Complimentary refers to non-traditional and/or non-western treatments that may be used in conjunction with traditional, western medicine treatments. Alternative medicine refers to non-mainstream, non-western treatments and interventions that are used in place of conventional medicine (see nccam.nih.gov).

Integrative Medicine is also a model of healthcare that focuses on the person and not the disease. It is an approach that is holistic and considers the whole person and all health conditions together and at the same time. Western medicine is traditionally highly specialized and compartmentalized. EIs affect all organ systems and the brain. Treatment approaches and planning need to address all these areas of impact. The Integrative approach may be preferable for individuals with EIs and mast cell/mast cell activation related disorders as there is not a single are of their lives left untouched by their illness.

Clients with an EI need to be asked about their CAM use at every visit. It is common for these individuals to seek out alternative medicines and interventions in the hopes of experiencing some relief from their symptoms. The client with an EI should be asked about current CAM and alternative treatments and interventions, current allopathic treatments and interventions, their history of allopathic, CAM, and alternative treatments, and their perceived effectiveness.

Centers for Integrative Medicine offer multiple services at one site, in the same building, as part of one practice where all the medical care providers work together as one collaborative team. This is another aspect of Integrative Medicine that may be beneficial for the person with an EI as it aids in minimizing their exposures to chemicals and environments when receiving medical services. Everything can be done in one building with appointments for multiple services scheduled for the same day/visit.

Plans for care and individual goals, in the Integrative medical model, are developed with each client's active participation in partnership with the doctor, nurse, therapist, and other health professionals. The medical team works with the client from the first visit considering all aspects of the client's physical, medical, emotional, and spiritual needs with a focus on healing and total health.

Suggested Reading:
Integrative Medicine, by Benjamin Kligler, et al

Narrative Therapy

The individual with an EI or suspected of having an EI is grappling with redefining who they are in terms of their illness, restructuring their life and future, and radically altering their dreams. Narrative Therapy is an approach perhaps ideally suited to the work of adjustment that individuals with an EI must go through.

In our society, a person's worth is based on what they do nine-to-five. The person with an EI may find themselves unable to work or able to work only limited hours after strict reasonable accommodations are in place. Regular schedules can be difficult to maintain due to fluctuating symptoms and the person's inability to sufficiently control their

environments and their exposures to chemicals in the shared workplace.

Narrative Therapy recognizes that the person is not defined by their illness and actively supports the positive separation of self from disease. Through Narrative Therapy approaches and techniques, the individual is able to re-author the narrative storyline of their lives and in this way move towards developing a new, better, and clearer understanding of who they are, their worth, and value.

Suggested Reading:
What is Narrative Therapy? by Alice Morgan

Online Resources:
Dulwich Centre www.dulwichcentre.com.au

Body, Mind, Spirit

The Body, Mind, Spirit approach in therapy begins with the understanding that a human being is one whole unit comprised of many parts, and that health and well-being are states of the whole that involve all the parts. We are a system. We can't compartmentalize. All parts affect the whole; all parts are the whole. An event, circumstance, or situation that impacts a person at one level affects the entire system.

The Body, Mind, Spirit approach addresses a person's physical health, emotional health, mental health, spirituality and spiritual health and uses techniques such as meditation, imagery, breathing, mindfulness, authentic movement, yoga, visualization.

The person with an EI or suspected of having an EI may profoundly benefit from Narrative Therapy strength-drawing practices. The client with an EI has a very real physical need for calm. Strong emotions, whether positive or

negative, as well as stress can cause and/or intensify their symptoms and their reactions (http://www.mastocytosis.ca/MSC%20Patient% 20Experience%20April2012.pdf).

The client with an EI may need concrete things to do while they are having what can be severe or life-threatening reactions, and throughout the day, in order to best manage their symptoms. Focusing, breathing, guided imagery, awareness of the body, meditation, visualization are all techniques of Body, Mind, Spirit that a client can practice and use effectively.

We go on because we have hope. Many people with an EI can feel without hope. They may look to suicide as a viable option, (Gibson, 2002, 56), unable to manage or find relief from the symptoms and burden of having a chronic illness that spans the spectrum from somewhat limiting to utterly devastating. It is important to consider the spiritual when working with individuals who have an EI such as MCS or a mast cell/mast cell activation related disorder as they redefine their understanding of who they are within the challenges of living with these chronic illnesses.

