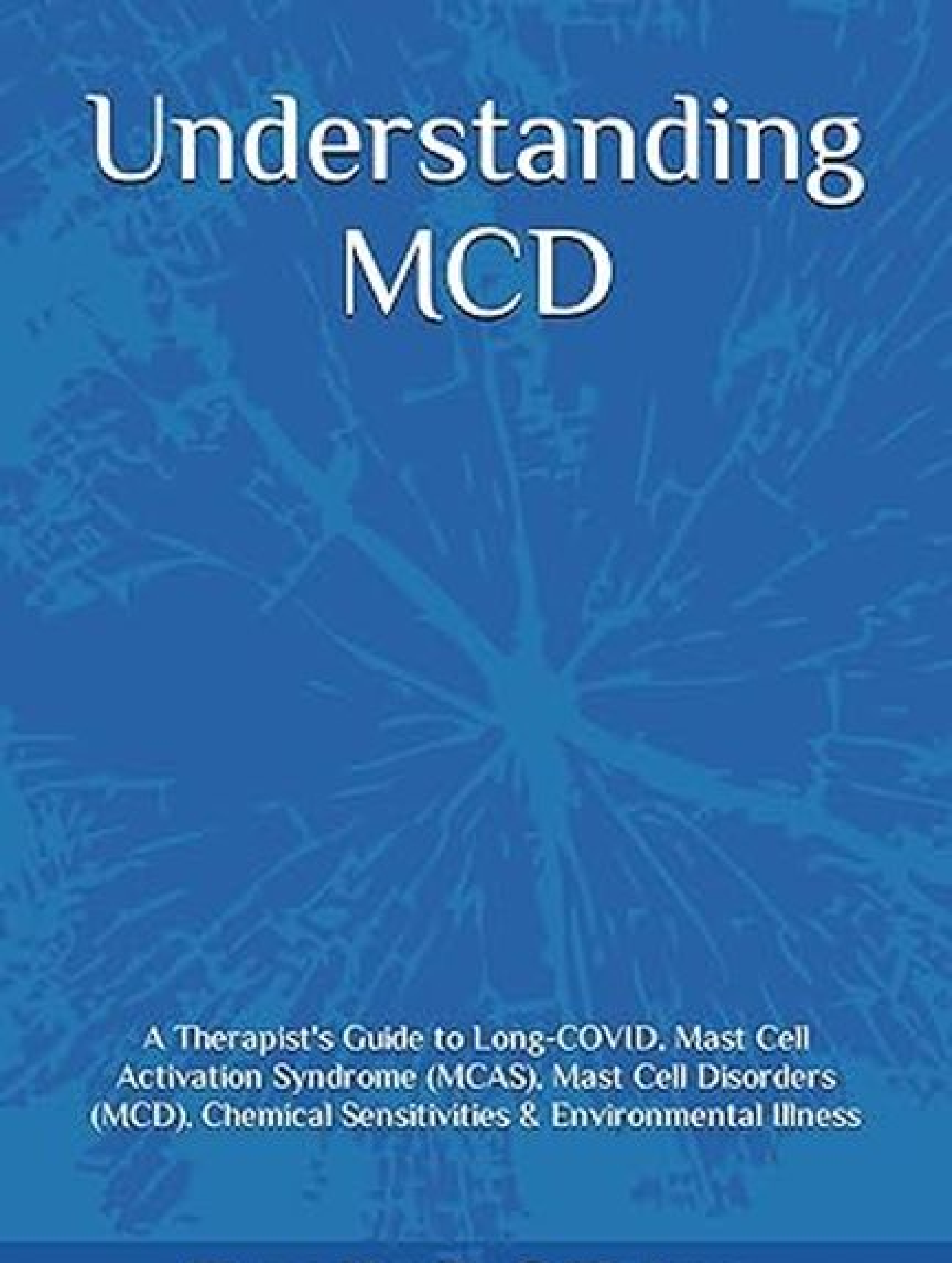
Understanding MCD



A Therapist's Guide to Long-COVID, Mast Cell Activation Syndrome (MCAS), Mast Cell Disorders (MCD), Chemical Sensitivities & Environmental Illness

Roselle P. O'Brien, LMHC

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

CELA Publishing
Boston, Massachusetts

for

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LMO'B
LBO'B

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Understanding MCD

Introduction

I began sharing the mast cell activation connection and its relationship to being sensitive to multiple chemicals in 2014 with my book, *Understanding MCS: A Therapist's Guide to Multiple Chemical Sensitivity and Environmental Illness*. Not everyone who read the book was willing to jump on board embracing the reality of mast cell activation as what goes on physically in our bodies that brings on reactions.

In 2014, I was invited as a guest speaker to share these insights with a group of individuals who were calling their experience of illness Multiple Chemical Sensitivity (MCS). I remember being excited and looking forward to the sharing, hoping having the facts might point sufferers in a direction where they could get an appropriate diagnosis leading to appropriate treatments and interventions and, ultimately, to their experiencing some relief from symptoms. I discovered that the majority of the people who attended rejected mast cells as having anything to do with what was happening with them. One person, in conversation with me, said that they had spent the last almost thirty years of their life fighting to have MCS be recognized as an illness and to say, now, that it's mast cells seemed too much like saying they had completely wasted those thirty years.

On another occasion, a few short years ago, I was invited to be interviewed on a podcast and to speak about mast cell activation and chemical sensitivities, especially focusing on strategies for supports. The interview was about forty-five minutes long. I listened to it in its entirety when it was first aired. A few hours later, I noticed when sharing the link with a colleague, that the length of the interview was now about twenty minutes. I re-listened to the podcast and discovered that every mention I made about mast cells had been edited out.

Jump ahead to the COVID-19 pandemic and long-COVID. At the time of this writing, the current medical research has been finding more and more evidence linking COVID-19 and long-COVID pathogenesis and symptoms to mast cell activation (for instance, see BMJ 2020;370:2722; Meng-Li Wu, Feng-Liang Liu et al, 2021; Hiu Yan Lam, Vinay Tergaonkar, Alan Prem Kumar et al, 2021; Sumantri S, Rengganis I., 2023).

It has been decades of people being marginalized, living on the fringes, misunderstood, stigmatized. People with mast cell activation issues or disorders have gone for years and years trying to find correct diagnoses, appropriate help and supports. It's unfortunate that it's taken the COVID-19 pandemic and the more than sixty-five million people worldwide suffering from the effects of long-COVID to bring mast cell activation disorders (MCD) to the forefront.

I have written this book as a tool and a guide primarily for therapists—social workers, clinical mental health counselors, creative arts therapists, psychologists, expressive therapists, psychiatrists—but it is my strong hope that it will be used to inform all clinicians and all healthcare 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 illnesses.

I have used a non-traditional format for inline citations, references, and the bibliography. This book is a teaching and learning tool. The inline citations are often the url link to referenced information and/or important information for practitioners to know. I encourage you to use them and not skim past. The supports we provide for our clients are based on our knowledge and insights as clinicians.

We need to be trained in how to work with clients with MCD in order to meet the needs of this growing population. I have designed and launched the first ever training program specifically for working with clients with MCD and mast cell activation related issues, applying my years of experience as a therapist specializing in working with clients with MCAS and mast cell activation related issues and disorders (12+ years) and my years of experience as a nurse (30+ years), as well as the shared insights of mast cell patients themselves. Why wait! Visit the website – enroll now!

Website: https://celacare-ecohealth.online

Roselle P. O'Brien
Boston, MA
2024

"If it looks like a duck, swims like a duck, and quacks like a duck, then it probably is a duck"

---Jaques de Vaucanson

"If it looks like a duck, and quacks like a duck, we have to at least consider the possibility that we have a small aquatic bird of the family Anatidae on our hands"

---Douglas Adams

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What are 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 even 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 even life-threatening reactions from their exposure to the chemical or substance.

Mastocytosis, Mast Cell Activation Syndrome (MCAS), mast cell activation related issues and disorders, and having sensitivities to multiple chemicals all 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.

A Brief Overview: MCS

Chemical sensitivities means when a person experiences reactions (such as brainfog, headache, rash, shortness of breath, difficulty breathing, agitation, anxiety to name only a few) when they are exposed to certain chemicals or substances. Being sensitive to chemicals comes under the heading of environmental illness (EI). In this type of EI, something in the environment is toxic, 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—even when the exposure is to the tiniest amount that another person might not even notice (counselingatcela.com).

Multiple Chemical Sensitivity (MCS) is a term that is used to describe and name the experience of being sensitive to multiple chemical substances and having mild to severe and/or life-threatening reactions when exposed to those substances.

Multiple Chemical Sensitivity (MCS) is not a medical diagnosis. Johns Hopkins Medicine (hopkinsmedicine.org/health/conditions-and-diseases/multiple-chemical-sensitivity) states:

> *At this time, it is a controversial issue as to whether it is a clinical diagnosis or not. Many in the medical community lean towards these symptoms being physical manifestations of psychiatric illness rather than a primary medical illness. While others in the medical community*

> *along with organizations agree that multiple chemical sensitivity is a negative physical reaction to certain chemicals. There is debate as to whether multiple chemical sensitivity should be classified and diagnosed as an illness.*

Current research has shown (see TC Theoharides, MD, PhD, mastcellmaster.com/publications.php) that the reactions to triggers a person experiences, and sensitivity to chemicals is just one area of potential triggers, have their basis in mast cell function and mast cell activation.

Mast cell disorders (MCD) are medical diagnoses. A person with a diagnosed mast cell disorder—Mast Cell Activation Syndrome, for example—can also say they have MCS. However, MCS is not the medical diagnosis and refers to symptoms. Mast Cell Activation Syndrome, in this example, would be the medical diagnosis and its symptoms include being sensitive to multiple chemicals.

EIs such as being sensitive to multiple chemicals 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 find themselves unable to work due to the onslaught of toxins in their work environment. Many people with these types of EIs have lost their jobs, their homes, their friends, their community, identity, and sense of self.

The Question of Cause: Total Load

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 substances 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* (see aaemonline.org).

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

Sherry Rogers, MD, a physician and specialist in the area of 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).

Brain to Cell / Cell to Brain Communication

The human brain multitasks 24/7. It regulates, choreographs, analyzes, and sifts through our emotions and our experiences while recognizing, organizing, and categorizing information about things like facial recognition, heat and cold, light and dark. Our brains engage us in understanding language both written and spoken, conducting simple and complex tasks of daily living, moving our limbs, our digits, moving the muscles of our face into a frown or smile. Neuroscientists have studied and continue studying exactly how our brains are able to successfully do all this and more plus give us the meaningful information that we use in living our lives and in understanding and making meaning in and of our world.

The cells in our body, including brain cells, communicate in spikes of electrical energy signals that move through and between neurons (also called nerve cells):

- Sensory neurons help us to sense our external world, working with physical and chemical information they receive from the external environment like sound, touch, light—physical inputs—and smells and tastes—and chemical inputs. Sensory neurons send information from our skin, eyes, nose (which are sensory receptors) toward the central nervous system (CNS).

- Motor neurons allow our brain and spinal cord to communicate with muscles, glands, and organs all over the body. They are crucial for voluntary and involuntary movement. They send information away from the CNS to the muscle, gland, or organ that needs to react.
- Interneurons are the most common type of neuron. They send information between sensory neurons and motor neurons. Many times they form complex circuits to help us react to external stimuli (for example, signalling to pull your hand away after touching a hot stove.)

(see https://www.mhanational.org/neurons-how-brain-communicates).

Neurons switch on and switch off and will set off a spike after deciding, based on which is pushing the hardest, to turn on or to turn off. If neurons make the decision to turn on, the spike goes down the cell's axon to its tip where information is relayed via chemicals through synapses to neurons that receive the information. Neuroscientists have been studying neuron activity to better understand what's happening in our brains.

Neurotransmitters are important in our everyday functioning. Over 100 neurotransmitters have been identified by scientists and each one plays a different part in our brain chemistry.

- Serotonin – important chemical that stabilizes moods and feelings of well-being and is important in digestion and sleep.

- Dopamine – important for memory, learning, behavior, and motivation. Sometimes referred to as the "reward" neurotransmitter due to its creating positive feelings that motivate us to continue with a task and the pleasure we feel when doing something we find enjoyable.
- Norepinephrine – also known as noradrenaline. It helps our body respond to stress. Norepinephrine increases as part of the fight or flight response. It has a part in signaling our body when to wake up in the morning, helps with memory storage, and increases our attention to tasks. Low norepinephrine levels have been associated with depression, anxiety, PTSD, and substance use. Bursts of norepinephrine can also lead to feelings of euphoria and feelings of panic and panic attacks

(see https://www.mhanational.org/neurons-how-brain-communicates)

The cells in our brain don't receive information always at the same time, or at the same rate, or in the same ways. Brain cells receive information as it happens, in the moment, at different times and through varying routes that lead to their having to have quick responses.

The human body is a multicellular organism. Our cells are constantly sending and receiving chemical messages in order to coordinate being human; coordinating the actions of organs, tissues, and cells of our body. The living cells in our body communicate through intercellular signaling and intracellular signaling. "Inter" means between. "Intra" means inside. When cells communicate it's called signaling. The cell that sends the information, that communicates, is called a signaling cell. The cell that receives the information being communicated is called the target cell. Target cells have proteins called receptors. Receptors bind to signaling molecules and bring about a response. (cell communication see https://rwu.pressbooks.pub/ bio103/chapter/cell-communication/).

There are four different categories of the types of chemical signaling that cells do: (1) autocrine signaling; (2) paracrine signaling; (3) endocrine signaling; and (4) direct signaling.

Autocrine signaling is when a cell responds to its own signaling molecule. In this type of communication, a particular type of cell sends out a message—a signal—to other cells and the signaling cell also joins its neighbor cells in responding to the signal (see https://rwu.pressbooks.pub/ bio103/chapter/cell-communication/).

Paracrine signaling is when cells are physically close together and they signal (send a message, communicate). This type of signaling tends to bring about quick responses only lasting a short period of time. Responses by cells are kept localized, the messages quickly degraded by enzymes or removed by neighboring cells. An example of this type of communication is "get your hand off the hot stove now!" Neurotransmitters quickly launch their electric impulse. The neurotransmitters are degraded fast or are reabsorbed by the presynaptic cell in order for the recipient nerve cell to recover quickly and be prepared to respond really quickly to the next signal (IBID).

Endocrine signaling is when signals are from distant cells. This type of signaling produces slower responses but they have a longer lasting effect. In endocrine signaling, hormones are released that signal molecules that are produced in one part of the body but affect other areas of the body that are located a distance away. Hormones travel those large distances by way of the bloodstream. Travel by bloodstream tends to be a rather slow way of moving and also dilutes the hormones. When the diluted hormones arrive at their target, they tend to be in low concentrations. In paracrine signaling, by comparison, there are very high local concentrations of signaling molecules (IBID).

Direct signaling is done using gap junctions in our bodies. These are water-filled connections between the plasma membranes of neighboring cells that allow small signaling molecules to communicate between each other. Small molecules like calcium ions are able to move between cells. Large molecules like proteins and DNA don't fit through these channels. Because the channels are so specific as to what cells do and don't fit through, it ensures that the cells remain independent but also can quickly and easily send signals. Through direct signaling, one group of cells can coordinate their responses to a signal that only one of them have actually received (IBID).

Cell-surface receptors (also called transmembrane receptors) are integral proteins that bind to external signaling molecules. Cell-surface receptor proteins are fundamental to basic cell functioning and a malfunction in any one of these proteins could have severe consequences to the body. Errors in the protein structures of certain receptor molecules have been shown to play a part in high blood pressure, asthma, heart disease, and cancer. Cell-surface receptors are involved in most of the signaling in multicellular organisms (IBID).

A Brief Overview: Mast Cells

Everyone has mast cells throughout their body - in their connective tissues and in every organ system including the brain. Mast cells are key players in our immune system response; the body's first responders. They also play an important role in inflammation.

Mast cells are a type of white blood cells. Although they can be found throughout the body, mast cells tend to congregate at the places where our body comes into direct contact with the outside environment: our skin, lungs and respiratory system, GI tract, and the brain.

Mast cells are part of and involved in several vital body functions including wound healing, bone growth, and forming new blood vessels (see clevelandclinic.org). As part of our immune system, when mast cells detect a germ or virus they set off an inflammatory—an allergic—response. It is a response that is intended to protect our body from germs and infections (see https:// clevelandclinic.org).

When a person comes into contact with a chemical or substance to which they react, their mast cells become activated which means the mast cells degranulate—they crumble. Activated mast cells send out hundreds chemicals called mediators into the body. Histamine and heparin are two examples of mast cell mediators.

Some mast cell mediators and their effects include:

- **Histamine –** urticaria, flushing, erythema (abnormal redness of skin or mucous membranes), angioedema, cough, wheezing, gastrointestinal manifestations gastritis (increased gastric secretion), headache, acts as a neurotransmitter
- **Leukotriene C4, D4, E4 -** airway inflammation and obstructive dyspnea
- **Prostaglandin D2 –** hypotension vasodilation, hypertension vasodilation at low doses and vasoconstriction at high doses
- **Triiodothyronine, 3-Iodothyroacetic acid; 3-Iodothyroanamine** – regulation of heart function
- **Heparin –** anticoagulant, problems with clotting

- **Serotonin (5-hydroxytryptamine) –** direct activation of pain nerve fibers; in the posterior horn of the spinal cord amplification or weakening or pain impulses
- **VGF Nerve Growth Factor Inducible –** chronic pain
- **Corticotropin Releasing Hormone –** mediating the autonomic, behavioral, and neuroendocrine responses to stress
- **Neuromedin B –** induction of sneezing following exposure to chemical irritants or allergens, diarrhea (stimulation of colonic smooth muscle contraction)
- **Milk Fat Globule EGF And Factor V/VIII Domain Containing –** enteritis/colitis
- **Somatostatin –** weight gain or loss, regulator of most hormones of the gastrointestinal tract
- **Leptin –** weight gain or loss, key regulator of energy balance and body weight control
- **Apolipoprotein E** – weight gain or loss, disturbed plasma and tissues lipid homeostasis

(Gerhard J. Molderings and Lawrence B. Afrin, 2023).

The histamine and other mediators pumped into the body 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, as well as anaphylaxis.

In a mast cell activation related issue or disorder, something has gone wrong with the mast cells. There may be, for example, too many of them (as in mastocytosis) or the mast cells could be degranulating—as in Mast Cell Activation Syndrome (MCAS) and non-mastocytosis mast cell activation issues and disorders—and be over active for unknown reasons. A person with a 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 activation issue or disorder need to avoid exposures to the chemicals and substances to which they react.

Current research (see T.C. Theoharides, MD, PhD, research at mastcellmaster.com) has shown that the reactions to triggers that individuals with chemical sensitivities, as well as many other illnesses and disorders, 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 Spectrum Disorder (ASD), Irritable Bowel Syndrome (IBS), Chronic Fatigue Syndrome (CFS), interstitial cystitis, migraines, and fibromyalgia, (see mastcellmaster.com/publications).

How Mast Cells Communicate

Mast cells are one of the first responders of our immune system to interact with potential threats and toxins in the environment. Mast cells can be activated by multiple signals. They can also secrete many different substances that can either positively or negatively regulate immune responses (see ncbi.nlm.nih.gov/books/ NBK45995/).

Mast cells communicate with other cells in many different ways including: the chemicals (mediators) that are released by activated mast cells can bind to receptors on other cells; the released mediators can also act on mast cell receptors; and through their being in physical contact with other cells. Through these ways of communicating, mast cells are able to impact the behavior of other cells (see mastattack.org/?s= cell+to+cell+ communication).

Mast cells communicate with many different cells and different types of cells in our body. Most often mast cells communicate by way of the chemicals (called mediators) that they release when they degranulate and crumble. Among the types of cells in our immune system with which mast cells communicate are B-cells and T-cells.

B-cells are a type of white blood cell that protect us from infections. They make proteins called antibodies. When our body detects something it considers potentially a threat like a bacteria or virus that has entered, B-cells become activated and produce antibodies to fight the threat. B-cells work with other cells in our immune system to fight harmful intruders. An activated B-cell will either turn into plasma cells that produce antibodies in response to an antigen (an intruder) or they become memory cells that remember antigens so our immune system can quickly identify and fight in the future (see clevelandclinic.com).

Mast cells produce and release substances that regulate the development of B-cells and which role the B-cells will develop toward—plasma cells that produce antibodies or memory cells to help identify and fight in the future (IBID).

T-cells are a type of white blood cell that help the immune system fight germs and protect us from diseases. There are two main types of T-cells: Cytotoxic T-cells which destroy infected cells and Helper T-cells that send signals that direct other immune cells to fight infection (IBID).

Mast Cells have a regulatory role in inflammatory diseases by way of their regulation of T-cell activities. They are able to bring on T-cell activation and influence T-cell activation, recruitment, proliferation, and differentiation (see pubmed.ncbi.nlm.nih.gov/28929455/).

Mast cells are pivotal for our body's defense against different antigens including allergens and microbial pathogens. Mast cells mediate acute inflammatory responses. The placement and location of mast cells on the boundaries between tissues and the external environment have mast cells involved in a multitude of immune system functions (see Sobiepanek, Kuryk, Garofalo et al, 2022).

A Quick Summing Up:

- Mast cells communicate with other cells by: (1) releasing chemicals to tell another cell to do something; (2) other cells releasing chemicals to tell mast cells to do something; (3) moving right up against other cells which allows the cells to "talk"
- B-cells are white blood cells that make antibodies and protect against infections
- T-cells are white blood cells that have many functions
- T-cells and mast cells are found close together in many inflammatory conditions such as ulcerative colitis
- Activated T-cells can activate mast cells
- Masts cells can tell T-cells to profilerate and produce inflammatory molecules

(see https://www.mastattack.org/?s=cells+communicate).

Mastocytosis and Mast Cell Activation Syndrome

Mastocytosis is a rare condition in which the body has produced too many mast cells or they are irregularly shaped. Mastocytosis has two forms: cutaneous where excessive mast cell infiltration is confined to the skin and systemic where an organ that is not the skin is affected by excessive mast cell infiltration. People with systemic mastocytosis can often have cutaneous mastocytosis as well (see mastattack.org/?s= mastocytosis).

Mast Cell Activation Syndrome (MCAS) is a condition that is not rare. In MCAS, a person's mast cells are normal in number but are over-reacting and not functioning correctly, typically for unknown reasons. These reactions can range from mild to severe and even life-threatening (see www.mastattack.org/ ?s= mastocytosis).

Recognizing Mast Cell Activation

Individuals who have or are suspected of having a mast cell activation related issue or disorder such as MCAS present with myriad complaints involving multiple organ systems. They frequently feel unwell all the time. Mast cell issues are often misdiagnosed or not diagnosed by physicians. Many doctors and medical professionals are unwilling to consider or acknowledge a diagnosis that even remotely includes or encompasses a person being sensitive to multiple chemicals, MCAS, or other mast cell activation issues or disorders, relegating them to either the realm of a medical specialty area (which, thus, is outside their scope of practice) or to the realm of psychosomatic/psychiatric/mental health issues.

I know a client who had a physician laugh in their face while telling them, "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 mast cell specialist, forcefully state, "What you need are intensive psychiatric interventions." This client has a medically diagnosed systemic mast cell disorder and carries the medical diagnosis of 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 release medication that was showing positive results.

The individual with MCAS or another mast cell activation issue or disorder who comes for counseling, therapy, and psychotherapeutic support may feel trapped into explaining their very real physiological illness in what are inappropriate psychiatric terms.

Although individuals with MCAS and other mast cell activation disorders may present as having psychological symptoms, it is vital to recognize that not all psychological-seeming 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, feeling that something is terribly, terribly wrong.

Some of the most common symptoms a person with chemical sensitivities and a mast cell activation issue or disorder may experience when reacting to an exposure include but aren't limited to: fatigue; head-aches; 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.

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-seeming symptoms stemming from a physical cause.

Unless informed otherwise, a doctor, clinician, or other healthcare professional may mistake symptoms of an EI such as MCAS (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-seeming symptoms stemming from a physical cause.

The behaviors of a person who has MCAS or other mast cell activation related EI can often be confused with the symptoms of mental illness, for example, Obsessive Compulsive Disorder or a delusional disorder.

A person with MCAS and severe chemical sensitivities 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 MCAS and other mast cell activation related EIs can experience mild to severe reactions from exposures to often very minute amounts of chemicals and/or substances. The chemicals and/or substances to which an individual can react vary from person to person, as do the specific reactions.

One person may experience dizziness, agitation, and cognitive impairments when exposed to car exhaust fumes. A second person may experience severe abdominal and stomach cramping, diarrhea, and nausea when exposed to car exhaust fumes. A third person may not react to car exhaust fumes at all. However, each and every person with MCAS or a mast cell disease/disorder (MCD) will have consistent reactions to their specific triggers. The person 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.

A partial list of chemicals, situations, and environments to which someone who has or is suspected of having a mast cell activation related issue or disorder 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
- Fruits ripening
- Fermented foods
- 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 MCAS or a mast cell activation disorder 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) are 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, (see https://www.safespace protection.com/). The evidence of studies and research continues to mount throughout medical communities about the harmful effects to our health from exposures to EMFs (IBID).

A partial list of common reactions individuals may experience when exposed to their triggers 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.

The Mastocytosis Society Canada has an article posted on their website (www.mastocytosis.ca) that provides clear and detailed information about EIs, Mastocytosis, MCAS, 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.

Although written in 2012, this article continues to be informative about the ways in which a person and their life can be impacted by having a mast cell activation related issue or disorder. However, some aspects of our understanding of mast cell disorders have moved forward since 2012 especially our understanding of how very common Mast Cell Activation Syndrome (MCAS) and other mast cell activation related issues and disorders actually are. Mastocytosis indeed is a rare disease in which, typically, there are too many mast cells in the person's body. Mast Cell Activation Syndrome (MCAS) and other non-mastocytosis mast cell activation issues are NOT rare disorders at all and doctors have been encountering them regularly in their medical practice for years without realizing what these particular presentation of symptoms might mean and indicate (Drbeen Medical Lectures interview of Dr. Afrin, 2021).

As you read the Mastocytosis Society Canada article, keep in mind:

- The name with which certain conditions are labeled have also changed over time. Currently the name for all mast cell issues is MCD and it is used for all mast cell disorders and diseases.
- Existing testing for mastocytosis includes and relies heavily on tryptase levels. An over-abundance of mast cells will raise tryptase levels and is a reliable biomarker for a diagnosis of mastocytosis.
- Tryptase levels are not a reliable test or biomarker for Mast Cell Activation Syndrome (MCAS) or for other non-mastocytosis mast cell activation related issues and disorders. There is no over-growth of mast cells and, thus, tryptase levels in 85% of patients tested will have results in normal ranges (standinguptopots.org/podcast?page=12).
- The symptoms of MCAS and other mast cell activation related issues and disorders can be life-threatening as they can immediately, sometimes within seconds of their onset, escalate to anaphylaxis.
- People with MCAS or another mast cell activation related issue do not necessarily experience "increasing limitations and greater suffering over their lifetime." It is noted on the MastAttack website

(mastattack.org) that it seems that, over time, the person's reactions may indeed change but their baseline stays the same.

The Mastocytosis, MCAS & IA Patient Experience

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 [they] ha[ve] 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.

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.

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... 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... 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,... 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.

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... 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.

by Mastocytosis Society Canada
https://mastocytosis.ca

A client I work with reported that on two separate occasions they had experienced muscle fatigue so severe that their legs were suddenly unable to hold them up, grabbing onto furniture and dragging their legs, and that they were briefly unable to make their hands and fingers work properly in order to pick up some medication tablets to take to help with the reactions. The client described it that in those moments it seemed as if circuits in their brain weren't working right, something not connecting, to pick up the pill, put it in their mouth and that they found saying the instructions out loud to themselves somehow seemed to over-ride the "brain glitch" and enabled their brain to direct the movements and actions more appropriately. Swallowing was also a challenge as their tongue, inside their mouth, the roof of their mouth, lips, and inside their nostrils were swelling. The client shared with me:

I have not had reactions that severe in years. Years. I haven't had to give myself an Epipen in eight years. And because of being hit with nearly simultaneous multiple medical situations over which I had no control—my mast cell specialist said they were no longer my doctor, my primary care doctor left to go three thousand miles away, I had to have extra mammograms done because of something that didn't look right, they found me having an immune deficiency that was getting worse and I needed a specialist for that, and lots of blood work—it's that total load. My system, my body, was so completely overwhelmed with the repeated toxic exposures that it crashed.

My mast cells were beyond over-drive and reacting to everything. I wasn't able to eat for almost two weeks because everything I put in my mouth spiraled me into anaphylaxis mode in seconds. It was terrifying. My reactions were so bad that I couldn't even take my meds that help to bring down the reactions. I was off all of them. And now I'm slowly increasing my doses, little by little, as my system will allow. It's a process that will take I don't know how many months for me to get back on all my meds and at the right doses again.

Meanwhile, I am physically not able to have the follow-up mammograms to monitor whatever the suspicious something is that the doctors found. I can't have my COVID booster and I *have an immune deficiency. I think it makes more sense for me to wait until I'm back on all my meds that help control my reactions because I do and will have reactions to the doctor visits and medical procedures that can be really bad, ramping up in seconds. There's no way my system can handle it unless I'm taking the full doses of all my meds. I was at the ER twice six weeks ago. I have to wait as my system calms down and no one can predict how long it'll take for that to happen. I have such problems with breathing. I just have to do everything I can to protect myself and pray I don't get COVID or some other infection.*

Illnesses, Issues, & Disorders Involving Mast Cell Activation (not an exhaustive list)

- Acid reflux
- Acute Coronary Syndrome
- Anaphylaxis
- Allergies
- Alzheimer's Disease
- Arthritis
- Asthma
- Autism Spectrum Disorder (ASD)
- Brainfog
- Cardiovascular disease
- Celiac Disease
- Chronic Fatigue Syndrome (CFS)
- Colitis
- Diabetes

- Eczema, psoriasis, dermatitis
- Ehlers-Danlos Syndrome (EDS)
- Endometriosis
- Fibromyalgia
- Food allergies
- Gastroesophageal Reflux Disease (GERD)
- Huntington's Disease
- Interstitial Cystitis-Bladder Pain Syndrome
- Inflammation / brain inflammation
- Irritable Bowel Syndrome (IBS)
- Kounis Syndrome
- Lyme Disease
- Lupus
- Migraines
- Multiple Sclerosis
- Obesity
- Pancreatic cancer
- Parkinson's Disease
- Postural Orthostatic Tachycardia Syndrome (POTS)
- Raynaud's Syndrome
- Urticaria (hives), rashes, skin eruptions, flushing
- Vertigo
- Wound healing

(see Appendix 1)

2

Clinical Considerations: Medical

Current Medical Treatment Protocols

The protocols used by doctors who treat patients with mast cell activation related disorders such as Mast Cell Activation Syndrome (MCAS) need to be highly individualized, focusing on relieving each person’s symptoms, understanding each person's triggers, and informed by each person's pattern of reactivity after an exposure to their triggers.

There is no cure for MCAS. There is no cure for mast cell activation related disorders. Individuals with MCAS and mast cell related diseases must avoid exposures to the chemicals, substances, and environments to which they react. Avoidance is the number one, front-line, essential treatment for MCAS and mast cell activation issues and disorders.

Repeated exposures can cause more and more harm. The person can become more and more sensitized to chemicals and substances with every exposure. Their reactions can often become increasingly severe while being exposed to smaller and smaller amounts of chemicals and/or substances. A client with 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 the specialist is in has the most fumes of any other hospital I've been in. Before I saw my 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.*

The Role of Mast Cells

Mast cells are found in the connective tissue throughout the body in virtually every organ system (https://www.ncbi.nlm.nih.gov/books/NBK499904/). Mast cells, when activated, are primary producers of histamine and many other chemicals—mediators—in our body. Mast cells play a very important role in inducing the inflammatory cascade (IBID).

The most common sites affected by mast cell activation are the mucosa of the respiratory tract (responding to airborne antigens), GI tract (responding to food borne antigens), blood (responding to wounds, absorption from the respiratory tract and/or GI tract), and connective tissues (ncbi.nlm.nih.gov/pmc/articles/PMC4701915/).

In the gut: exposure to an antigen causes the GI system to increase fluid secretion, increase smooth muscle contraction, and increase peristalsis which activates mast cells and their subsequent release of mediators (IBID). These mediators increase vascular permeability causing edema and smooth muscle contractions in the gut leading to vomiting and diarrhea. Uptake from the GI tract can introduce antigens into the blood which then transports them throughout the body where they bind to mast cells in the connective tissues in deep layers of the skin causing urticaria and andioedema (IBID).

In the respiratory tract: in response to mast cell activation airways constrict, there is increased mucous production, and coughing. Mucosal mast cells in the nasal epithelium when activated lead to increased vascular permeability and local nasal edema/swelling which can obstruct the airways. Mast cells also play a pivotal role in the pathophysiology of allergic asthma (IBID).

In the skin: mast cells in the deep layers become activated releasing histamine and other mediators causing urticaria (hives) and angioedema. A prolonged response of this type can lead to dermatitis or eczema (IBID).

Activated mast cells release a wide variety of inflammatory mediators. The mediators that activated mast cells produce and pump into the body include but are not limited to: (1) histamine whose effects can include flushing, itching, diarrhea, hypotension; (2) leukotrienes whose effects can include shortness of breath; (3) prostaglandins whose effects can include flushing, bone pain, brainfog, cramping; and (4) interleukins whose effects can include fatigue, weight loss, enlarged lymph nodes (tmsforacure.org).

Histamine and its receptors have multiple functions in the body and with our immune regulation system, both promoting inflammatory and regulatory responses that contribute to many disease processes, as well as homeostatic functions that keep our body functioning and stable. Histamine plays a primary role in allergic rhinitis, urticaria, anaphylaxis, and asthma (https://www.pubmed.ncbi.nlm.nih.gov/1699987/).

Leukotrienes are fatty signaling molecules the body produces when there is inflammation and can play a key role in triggering symptoms such as swelling in the airways, airflow obstruction, airway constriction, and increased secretion and build-up of mucus. Leukotrienes cause swelling and inflammation in the lungs and airways including symptoms such as shortness of breath, wheezing, and coughing (medical newstoday.com/articles/ 248209#about). Leukotrienes are mediators released by mast cells when they are activated.

Prostaglandins can activate or inhibit platelet build-up for blood clot formation, cause vasodilation or vasoconstriction, cause bronchoconstriction or bronchodilation, cause fever, influence pain perception, cause your uterus to contract during menstruation to shed the uterine lining, decrease pressure within the eye, inhibit acid secretion in the stomach, regulate hormones, and more (see https://my.cleveland clinic.org/health/articles/24411-prostaglandins). One specific prostaglandin, prostaglandin D2 (PGD2), is the predominant prostaglandin released by mast cells. It is found prevalently in the central nervous system and peripheral tissues where it performs both inflammatory and normal processes (https://www.mastattack.org/2015/04/mast-cell-mediators-prostaglandin-d2-pgd2/). PGD2, in the brain, helps to regulate sleep and pain perception. It is a strong bronchoconstrictor and is two times more potent in this capacity than histamine (IBID). PGD2 has a role in nerve pain and may be important in resolving inflammation in some processes (IBID).

Medications

The first line treatment medications for the symptoms of mast cell activation include histamine 1 (H1) receptor blockers and histamine 2 (H2) receptor blockers. Cromolyn sodium (brand name Gastrocrom), ketotifen, and Prednisone are three medications that are mast cell stabilizers. Aspirin has also been found to be a mast cell stabilizer. Quercetin and luteolin are flavonoids found in many fruits and vegetables that are mast cell action inhibitors. Singulair (generic montelukast) is also prescribed as it blocks the action of particular mast cell mediators.

H1 receptor blockers – 1st generation: Benadryl (generic diphenhydramine), Atarax and Vistaril (generic hydroxyzine), Xyzal (generic levocetirizine), NyQuil (generic doxylamine), Chlortrimeton (generic chlorpheniramine) (my.clevelandclinic.org/health/ drugs/21223-antihistamines).

H1 receptor blockers – 2nd generation: Claritin (generic loratadine), Zyrtec (generic cetirizine), Clarinex (generic desloratadine), Allegra (generic fexofenadine) (IBID).

H2 receptor blockers – currently three available for use in the U.S. as either over-the-counter or by prescription: Pepcie (generic famotiden, over-the-counter and prescription), Tagamet (generic cimetidine, over-the-counter and prescription), and Axid (generic nizatidine, prescription only) (ncbi.nlm.nih.gov/books/ NBK525994/).

Cromolyn sodium was discovered in 1965 by a physician, Roger Altounyan, in the UK who suffered from asthma. It is a non-steroidal anti-inflammatory medication that has been widely used as a treatment for mast cell disorders and diseases (Abd-Elaziz, Elberink, & Diament, 2020). It is a mast cell stabilizer.

Ketotifen was patented in 1970 by Sandoz Pharmaceuticals of Switzerland and was first marketed as an anaphylaxis inhibitor. Clinical trials were run in the USA in the 1980s. Oral ketotifen has been used in Japan, Canada, Europe, Mexico for the treatment of mast cell activation-based conditions such as, asthma, allergic rhinitis, allergic conjunctivitis, atopic dermatitis, chronic urticaria, cold-induced urticaria, exercise-induced urticaria, mastocytosis, and food allergies (Sokol, Amar, Starkey et al, 2013). In the USA, ocular ketotifen is used in the treatment of, for example, allergic conjunctivitis and oral ketotifen used in the treatment of such mast cell activation-based conditions as fibromyalgia, atopic dermatitis, allergic rhinitis, and asthma (IBID).

Prednisone is a corticosteroid that relieves swelling, itching, redness, allergic reactions and is used in the treatment of several different medical issues and disorders including: severe allergies, adrenal problems, arthritis, asthma, bowel problems, lupus, ulcerative colitis, multiple sclerosis flare-ups, eye or vision problems, skin conditions (see Mayo Clinic https://www.mayoclinic.org/drugs-supplements/prednisone-oral-route/description/drg-20075269). Prednisone is a mast cell stabilizer and helps in suppressing the production of inflammatory mediators by mast cells (mastattack.org).

Aspirin is commonly used to inhibit prostaglandin production in mast cells (mastattack.org/2015/04/mast-cell-mediators-prostaglandin-d2-pgd2/). Aspirin has been found to be a mast cell stabilizer and is often prescribed in small doses and/or up to 325mg daily, if tolerated, and/or in combination with histamine blockers to help manage symptoms of mast cell activation (see mastcellhope.org/ education/common-treatments/ and https://tmsforacure.org).

Quercetin and **luteolin** are flavonoids. Flavonoids are anti-inflammatory and antioxidants that inhibit mast cell actions (Weng, Asadi, Sismanopoulos et al, 2012). Foods that contain quercetin include: capers; red onions; shallots; red apples; grapes; berries; cherries; scallions; kale; lettuce; broccoli; cabbage; grapefruits (in the pulp); almonds; pistachios; cocoa powder; green tea. Foods that contain luteolin include: chamomile tea; sweet green peppers; celery; pumpkin.

Singulair (generic montelukast) is a leukotriene inhibitor and blocks the action of leukotrienes. Leukotrienes are released from mast cells and other cells in the body. Blocking the action of leukotrines helps to reduce inflammation and the narrowing of blood vessels (vasoconstriction) which helps to improve symptoms such as coughing, wheezing, difficulty breathing, and chest tightness (https://www.medicalnewstoday.com/articles/leukotriene-modifiers-for-asthma#how-they-work).