Suggested Reading:
The Faithful Gardener, by Clarissa Pinkola Estes
The Sun My Heart, by Thich Nhat Hanh
A Handful of Quiet, by Thich Nhat Hanh
The Long Road Turns to Joy, by Thich Nhat Hanh

Online Resources:
Plum Village (plumvillage.org)

Ecotherapy

We are creatures of relationship—with ourselves, each other, and our world. An Ecotherapy approach used in counseling provides an opportunity to include this particular "system"—our relationship with our environment and the

natural world—as part of the therapy. It is a system as vital as family. Relationships and their impact on the individual reach far beyond the systems of workplace, family, community, and significant others. All these relationships are contained and sustained by the natural environment (Roszak, 2001, 328).

In his essay, "Ecotherapy Ressearch and a Psychology of Homecoming," Craig Chalquist, PhD, psychologist and department chair of East-West Psychology at the California Institute of Integral Studies, writes, "A good start on all this would be to experience the breathing planet by listening through the heart for a resonance to this hillside or that street corner, my house or your garden, these shores and those forests. To awaken to how one's own story aligns with the story of a place, and of the planet," (Buzzell, 2009, 82).

The relationship a client with an EI has with the natural environment can be challenging and changeable. One vantage point reveals the environment as hostile, chemical-ridden, dangerous, harmful to one's health. A second, simultaneous viewpoint understands the natural environment as beneficial and cleansing, bringing us emotional, physical, and spiritual strengthening and rejuvenation. Inviting the natural world to be part of the therapeutic process is especially significant when working with a client who has an EI. Individuals with an EI often feel alone, isolated, separated from all systems by the demands of avoidance and the symptoms of their chronic illness. Eco-therapeutic approaches in counseling help clients to reconnect and to learn new ways of connection. It can be something as simple as meeting with this person out of doors, away from the chemicals.

The role that gardens and outdoor settings play in healing have been explored by numerous research studies, showing, according to one study, that older adults participating in an activity in a garden had significantly lower cortisol levels, indicating lower levels of stress, than adults performing the same activity indoors (Buzzell, 2009, 168-

170). Certain scents, including garden plants and flowers, have been found that stimulate body organs to release neurochemicals which help eliminate pain, induce sleep, and create a sense of well-being (Buzzell, 2009, 168-170).

Consider a garden. Even in the most urban landscape, there are gardens. Potted plants are watered and nurtured in the tiniest one-room dwelling or inner-city office. Nature heals. Elizabeth R. Messer Diehl, landscape architect and Horticulture Therapist, describes it this way, "A healing garden in a healthcare setting is a place to relax, connect with nature, reduce and relieve stress," (Buzzell, 2009, 168).

Suggested Reading:
Ecotherapy, by Linda Buzzell and Craig Chalquist (eds.)
The Voice of the Earth, by Theodore Roszak
Gardens for the Senses Gardening as Therapy, by Hank Bruce

Online Resources:
American Horticultural Therapy Association
http://ahta.org/

Intermodal Creative Arts Therapy

We move through our days interpreting our environments and experiences using all of our senses—hearing, sight, smell, touch, taste. There are moments when we need to sing, or have to move and dance. Other times we turn to writing or a book to process and understand events in our life. There are days when the only thing that soothes is working in the gar-den, or walking by the sea. The creative arts areas include language arts, dance and movement, culinary arts, music, drama, horticulture and permaculture, the visual arts and architecture, and each arts area has its own unique language. All of the creative arts areas are significant and integral parts of healing and health.

An intermodal approach to using the creative arts in therapy is one where instead of focusing on one arts area, for example, Art Therapy, or Music Therapy, or Poetry Therapy, the therapist moves among different creative arts areas in order to best meet a client's individual needs.

The therapeutic relationship and therapeutic environment have often been described by professionals in the field as "a safe container," with the work of therapists, through their counseling skills and techniques, referred to as "creating a safe container." The imagery here is of the clinician literally creat-ing in their office space during each and every fifty-minute hour a safe "place" within which the client can explore, feel, work, share.

Through the creative arts, and using the creative arts in therapy, I have come to understand that we don't "create a safe container." The client *is* the container. We are—all of us— containers. We fill ourselves, through the daily events of our lives, with joy, sadness, compassion, anger, hope, longing, love. We live our days. Things happen to us that make us weep, laugh, cringe. We fill, and fill, and fill until there's no more room inside. Sometimes we are so full, the emotions are so intense or so confusing, we look for support. We need a witness to our journey.