Emergency Protocols

The Mastocytosis Society Canada (mastocytosis.ca), in the US the Mast Cell Disease Society (tmsforacure.org), UK Mastocytosis Support (ukmasto.org), UK Mast Cell Action (mastcellaction.org/management) all provide on their website information and, on some sites, brochures that can be downloaded providing generalized medical protocols for emergency situations. These are important resources to have on hand when working with clients who have or are suspected of having MCD.

Emergency brochures to download can also be found on The Counseling Center at CELA website at counselingatcela.com.

The brochure(s) detail precautions for these patients that include:

- 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)

Compounded Medications

MCAS and other mast cell activation disorders (with and without chemical sensitivities) do not follow the regular rules of drug-oriented medicine. Drugs and surgery are currently the first line approaches in conventional western medicine in the treatment of most diseases. If you give a drug, something that is a foreign chemical and/or foreign substance, to a person who already has a compromised system, you run the risk of making that person worse and potentially bringing on what can be severe to life-threatening anaphylaxis reactions. The varied inert ingredients, dyes, and other substances that are part of making a medication into a tablet, capsule, or liquid form can be triggers for some individuals and bring on systemic mast cell activation and mediator release reactions. An important option for people with a mast cell activation related issue or disorder is to have their medications compounded. When a medication is compounded through a compounding pharmacy, a lot of potentially troublesome ingredients are eliminated.

Compounded medications are often powders in capsule form. One can request that the capsule covers used are vegetable capsule covers and made of vegetable cellulose instead of the traditional gelatin capsule covers. Vegetable capsule covers many times are better tolerated by some individuals with MCD. People who are vegetarians or vegans might prefer vegetable capsule covers being used as the gelatin capsule covers are derived from animal products. Compounding pharmacies can compound vitamins and supplements as well as medications.

A medication, vitamin, or supplement that is compounded frequently will require some type of filler to be used in addition to the medication/vitamin/supplement itself during the compounding process as each capsule needs to be filled to a certain minimum amount in order for the machine that puts the capsules together to work correctly. The choices for filler are either a chemical powder or corn starch. Many people with sensitivities and/or a mast cell activation related issue or disorder opt for the corn starch to be used as the filler. The compounding pharmacist can work with each person to meet each individual's specific compounding needs, including their selecting what size capsule to use to meet the prescribed dosage that holds the most amount of the medicine and least amount of filler/corn starch per capsule. In order to have something compounded, the compounding pharmacy needs to have a prescription from the treating medical care provider (physician, NP, etc.) with the specifics written on the prescription. For example, a prescription for cromolyn sodium can read: "200mg cromolyn sodium, to be compounded. Take 200mg four times daily by mouth, use corn starch and vegetable capsules."

Many healthcare providers suggest their patients with MCD take increased doses of, for example, vitamin C as it can help with the management of mast cell activation reactions. Over-the-counter vitamins and supplements as well as medications that are not over-the-counter purchases must have a written prescription for it specifying that it be compounded in order to be filled by a compounding pharmacy.

If a vitamin, supplement, or multiple vitamin is going to be compounded, it is important to note that for the first, original prescription, the compounding pharmacy will need either a prescription that lists all the individual ingredients or one prescription for each individual ingredient. For example, if the treating medical practitioner was wanting to have a multiple vitamin compounded for their patient who has reactions to multiple foods, and the multivitamin has the typical ingredients such as vitamin A, vitamin C, vitamin D, vitamin E, thiamin, riboflavin, niacin, vitamin B6, folic acid, vitamin B12, pantothenic acid, calcium, the compounding pharmacy needs a prescription for each ingredient and how much of each ingredient. The prescription, using the ingredients in the example, would need to list all of the ingredients and their dose or a separate prescription for each ingredient:

Vitamin C 60mg; Vitamin A 3000 IU; Vitamin D400 IU; Vitamin E 30 IU; Thiamin 1.5mg, Riboflavin 1.7mg; Niacin 20mg; Vitamin B6 2mg; Folic Acid 400mcg; Vitamin B12 6mcg; Pantothenic Acid 10mg; Calcium 45mg (see https://www.cvs.com/shop/cvs-health-essential-multivitamin-tablets-365-ct-prodid-252387).

The prescription(s) also needs to include the wordage: "To be compounded. Use vegetable capsules. Use corn starch." Remember, having a medication compounded does not guarantee the person with a mast cell activation issue or disorder will be able to tolerate taking it.

Who Prescribes?

If a person in the U.S. has allergy symptoms, they can go to a local pharmacy and pick up an over-the-counter product to help ease their symptoms. Typically, these over-the-counter options contain ketotifen or cromolyn sodium as their active ingredient. "Bausch + Lomb Alaway" and "Equate Eye Itch Relief" both contain ketotifen. "Nasalcrom" and "Cromolyn Sodium Nasal Solution USP" both contain cromolyn sodium. These over-the-counter medications are also available outside the U.S. carrying different brand names.

Primary care providers/general practitioners regularly treat and write prescriptions for many different conditions that have their basis in mast cell activation. For instance, eczema, urticaria, arthritis, rashes, skin eruptions, acid stomach, acid reflux, celiac issues, inflammation, asthma, irritable bowel, stomach ulcers, dermatitis. They treat these conditions and write patients prescriptions for all these conditions because they feel these medical issues are within their scope of practice as a primary care provider/general practitioner.

The treatment for urticaria (hives), for example, according to the Mayo Clinic, starts with over-the-counter antihistamines and H1 receptor blockers such as Clarinex (generic name desloratadine) and Zyrtec (generic cetirizine.) Treatment, if the symptoms aren't sufficiently eased, can then include H2 receptor blockers such as Pepcid, Zantac (generic famotidine), and Tagamet (generic cimetidine.) Mast cells are the major producer of histamine (https://www.ncbi.nlm.nih.gov/pmc/articles/ PMC6099187/ and https://www.mayoclinic.org/diseases-conditions/ chronic-hives/diagnosis-treatment/drc-203527 23) and doctors who recommend and prescribe these medications for the treatment of hives are prescribing medications to treat a mast cell activation related issue.

Another condition that primary care providers/general practitioners regularly treat is asthma. When treating asthma, to use it as a second example, Singulair (generic montelukast) is often prescribed. In prescribing this medication for asthma, the primary care/generalist is treating a mast cell activation related issue and disorder.

Hydrocortisone cream is a medication that is often prescribed by primary care providers/general practitioners to treat eczema and other skin conditions that bring about swelling, redness, itching, and rashes. It's a topical steroid that decreases inflammation (see my.clevelandclinic.org). Hydrocortisone is a mast cell stabilizer (see https://pubmed.ncbi.nlm.nih.gov/33116043/). Once again, primary care providers/general practitioners are treating and prescribing a medication for a mast cell activation issue or disorder.

Medical and healthcare professionals have been diagnosing and treating mast cell activation related issues and disorders for many, many years without necessarily making the connection between the issue and its basis in mast cell activation. They have become familiar, over time, with these specific presentations of symptoms, how to interpret these specific presentations of symptoms and diagnose them correctly, and the available appropriate treatments to prescribe. It does not require the intervention of a specialist or that only a specialist be the one to prescribe, for instance, Singulair, Prednisone, Zyrtec, Benadryl, aspirin, hydroxyzine, Pepcid, Nasalcrom, Zantac, or the Bausch + Lomb Alaway.

A client with whom I work recently shared with me that they had asked a Nurse Practitioner (NP) if they would prescribe cromolyn sodium for the client's mast cell activation issues to help manage their symptoms and reactions. The NP felt the client definitely has mast cell activation related issues based on the client's medical history and various assessments, and quickly responded that they have no problem writing the prescription and treating the mast cell activation related issues and reactions, but they didn't think the insurance companies would approve it unless it's prescribed by a specialist. In conversation with me, the client puzzled over how the NP and primary care physicians can treat other mast cell activation conditions like eczema, migraines, asthma, and allergies with similar medications or versions of the exact same medication my client was wanting prescribed, but with my client's situation of mast cell activation, in essence and in reality no different than these others, say it needs a specialist—and that apparently insurance companies are dictating the scope of practice of primary care physicians.

Another client shared that their new primary care physician would not prescribe their cromolyn sodium because treating systemic mast cell activation was outside their scope of practice. Yet the doctor has no problem prescribing the client's hydrocortisone cream, vitamin D3, Prednisone, diphenhydramine, hydroxyzine, Epipens, and various compounded medications such as vitamin C—all of which my client takes to control and manage their systemic mast cell activation related reactions and symptoms.

Traditionally, medical doctors only receive the most brief and cursory introduction to and learning about mast cells in their training even though mast cells play such a vital role in the human body's immune and inflammatory response systems as well as in the pathogenesis of multiple diseases, disorders, and health issues. Mast cell activation related disorders

(MCD) have been historically relegated to the realm of "rare diseases" and, thus, the purview of "specialists" (i.e., somebody else's problem, not the primary care provider's.) Mast cell activation related issues and disorders, especially Mast Cell Activation Syndrome (MCAS), are not rare.

The reality of mast cell activation related issues and disorders and their prevalence have been thrust to the forefront by COVID-19 and long-COVID sufferers. Research has shown mast cell activation present with COVID-19 and mast cell involvement with its pathogenesis and symptoms. Although we are, globally, no longer in the acute phase of the COVID-19 pandemic, at least 65 million people are currently living and struggling with long-COVID and its what can often be severely debilitating symptoms that can last from months to years (Lancet, 2023). The reality of long-COVID, the severity of its symptoms and its harm continues to affect people globally of all ages, their health, their ability to work resulting in extensive losses – physically, emotionally, and economically (IBID).

Who can prescribe? According to the Mayo Clinic, oral cromolyn sodium (brand name Gastrocrom) "is available only with your doctor's prescription" with no mention that the doctor who prescribes the cromolyn sodium must be a specialist (see https:// www.mayoclinic.org/drugssupple ments/ cromolyn-oral-route/proper-use/drg-20063181?p=1).

Rather, doctors appear able and comfortable to prescribe when they feel they have the knowledge base that enables them to recognize a particular presentation of symptoms accurately leading to the correct diagnosis. Peer-to-peer consultations with the right mast cell specialist whose focus is MCAS and mast cell activation issues and disorders can assist primary care providers in attaining that needed knowledge base in order for them to best serve and treat their patients.

3

Diagnosing

Diagnosing MCAS and Mast Cell Activation Disorders

A person who has or is suspected of having a mast cell activation related disorder can present with myriad symptoms affecting all body systems. The majority of these people, when they have blood work and other labs done, have test results within normal ranges. Mast cell disorders (MCD) and Mast Cell Activation Syndrome (MCAS) is an area of medicine where traditional tests are more often than not inconclusive of mast cell disease and, therefore, not reliable in the search for biomarkers with repeatably accurate results across the boards for every potential mast cell activation disorder and person who may have a disorder like MCAS.

Mast cell diseases/disorders (MCD) are highly individualized and each person can present with a completely different array of reactions affecting completely different body systems from the next person. The differences do not exclude the reality of the disorder or the fact that possibly both of these people should carry the diagnosis of, more often, Mast Cell Activation Syndrome (MCAS).

The diagnosing process for mast cell activation related disorders and MCAS can include traditional mast cell activation tests but because of the nature of these disorders, diagnosis can't be completely dependent upon these test results due to their unreliability as a consistent biomarker. Many medical professionals try to use and apply a person's tryptase levels as a consistent indicator of mast cell activation and therefore a reliable test for diagnosing mast cell activation illnesses and disorders. Some apply a formula where, in a second tryptase blood test, the results need to be 20 points greater that the first tryptase test plus 2 points.

Tryptase is a mediator, a protein, that is manufactured only by mast cells in the human body. There is much that is not known about tryptase. When mast cells become activated they pump mediators into the body, for instance during anaphylaxis or an allergic reaction. Tryptase isn't the only mediator mast cells release.

A recent research study involving hundreds of people with mast cell disorders (see Afrin, MD, et al, "Characterization of mast cell activation") has shown that, of the participants tested for tryptase levels, approximately 15% had abnormal labs. This means that approximately 85% of the participants tested for elevated tryptase levels, participants who all had mast cell disorders, had results within normal ranges.

When diagnosing MCD, especially MCAS, one needs to take a step back and look at the whole picture of presentation of symptoms, the person's medical history, diagnoses a person may already carry and what these diagnoses are for, and be on the lookout for other known medical conditions (such as allergies, asthma, migraines, IBS, CFS, Ehlers-Danlos Syndrome, Parkinson's, to name only a few) that research has shown the involvement of mast cell activation. It is important to do a ruling out process to be certain symptoms are not attributable to another medical condition.

An essential tool in the diagnosing of a possible mast cell activation disorder is the "Mast Cell Activation Assessment Questionnaire" which is a validated diagnostic tool created by Lawrence Afrin, MD, and Gerhard Molderings, MD.

Another component of diagnosing is whether or not a person responds positively to anti mast cell mediator release medications that are mast cell stabilizers and/or that bring down mast cell reactivity. These medications include but are not limited to:

- Histamine 1 (H1) receptor blockers such as, Benadryl (generic name diphenhydramine), Atarax or Vistaril (generic name hydroxyzine), Zyrtec (generic name cetirizine), Xyzal (generic name levocetirizine)
- Histamine 2 (H2) receptor blockers such as, Pepcid (generic name famotidine) and Tagamet (generic name cimetidine)
- Cromolyn sodium, the oral version, is available by prescription only. It works by acting on mast cells in the body to prevent them from releasing their mediators (see Mayo Clinic, mayoclinic.org/drugs-supplements/cromolyn-oral-route/description/drg-20063181).

If a person feels relief of symptoms after taking a medication that inhibits mast cell activation or stabilizes mast cells, then mast cell activation is evidenced through the very easing of the physical symptoms which were brought on by mast cell activation.

In 2012, I was informed by a leading mast cell physician who specializes in mastocytosis and cancer practicing at a major hospital whose allergy and immunology department and mast cell clinic were considered by many doctors and health-care professionals as *the* place to go, that the new consensus for the newly established criteria for mast cell disease diagnosing consisted of three items: (1) the person needs to exhibit what appear to be the symptoms of mast cell activation; (2) the person needs to have lab results that are abnormal, mainly an elevated tryptase level obtained through a blood test and/or an abnormal N-methylhistamine test which is done by obtaining a 24-hour urine specimen; and (3) the person needs to have a positive response to taking anti mast cell mediator release medications such as Benadryl (diphenhydramine), Pepcid (famotidine), Zantac (formerly ranitidine currently famotidine), Gastrocrom (cromolyn sodium). Genetic c-Kit mutations were also explored. If the person had all three, I was told—exhibited the symptoms, abnormal lab results, and responded positively to the medications—they were given the diagnosis of mastocytosis. If the person had two of the three criteria, for example, exhibited all the symptoms, responded positively to the medications, but had lab results within normal ranges, then the diagnosis of Mast Cell Activation Syndrome (MCAS) was given. The doctor also would do a ruling out process to make sure that what the person was experiencing could not be attributed to some other condition or disorder.

Eleven years later, that same doctor and that same hospital jettisoned patients with a diagnosis of Mast Cell Activation Syndrome (MCAS) and/or a diagnosis of having a systemic mast cell disorder that was not mastocytosis, gave them approximately 44 days to find another mast cell specialist, and banned them from seeing any other mast cell specialist or any other allergist at that major hospital (where the overwhelming majority of the mast cell specialists were found) because these individuals carried a diagnosis of MCAS or a systemic mast cell activation disorder. The hospital and its doctors were moving in a new direction and were only going to be seeing patients with mastocytosis and cancer. Patients were informed in writing that after that 44 day period lapsed, the doctor/hospital would no longer write refill prescriptions for the patients' mast cell medications. A client I work with, after having to go to the emergency room due to their severe mast cell activation reactions quickly becoming anaphylaxis and necessitating their administering an Epipen, was told by the emergency room social worker that the social worker was going to personally and directly contact the allergy and immunology department from which my client had recently been jettisoned wanting to know why my client was being denied care. The social worker was told that my client no longer met the criteria for having a systemic mast cell activation disorder due to having tryptase levels within normal ranges. The hospital was effectively trying to dismantle the client's diagnosis. Without that diagnosis, a correct one that the client had carried for easily a decade, my client would no longer be able to receive their cromolyn sodium, the mast cell stabilizing medication that helps bring down the severity of my client's reactions—reactions that can go from not there to anaphylaxis and life-threatening in fractions of seconds. Anaphylaxis can kill.

In 2019, an updated "consensus" was announced in various medical publications for the diagnosing of mastocytosis and Mast Cell Activation Syndrome (MCAS). No longer was a presentation of two of the three criteria sufficient for an MCAS diagnosis. The group now determined that individuals must meet all the criteria to be diagnosed: they must have significantly elevated tryptase levels.

There are two important issues at play here. The first is a known issue: tryptase levels are not a reliable biomarker for mast cell activation, for Mast Cell Activation Syndrome (MCAS), or for a systemic mast cell activation disorder that is not mastocytosis.

A particular group of medical professionals have taken it upon themselves to decide and insist—calling it a consensus which implies that there is unanimity and general agreement, and that a judgment has been arrived at by most of those concerned—that a person must have an elevated tryptase level to be diagnosed with Mast Cell Activation Syndrome

(MCAS) and/or be diagnosed with a systemic mast cell activation disorder that is not mastocytosis. Typically, approximately 85% of people with MCAS or a systemic mast cell activation disorder that is not mastocytosis have normal, not elevated, tryptase levels. The medical research is readily available and easily accessed—doctors who work in this area know this.

Mastocytosis is a rare disease in which the body has made too many mast cells. Therefore, a person's tryptase levels (tryptase is a mediator produced by our mast cells) will be elevated due to the increased number of mast cells producing the tryptase. However, in MCAS and in non-mastocytosis mast cell activation issues and disorders (which are **not** rare) the body does not have increased numbers of mast cells. What's happening is that the body's mast cells are behaving inappropriately. The medical research is out there and available.

The doctors comprising the "consensus" group know this, yet they continue to adamantly insist that this criterion of having an abnormal and elevated tryptase level must be met—and use this as a basis for denying care for people who do not meet this criterion but who may in every other way present with and meet the criteria for MCAS and having a systemic mast cell activation disorder diagnosis.

Dr. Lawrence Afrin and Dr. Gerhard Molderings are two leading mast cell and mast cell activation disorder (such as MCAS) specialists who both have worldwide recognition in their field. Dr. Afrin is in the United States and Dr. Molderings is in Germany. Both Dr. Afrin and Dr. Molderings have been in disagreement with the notion of elevated tryptase levels being the gold standard for determining a mast cell activation diagnosis and basing any subsequent provision of medical care and support on whether or not a person has elevated tryptase levels. I am including here a portion of the highly significant and important information that Dr. Afrin so generously shares in his April 4, 2023 POTScast interview:

> *Originally, back in the '80s, the tryptase level was originally described as a marker of mast cell activation in patients with mastocytosis. As more research was done it became increasingly clear that actually the tryptase level is a fairly poor marker for the general mast cell activation state in a human being. It became understood that what the tryptase level typically represented was simply the number of mast cells in a patient's body...But the issue in mast cell activation syndrome is not a gross overproliferation of mast cells. It's a chronic inappropriate activation of the mast cells where there's relatively little to even sometimes just no excessive proliferation of the mast cells.*
>
> *But nobody should go thinking that just because you don't have an increased proliferation of the mast cells, that you can't have any problems from the mast cells. Actually the mediators that are produced by the mast cells are so potent in their actions once those mediators are released from the mast cells, that there's a phenomenal amount of chaos in the body that the mediators can produce when inappropriately released...But when you don't have such a great number of mast cells, and since tryptase is not such a great marker of activation of the mast*

cells, therefore, in patients who have the activation syndrome, typically tryptase is not elevated at all. In fact, the published research suggests the tryptase is elevated in only about 15% of MCAS patients. But in the 85% or so of MCAS patients who don't have an elevated tryptase, it's instead these other markers of mast cell activation that you have to go looking for to prove that, yeah, there really is a problem here with these mast cells...

As the years went on, the first group, so to speak, they came out with some occasional updates to their criteria, though in general it still remained pretty much a tryptase-focused set of criteria...it was a little concerning that the first group...declared that their criteria were so-called consensus criteria, which, I mean, if you think about it, that word has a lot of significant implications to it. It kind of implies people are just going to accept when they hear that word that, oh, all the doctors who are interested in this field, they got together and there was just a lot of agreement from most of the doctors involved in this area that this is the most reasonable way to regard this area. And yet we knew that, in truth, there was no consensus, and that we were seeing quite a number of doctors who were being influenced to think that the first approach was really *the only acceptable approach to diagnosing this...Unfortunately, this was leading to a lot of patients whose symptoms were strongly suggestive that MCAS was at the root of their problems, but nevertheless they had a normal tryptase level. Even when they were having terrible flares of the disease, they had a normal tryptase level and therefore they were being told that, no, you can't have a mast cell disorder...*

But that word consensus was a real issue, that there were so many doctors out there thinking there was only one consensus. Even if the group involved with the first consensus, even if they wouldn't be happy about it, and even if they wouldn't be in agreement with any other approach to diagnosing the disease, we thought it was most important for the patients and the other doctors attending to those patients to understand that there was an alternative approach to looking at this. There was an alternative consensus. No, it's still not at the stage where there's one, big, happy global agreement on this and there probably won't be for a long time to come...It has an impact on patient well-being that we felt it was important to make more folks aware that there was a different approach to diagnosing this and it was an approach that had already been adopted by quite a great number of

> *doctors than had originally signed on to that original consensus...*
>
> *So, given all these factors, it's best to make physicians aware. There are compelling schools of thought for this, and there's nothing wrong with having different approaches to thinking about a complex subject where the science is far from resolved. But if, in the end, it winds up helping more people sooner rather than later, my opinion, anyway, is that that's a good thing.*

(see Dr. Afrin interview on Standing up to POTS podcast #129, https://www.standinguptopots.org/podcast?page=12 and https://www.youtube.com/watch?v=bpZlXgiuiJo).

The second equally as important an issue as the first is the healthcare professionals' need for basic education and knowledge regarding mast cells, MCAS, and mast cell activation related issues and disorders. In the Standing up to POTS podcast #129 (as previously referenced,) Dr. Afrin notes that in the 16+ years he has been specializing in and working with MCAS and non-mastocytosis mast cell activation issues and disorders, the medical training that doctors receive has not grown to include mast cells in other than the traditional and cursory manner that it's always been taught. Dr. Afrin describes it as receiving roughly about one minute of teaching in ten years of a physician's training (IBID).

4

COVID-19, Long-COVID & Mast Cells

There have been three outbreaks of coronaviruses during the past twenty years with Severe Acute Respiratory Syndrome (SARS-CoV-1) first detected in China in 2002, then the Middle East Respiratory Syndrome coronavirus (MERS- CoV) in Saudi Arabia in 2012, and the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) COVID-19 pandemic (Hiu Yan Lam et al, 2021). COVID-19 is a disease that is caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection and can affect virtually all systems and organs of the human body (Szukiewicz et al, 2022).

COVID-19

Evidence is growing that demonstrates the involvement of mast cells in the pathogenesis of coronavirus, including COVID-19 (Hiu Yan Lam et al, 2021).

2020:

"Mast cells are known to be the main source of cytokine release that leads to lung damage in SARS-CoV-2. Mast cell stabilisers together with mediator blockers may therefore help to ameliorate the pro-inflammatory effects of covid-19" (BMJ 2020;370: m2722)

2021:

"SARS-CoV-2 [the COVID-19 virus]-triggered MC [mast cell] degranulation initiated alveolar epithelial inflammation and lung injury...Importantly, the administration of clinical MC stabilizers for blocking degranulation dampened SARS-CoV-2-induced production of pro-inflammatory factors and prevented lung injury. These findings uncover a novel mechanism for SARS-CoV-2 initiating lung inflammation, and suggest an off-label use of MC stabilizers as immunomodulators for COVID-19 treatments" (Meng-Li Wu, Feng-Liang Liu, Jing Sun et al (2021).

"Recent studies have revealed an elevated density of perivascular and septal MCs [mast cells] in the broncho-alveolar lavage fluid of COVID-19 patients and a higher number of activated MCs in the bronchoalveolar lavage fluid of COVID-19 patients as compared to samples from healthy individuals. Furthermore, there was more MC-specific protease, CPA3 [a gene expression only detected in mast cells] found in the serum of COVID-19 patients compared to control group and there was a significant positive correlation between CPA3 and circulating neutrophils as well as C-reactive protein which are associated with exacerbated inflammatory response and thereby disease severity in COVID-19 patients... Serum from COVID-19 patients had significantly higher levels of chymase, tryptase and CPA3 comparing to uninfected controls, indicating systemic MC activation in these patients. In addition, there were also elevated gene expression of TPSB2 and TPSAB1 which encode for MC tryptase in the lungs of COVID-19 patients. In line with this, Tan et al. have reported that blood from severe COVID-19 patients during the acute phase had upregulation of genes associated with MC functions and MC precursor maturation. Further, Tan et al. have also shown that severe COVID-19 patients have elevated plasma chymase, again indicating MC activation in COVID-19 patients" (Hiu Yan Lam, Vinay Tergaonkar, Alan Prem Kumar et al, 2021).

In their study, Gebremeskel et al (cited in Hiu Yan Lam et al, 2021) reported that the serum from COVID-19 patients had significantly higher levels of chymase (a mast cell emzyme), of β-tryptase (a mast cell protease/enzyme), and of CPA3 (a mast cell enzyme) compared to controls who were not infected with COVID-19, indicating systemic mast cell activation in these patients (Hiu Yan Lam et al, 2021).

In a different study, Tan et al (cited in Hiu Yan Lam et al, 2021) have reported that blood from severe COVID-19 patients during the acute phase had increased production of genes associated with mast cell functions and have shown that severe COVID-19 patients have elevated plasma chymase, again indicating mast cell activation in COVID-19 patients (Hiu Yan Lam et al, 2021).

2023:

"Mast cells (MCs) are polyfunctional immune cells present in the airways, where they respond to certain viruses and allergens and often promote inflammation...MC activation in humans was confirmed through detection of MC-specific proteases, including chymase, levels of which were significantly correlated with disease severity and with biomarkers of vascular dysregulation. These results support the involvement of MCs...and the association of MC activation with severe COVID-19 in humans suggesting potential strategies for intervention" (Tan, J.Y.J., Anderson, D.E., Rathore, A.P.S. et al, 2023).

Long-COVID

According to a March 11, 2023 Lancet article, "Long COVID: 3 years in" (2023), an estimated 65 million people worldwide are struggling with long COVID and it affects people of all ages, including children, with most cases occurring in people whose experience of COVID-19 was mild and not severe. People frequently experience fatigue, shortness of breath, cognitive dysfunction that can impair their ability to perform daily activities for several months or years. The article goes on to estimate that one in ten people who develop long COVID stop working, which results in widespread global harm to people’s health, wellbeing, and livelihoods causing extensive economic losses (see https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)00493-2/fulltext).

2021:

"In this study [titled "Mast cell activation symptoms are prevalent in Long-COVID"], MCA [mast cell activation] symptoms were significantly increased in LC [Long-COVID]" (Weinstock LB, Brook JB, Walters AS, et al, 2021)

Current research has shown a high prevalence of mast cell activation symptoms in long COVID patients prior to Mast Cell Activation Syndrome (MCAS) treatment. Increased activation of aberrant mast cells induced by SARS-CoV-2 infection by various mechanisms may underlie part of the pathophysiology of long COVID (Weinstock et al, 2021).

2022:

"It has been shown that the development of MCAS during the course of SARS-CoV-2 infection is correlated with COVID-19 severity and development of PCS [Post-COVID Syndrome]... MCAS is augmented in PCS due to the activation of mast cells by SARS-CoV-2 through different mechanisms...The emergence of MCAS during the course of SARS-CoV-2 infection is linked to the severity of COVID-19 and the emergence of PCS. Therefore, the use of antihistamines, inhibition of synthesis/release of mediators, and suppression of mast cell degranulation...may reduce MCAS-induced development of PCS" (Gaber El-Saber Batiha, Hayder M. Al-kuraishy, Ali I. Al-Gareeb, et al, 2022).

2023:

"Long COVID-19 is the consequence of multiple immune system dysregulation, such as T-cell depletion, innate immune cell hyperactivity, lack of naive T and B cells, and elevated signature of pro-inflammatory cytokines, together with persistent severe acute respiratory syndrome-coronavirus 2 reservoir and other consequences of acute infection. There is an activated condition of mast cells in long COVID-19, with abnormal granulation and excessive inflammatory cytokine release...Diagnosis and treatment of MCAS [Mast Cell Activation Syndrome] in patients with long COVID-19 will provide further symptomatic relief, and manage mast cell-mediated hyperinflammation states, which could be useful in the long-term control and recovery of such patients" (Sumantri S, Rengganis I., 2023)

Discussion:

In spite of the mounting research regarding and evidencing the involvement of mast cells in COVID-19 and long-COVID disease processes and presentation of symptoms, there are many doctors and healthcare professionals who appear reluctant to go there. In choosing skepticism in the face of growing research, they are, ultimately, rejecting potentially appropriate care for their patients that could bring about some very needed relief from their symptoms.

It is important to have scientific evidence to support a scientific theory. However, abductive reasoning has its legitimate place, as well. By definition, according to Merriam Webster, abductive reasoning is making a probable conclusion from what you know. Our understanding of mast cells, Mast Cell Activation Syndrome (MCAS), systemic mast cell activation related issues and disorders—of which COVID-19 and long COVID appear most strongly to be a part—is in its infancy. Still, the diagnosing criteria as was initially described to me in 2012 by the mast cell specialist, was one used and followed for seven years. It enabled many patients to receive needed medical care and some degree of relief from what can be devastating and disabling systemic reactions due to mast cell activation. Healthcare can't be like flipping a switch: yesterday, people were diagnosed correctly and were able to receive appropriate medical care; today, the same people are being denied care. Individuals with long-COVID appear to be getting caught up that "consensus" thinking when it comes to the question of MCAS and its diagnosis. The only real course of action, for healthcare professionals and patients, is in their education—learning about mast cells and mast cell disorders, listening to the people who have these disorders.

As increasing numbers of individuals are developing illnesses that are environmentally based, caused, and/or triggered (World Health Organization, 2022), many primary care physicians continue to dismiss these clients' symptoms, and often the clients themselves, as "hysterical" or psycho-somatic, do not recognize the symptoms as those of a physical illness, such as long-COVID, and refer these clients to therapists for mental health and psychological interventions, leaving therapists to make important clinical judgments and to provide counsel and support on the basis of at best limited information (AMA, 2022). Therapists bear the burden of assessing, diagnosing, treating, and supporting clients who have been referred to them but who, in reality, may not actually have a mental illness or mental health issue at all.

5

DSM-5 and ICD Codes

The discipline of psychology has its own particular and specific lens through which its practitioners understand, assess, interpret, diagnose, and treat, for example, anxiety and/or depression. Assessments are made using established criterion as presented in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), which is used in the USA only, as well as the International Classification of Diseases (ICD) which is used both in the USA and globally. The discipline of psychology is firmly entrenched within these accepted standards for mental health issues and disorders, their definitions, the character and presentation of their symptoms, the appropriate tools for assessing and diagnosing, the criterion upon which specific diagnoses are made, and strategies for treatment.

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.

In 2024, the ICD in use around the world, and in the US, is the ICD 11 (https://www.who.int/news/item/11-02-2022-icd-11-2022-release).

It is important to keep in mind that the goal of the DSM-5 and the goal of the ICD-11 are different. The DSM-5 goal "is to provide a common research and clinical language for mental health problems," (see https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5328289/) while the WHO has emphasized, "the ICD-11 should pay particular attention to issues of clinical utility in a broad range of settings, globally applicability, and scientific validity," (see https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5328289/).

It is important to keep at the forefront when diagnosing, coding, and planning for a client with or suspected of having a mast cell activation issue or disorder such as MCAS, that many of the issues they present with are secondary or due to the physical illness, are psychiatric-seeming only, and that these symptoms are then often compounded by the normal emotional reactions one experiences to having and living with a chronic illness. However, there can also be clients with MCAS or another mast cell activation related issue who have an actual history of mental illness.

It is not always an easy task to tease apart what symptoms are physiological and mast cell activation based from the symptoms that are indeed psychologically based. A history of mental illness by itself does not negate a systemic mast cell activation diagnosis such as MCAS but should incur further examination and observation regarding each person's symptom manifestation history and severity as presented by the client, supported by a possible peer-to-peer consultation with a physician who specializes in mast cell issues and disorders and/or a client referral to a physician who specializes in mast cell activation issues and disorders.

Within the discipline of psychology, anxiety is defined and understood as a disorder that features excessive fear where "fear is the emotional response to real or perceived imminent threat, whereas anxiety is anticipation of the future threat" (DSM 5, 2013, 189). Anxiety is further defined and understood by the discipline of psychology as having varying and different "types of objects or situations that induce fear, anxiety, or avoidance behavior, and the associated cognitive ideation" (DSM-5, 2013, 189). Nowhere is it included in the DSM-5 or the ICD codes that anxiety can be a symptom solely of a physical illness or disorder such as one involving mast cell activation and not be emotionally or psychologically based. The same is true for depression. Although there do exist diagnosing criteria and codes for both anxiety and depression, to continue with the example, as occurring secondary to a physical illness, anxiety and depression are still being defined and understood through the fixed lens of the discipline of psychology as being due to avoidant behavior and associated cognitive ideation.

There are current, published, medical research studies that strongly point to mast cell activation in COVID-19 and long-COVID (Weinstock et al., 2021 and Hiu Yan Lam et al., 2021). However, due to the disconnect in communication between the discipline of medicine and the discipline of psychology, this research appears over-looked by those in the discipline of psychology. Thus, the medical awareness and knowledge of mast cell activation in long-COVID and other mast cell diseases that is essential for a correct diagnosis does not appear as a factor in the diagnosis and treatment of individuals who may have long-COVID or another mast cell activation issue from the psychotherapist to whom they may have been referred, nor does it appear in the care and interventions that individuals may receive.

The biomedical model, as defined by Oxford Reference, is a model of health that focuses on purely biological factors and excludes psychology, the environment, and social influences. It is considered the leading modern way for healthcare professionals to diagnose and treat a condition in most Western countries. Knowledge and expertise are controlled by the medical profession (https://www.oxfordreference.com/display/10.1093/acref/9780191828621.001.0001/acref-9780191828621-e-5075).

Developed in the 1950s, the biomedical model of health "failed to account completely for the fact that not everyone who is exposed to the same virus will acquire a particular disease; furthermore, even when people do get sick, there are large differences among individuals in terms of the severity of symptoms they experience and how they respond to treatment" (Gruman, 2017 as cited in https://sites.psu.edu/aspsy/2021/02/16/ biomedical-model/). This is especially true with people who are trying to manage the symptoms of long-COVID or any mast cell activation related issue or disorder.

In 1977, George Engel proposed a new model for medicine, the biopsychosocial model, contrasting with the biomedical model. Engel argued that the biomedical model was limited and insufficient and failed to take into account: the person who has the illness; their experience of the illness; their attitude toward the illness; whether the person indeed regards their condition as an illness at all; how factors of living and of life affect the conditions onset, presentation, and the course of the condition; care of the patient as a person; the healthcare system itself (https://www.ncbi.nlm.nih.gov/books/NBK552030/). Engel felt a new biopsychosocial model was needed in order to take into account all of these factors that contribute to both illness and the patient experience (IBID).

In consciously moving away from a biomedical model towards a biopsychosocial model, coupled with the manner in which the biopsychosocial model has been defined, adopted, and is adhered to (Ghaemi, 2018), there is a certain rejecting of the medical aspect that includes criticism that health psychology positions itself as a partner supporting and sustaining the "medical agenda" (Fox et al., 2009).

As long as depression and anxiety, as the examples, are only understood through the lens of psychology by therapists, then their clients who may have long-COVID or MCAS and are presenting with the symptoms of depression and anxiety due to mast cell activation will be misunderstood, misdiagnosed, and will not receive appropriate treatments. The symptoms of long-COVID, which can include anxiety, depression, chronic fatigue, brainfog, cannot be understood, assessed, and treated through the lens of, for instance, Cognitive Behavioral Therapy. The symptoms of long-COVID and MCAS can include symptoms whose presentation appear to be psychological in nature but are, in reality, a presentation of symptoms that have a physical basis in mast cell activation. Cognitive Behavioral Therapy traditionally is focused on changing a person's maladaptive behaviors (Sperry, 2006). In any health situation involving mast cell activation (such as long-COVID, COVID-19, MCAS, chronic fatigue, sensitivities to multiple chemicals, and other MCDs) it is not a question of a person's maladaptive behavior patterns at the root or as a cause of the person's symptoms. Therefore, psychology-informed treatments are not appropriate or effective when working with a client with a mast cell activation related issue or disorder, such as COVID-19, long-COVID, and MCAS as they are not addressing the real issues through the right lens.

Because the medical aspect has been criticized and often pushed to the side in favor of the biopsychosocial model by psychology, there exists a gap in knowledge evidenced most clearly by the disconnect of information and understanding between the domains of medicine and psychology regarding COVID-19, long-COVID, mast cells and MCD, their respective mechanisms of action, disease process, and presentation of symptoms (Fox et al, 2009).

It is essential for there to be on-going communication between a client's medical team (i.e., medical doctor, nurses, medical assistants, physician assistants, etc.) and the person's psychotherapist especially in the recognizing and diagnosing stage. Long-COVID and other mast cell disorders (MCD) are chronic illnesses and clients with these types of diagnoses will need ongoing support that includes the management of mast cell activation controlling medications, medications that may target controlling or easing specific reactions due to mast cell activation, as well as supports with strategies for managing both the physical symptoms themselves of a mast cell activation issue or disorder (which often include psychiatric-seeming symptoms that are not actually psychiatric issue-based but due to the physical disorder) as well as the emotional reactions that any person who is living with and coping with a chronic illness may experience. There is an interaction and interplay between the physiological and the emotional/psychological when it comes to long-COVID, MCAS. and mast cell activation related issues and disorders, their presentation of symptoms, and their impact on lives. Therefore, there needs to be that on-going communication and partnership between psychotherapists and doctors/the treating medical team that is based on an exchange of information that is both accurate and well-researched.
The reality of the COVID-19 pandemic has brought to the forefront the long overdue awareness of a previously silenced population. To meet the needs of COVID-19 sufferers, long-

COVID sufferers, those with MCAS and other mast cell activation related issues and disorders involves ultimately changing our understanding of what constitutes a mental illness.

It is important for therapists to be familiar with the medical codes for various mast cell activation disorders that treating physicians may use when diagnosing.

ICD codes (medical) can include:

- D89.40 Mast cell activation unspecified; mast cell activation syndrome (for the client with MCAS or another mast cell activation disorder)
- U09.9 Post COVID-19 condition, unspecified (for the client with long-COVID)

DSM-5 codes for a client with MCAS, long-COVID, or other MCD can include:

- 293.84 Anxiety disorder due to another medical condition
- 293.83 Depressive disorder with depressive features due to another medical condition
- 293.83 Mood disorder with depressive features due to toxic exposures
- 310.8 Cognitive disorder due to neurotoxin exposures
- 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

ICD codes (mental health) for a client with MCAS, long-COVID, or other MCD can 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

The Diagnosing Format

The DSM-5 ushered 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 codes. Lists of these codes are included in their own section at the back of the DSM-5.

The DSM-5, instead of the multi-axial approach, 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 MCAS

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.

- 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 MCAS, mastocytosis, mast cell activation related issues or 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 or reactions after an exposure to a trigger or multiple triggers. At the times when the person is 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 MCD to answer. Every person with a mast cell activation related issue or disorder is at risk for chemical and other exposures in any and all environments, especially those that depend on the behaviors of others.