The creation of art is a profound experience of process. Through creating art, choosing a medium, choosing materials, we move through our interior stores giving expression and voice, analyzing, understanding, emptying, to finally present to an audience—a witness—this tangible culmination of a living journey.

The person with an EI or suspected of having an EI or a mast cell related disorder is living a life of disconnect. The creative arts areas are places and avenues of connection that reach beyond the imposed limitations of avoidance to sustain and nurture.

Suggested Reading:
Illness and the Art of Creative Self-Expression, by John Graham-Pole, MD
The Secret World of Drawings, by Gregg M. Furth
The Sonic Self, by Naomi Cumming

Online Resources:
The Counseling Center at CELA
www.counselingatcela.com

Intermodal Creative Arts Therapy Certification and Training
www.celaonline.com

The International Expressive Arts Therapy Association
www.ieata.org

The Transformative Language Arts Network
www.tlanetwork.org

Resources

MCS Informational/MD Websites:

American Academy of Environmental Medicine
www.aaemonline.org

Environmental Working Group
www.ewg.org

The Massachusetts Association for the Chemically Injured
www.maci-mcs.org

Alan Lieberman, MD
https://coem.com/staff/dr-allan-lieberman/

Ann McCampbell, MD
http://annmccampbell.com/

Claudia S. Miller, MD
http://drclaudiamiller.com/

Lisa Nagy, MD
http://www.environmentalmedicineinfo.com/

Doris J. Rapp, MD
http://www.steveakash.com/drrapp/toxicplaces.html

Ritchie Shoemaker, MD
www.survivingmold.com/about/ritchie-shoemaker-m-d

Grace Ziem, MD
http://www.chemicalinjury.net/index.htm

MCS Research Websites:

MCS Research at James Madison University
www.mcsresearch.net

Claudia S. Miller, MD
http://drclaudiamiller.com/

Raymond Singer, PhD
http://neurotox.com/

Anne Steinemann, PhD
http://www.drsteinemann.com/

Jack Dwayne Thrasher, PhD
http://www.drthrasher.org/

Mast Cell Disorders Informational Websites:

Mast Attack
https://www.mastattack.org/

The Mastocytosis Society USA
www.tmsforacure.org

Mastocytosis Society Canada
www.mastocytosis.ca

T.C. Theoharides, PhD, MD
www.mastcellmaster.com

Mast Cell Specialists:

Mariana Castells, MD
https://physiciandirectory.brighamandwomens.org/Details/1728

T.C. Theoharides, PhD, MD
www.mastcellmaster.com

Cem Akins, MD
https://health.usnews.com/doctors/cem-akin-100872

Additional Resources:

The Counseling Center at CELA
http://counselingatcela.com

UK Mastocytosis Support
www.ukmasto.org

My Chemical Free House
https://www.mychemicalfreehouse.net/p/about-this-blog.html

American Academy of Environmental Medicine
https://www.aaemonline.org/

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Chemical Sensitivity Foundation http://www.chemicalsensitivityfoundation.org

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Dr. T. C. Theoharides, MD Ph.D., "Mast cells, autism, inflammation." http://www.mastcell master.com

Dr. Claudia S. Miller
http://www.drclaudiamiller.com

Dr Grace Ziem
http://www.chemicalinjury.net

Environmental Illness Resource
http://www.ei-resource.org

Epipen
http://www.epipen.com

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http://www.chemicalsensitivity foundation.org

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http://www.tmsforacure.org

Safe Space
https://www.safespaceprotection.com/emf-health-risks/emf-health-effects/

The UK Mastocytosis Support Group
http://www.ukmasto.org

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Multiple Chemical Sensitivity (MCS) is a real, physiological illness affecting increasing numbers of people, including veterans returning home in need of care.

Aligned with the DSM-5, this book is a tool and guide written for therapists--social workers, mental health counselors, expressive therapists, psychologists--but with the hope that it will be used to inform all clinicians and healthcare professionals, to raise their awareness, and to deepen their knowledge and understanding as they plan the care and services they will provide for individuals suffering from the very serious chronic diseases of MCS, Environmental Illness, and mast cell related disorders.

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