A person with MCAS or another MCD 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 a mast cell activation issue or disorder has no control over roadwork, construction, blasting, the neighbor painting next door, mulch. All of these are factors that impact the MCD 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 MCAS or another MCD avoid people they do not know. Strangers are a minefield of chemicals and unknown, potentially harmful substances. A person with MCAS or other mast cell activation related issue or disorder 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 insights into how an individual with MCD 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 MCD; each question the start of an important conversation.

Level 1 Cross-Cutting Symptom Measure and MCD

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 hopeless; 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 a mast cell activation related issue or disorder 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.

Mast cell activation disorders 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 MCAS or other mast cell activation issue or disorder also experiences these symptoms when they are having a reaction to a chemical exposure or exposure to another of their triggers—psychological-seeming symptoms that are due to a physical and not psychological cause.

Cultural Formulation Interview and MCD

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 MCAS or other MCD as well as with those of chronic illness and disability when conducting the DSM-5 recommended *Cultural Formulation Interview* with a client who has MCAS or another mast cell activation related issue or disorder.

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 MCAS and MCD. Through the questions regarding, for example, cultural perceptions relating to cause, context, and support, the clinician can elicit insights regarding how a client with MCD 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 disorder 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 their 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 MCAS or other MCD, especially when their triggers include being sensitive to multiple chemicals. The answer a client with MCD 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 their ethnic and racial cultural groups, but also their conceptualization of disability, function, resilience, and self-worth within the cultural context of environmental illnesses, mast cell activation related issues and disorders, and chronic illness.

6

Clinical Considerations: Psychotherapy

A person who may have a mast cell activation related disorder or illness, such as MCAS and long-COVID, frequently presents with complaints and symptoms involving multiple organ systems. These can include neurological complaints of pain, migraines, numbness, tingling. Their complaints and symptoms can also include brainfog, exhaustion, overwhelming fatigue, depression, anxiety, insomnia, bone/joint/muscle pain, digestive/GI issues, dizziness, tinnitus. The person will go to their doctor. The doctor will assess and more often than not request specific testing be done to determine what may be physically going on to cause these symptoms. Typically, the tests come back within normal ranges. At this point, the person's primary care physician often refers the person to a psychotherapist, determining that since the tests came back within normal ranges, the issue must, therefore, be psychological in nature.

The psychotherapist (and this could be a psychologist, psychiatrist, clinical mental health counselor, social worker) will assess and evaluate through the lens of psychology and treat the person accordingly. What frequently happens, for the person with the mast cell activation related issue or disorder, is that they have not been correctly assessed or diagnosed and, therefore, the recommended interventions and treatments are not necessarily the correct ones. The psychotherapist (as well as the medical practitioner who made the determination and subsequent referral to the psychotherapist) was unable to recognize the person's presenting symptoms correctly as possibly being due to mast cell activation because mast cells, mast cell activation, and the symptoms of mast cell activation are medical concerns and, therefore, do not come under the scope of practice of a psychotherapist nor are they considered to be part of the disciple of psychology. The medical fact of mast cell activation, the multiple body systems it impacts, and the ensuing symptoms a person can experience is knowledge that is not part of the education, training, or lens through which assessments, evaluations, and diagnoses are made, interpreted, and understood within the discipline of psychology.

The discipline of psychology has its own particular and specific lens through which its practitioners understand, assess, interpret, diagnose, and treat, for example, anxiety and/or depression. Assessments are made using established criterion as presented in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), which is used in the USA only, as well as the International Classification of Diseases (ICD) which is used both in the USA and globally. The discipline of psychology is firmly entrenched within these accepted standards for mental health issues and disorders, their definitions, the character and presentation of their symptoms, the appropriate tools for assessing and diagnosing, the criterion upon which specific diagnoses are made, and strategies for treatment. Within the discipline of psychology, anxiety is defined and understood as a disorder that features excessive fear where "fear is the emotional response to real or perceived imminent threat, whereas anxiety is anticipation of the future threat" (DSM 5, 2013, 189). Anxiety is further defined and understood by the discipline of psychology as having varying and different "types of objects or situations that induce fear, anxiety, or avoidance behavior, and the associated cognitive ideation" (DSM-5, 2013, 189). Nowhere is it included in the DSM-5 or the ICD codes that anxiety can be a symptom solely of a physical illness or disorder such as one involving mast cell activation and not be emotionally or psychologically based. The same is true for depression. Although there do exist diagnosing criteria and codes for both anxiety and depression, to continue with the example, as occurring secondary to a physical illness, anxiety and depression are still being defined and understood through the fixed lens of the discipline of psychology as being due to avoidant behavior and associated cognitive ideation.

Medications

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.")

What this means is that a client with an unrecognized or not diagnosed mast cell issue or disorder such as long-COVID or MACS who is experiencing, for example, anxiety and is prescribed certain anti-anxiety medications, the person may show positive effects and decreased symptoms. But the positive effect and the reduction 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 or antihistamine-like properties, is a mast cell activation inhibitor, and/or is a mast cell stabilizer.

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 activation 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 (1) mast cell degranulation decreases, (2) as mast cells are stabilized, less mediators are being pumped into the body, and (3) also because of the antihistamine and/or antihistamine-like properties of the medication blocking histamine receptors and, thus, 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).

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, hopelessness. An individual living with the chronic environmental illness of MCAS or another mast cell activation 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 after exposure to a trigger, a person with MCD can become agitated, emotional, irritable, tearful, exhausted, anxious, depressed, angry, have suicidal thoughts. They can have panic attacks, experience what can be severe neurological pain, have irregular heartbeats, have "air hunger," that experience of not being able to draw a full, complete breath. An exposure to chemicals, substances, or an environment to which they react (to their trigger or multiple triggers) can cause cognitive impairments for the person with the MCD leaving them confused, unable to remember, not knowing where they are. Reactions to 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 a mast cell activation related issue or disorder should be encouraged to pay attention to and learn to identify the ways they react and to which specific chemicals, substances, and environments—their personal triggers—in order for them to not only better understand and manage their symptoms when experiencing reactions to an exposure, 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 MCAS or mast cell activation issue or disorder, 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 their anxiety, or their agitation, or panic, or restlessness, or cognitive impairment and brainfog, or whatever their reaction(s) may be to the trigger.

It is very easy for the person with MCD, as well as for the clinician, to confuse the symptoms of mast cell activation with those of a psychological condition. Keep in mind that the person with the mast cell activation issue or disorder can react hours or even days later following an exposure to chemicals, substances, and/or environments to which they react, 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. The supports accompanying these approaches typically include: (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 health-care 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 issue is noncompliance and 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 MCAS or a mast cell activation related disorder. These clients will experience symptoms when exposed to the chemicals, substances, and/or environments 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 MCAS, long-COVID, or other mast cell activation related issue or disorder 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 these medical issues and concerns is avoidance. They must avoid exposing themselves to the chemicals, substances, and environments that cause their reactions. Going to the doctor, to the hospital, to the clinic necessitates exposures to chemicals, substances, and environments that can cause mild to severe and life-threatening reactions and/or anaphylaxis, and absolutely should be avoided but, in so many health care situations and in meeting health care needs, is unavoidable.

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 mast cell activation related issues or disorder may or may not already have the medical diagnosis of MCAS, systemic mast cell disorder, 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 who has or is suspected of having MCD 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 a mast cell activation issue or disorder, 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 client may report symptoms that 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 they do 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 the chemicals and substances to which they react 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 or suspected of having MCD experiences in order to better assess the client’s needs and the best direction in which to proceed regarding their 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 and substances (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 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 product or 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. Completing the CC-WEA (CELACare Wellness & Environment Assessment) can be extremely insightful in these situations (see https://counselingatcela.com/contact to request a pdf of the assessment).

Therapists assessing and evaluating a client who may have MCAS or another mast cell activation 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 or substances 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 long-COVID, MCAS, or other mast cell activation issue, or who is suspected of having one, presents with symptoms that may include but are not limited to:

- Headaches, migraines
- Feelings of pressure around the face and head
- Feeling spacey, problems concentrating, problems remembering
- Brainfog
- Feeling tense and anxious, panic attacks
- Irritability
- Emotionality, e.g., crying spells, spells of rage
- Feeling something is terribly wrong, sense of doom
- Loss of interest in things
- Suicidal ideation
- Rashes, hives, itching
- Eczema. dermatitis
- Swelling (face, lips, extremities, etc.)
- Irregular heartbeat
- Tachycardia
- Burning and watery eyes, blurred vision
- Tingling and/or numbness anywhere on their body and especially their extremities
- Tinnitus (ringing in the ears), muffled hearing

- Problems breathing including problems with their tongue swelling, coughing, increased phlegm and mucus, asthma-like symptoms
- Itching, burning
- Chest pressure (often with normal EKGs)
- Nausea, vomiting, diarrhea
- Abdominal pain
- Muscle/joint/bone pain
- Pain anywhere in the body
- Muscle weakness
- Extremities feeling cold independent from their external environment temperature (e.g., a warm day but freezing hands and feet) often described as a coldness from the inside out
- Suddenly feeling extremely hot inside their body independent from their external environment temperature
- Fever, flu-like symptoms
- Swollen lymph nodes
- Exhaustion—often extreme exhaustion

There are also physical medical conditions that often are a part of having a mast cell activation related issue or disorder due to their having a basis in or involving mast cell activation. These include but are not limited to:

- Ehlers-Danlos Syndrome (EDS)
- Fibromyalgia
- Chronic Fatigue Syndrome (CFS)
- Arthritis
- Multiple Sclerosis (MS)
- Autism
- Raynaud's Syndrome
- Lyme Disease
- Lupus

- Neuropathy
- Vertigo
- Parkinson's Disease
- Ulcerative colitis
- Celiac issues
- Migraines
- Irritable Bowel Syndrome (IBS)
- Gastroesophageal Reflux Disease (GERD)

(see: mastocytosis.ca/mast-cell-disease/related-disorders; my.clevelandclinic.org/health/diseases/9849-raynauds-phenomenon; mastcellmaster.com/publications.php; and Appendix 1).

The questions a clinician asks clients 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, substances, and/or environments to which they react.

An assessment tool that can be used to uncover some of this vital information is the CELACare Wellness & Environment Assessment (CC-WEA). This is not a diagnosing tool. Rather, it's a questionnaire that can be clinician administered or that a client can self-complete whose results put into a clearer perspective such areas of question as triggers, reactions, and pertinent medical history. The CC-WEA results can add a tremendously important level of clarity and objectivity regarding a person's experience of their symptoms and triggers that many times is challenging for the client to have, express, or maintain due to those same reactions and how they may impact the person's ability and functioning. (Contact counselingatcela.com for more information about the CC-WEA).

Barriers to Accessing Healthcare

If a person's symptoms interfere significantly with their ability to breathe, work, attend school, or do housework, then 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 that it is "easily accomplished and able to be carried out without much difficulty or expense," (www.ada.gov). The client with a mast cell activation issue or disorder faces many barriers and potential barriers to accessing healthcare.

Transportation is frequently difficult for a person to manage. Public transportation is often impossible because of the concentration of chemicals and substances and residual chemicals and substances in the confined space of a bus, subway train, or taxi. Elevators can also be prohibitive for the same reason. Many people with a mast cell activation related issue or disorder have extreme difficulty with cars due to the exhaust fumes, plastics, and toxins 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, toxins, environments, and the multiple triggers, sometimes for many weeks afterwards.

Public areas, offices, and hospitals are full of chemicals, substances, and toxins that can negatively impact a person who has MCAS or a mast cell activation issue or disorder. 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 MCD, most environments are layered with chemicals and toxins 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 and its monitor, your personal belongings such as a backpack, tote bag, purse or pocketbook. 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 and potentially toxic fumes we can’t see but to which the person who has MCAS, long-COVID, or a mast cell activation related issue or disorder 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. Formaldehyde is a common chemical with which furniture and car upholstery are treated. Many people with a mast cell activation related disorder, of which being sensitive to multiple chemicals is a part, 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? These individuals can react to the chemicals given off from particle board, wood, and many other construction materials and construction processes.

People with a mast cell activation related issue or disorder 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, public spaces, air fresheners, carpet fresheners or refreshers, room scents and deodorizers, products used to clean the bathrooms.

Still another layer of chemicals the person has to contend with is the chemicals and toxins 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 and on their clothing and accessories residual toxins and chemicals—fumes. There are 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 over the course of the day prior to their arrival to your office.

Everyone leaves their residual chemical and toxin 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 a mast cell activation disorder who reacts to all the items, chemicals, substances, and residuals in the environment and needs to avoid exposures.

Reasonable accommodations need to be discussed in advance in order to provide the client who has MCAS or other mast cell activation related issue with as safe an environment as possible.

Reasonable Accommodations

The fact of MCD. whether it's MCAS or another mast cell activation related issue or disorder. cannot be removed from any equation involving a client who has or is suspected of having one as it impacts everything they do.

A client I know related to me a situation where they contacted their health insurance company in writing to request the insurance company's approval of an out-of-network psychologist who had experience working with clients with mast cell activation issues. Initially, their request was denied by the insurance company and, in a letter, the insurance company provided them with a listing of twelve therapists and agencies who were part of their network of providers and instructed the person 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, bipolar disorders, psychopharmacology, schizoaffective disorder.

Several of the agencies were straightforward about their inability to meet the medical needs of a client with MCAS or other MCD. The client shared with me the response of one of the Intake Coordinators in particular with whom they spoke over the telephone: [names have been changed]

> *J.D., the Intake Coordinator, said that they have serious concerns about the possibility of my*

> *receiving treatment at their facility due to my physical disability. Their facility, J.D. explained, occupies a first floor and two sub-levels on a very busy street. J.D. said that car, bus, and truck exhaust fumes are an issue. J.D. 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. J.D. said they understood about having MCAS 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 MCAS or mast cell activation related issue 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, substances, and toxins 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. These are general accommodations. Triggers and symptoms can vary from person to person. Ask your client for their specific triggers and sensitivities to best accommodate their needs.

Creating a Safer Environment

Creating a safer environment for a client with MCAS or another mast cell activation related issue or disorder, who almost certainly will have chemical sensitivities because of their mast cell activation issues, begins with addressing and implementing specific reasonable accommodations to make the physical environment more tolerable.

A safer environment for a client with MCAS or other MCD also involves learning how to best support the individual when they are 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.

Clients should carry with them a letter to first responders and emergency rooms, signed by their doctor, listing their diagnosis, their triggers, their reactions, what to do to support them, and emergency mast cell medical protocols. 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

Therapists and healthcare support providers should: (1) have ready the client's emergency contact information including their hospital of choice; (2) be trained in how to administer an Epipen in cases of severe reactions and anaphylaxis; (3) write anything down that you want the person with MCAS or mast cell activation issue to remember. Reactions can affect the person's memory; (4) don't make decisions based on your own sense of smell. People with MCAS and other MCD can react to even the smallest amounts of chemicals in their environment that you might not even notice; (5) remember that a person who is experiencing a reaction to an exposure to one of their triggers isn't able to "remain calm" and that requests to do so—with the best of intentions—often worsen the reaction; (6) remove the person who is having the reaction away from the environment/trigger to the outdoors as reactions often resolve when triggers/incitants are removed.

Offering telephone and online/telehealth session options is a way of creating a safer environment for your clients who are physically unable to come every week or every-other week to an office due to their illness and mast cell activation issues.

Clinician Flexibility

A client with MCAS or other mast cell activation related issue or disorder lives perpetually at the mercy of other people's behaviors, external conditions, and circumstances over which they have no control. The client with MCD can wake up in the morning feeling reasonably alright but then a random truck spewing what are very toxic to the client exhaust fumes can drive by near to where the client lives, and the client may suddenly find themselves reacting, for example: nauseous, dizzy, extreme muscle weakness, extreme fatigue, brainfog, difficulty breathing, headache and migraine symptoms, diarrhea, tongue and airway swelling. Their reactions can ramp up very quickly in the moment from being barely there if at all to severe and anaphylaxis in seconds; sometimes fractions of seconds. How long reactions may last varies from person to person, from exposure to exposure. Reactions can happen in the moment as well as be delayed reactions and happen hours or days later.

A client with MCAS or another MCD may frequently cancel and reschedule their appointments due to mast cell reactions rendering them unable, in that moment in time, to keep a scheduled appointment. These are not situations of psychology, psychological avoidance, malingering, denial, manipulation, avoidant behaviors nor are they symptoms or a presentation of symptoms indicative of some psychological diagnosis (for instance, borderline personality disorder or obsessive compulsive disorder.) These are situations typical of a person with MCAS or other MCD and how they are physically impacted by their disorder—which includes their what can be psychiatric-seeming symptoms that, in reality, are reactions to mediators released from activated mast cells in multiple organ systems throughout their body.

The clinician working with a client having MCAS or other MCD needs to have this understanding of these disorders and be able to incorporate the possibility of frequent and often last minute cancellations and rescheduling (which *will* happen) as an inescapable aspect of working with a client with MCAS or other MCD. Mast cell activation related issues and disorders can make planning in advance or keeping to any kind of schedule challenging at best due to the unpredictability of exposures to triggers and the varying intensity of each person's systemic reactions to those exposures. It is more realistic to view this type of clinician flexibility through the lens of it being a specific reasonable accommodation for the client due to their mast cell activation issues and not penalize the client in any way for what are predictable occurrences when one has a mast cell activation related disorder. That does not mean there aren't going to be clients who, in addition to having MCAS or another MCD, also carrying a mental health diagnosis. It isn't an either-or situation. Treating clinicians need to know that there is a difference and be able, through their knowledge, insights, understanding, and experience, to recognize the difference in what are mast cell activation based and what may not be mast cell activation based presentations of symptoms.

7

Building the Treatment Plan

Treatment planning for the person with an EI such as long-COVID, MCAS, or other mast cell activation issue or disorder, especially as being sensitive to multiple chemicals can many times be involved, needs to begin with the knowledge and understanding that many—if not most or all—of the client's presenting symptoms occur as reactions and they have a physical cause. 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 a mast cell activation related issue or disorder can be many and varied. Mast cell activation specific areas of clinical consideration should include:

- **Avoidance**—how successful is the client in avoiding triggers and minimizing exposures to the chemicals, substances, and environments to which they react

- **Ongoing exposures**—what level of toxic and harmful 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 chemical and toxin-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 mast cell activation and their illness/disorder** —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 and health needs and concerns

- **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 a mast cell activation issue or disorder. 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, than we are with long-COVID, MCAS, 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 personal 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 MCAS or a mast cell activation 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 re-adjust 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, with 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 or are suspected of having a mast cell activation illness or disorder, such as MCAS, when reacting to a trigger, may experience profound exhaustion and other disabling symptoms that can last for hours, 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 their 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, substances, toxins, and/or environments to which they react. 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 trigger-, toxin-, and 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 trigger-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 MCAS or a mast cell activation related issue or disorder. Anyone going into the home of a person with a mast cell activation issue or disorder, or who is suspected of having one, will need to be as chemical and toxin-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 mast cell activation issues react to plastics and petroleum products) and the places they have been prior to arriving at the home of the client with the mast cell disorder. Often the best meaning friend can make a person with MCAS or other MCD 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, substances, and environments to which they react.

Phase Two Interventions:

The goals of Phase Two support—*Stabilization*—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. Strategies such as list-keeping and journaling can help with tracking reactions and possible triggers; learning to recognize what circumstance, event, activity, or exposure may bring on which particular reactions; learning what dietary/nutrition modifications may need to be put in place to help bring down reactions and support mast cell stabilization (for instance, making low histamine food choices.)

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 who has MCAS or a mast cell activation related issue or disorder experiences enormous loss; loss of identity, self, home, partners, friends, and dreams. These losses need to be respected and grieved. It is no easy task to become that phoenix rising from the ashes.

Phase Three interventions embrace the existential while supporting the client's growth process and include: journal keeping; re-authoring life narratives; expression through the visual arts, music, dramatic arts, dance and movement; body-mind-spirit practices; exercise. 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. A key component of Phase Three interventions and supports need to not only allow room for the client's expression of their emotions but also validates and accepts without negative judgment their feelings and emotions as an understandable response to having a chronic illness in general, having a chronic mast cell activation related illness, and the life changes they incur.

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 of their interior cognitive and emotional landscapes; body-mind-spirit practices especially ones that target stress management; journal keeping; regular exercise; socializing as much as able within the boundaries of their maintaining their optimum physical, mental, and emotional health needs; maintaining their relationships with family and friends; developing new associations and friendships.

Suggested Reading:

- *Never Bet Against Occam: Mast Cell Activation and the Modern Epidemics of Chronic Illness and Medical Complexity*, by Lawrence B. Afrin, MD, Kendra Neilsen Myles, et al
- *Psychological Treatment of Chronic Illness*, by Len Sperry, MD, PhD

- *Managing Chronic Illness Using the Four-Phase Treatment Approach*, by Patricia A. Fennell
- *The Chronic Illness Workbook*, by Patricia A. Fennell, MSW, LCSW-R
- *Surviving Our Catastrophes: Resilience and Renewal from Hiroshima to the Covid-19 Pandemic*, by Robert Jay Lifton

8

Disability, Social Security, and the Functional Assessment

It is not uncommon for many individuals suffering with MCAS or a mast cell activation disorder 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 MCAS or other MCD. Having medical and healthcare practitioners and professionals who understand MCAS 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, thinking, concentrating, 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 MCAS or another mast cell activation related disorder experiences when exposed to chemicals, substances, and/or environments to which they react typically affect multiple body systems and can impair all major life activities.

The definition of disability that 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 MCD needs to convince examiners who may know nothing at all about MCAS or 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, household products, substances in the environment, and environments themselves especially public ones and (b) have no control over these exposures because they cannot control the behaviors of others. The burden of proving functional limitation falls to the person with the mast cell activation issue or disorder and their treating healthcare professionals.

Private Disability Insurance

Employers sometimes offer private disability benefit options in addition to health insurance to their employees. However, these insurance policies often have exclusions for conditions that include being sensitive to multiple chemicals—a symptom of MCAS and mast cell activation issues and disorders. Many insurance companies also will not cover anything that has been self-diagnosed or self-reported.

Medicaid

Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities (see https://www.medicaid.gov/medicaid/index.htmi). Medicaid is jointly funded by states and the federal government but is administered by each state. 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, assistance with food/food stamps, help with childcare, 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 benefit payments should the individual be approved for disability assistance through Social Security Administration, (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 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 (https://www.ssa.gov/applyfordisability).

The SSDI application is lengthy and detailed requiring specific information regarding the disability, its onset, the person's physical and mental health medical history, the person's 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 to receive 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 individual 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 Medicaid 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, considering 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/OPHom e/ 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 they are 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 28, year 1. LW has become so disabled they can no longer work. Their last day of employment is January 28, 3015.

February year 1. LW completes and submits an online application for SSDI benefits and a telephone application for SSI with SSA. LW also applies for state Medicaid assistance, completing and submitting an online application with their 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 LW 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 MCAS or mast cell activation related issues or disorders, or even believes they're real. If LW does not agree to the examination should they request one their application can be denied, regardless of how their health may be negatively impacted by trying to comply.

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.

LW 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 LW 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 LW 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 year 1. LW receives the first direct deposit of state Medicaid 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 year 1. LW receives notification from SSA that their applications for both SSI and SSDI disability benefits have been denied. LW 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. LW noticed that one of the hospitals/agencies listed by SSA was the breast clinic at his local hospital. LW 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 LW had received repeated emergency room treatments for their severe mast cell activation reactions) but instead they had contact information for the hospital's breast clinic **only,** where there was no record of their ER visits and the treatments they received.

May year 1. LW receives notification in the mail that their 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. LW is unable to follow their doctor due to the inner-city location, the exhaust fumes, the toxic chemicals, substances, and environments. They decide to try one of the doctors remaining at the practice as their primary care physician.

June year 1. LW receives written notification in the mail that their state Medicaid benefits will stop as of August 3015. The state agency has determined that they are 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 they received after the initial stopping of benefits date (in this example, August 3015.)

LW contacts their state agency case manager to verify the information and procedures. The case manager, understanding the need for avoidance, tells them to write all over the appeal form that they need to have a telephone hearing due to their disability.

July year 1. LW files the Reconsideration, including all of the supporting documentation they gathered, with SSA.

LW now retains a disability lawyer. The disability lawyer informs them 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 SSA determination services has denied the Reconsideration 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 LW be examined by a physician, psychiatrist, and/or psychologist of their choosing. This may not necessarily be a doctor who is informed or who knows anything about MCAS or mast cell activation related issues or disorders, or believes they are real and/or understands the symptoms LW experiences are physiological and not due to a mental health issue. If LW does not agree to the examination, should SSA request one, their application can be denied.

August year 1. The new primary care physician appears very reluctant to write prescriptions for the medications that LW takes, especially the Prednisone, and unwilling to write letters stating LW has anything related to or involving chemical sensitivities. The doctor will, however, write letters saying LW is suffering from a mental illness.

September year 1. LW is examined by a medical specialist in a pulmonary clinic at their city's number one hospital. This specialist refers them to an allergy and immunology specialist feeling there may be some mast cell issue based on the symptoms with which LW presents.

October year 1. LW's Reconsideration is denied by SSA.

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

November year 1. LW is examined by the allergy immunology specialist who schedules them for testing for mastocytosis and prescribes Gastrocrom, a mast cell stabilizer, and recommends having it be compounded sharing that most of his patients react to plastics and Gastrocrom is a liquid that comes in small plastic vials. The doctor tells LW that it is his hope that the cromolyn sodium (generic name for

Gastrocrom) 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 for LW to get to the maximum dosage.

LW's primary care physician writes letters for various agencies including the housing authority as LW now has a Section 8 voucher to subsidize their rent. The doctor also writes letters requesting reasonable accommodations due to disability for LW to not be physically present at meetings. The doctor, however, is reluctant to complete the SSA functional assessments or their lawyer's disability assessment form saying he doesn't know enough about the illness to say outright that LW is totally and permanently disabled. He suggests that the specialist complete these forms.

February year 2. The allergy and immunology specialist officially gives LW the diagnosis of Mast Cell Activation Syndrome (MCAS) but declines completing the SSA forms suggesting they be completed by the doctor who referred LW to the allergy and immunology specialist. The specialist (at the pulmonary clinic at the hospital) said the primary care physician should complete the forms.

February year 2. LW has a telephone hearing with the state Medicaid agency. Prior to the telephone hearing, LW was able to submit copies of the allergy and immunology specialist's notes, his diagnosis of MCAS, and copies of the pulmonary clinic specialist’s notes from the medical records at both of these hospitals. The state determines that LW is disabled and their application for state emergency benefits is accepted.

April year 2. LW receives notification in the mail that their primary care physician is leaving the practice July 1st.

July year 2. LW receives notice in the mail that their case has been assigned to an administrative law judge and that they are scheduled for a hearing in two months time.

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

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

September year 2. LW is referred by their primary care physician to a dermatologist regarding strange-looking rashes LW has on their legs and arms. The dermatologist immediately upon examination said, "Yes, that's mast cell activation. That's mast cells."

September year 2. LW 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. LW 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 environmental illnesses like MCAS and mast cell activation issues and disorders, especially when they involve being sensitive to multiple chemicals. LW shared with me, "I really think that I was approved for disability in the end because I was able to have a diagnosis—the mast cell stuff—that is medically recognized and accepted, if not well understood," they laugh and shake their 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."

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 person's 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 a mast cell activation issue or disorder 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).

MCAS and mast cell activation related issues and disorders and their symptoms are dependent upon a person's exposure to triggers. As long as the individual with the mast cell activation disorder is successful in avoiding the chemicals, substances, and environments to which they react and they receive appropriate medication supports, their reactivity can often 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 their many triggers and are reacting. But even those moments aren't necessarily long-lasting as people with MCAS and mast cell activation disorders live perpetually at the mercy of the behaviors of others over which they have no control.

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.

There is also the SSA Adult Consultative Examination Report for Mental Disorders. It is imperative that clinicians keep in mind that to even complete this form is inappropriate for a person with a mast cell activation issue or disorder as they will be experiencing and presenting with psychiatric-seeming symptoms (such as anxiety and/or depression) that are not psychiatric or psychological issues and are occurring due to *physiological* reasons. The assumed premise of the form is that the individual has a mental health issue and not a physiological issue. MCAS and MCD are not mental health disorders.

A person having MCAS or a mast cell activation related issue or disorder does not automatically rule out the person *also* having a mental illness. It falls on the treating clinician to be able to accurately differentiate between a person presenting with symptoms of mast cell activation (such as depression and/or anxiety) and a person presenting with symptoms of a mental health issue (such as depression and/or anxiety.)

In all instances where there is a question of a mast cell activation issue or disorder, clinicians should administer both the Mast Cell Activation Assessment Questionnaire, which is a validated diagnosing tool, and the Wellness & Environment Assessment (CC-WEA) which provides pertinent information regarding a person's reactions, triggers, and medical history.

As a treating clinician, a therapist can and should submit paperwork and completed forms in support of their clients. Below is a sample letter for disability determination services. This is only an example to provide a template of information SSA Disability Determination Services typically look for:

Social Security Disability
Re: Case #_______

To Whom It May Concern:

I am writing regarding my client, ____________ (DOB_____, case #_______). The following is an assessment of ________'s health issues, their impact on ________'s life, and their degree of limitation due to their health issues.

"Name of Client" sought out therapy supports regarding issues of __________________ [For Example: anxiety, depression, and chronic health issues.] Our most recent session dates are: _________, _________, ________, and we will be continuing to meet weekly. The next session we have scheduled is _________.

Diagnoses:
[a bulleted list that includes DSM-5 code. For example:

- Anxiety Due to Another Medical Condition (DSM-5 293.84)
- Depression Due to Another Medical Condition (DSM-5 293.83)]

General Observations and History of Present Illnesses: [write narrative here. For example: "Name of Client" is a pleasant, alert 43 year old who presents with a subdued manner, speaking in a gentle tone of voice. Their affect appears appropriate and in keeping with their reported depression, anxiety, and other health issues. The report a medical history that includes (list medical diagnoses with dates diagnoses given whenever possible and treating physician who gave diagnoses.) Include any and all surgeries and/or medical procedures.]

Prescribed Medications:
[list medications here.]

Symptoms and their Presentation:
[write narrative here. For example: The symptoms/reactions "Name of Client" has shared they experience appear typical of MCD and mast cell activation related medical illnesses. These reactions include but are not limited to: *list all of the client's reactions that they experience.*]

Activities of Daily Living:
[write narrative here. For example: "Name of Client" reports that the impact of their physical illnesses on their ability to perform activities of daily living is severe and that because of the severity of their systemic reactions they are forced to be housebound. "Name of Client" also include simple physical exertion to cause and exacerbate reactions leaving them unable to perform most activities of daily living and many of the ones they do perform, they are unable to do so without support. These tasks include bathing, cooking, cleaning, any kind of physical exertion such as lifting, carrying, pushing, pulling, walking.]

Medical History:
[write narrative here. For example: "Name of Client" carries several medical diagnoses and has a history of medical issues: *list medical issues and diagnoses here*. All of these medical issues have a basis in mast cell activation. Mast cells are part of our body's immune system response and inflammatory response networks. Mast cells are found in all organ systems of the body especially where the body comes into direct

contact with the outside environment (skin, respiratory system, GI system, central nervous system.) Mast cells are also found in the brain.

Mast cells can be activated when they detect chemicals, substances, germs, viruses. Mast cell activation means that the mast cells degranulate or crumble. When mast cells degranulate they start the body's inflammatory response by releasing different chemicals (called mediators) especially histamine into the body, affecting all organ systems. Mast cells can be activated by substances that are ingested, inhaled, and/or that can pass through the blood-brain barrier.

Common reactions a person with Mast Cell Diseases (MCD) may experience include but are not limited to: anxiety; depression; anaphylaxis; *continue with listing reactions.*]

Evaluation:
[write narrative here. For example: I have administered the following: Hamilton Anxiety Rating Scale (HAM-A); Quick Inventory of Depressive Symptomatology (QIDS); Mini Mental State Examination (MMSE); Global Pain Scale (GPS); Mast Cell Activation Assessment Questionnaire; Wellness & Environmental Assessment (CC-WEA)]

Scores:
[a bulleted list of the scores here for each assessment administered. For example:

- HAM-A: total score of ____ indicating _____
- QIDS: total score of ____ indicating ____
- MMSSE: total score of____ indicating ____
- GPS: total score of ____ indicating____
- Mast Cell Activation Assessment Questionnaire: total score of ____ indicating____

- CC-WEA: results show ____ in all three areas scored: Section B-Exposures & Triggers total score ____ out of ____; Section C-Reactions & Symptoms total score ____ out of ____; Section D-Health History total score ____ out of ____.]

[continue with written narrative here explaining the CC-WEA, the Mast Cell Activation Assessment Questionnaire, and the Global Pain Scale as these are not typically or frequently administered assessments. For example: The CC-WEA is an assessment specifically designed for clients who have or are suspected of having MCD and mast cell activation related health issues (these include ___, ___, ___, *list client's issues*) as an aid in pinpointing specific reactions and triggers to best develop support strategies. The CC-WEA assesses the client in three specific areas: (1) exposures and triggers; (2) reactions and symptoms; and (3) health history as it pertains to MCD and mast cell activation related health issues. "Name of Client" 's CC-WEA assessment responses, Section C-Reactions & Symptoms, indicate multiple organ systems that they report with severe to disabling symptoms that include *list here the symptoms as they match up with the assessment scored items*. The CC-WEA assessment indicates that "Name of Client" and most, if not all, aspects of their life are negatively impacted by their severe reactions to multiple triggers.

The Global Pain Scale assesses for physical pain and also assesses regarding the effects pain has on individuals in four specific categories including a numeric rating scale, how pain has affected the person's emotional wellbeing, clinical outcomes, and the effect a person's pain has on their activities of daily living. "Name of Client" scored ____ out of ____ regarding their level of pain and its negative impact on them and on their life.

And so on.]

Assessment:

[write narrative here. In the assessment connect all the dots, keeping in mind that the person who may be reading and reviewing your documentation most probably is not knowledgeable about mast cells and mast cell activation issues and disorders. It needs to be clearly shown and explained the degree of disability the client experiences from the severity of their symptoms, that avoidance is the first-line treatment for anyone suffering from MCD, and that the client is at the mercy of the behaviors of others over which they have no control.]

Treatment Plan:

[write narrative here clearly explaining goals and objectives address two areas simultaneously: (1) managing reactions and triggers, and (2) managing, for example, anxiety and depression as these were listed as the client's diagnosed issues. Goals can include deepening understanding of physical health issues in order to best support highest levels of wellness; to learn strategies to manage stress; to learn strategies to manage anxiety; etc. Objectives can include keeping a histamine food journal with goal of making food choices that are low in histamine to bring down reactions and their severity which can lead to improvement in pain, anxiety, and depression symptoms, using mindfulness meditations to bring down stress, using bilateral stimulation to improve depression and ease anxiety; practice avoidance to reduce exposures to triggers and reactions; vagus nerve focused exercises and breathing strategies to reduce stress; making food choices that include mast cell stabilizing and mast cell strengthening items, Dialectical Behavior Therapy approaches, etc.]

Recommendations:

[a bulleted list of your recommendations here. For example:

- Have "Name of Client" discuss with primary care physician about carrying an Epipen
- Continue with regular weekly therapy]

End with a statement such as: Please feel free to contact me with any questions you may have. I am happy, with "Name of Client" 's permission, to further discuss their therapy and diagnoses.

Sincerely,

____
Your Name, Title, and License Number

9

Expanding the Lens

We go on because we have hope. Many people with a mast cell activation issue or disorder can feel without hope and unable to manage or find relief from the symptoms and the burden of having a chronic illness that spans the spectrum from somewhat limiting to utterly devastating.

The emotional and psychosocial needs of a person who has MCAS, long-COVID, or a mast cell activation issue or disorder 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 appropriate services, we need to be able to reach outside the therapy "box" for alternatives in how to best support our clients who have or are suspected of having MCAS or a mast cell activation disorder as they redefine their understanding of who they are within the challenges of living with these chronic illnesses.

Holistic Health and Holistic Therapy

The goal of holistic health is for each person to achieve their maximum level of wellness and wellbeing. Holistic health focuses on the whole person and not just on separate systems, an approach that is especially significant for the client with MCAS or other MCD. Health is more than simply not being sick. Think, for a moment, of health as a timeline or continuum. At the far left of the timeline is the poorest state of health. At the far right, the highest state of health and wellness. Holistic health approaches are an ongoing process that focus on moving each person to the right on the continuum and towards their highest levels of health, wellness, and wellbeing.

Holistic Therapy focuses on the physical, emotional, social, cognitive, and spiritual wellbeing of each person, who they are, and their life as a whole. Each individual's concerns and goals are looked at and explored on these multiple levels. The holistic approach in therapy is comprehensive. Instead of treating symptoms only, an holistic approach focuses on the needs of the whole person (crearthcare.com).

Integrative Medicine

People who have MCAS or a mast cell activation related disorder may have grown to feel that conventional medicine does not address or understand their medical needs. It is common for individuals who have a mast cell activation disorder, or are suspected of having one, to have negative experiences of healthcare from providers. Mast cell activation issues and disorders are not well understood in the conventional medical and mental health communities. The person with MCD may feel angry, hurt, betrayed, or abandoned by doctors and healthcare providers, 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 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. Mast cell activation disorders 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 MCD as there is not a single area of their lives left untouched by their illness.

Clients with a mast cell activation disorder need to be asked about their CAM use at every visit. It is common for these individuals to seek out alternative medicines and alternative interventions in the hopes of experiencing some relief from their symptoms. This includes supplements a person make take, how foods as medicine may be utilized by a person, interventions for managing stress and reactions. The client with MCD should be asked about current CAM and alternative treatments and interventions, current conventional medical treatments and interventions, their history of conventional mainstream, CAM, and alternative treatments and their perceived effectiveness.

Centers for integrative medicine tend to 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 a mast cell activation issue or disorder as it aids in minimizing their exposures to what are for them potentially toxic chemicals, substances, 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.

Humanistic Therapy

A humanistic therapist focuses on the individual and each person's perception, understanding, and internalization of their experiences. Humanistic Therapy is holistic, examining the whole person as greater than the sum of its parts, and encourages clients in self-actualization through self-understanding, self-mastery, and through their creative expression (see crearthcare.com/approaches/).

Narrative Therapy

The individual with MCD or suspected of having a mast cell activation disorder 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 a mast cell activation disorder must go through.

In our society, a person’s worth is based on what they do nine-to-five. The person with MCAS or mast cell activation issue or disorder may find that they are unable to work or are able to work highly limited hours and only 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 exposures in the shared workspace and work environments.

The person who has or is suspected of having MCAS or a mast cell activation issue or disorder may profoundly benefit from Narrative Therapy strength-drawing practices. Narrative Therapy, an approach originated by psychologist Michael White in Australia (see https://dulwichcentre.com.au), recognizes that the person is not defined by their illness and actively supports the positive separation of self from disease.

Narrative Therapy is a way of understanding how problems affect people's lives. In Narrative Therapy, individuals view their problems as separate from themselves. The client has a significant and active role in determining the direction in which their therapy will move. A Narrative Therapist is non-blaming, respectful, and sees the individual as the expert in their own lives. In Narrative Therapy, clients re-author the dominant stories and conversations of their lives to make new meanings of their relationships, their understanding of self, and how they live and form their life (crearthcare.com).

Through Narrative Therapy approaches and techniques, the individual is able to move towards developing a new, better, and clearer understanding of who they are, their worth, and value.

Contemplative Therapy

A contemplative therapist uses mindfulness, openness, clarity, and compassion to support their clients. Openness and clarity in Contemplative Therapy are the bringing of mindful awareness to everything we experience through our senses, including our thoughts and emotions, and not turning away from the experience because we are frightened, or because of its intensity, or in fear of pain (crearthcare.com).

Through our understanding of mindfulness—touching life deeply in the present moment—we can receive our life experiences and recognize our thoughts and emotions, whether positive or negative, as being simply thoughts and emotions. In this way, we are able to disengage and experience them without fear. Contemplative Therapy believes in each individual's innate capacity for compassion, connection, brilliance, and beauty (IBID).

Ecotherapy / Horticultural Therapy

Human beings are creatures of relationship; with ourselves, each other, and our world. An Ecotherapy and Horticultural Therapy approach used in therapy 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 educator (see https://www.chalquist.com/) 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 MCAS or mast cell activation disorder has with the natural environment can be challenging and changeable. One vantage point reveals the environment as hostile, ridden with toxins and chemicals, dangerous, and 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 a mast cell activation issue or disorder. Individuals with MCD 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 not in your office but 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). This is highly significant for individuals with a mast cell activation disorder as stress and cortisol have been found to cause mast cell degranulation. 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 wellbeing (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).

Creative Arts Therapy and Expressive Therapy

The person with or suspected of having MCAS or a mast cell activation 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.

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 garden, 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.

Creative Arts Therapy and Expressive Therapy both encourage clients to explore and process their thinking, emotions, reactions, insights, and experiences through the visual arts, music and sound, writing, literature, poetry, movement, dance, culinary arts, and other arts areas.

Creative Arts Therapy and Expressive Therapy, however, are not the same thing and the two terms should not be used or understand as being interchangeable.

In Expressive Therapy, the therapist does not need to have any formal training or a degree as an artist in an arts area. An Expressive Therapist, for example, may have a degree in psychology, counseling, or social work and have studied how to use various arts areas within a clinical practice to augment and enhance their work as a psychotherapist and the client's experience of psychotherapy. The focus, in Expressive Therapy, is on the process and not the product—not the created artwork.

In Creative Arts Therapy, the therapist has had formal training as an artist in an arts area as well as formal training in psychology, counseling, or social work. A Creative Arts Therapist, for example, may have formal training and a degree as a visual artist or writer, and also as a psychologist. The focus, in Creative Arts Therapy, is equally on the created artwork and the therapy—but through the lens of an artist.

Arts Therapies: Multimodal and Intermodal

Multimodal means that the therapist uses different modalities in their work. A Music Therapist, for instance, is not multimodal as they are only using the one art modality, music, in their work with clients. An Art Therapist, as another example, is not multimodal as they are using only one art modality, visual arts, in their work. Music Therapists and Art Therapists are single modality therapists using a single modality approach in their work.

A multimodal Expressive Therapist will use more than one art modality in their work with clients, such us visual arts, music, and dance, but is not required to have formal training as an artist in these arts areas. A multimodal Creative Arts Therapist will use more than one art modality in their work with clients, such as visual arts, music, and dance, and also has formal training as an artist in each of the arts areas.

An intermodal approach is one where the therapist moves through different art modalities in their work with their clients within a single session in order to best meet a client's individual needs. Using an intermodal approach, one session with a client can include language arts, music, visual arts experientials within a single session.

Meditation, Mindfulness, and Mast Cell Activation: Body Mind Spirit

The Impact of Stress

The client with MCD has a very real physical need for calm. Strong emotions, whether positive or negative, as well as mental stress and physical stress, can cause and/or intensify their symptoms and their reactions. Mast cell activation plays an important role in stress-mediated diseases (Kempuraj, D., Mentor, S. et al, 2019). An example is migraines. Migraines have a basis in mast cell activation. Stress is the second most common trigger of headache due to mast cell activation (see: Kempuraj, D., Mentor, S. et al, 2019 and mastcellmaster.com/publications.php).

T.C. Theoharides, MD, a leading mast cell specialist, lists the following conditions that involve mast cells and that worsen with stress: allergies, anaphylaxis, angioneurotic edema (an acute swelling that occurs under the skin, unlike hives whose swelling occurs on the surface of the skin, and can involve the lips, eyes, face, tongue, larynx, abdomen, arms, mucous membranes), asthma, eczema, Autism Spectrum Disorder (ASD), chronic inflammatory response system, mastocytosis, idiopathic urticaria (hives), Irritable Bowel Syndrome (IBS), Mast Cell Activation Syndrome (MCAS), non-IgE food allergy, rhinitis (Theoharides, T.C., 2020).

Theoharides, MD, also lists common symptoms that involve mast cells and worsen with stress: angioedema, anxiety, brainfog, diarrhea, Postural Orthostatic Tachycardia Syndrome (POTS), fatigue, flushing, headache, heart rate, hives, hypotension, itching (pruritis), lightheadedness (syncope), muscle pain (myalgias), pain, palpitations, polyuria (increased urination), shortness of breath, weakness, wheezing (IBID).

Body Mind Spirit Interventions

Meditation

Research has shown that meditation practices reduce anxiety, improve focus and memory, can improve the symptoms of depression, and more. Meditation, research has found, helps to keep our brains from having more pronounced volume loss as we age based on comparison research sample groups of long-term meditators, shorter-term meditators, and non-meditators (Forbes 2015).

Studies have shown benefits of meditation practices in conditions such as fibromylagia and irritable bowel syndrome (see: news.harvard.edu/gazette/story/2018/harvard-researchers-study-how-mindfulness-may-change-the-brain-in-depressed-patients/). Both of these conditions have a basis in mast cell activation (see TC Theoharides, MD, PhD, mastcellmaster.com/publications/php).

Breathing and the Vagus Nerve

New research exploring the symptoms of long-COVID shows that the virus may have adverse effects on the vagus nerve causing persistent voice problems, dizziness, and low blood pressure (see: https://www.eurekalert.org/newsreleases/943102 and https://health.clevelandclinic.org/vagus-nerve-stimulation).

The vagus nerves are part of the body's nervous system. They are the longest cranial nerves, running from the brain to the large intestine. The left vagus nerve travels down the left side of the body and the right vagus nerve travels down the right side of the body (my.clevelandclinic.org.)

The vagus nerve takes a long, meandering route through the body, exit from the medulla oblongata in the lower brain-stem, then pass through our connect with our:

- neck between the carotid artery and jugular vein
- chest (thorax)
- heart
- lungs
- abdomen
- digestive tract

(my.clevelandclinic.org).

The left and right vagal nerves join together to form the vagal trunk, connecting at the esophageal hiatus—the opening where the esophagus passes into the belly. The front and back of the vagal trunk has gastric nerves that go to the abdomen (IBID).

There are three vagal nerve branches:

- Inferior ganglion branch – serves muscles and nerves to the throat (pharynx) and voice box (larynx)

- Superior ganglion branch – serves nerves to the heart, lungs, and esophagus (tube that connects the mouth with the stomach)
- Vagus nerve branch – serves nerves to the heart, lungs, esophagus

(my.clevelandclinic.org).

The vagus nerve can be involved in certain conditions such as:

- Gastroparesis which is when damage to the vagus nerve stops food from moving into the intestines from the stomach. This type of vagal nerve damage can be the result of diabetes, viral infections, abdominal surgery, and scleroderma (a condition where the body produces too much collagen)
- Vasovagal syncope (fainting) occurs when a vagus nerve to the heart overreacts to certain situations, for example, extreme heat, anxiety, hunger, pain, or stress causing blood pressure to drop very quickly which makes a person feel dizzy or faint

(my.clevelandclinic.org/health/body/22279-vagus-nerve).

Signs and symptoms of vagus nerve problems can be different depending on the specific cause and the affected part of the nerve and can include:

- abdominal pain and bloating
- acid reflux (gastroesophageal reflux disease, GERD)
- changes to heart rate
- changes to blood pressure
- changes to blood sugar
- difficulty swallowing
- loss of gag reflex
- dizziness or fainting
- hoarseness, wheezing, or loss of voice
- loss of appetite
- feeling full quickly

- unexplained weight loss
- nausea
- vomiting

(my.clevelandclinic.org/health/body/22279-vagus-nerve).

During a state of danger, or stress, or excitement, the sympathetic nervous system rings bells of alarm throughout the body: something is wrong and we need to prepare for battle. The messages send the brain and body into survival mode. When the threat or danger has passed, the brain sends signals to the body through the vagus nerve to relax the tension (health.clevelandclinic.org).

Our fight-or-flight response, however, doesn't know the difference between an immediate danger and the life stresses that we're hit with every day (IBID). In our modern world, we're not confronting wild animals as the danger and threat. The threats in our world involve abuse, discrimination, dysfunctional relationships, loneliness, poverty, poor sleep, trauma (my.clevelandclinic.org/health/body/22279-vagus-nerve).

A healthy vagus nerve can very quickly offset the body's stress response and can help to reduce anxiety while improving one's overall health—if you know how to get it in motion (health.clevelandclinic.org).

Vagus Nerve Strategies, Exercises, & Interventions

Breathing:

- Deep, slow breathing—with emphasis on each exhale—will stimulate the vagus nerve and lower heart rate
- Smile and be kind – the vagus nerve can be affected by emotions and the two-way street of how we

communicate, both sending and receiving. Prosocial behaviors such as being friendly, compassionate, and grateful can strengthen vagal tone
- Gently massage your face and neck - all the vagal pathways in the face relate to how we connect with others through our smile, our eyes, and our voice. Gently massage tender spots around the eyes, ears, neck, and jaw to stimulate the vagus nerve. Remember to massage gently as self-massage can in some instances cause the blood pressure to drop and potentially cause a person to faint/lose consciousness
- A good laugh stimulates diaphragmatic breathing which activates the vagus nerve

(https://www.mindful.org/why-your-breath-is-connected-to-your-well-being).

Physical vagus nerve exercises:

- Gargling (can do this with water, aim for 30 seconds to 1 minute)
- Singing (doesn't matter how you sound, turn on some music and sing *con gusto*)
- Laughing

Psychological vagus nerve exercises:

- Gratitude journaling
- Deep breathing (with emphasis on the exhale and as you exhale sigh aloud—make a vocalization)
- Meditating

(https://www.parsleyhealth.com/blog/how-to-stimulate-vagus-nerve-exercises/).

Food as Medicine

The role that food and food choices play in the health and wellness of a person with MCAS or another mast cell activation issue or disorder is enormous. Through informed food choices, more and more people suffering with the symptoms and reactions brought about by mast cell activation and the release of mediators can improve their health, decrease reactions, and potentially raise their baseline of wellness in their day-to-day lives.

Histamine is a major mediator released by activated mast cells that brings on many reactions in various organ systems. Histamine plays a part in the body's allergy and inflammatory responses, as well as anaphylaxis. There are four types of histamine receptors in the body that researchers have identified and the effect histamine has depends on which histamine receptor it binds to (https://my.clevelandclinic.org/health/articles/24854-histamine).

H1 Receptors: these receptors are found throughout the body including in brain cells (neurons), the smooth muscle cells of the airways, and blood vessels. Activation of H1 receptors causes:

- Itchy skin (pruritis)
- Blood vessels to expand (vasodilation)
- Low blood pressure (hypotension)
- Increased heart rate (tachycardia)
- Flushing
- Narrowing of your airways (bronchoconstriction)
- Pain

(https://my.clevelandclinic.org/health/articles/24854-histamine).

H1 receptors also help regulate:

- Sleep-wake cycles
- Food intake
- Body temperature
- Emotions
- Memory
- Learning

(IBID).

Activated mast cells that bind to H1 receptors can influence and cause reactions in any and all of these areas.

H2 Receptors: are located mainly in the cells of the stomach that release acid, the smooth muscle cells, and heart cells. Activation of H2 receptors leads to:

- Stomach acid secretion (which helps with digestion)
- Stimulation of mucous glands in the airways
- Vascular permeability
- Hypotension
- Flushing
- Headache
- Tachycardia
- Bronchoconstriction

(IBID).

H3 Receptors: are mainly involved in blood-brain barrier function. They can be found in neurons in the central nervous system. These receptors regulate the release of histamine and neurotransmitters like dopamine, norepinephrine, and acetylcholine.

H4 Receptors: these receptors are present in the bone marrow and hematopoietic cells (immature cells that can develop into all types of blood cells.)

- They play a role in the formation of certain blood cells

- They play important roles in inflammatory disorders and autoimmune diseases

(IBID).

Making food choices that are low in histamine is one way food can be used to help bring down and not intensify mast cell reactions. Another way is choosing items that are mast cell strengthening foods and/or foods that are mast cell stabilizers. For example, green tea is a mast cell stabilizer. A third area of focus for food choices is making selections that are mitochondria strengthening foods as mitochondria are affected and impacted by mast cell activation.

Have your client keep a record, for a minimum of three weeks, where they jot down each day every single thing they eat and how they felt that day. They can use a symbol or some other kind of short hand for how they felt—smily faces, etc. After three or four weeks, together with your client review the entries starting with how the client felt each day. Look for days client may have noted, for example, they felt unwell, or agitated, anxious, depressed, with a lot of fatigue. Compare each of the days the client noted some aspect of not feeling too terrific looking for commonalities. An example would be noticing that there were several days the client noted down they felt anxious and on each of those days the client ate a spinach salad. Spinach is high in histamine. The next step is eliminating that food from their diet and see if they notice a change or improvement in how they feel. It's not to not have salads but, instead, to not have spinach or arugula in their salad and choose a different green that's low in histamine instead.

Another category of food as medicine to support health for individuals with MCAS or other MCD is choosing foods that are mast cell stabilizers, mast cell activation inhibitors, and/or have mast cell stabilizing agents. Some mast cell stabilizing foods include: green tea; red. blue, and purple berries; bananas; black beans and kidney beans; walnuts; red onions (high in quercetin); scallions/green onions (high in quercetin) to name only a few.

One factor that needs to be included when targeting particular foods as possibly being helpful with reducing mast cell activation symptoms and reactions is that many foods that are high in histamine and might be on the "foods to avoid" list—such as green tea—are also on the list of "foods that are mast cell stabilizers"—such as green tea. Food choices need to be individualized as, for example, person A may be fine with having green tea while person B experiences reactions from mast cell activation after drinking green tea.

A third area to include when making food choices to support health and mast cell health is our mitochondria. Mitochondria are located in every single cell in the body. They produce energy and are often called the powerhouses of the cells. Mitochondria help turn the energy we take in through the food we eat into energy that our cells can use. Mitochondria also play a role in regulating calcium and generating heat in our body through non-shivering thermogenesis.

Some conditions that are thought to involve some degree of mitochondrial dysfunction include: Parkinson's disease, Alzheimer's disease, Huntington's disease, Chronic Fatigue Syndrome (CFS), Autism Spectrum Disorder (ASD), diabetes, fibromyalgia, Ehlers-Danlos Syndrome, connective tissue disorders (see Khan at https://lymphapress.com (2022) and https://medicalnewstoday.com/articles/320875#disease).

A 2012 study at Tufts University in Massachusetts identified mitochondrial particles secreted from live, activated mast cells as a possible trigger for the body's inflammation process in many illnesses (see https://now.tufts.edu/2012/12/17/

mitochondrial-components-are-possible-trigger-auto-inflammatory-illnesses). To quote Dr. T.C. Theoharides, the senior author of the study, "Our work provides a possible explanation for the inflammation that arises without apparent disease or injury."

Creating mast cell activation informed menus is not a one-size-fits-all endeavor. Making mast cell informed food choices includes: (1) knowing the histamine content of foods (i.e., very high, high, medium, and low in histamine); (2) knowing which foods are mast cell stabilizing foods; (3) including foods that are mitochondria strengthening choices; and (4) each person learning and knowing which foods they react to in which way.

Essential Food as Medicine Resources

The Counseling Center at CELA free downloads:

- Food as Medicine: Histamine & Food
- Food as Medicine: Mast Cell Stabilizing Foods
- Food as Medicine: Mitochondria Strengthening Foods

Visit: https://counselingatcela.com/helpful-links/food-as-medicine-2/ to download the above.

Exercise

We all know that exercise is good for our health and that we should exercise regularly. What we may not be as well versed in is the role exercise plays with our immune system and especially mast cells.

Dr. Mariana Castells, a mast cell specialist whose focus is in mastocytosis and cancer, has shared that lifestyle changes are the most important thing and within the lifestyle changes, the two most important pieces are exercise and diet—equally as important (https://healinghistamine.com).

Included in maintaining those mast cell activation aware choices that support mast cell health is doing at least 30-40 minutes of exercise each day. The exercise is moderate (not intense or mild) and many times interval training where one does, for example, forty seconds of an exercise followed by twenty seconds of rest without exercising, followed by forty seconds of an exercise then twenty seconds of rest, and so on. In this way, we retrain our mast cells to not degranulate. Regular practice of interval training, research has found, can contribute to improved immune function (see https://healinghistamine.com and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8465842/).

Chronic fatigue is often a symptom many people with MCD experience that can interfere with a person's ability to maintain a regular exercise routine. Fatigue does not respond well to all the medications used in treating symptoms of mast cell activation. As Dr. Castells notes, "Fatigue only responds to changes you make to your tissues through exercising or changes you make to your intestinal absorption by changing what you eat," (https://healinghistamine.com).

Dr. Castells' mast cell specialty area is mastocytosis and cancer. Through her work with these patients she has found, when it comes to inflammation, "There is a tremendous inflammatory component... just by educating the mast cells to a certain level of activity tremendously reduces that inflammatory component," (https://healinghistamine.com).

Support your clients in their developing a 30-40 minute regular aerobic exercise routine as many days per week as they can. Having a variety of choices (for example, from various videos available online) ranging from very mild and seated exercises to more moderate intensity—with having interval training be a primary feature—will help them continue their exercise schedule on days when they might be feeling with less energy than other days.

Circadian Clock and Mast Cells

The human biological clock—the circadian clock—is an internal biochemical oscillator (moves back and forth like a pendulum or travels from one point to another.) You can think of the circadian clock as the body's internal alarm clock. A circadian cycle, or circadian rhythm, is a natural oscillate (back and forth movement from one point to another point) that repeats approximately every twenty-four hours. Circadian rhythms can refer to any process that is endogenous (originates within an organism) and is entrained by the environment (responds to and/or is determined or modified by the environment.) Plants as well as other animals have circadian rhythms (https://www.medicalnewstoday.com /articles/circadian-rhythms#what-it-is).

In human beings, the circadian rhythms are approximately twenty-four hour patterns that the brain and body go through which allow for changes in the body's mental and physical states, along with mood and behavioral changes (https://www.medicalnewstoday.com /articles/circadian-rhythms#what-it-is).

One of the most recognized circadian rhythms is the body's sleep-wake cycle. We typically get tired at night and feel more awake during the day. Circadian rhythms/biological clocks exist naturally in humans and their cells, playing a vital role in processes that function without external factors. People usually think of the sleep-wake cycle when they think of circadian rhythms, however, there are additional circadian rhythms involving and regulating, for example, hormonal activity, the body's temperature, digestion, and the function of our immune system (IBID).

The National Institute of General Medical Sciences notes that almost every tissue and organ of the human body contain their own biological clocks, the result of specific proteins that interact with cells in the body and tell them to be more active or to slow down (https://www.nigms.nih.gov/education/fact-sheets/Pages/circadian-rhythms.aspx).

There is one "master clock" in the body that controls all of the individual body clocks, called the suprachiasmatic nucleus (SCN). It contains about 20,000 nerve cells and receives information and direct input from the eyes. As our eyes perceive the brightness of day or night's darkness, the SCN picks up on this information and instructs the body's cells to function accordingly. Light keeps the circadian rhythm in sync with a twenty-four hour day (https://www.medicalnewstoday.com/articles/circadian-rhythms#how-it-works).

In addition to the reactions that cells may have, chemicals in the brain adjust in response to the circadian cycle of the day. Some of the factors these chemicals adjust include hunger, temperature, arousal and awakeness, and mood (IBID). Circadian rhythms control the body's sleep-wake cycle due to how the body and brain respond to darkness, the time when most people feel tired and tend to sleep. As darkness settles in the evening, melatonin begins to rise and allows sleep to occur, it peaks at around 2-4 AM then lowers in the morning and lets wakefulness happen (https://www.medicalnewstoday.com/articles/circadian-rhythms#what-it-is).

Light is the major outside factor that controls our body's circadian rhythms and keeps the circadian rhythms in sync with the earth's natural 24-hour cycle. There are other environmental cues that help synchronize our circadian rhythms such as food intake and one's activity level (IBID).

Factors that can disrupt the body's circadian rhythms include:

- Light that is irregularly timed
- Using bright lights in the evening two hours before a person's usual bedtime (when the circadian clock is most sensitive) can shift sleep-wake times to occur later
- Using bright lights in the morning can shift the need to sleep to earlier
- Sleeping in a bright room can wake a person up earlier than necessary and disrupt sleep time
- The color of lights appears to disrupt circadian patterns:
    - Blue lights have the strongest impact
    - Blue and white lights during sensitive periods of the day such as two hours before sleep can make it difficult to fall asleep or stay asleep.
    - Common sources include electric screens on devices such as phones, computers, televisions
- Unhealthy sleep habits such as: going out late and waking up early; having no set sleep time; eating and drinking late at night; having caffeine late at night; using electronic devices at night; doing activities that are mentally stimulating late in the day; experiencing pain or discomfort in one's sleeping space
- Shift work (i.e., working the overnight shift)
- Travel

(https://www.medicalnews today.com/articles/circadian-rhythms#how-it-works).

Recent research has shown that mast cells are controlled by their own internal clock that is regulated by specific clock genes and by external factors such as light sensed by the SCN, hormonal status, diet, and exercise (Christ, P., Sowa, A.S., Froy, O. et al 2018). The mast cells' internal circadian rhythm affects activation of signaling molecules and, thus, the functionality of mast cells, resulting in circadian production and release of mast cell mediators (IBID).

New studies have shown that the circadian clock activity is embedded in mast cell activation and dysregulation of the circadian clock by genetic and environmental factors can alter the intensity and temporal profiles of mast cell activation. Environmental and lifestyle factors that disturb the normal rhythmicity of the circadian clock, such as irregular eating habits, can lead to the loss of circadian control of mast cell activation and, as a consequence, the degree of mast cell activation becomes equally strong at all times of day and worsening symptoms (Nakao, A., Nakamura, Y. 2022).

The timing of meals, light, exercise, mental stress, and social activities have the ability to reset the circadian clock. Our modern world is filled with lifestyle and environmental factors that upset and disturb circadian rhythm including but not limited to: variations in nighttime brightness such as due to night use of electronic devices (for example, smart phones) that emit short-wavelength-enriched light, mental stress, irregular eating habits such as late night snacks. These types of misalignment between environmental and lifestyle cycles and endogenous circadian rhythms can affect the rhythmicity of the mast cell clock and affect the intensity and temporal profiles of mast cell activation (Nakao, A., Nakamura, Y. 2022).

Support your clients in their maintaining regular sleep habits and sleep-wake schedules; developing mast cell activation informed menus and food choices; doing 30-45 minutes of moderate intensity interval aerobic exercise as many days a week as possible; using mindfulness, contemplative, and Dialectical Behavior Therapy (DBT) approaches (e.g., radical acceptance and the neutral focus) to manage stress daily.

10

Lifestyle Changes

The significance in maintaining one's optimum level of wellness through making lifestyle changes cannot be over-emphasized for the person with a mast cell activation issue or disorder such as long-COVID, MCAS, being sensitive to multiple chemicals, chronic fatigue, and more.

These are people who live each day constantly frisking and monitoring themselves and their surroundings for potential toxins in an effort to minimize their exposures, keep reactions down, and maintain their best health. Some days it can feel like a losing battle—how do you fight air pollution or Monsanto? How do you control the brand of shampoo or laundry detergent the stranger next to you in line at the market uses that you are reacting to? How do you stop other people from, unmasked, coughing germs and viruses into the shared air we all breathe?

We are part of a culture that emphasizes a construct within which humans exist as independent and self-contained, separate from the natural environment and impervious to the consequences of their behaviors. Sarah A. Conn, PhD, in the book *Ecopsychology: Restoring the Earth, Healing the Mind*, writes, "Because we experience the self as separate from the Earth, we feel either overwhelmed by or removed from what we learn about environmental deterioration; we become helpless or indifferent in the face of it, unable to respond except with numbness and denial," (Roszak et al, 1995). This numbness and denial is carried over into our responses to the people who are living with the effects and accompanying health issues and disorders that are the direct consequences of human behaviors.

The symptoms a person may experience when exposed to any of the many chemicals, substances, and environments to which they react can range in intensity from mild to severe and life-threatening. Reactions can kick-in suddenly and have immediately identifiable trigger or triggers. They can appear to happen out of nowhere and disconnected to a person's immediate surroundings making the trigger(s) difficult to identify. Reactions can be delayed, happening hours, days, or weeks after an exposure. Reactions many times can feel as if they move like waves of the sea, intensifying, then receding, intensifying, receding over and over almost non-stop throughout the day. They can shift in fractions of seconds from mild to overwhelming and anaphylaxis, requiring an Epipen be administered.

For each person with a mast cell activation issue or disorder, there was a day one; the day where everything shifted and changed. Many if not most people with MCD can pin-point it, relate it to a particular event, and tell you, "this is what happened." Some had a serious infection. Others had surgery or a medical procedure. Intense periods of extreme stress, emotional or physical and including trauma, mark the shift for other people. It could have been after exposures to pesticides. It could have been after giving birth.

There are people who, prior to day one, never had allergies. Others who, in retrospect, realize they had mast cell issues going on all of their lives. It's a continuum from that day one to this moment in time. The client with whom you may work can be anywhere on their personal MCD day one and after continuum. Regardless of where precisely they may be on the continuum, it is a continuum of drastic measures, radical unlearning, and the steepest most relentless learning curve you can imagine.

Lifestyle Change Supports

Not all the clients with whom you may work will have an appropriate diagnosis in place when they come to you. You may see what you recognize as most probably mast cell activation related activity in the client's medical history and presentation of symptoms. They may already have diagnoses of eczema, asthma, some kind of hives, migraines, Parkinson's disease, acid reflux, mystery pains that have been given along the way. Not all doctors and treating medical practitioners have learned to recognize the presentation of symptoms and/or disorders that indicate or involve mast cell activation, in spite of the fact that mast cell activation issues and disorders are common and not rare. Wherever they are on their MCD continuum, they will cross your threshold.

The majority of my clients with MCAS or other mast cell activation issue or disorder have shared with me that following their being correctly diagnosed and prescribed, for instance, cromolyn sodium and other medications to help manage symptoms, they were kind of set a-drift. No one explained to them the importance of lifestyle changes, especially avoidance, in maintaining optimum health and quality of life. One client spoke with me about a doctor telling them at the beginning when their symptoms were most severe that they *would* get better, though no one could tell how much better or how long "better" would take to achieve. The client shared they clung on to those words like a life raft: "You will get better."

Supporting the Journey

I share with clients strategies and options for maintaining their health and keeping down reactions as a part of our conversations, keeping in mind always that a client's mast cell activation reactions can include periods of brainfog, poor memory, and trouble thinking things through clearly. Writing things down, making and keeping lists are strategies that work in almost all situations and circumstances for the majority of my clients.

Avoidance

Having MCAS or another MCD impacts all areas of the person's life. Some people can experience reactions every day, 24/7. Recognizing triggers and reactions are a major part of the learning curve for the person with MCD in order to keep their reactions down and to keep themselves at their optimum baseline for health, wellness, and quality of life.

Rule #1: Avoid the things to which you react.

This is not an easy task. We can't control the behaviors of others. People at large aren't going to change their laundry detergent because it causes you to have terrible reactions that make you feel so unwell and sick for days or sometimes weeks. They're not going to change the products they use to mop the floors or wipe down registers at your local market because exposure to them brings you to the brink and then over the edge of mast cell activation, requiring administering an Epipen and then sitting at the hospital emergency room for four hours afterwards, exposed to the ER chemicals and that environment, adding to your body's total load of toxins and re-igniting and exacerbating mast cell activation and reactions.

Support your clients with identifying triggers and the types of reactions they may experience when exposed to the triggers. It can help for clients to log and document, for example, by time of day their reaction experience with the time noted at each point where they felt their reactions intensify as well as the points where they felt their reactions ease. They should absolutely note what they feel has brought on the reactions, what they were exposed to, at the start. Remind them to think beyond the moment when trying to identify triggers as it could have been something they were exposed to days before as, with total load always being a part of things, it could involve delayed reactions.

Safe Haven

Rule #2: Create a safe haven.

Having a "safe haven" somewhere where they live that is maintained as trigger-free as possible is imperative. The person with MCAS, long-COVID, or other MCD needs to have a place to which they can retreat that isn't filled with what are triggers for them; a space to support their body in bringing down and keeping down reactions. Ideally, this would be their entire living space and not a room within their living space.

Support your clients with the reality and ensuing challenge of possibly having to throw things away, give them to others, donate them to a thrift store, or put them in storage because they react to them and they need to have them not be in their "safe space" home environment. Many individuals with

MCD are highly reactive to plastics. Plastics includes several fabrics that clothing and other items are made from, such as, fleece, polyester, nylon, and micro fibers.

Support your clients with their finding personal care and household products that they are able to tolerate and using only those products. Some clients are able, after searching diligently, to find products they can tolerate. Other clients are only able to tolerate baking soda and vinegar as household and laundry cleaners. Don't forget that many times people react to the container a product is in, especially the plastics, and that plastics leech their chemicals into the product they contain—including foods.

Support your clients with the reality that they may have to move from where they currently live if it's too toxic for them and their health to continue there. Finding a place to move to is its own huge challenge. It's hard to assess a potential place to live if the person is reacting to the many exposures they may have experienced simply by traveling to get there. This is highly individualized with each person's tolerance and triggers differing. If someone is reacting to, for example, the exhaust fumes from their car and the other vehicles on the road, it becomes difficult if not impossible to accurately and correctly assess the potential living space for triggers. People are not always able to tell. If moving is too daunting for a client, continue to support them with their creating a safe haven where they live and removing from their living space all items to which they react and are triggers.

Support your clients with maybe having to replace their relatively new car with a model that is at least eight years old, allowing for the plastics and other chemicals to off-gas. Some makes and models of cars, no matter how old, can be toxic to one person while not to another.

The Assumptions We Make

Rule #3: Assume nothing.

Food and Foodstuffs: don't assume it can be eaten.

Lifestyle change: grocery stores. They seem to always be rearranging where they place items in the store, trying to boost sales. Products are imported from different countries, supplied by different vendors, packaged differently, stored differently in back areas, shipped differently. Products we rely on can be without warning discontinued. The way your client with MCD finds out is that a staple product they always count on and rely on having they now suddenly react to.

Support your clients with managing not only their stress and upset over these changes but also in their search for their replacement items. Most likely, this means trying to find a different market.

Finding a different market is not easy. There are many stores and markets that people with MCD are unable to enter because they are so toxic for them, triggering reactions. Forget about actually buying food there. I have found it common with clients that they buy certain products from certain markets and simply because they can eat product A from market A doesn't mean they can eat any other product from market A.

As with moving and getting a car, finding food items the person with MCD is able to eat can be difficult due to their being in a reactive state from getting to the market or store and, thus, be unable to accurately assess whether or not a food item is toxic for them. Some are able to tell from touching or holding an item as reactions can happen within fractions of a second. But if they're too reactive from getting there (or have handled too many items while shopping) they're not going to be able to make that judgment. Many times this means food gets thrown away or given away a day or two later when the person's reactions have come down and they are able to tell that the item is, for them, highly toxic and fumy.

Lifestyle change: mast cell activation informed food choices and menus.

Support your clients with food and menu choices each day, each meal, that contain foods that are mast cell stabilizers, mast cell strengtheners, mitochondria strengtheners, and are low in histamine.

Support your clients with their understanding that "organic" doesn't mean without chemicals. Different chemicals (e.g., pesticides, herbicides, fertilizers) are used with organic foods rather that the more traditional ones used with non-organic food items. Organic foods are not necessarily chemical-free and the client with MCD may react to organic foods as well as non-organic foods.

Water: don't assume everyone can drink it.

Many individuals with MCD have little to no tolerance for tap water. Others are able to drink water from the faucet. There are individuals who can only use bottled water to drink and it must be a particular brand of bottled water—but they can take a shower using tap water and not have reactions.

Clothing: don't assume it can be worn.

Lifestyle change: potentially everything. Items of clothing that are new are typically treated with chemicals that are flame retardants, especially bedding and children's clothing. The dyes with which these types of items are colored can also be problematic as many dyes contain plastics in addition to the chemicals from which they are made. Polyester, fleece, and nylon are all made from and/or contain plastics. The client with MCD may find going into stores or into shopping malls intolerable due to the severity of their reactions from their exposure to the chemicals and substances on others and in these environments. If the client is able to go in-person, they may not be able to judge if an item is toxic for them as they may be highly reactive from traveling to the store.

Support your client with managing their stress, upset, and frustration that are genuine emotional reactions to a very trying situation as you support their stress, upset, and frustration that are mast cell activation related reactions.

Finding clothing that is 100% cotton and/or whose dyes are vegetable-based may be a help with clothing choices for some clients. Choosing to buy certain items (shirts, T-shirts, pants, jackets, coats) from thrift stores can also be an option as these clothes are not knew and have had a chance to air out and off-gas. Suggest to clients that these, too, be items that are 100% cotton. Remind them that if they're handling an item of clothing and they begin to have reactions, even minimally, to not buy that particular item.

Depending on the item of clothing and the person's reactions, some clients with MCD are able to wear new clothing after its undergone repeated washings. This can sometimes mean repeated washes over several months. Washing clothes in hot water and drying them for an hour on high heat has been reported effective by clients with MCD, as has using baking soda when washing - toss in the whole box if needed.

Health Needs Come First

Rule #4: Own your space.

Other people cannot tell if something will or will not cause the person with MCD to react. Everyone will go by their own sense of smell, or what they remember that someone may have shared with them, or their sense of reactivity that they personally may experience, or their understanding of things. No one, on the outside, can determine or predetermine what may or may not be a mast cell activation trigger for another person—even if it's a person who has MCD themselves.

The individual with MCAS, long-COVID, or other MCD needs to put their health needs first in all situations, regardless of the reception from others their health needs may incur.

Support your clients in their creating new boundaries with friends and family based on their health needs. This can include whether or not others can come into the homes of people with MCD and in order to do so, what they might need to adjust or change in their own personal choices of, for example, their laundry detergent, wearing of scents and scented products.

Although some boundaries need to be told directly to, for example, those who want to enter into the client's home space, many boundaries are new ones that the client sets for themselves and don't require too lengthy an explanation to others if at all. Support your clients in differentiating between the two types.

Examples of new boundaries for health the client should set for themselves include but aren't limited to:

- Managing their stress level (physical and emotional) to keep reactions down:
    - Example: whether or not, at any given time, the client feels up to engaging in a phone, video, or in-person conversation;
    - Example: the length of any conversation and not staying engaged in the conversation if reactions start to ramp up;
    - Example: frequency of meals as being hungry and going hungry, for many individuals with MCD, can bring on or worsen their symptoms. Some people need to eat every three hours while other can go a bit longer.
- Managing their physical activity as sometimes even minimal physical exertion can bring on or worsen reactions
- Participating in mild to moderate exercise (preferably aerobic, interval workouts, or even dance, for 30-40 minutes as many days a week that they're able)
- Managing their excursions into toxic environments (such as going grocery shopping or to the laundromat) so as to not over-do on any one day as well as not to do too much all in the same week)
- Manage medical appointments and spread them out so as to not over-do on any one day as well as not to do too much all in the same week:
    - Pay attention to how much recovery time is needed from going to one medical visit or having one procedure to be able to space things out to not bring on or worsen reactions

Examples of boundaries for health the client should set for others include but aren't limited to:

- Entering the client's home space:

  - Laundry detergents and personal care products others need to use/not use if they want to enter the space (some people with MCD can react to others wearing make-up, to the antiperspirant/deodorant another person uses);
  - Not to have a car tree or other scent in their car as they will bring these residual chemicals into the person's space and can bring on or worsen the person's reactions. This means not ever having a commercial car tree in their car because residual chemicals linger. A better option, which can be discussed with others, is making sachet from items the person doesn't react to such as cloves, citrus fruit rinds, cinnamon sticks—all of brands the client can tolerate—ground or whole then wrapped in something like 100% cotton cheese cloth that the client can tolerate;
  - Where and on which furniture it's okay for the visitor to sit (due to the residual chemicals visitors bring in with them.)

Relationships

Rule #5: Things are always going to change.

There is a lot of loss that accompanies having a mast cell activation related disorder and diagnosis. It is often most keenly felt in the responses from others. I have had clients whose family members did not believe their medical issues, who intentionally would adopt behaviors such as wearing perfumes or using particular laundry detergents that the client made clear to their family would make them very ill.

Others have had friends of a life time stop talking to them; ghosted, gone.

With an MCD diagnosis such as MCAS, you lose time. Time can be days, weeks, months where you feel so completely unwell you're not able to do anything except lay there lost in the miasma of brainfog, physical pain, sadness, and so much more. You can lose your job, your home, your identity, your sense of self.

We are creatures of relationship; relationship with others, with our world, and, most importantly, with ourselves. Things are always going to change within and around these deep relationships. It's not limited to our health although greatly impacted by it in every capacity. Things are always going to change. One's health may fluctuate but with support in making mast cell activation aware and informed choices and lifestyle changes, health can continue to improve.

Support your clients with their understanding that not everyone they know, including family and those most loved, are going to be able to share this journey of MCD with them.

Support your clients in grieving their losses. Grief and mourning are very real factors of chronic illness, especially a chronic illness like MCAS or long-COVID that necessitate what are often drastic life and lifestyle changes. People need to acknowledge their sense of bereavement and find ways to express their sadness. These are individuals who are struggling with the death of their dreams, their futures, a particular trajectory of their life—gone while they were in the middle of living it.

Support your clients with their understanding that change is not always bad or to be feared.

Empower and support your clients in adopting a pro-active position in their relationship with themselves, embracing their strengths, valuing who they are because who a person is should not ever be defined by a chronic illness. The illness may be part of their world, but it is not what defines them nor is it who they are.

11

Training, Resources, and Supports

Education and Training:

CELACare Eco-Health Certificate Programs
The first ever training in understanding, working with, and supporting individuals with MCAS, long-COVID, chemical sensitivities, and mast cell activation related issues and disorders. Four certificate levels are offered:

- For individuals and non-medical professionals
- For direct care providers
- For medical professionals
- For therapists

Learn more/Enroll/Contact: celacare-ecohealth.online

CELA – The Center for Expressive Living & Creative Arts
Contact: celaonline.com

Resources and Supports:

The Counseling Center at CELA
Mast cell activation informed therapy, counseling, supports, coaching, consulting, and more
Learn more/contact: counselingatcela.com

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Appendix 1

Chapter 1 - Illnesses, Issues, & Disorders Involving Mast Cell Activation (not an exhaustive list)

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Mast cell disorders are not rare. An estimated 65 million people world-wide are suffering from Long-COVID which research has found has its basis in mast cell activation and can lead to diagnoses of Mast Cell Activation Syndrome (MCAS) and other mast cell activation related issues and disorders. *Understanding MCD* has been written to demystify the vital role of mast cells, what is and isn't happening in our bodies, Long-COVID, MCAS, and mast cell activation related ailments and their symptoms. It is an essential tool and reference for licensed therapists—social workers, clinical mental health counselors, psychologistss—with suggestions for strategies, interventions, diagnosing, and treatment planning. *Understanding MCD* has also been written with the hope that it will be used to inform all clinicians and healthcare providers, to raise their awareness, and to deepen their knowledge and understanding as they plan the care and services they will provide for their clients who have or are suspected of having mast cell activation related issues and disorders.

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